

Parliamentary Committee on Palliative and Compassionate Care

Not to be Forgotten

Care of Vulnerable Canadians



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Parliamentary Committee on Palliative and Compassionate Care



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Executive Summary

The Committee:

- The Parliamentary Committee on Palliative and Compassionate Care (PCPCC) is an ad hoc, all party group of MPs, dedicated to improving care for elderly, dying and vulnerable Canadians. It is unique in the history of the Canadian Parliament as it was formed by the MPs on their personal initiative and funded out of their member office budgets.
- The committee is an example of what is possible when MPs work closely across party lines on issues of profound concern to everyone. The spirit of non partisan collaboration exhibited by the members of the committee is a great example of what parliament is at its best.
- Receiving testimony from hundreds of people at twenty four hearings, and local round tables, MPs were profoundly impressed by the dedication and depth of concern expressed by Canadians for issues surrounding the way palliative and compassionate care is practiced in our country.

The committee grew out of our MPs' personal concern for compassionate care for vulnerable people. The issues primarily dealt with were: 1) Palliative and end-of-life care, 2) Suicide Prevention, 3) Elder Abuse, 4) A disability perspective on health care and inclusive community living.

As our testimony came in, the palliative care section of the report expanded to include an integrated community care model best able to address the care needs of persons with chronic conditions, a framework which is important to all our issues. A section on the urgent need for better pain treatment, including chronic pain, was also included; as was material on homecare and long term care. It also became clear that the issue of family caregiver support needs to be addressed, as family caregivers really are the unsung heroes of compassionate care in Canada.

Part –1. Palliative and end-of-life care:

- While progress has been made, Canada still falls far short of quality end-of-life care for all, with only 16-30% of those who need it receiving palliative care.
- Even where palliative care is available quality and accessibility will vary based on place of residence. In Toronto for example some parts of the GTA have palliative care services and some do not. The same is true of Montreal. This patchwork of services becomes still more pronounced in less populated regions. Many parts of Canada have no palliative care services at all.
- As our population ages, health services directed towards seniors will become a much greater need, and at present our health care system seems ill prepared for this shift.
- Our health care system is good at short term acute care but less so at dealing with people with chronic conditions, with serious pain, with mental health concerns, or with the psycho-social and spiritual needs of patients and their families surrounding the dying process.
- People with chronic conditions need holistic care that looks at them as a whole person. They require patient centered care that recognizes their individual needs and not those of the bureaucratic system, as most important. They require integrated continual care that does not allow them to become lost in a fragmented and confusing world of multiple siloed health systems with less than satisfactory inter-communication between them.

- The **palliative care philosophy** is person-centered, family-focused and community-based. It moves us from disease or condition-specific care to person-centered care. It recognizes that the psycho-social and spiritual dimensions have profound impact upon health and well being, and that a variety of specific conditions may be operating on different levels in the chronically ill or dying person's life. The philosophy of palliative care permeating medical culture is more important than the simple delivery of "services". As family physicians and local nurses come to accept a palliative care philosophy, palliative care services can begin to develop organically in communities.
- Palliative care is best delivered within a home and community-based integrated care system, which is generally more cost effective and care effective.
- Palliative care should be delivered in an integrated fashion, including: home care, small community hospices, and palliative care in nursing and LTC homes.
- While fully recognizing the importance of this range of palliative care options, the committee wishes to emphasize the **ideal** of caring for a person as close to their home and community as possible. Care in the home, surrounded by family and friends, with little institutional and bureaucratic overlay, is practiced successfully throughout the world and in parts of Canada. These successes need to be replicated nationwide.
- Capacity building is required to meet the needs of Canadians for palliative and chronic care. Building up home care capacity is extremely important.
- A national Palliative Care Strategy is desperately needed. Even Georgia, in the former Soviet Union, and Poland have national strategies.
- Research, knowledge translation and training are foundational to community capacity building.

Palliative Care delivery for First Nations peoples:

- Palliative care capacity for First Nation people needs to be built on existing local resources.
- A strengthened home care program for First Nation Communities is essential both for building palliative care capacity, and for addressing chronic care needs.
- At the present time far too many elders die in facilities far from their families and home communities.
- Community based models need to be developed, respectful of First Nation cultural beliefs, traditions, practices and preferred language.

Rural Palliative Care delivery:

- Rural people prefer to receive healthcare in their home communities, and especially don't want to travel to urban centres in their final days of life.
- Community based palliative care resources need to be developed utilizing home care services and local long term care homes.
- Hospice volunteers are a vital part of building rural capacity, supporting people receiving palliative care and their families.

- The whole community takes part in the dying process and supports the dying person and their family by meeting their physical, emotional, spiritual and psychological needs.
- Small local long term care homes can be an important resource for palliative care in rural and First Nations settings.

Pain Management:

- Adequate pain management should be regarded as a basic human right.
- Millions of Canadians suffer from unmanaged and undermanaged pain both chronic and acute. This has severe impact in terms of health and wellbeing, and significant costs in terms of the health care system and work place lost time/productivity expenses.
- Pain management training is inadequate for most medical professionals and must be given a higher priority in the health care curriculum.
- Capacity building is essential to develop centres of excellence in pain control across the country.
- Canada needs to develop and implement a National Pain control strategy.

Legal and Human Rights Perspectives on Palliative Care:

- Palliative care is part of a movement toward fundamental justice and basic human rights for citizens facing the last fragile stage of life.
- A growing body of human rights declarations is recognizing the importance of palliative care and pain management.
- Charter law in Canada specifically section 15 (the equality section) may provide a basis for palliative care services being “insured services” under the Canada Health Act. The CHA seems to assume an implicit distinction between cure-focused care i.e. hospital acute care (funded) and care without cure i.e. palliative care (not funded). Chronic conditions and dying persons are palliated but not ultimately cured. This distinction (cure/care) is based on the nature of the disability giving rise to the need, and is arguably discriminatory under section 15 as discrimination based on disability. If caring for a patient is as important as curing the patient (and it should be); palliative care should be included as part of “insured services” under the CHA.

Home and Long term care:

- Adequate Home care is foundational to transforming Canada’s health care system.
- Home care delivery within a continuing care system relieves burdens on the acute care system.
- An adequate home care system is an effective way to care for people with chronic conditions in a way that is good for patients and families, as well as being cost effective.
- At present home care systems are often fractured and services inadequate to meet patient needs. In the absence of national standards and adequate funding; seniors, persons with disabilities and chronic disease, as well as those in need of post acute care, are falling through the cracks, ultimately costing the system more money as people who could live at home with adequate support are forced into institutional care.

- Local long term care residences are needed as part of the continuum of care to provide care for people with complex health needs close to their own community.
- Long term care facilities would ease the burden on the acute care system which is presently housing people who would be better cared for in LTC, however the shortage of LTC beds makes this impossible.
- Additional LTC facility infrastructure is badly needed in the face of an aging population and increasing chronic conditions including significant growth in the number of people with dementia. Government and local communities need to plan ahead to meet future demand.
- The different levels of government need to collaborate on developing national standards for home and long term care.

Family Caregiver Support:

- Family care givers provide a substantial amount of care, some 70% - 80% of care given in Canadian homes and communities, worth an estimated \$25 billion per year. Family and friends have been described as the invisible backbone of the Canadian healthcare system. Canada like so many other nations must undertake the task of surveying and tackling caregiver issues. Family caregivers are essential to sustaining our health and social care system.
- It is necessary to find ways to support caregivers and conserve this important social resource. Care giving can often place people in grave financial hardship, especially when forced to quit their job while caring for a loved one.
- Family caregivers face significant physical, emotional and financial stresses in carrying out their tasks. Caregivers need recognition and support (financial, informational, emotional, respite, legal, etc.) in carrying out their care giving role.

Part 2 -- Suicide Prevention:

- At least ten Canadians die by suicide every day, almost 4000 every year.
- Suicide is the second leading cause of death among Canadian young people aged 10-24.
- Suicide rates among aboriginal young people are five to seven times higher than among non-aboriginal youth.
- Suicide has devastating impact taking its toll in shortened lives, grieving families, friends and communities.
- **Suicide can be prevented.** Suicide intervention does save lives. Yet suicide prevention and intervention is a patchwork in Canada mostly depending on the generosity of volunteers.

A Public Health Approach to Suicide Prevention:

- Suicide is a complex phenomenon with multiple intertwined causes, resulting in the need for a multi faceted approach to finding effective solutions.
- A **public health approach** emphasizes **primary prevention** reducing risk factors and increasing protective factors, **surveillance and evidence based response** – careful **research** on causes, risk and protective factors, and on interventions that work, **multidisciplinary perspectives** to complex

problems, and a **community health approach** which focuses on problems from the perspective of the whole community and not only of individuals.

- Suicide is not reducible to a mental health problem, though mental health problems can be a significant factor.
- Significant reductions in suicide rates have been effected in various countries by such public health approaches as a) **toning down media reports** -- the way suicide is reported in the media b) **controlling facilitating factors** – i.e. substance availability and addiction treatment (drugs and alcohol) c) **Means restriction** i.e. various forms of gun control, detoxification of cooking gases, restricting access to poison substances, environmental controls such as barriers on bridges.
- Efforts to support the person at risk, to alleviate isolation and loneliness, to build a community ethos of social inclusion, are highly effective ways of reducing suicide risk in vulnerable persons.
- Suicide risk detection and intervention is also a vital aspect of effective suicide prevention.

The need for a National Suicide Prevention Strategy:

- A National strategy and coordinating body are essential in order to mobilize resources in an effective way.
- Despite the centrality of Canadian expertise in developing UN guidelines for implementing National Suicide Prevention Strategies, suicide prevention in Canada remains fragmented, disconnected and lacking in an overall vision. In Canada we start from the disparate local parts without any idea where they fit into the big picture.
- Research is lacking as to causes, risk factors, protective factors, effective interventions, and evaluation of existing programs, resulting in suicide intervention that is done in an impromptu manner.
- Resources remain inadequate with no clear planning as to what is needed and how to implement needed infrastructure in an efficient manner.
- The Canadian Association for Suicide Prevention (CASP) developed The **CASP Blueprint for a Canadian National Suicide Prevention Strategy** in 2004. This document has helped many nations in developing their own national strategies, and would be an important starting point in developing our Canadian Strategy.
- The development of a national strategy is a collaborative process uniting communities, governments, and organizations in pooling resources and in coming to understand and respond to suicide in a unified and effective way. It is a catalyst to research and action.
- A National Suicide Prevention Strategy encompasses a wide range of issues with a few mentioned below:
 - 1) Suicide Prevention requires a **public awareness campaign** to teach that suicide is a significant problem that is preventable. Awareness is a key to suicide prevention, and a social marketing campaign needs to be carefully planned for maximum effectiveness.

- 2) Broad based support for suicide prevention needs to be developed among organizations and groups across the social spectrum. These groups provide the back bone of suicide prevention efforts.
 - 3) Stigma about suicide intervention and mental health issues needs to be overcome.
 - 4) The media needs to be educated on the most effective ways to deal with suicide.
 - 5) Sustainable community-based suicide prevention programs need to be developed across the country.
 - 6) Suicide intervention infrastructure is desperately needed, as well as long term social support infrastructure for isolated, depressed, and suicidal persons. Funding is virtually nonexistent at present with what intervention there is, being largely the result of volunteer efforts.
 - 7) Training is needed for risk recognition and effective intervention by gatekeepers, volunteers and professionals.
 - 8) Bereavement support is needed for families, friends and communities affected by suicide.
 - 9) Surveillance systems and research are desperately needed to deepen our understanding of suicide and of how to effectively intervene.
 - 10) Knowledge translation is vital to bring important research to the attention of front line suicide interveners, who need effective ongoing training and support.
 - 11) Strategies to reduce the availability and lethality of suicide methods are essential, as is work to strengthen protective factors (personal/social/cultural factors making it less likely a person will attempt suicide)
- The **federal government** has a key role to play in suicide prevention and intervention efforts: providing national health surveillance/statistics, health research funding, having an important role in public health awareness campaigns, facilitating collaboration between the various levels of government and the wider society, as well as having primary health care responsibility for several sectors of society particularly vulnerable to suicide including aboriginal people, those in the military, and inmates of federal prisons. Federal leadership and coordination is vitally needed if we are to succeed.
 - Working together in a coordinated manner many lives can be saved. Suicide prevention has been successful in many nations, and the time has come for Canada to seriously address this problem. A national strategy for the prevention of suicide is long past due.

Part 3 – Elder Abuse

- Between four and ten percent of seniors will experience some form of abuse during their lifetime and this may underestimate the extent of the problem as most abuse is never reported.
- Any senior can become the victim of abuse. Abuse is often committed by someone known to the victims including family members, friends, caregivers, neighbors, landlords, or persons paid to carry out work for them.
- There is a lack of accurate statistics in Canada. A large population based survey of elder mistreatment is badly needed. The only detailed survey on elder abuse is from 1989; hence prevalence statistics are extremely outdated. The *National Initiative for the Care of the Elderly* (NICE) has just **done the preparatory work** for a national prevalence study, work commissioned by *Human Resources and Skills Development Canada* (HRSDC), and could do a prevalence study if given the necessary funding.

- Much of what we know of elder abuse comes from anecdotal evidence. The report recounts some representative stories from across the country, putting a human face to the numbers.
- Abuse takes many forms ranging from physical violence, sexual abuse, psychological abuse, financial abuse, neglect, and various forms of institutional abuse. Some cases are remarkably tragic, but even lesser forms of abuse leave wounded, frightened people.

Causes of Abuse:

- The **ecological approach** is a powerful paradigm recognizing the complex interplay of **individual factors**, **relationship factors**, **community factors**, and **societal factors** in elder abuse. Violence is a multifaceted problem with biological, social and environmental roots, which all need to be considered in effective intervention.

Canada's agenda against elder abuse:

An adequate response to elder abuse requires a number of things, to occur simultaneously.

- A **public awareness campaign** would be needed to continue the important work of the Federal Elder Abuse initiative. It would need to speak with one voice, with Federal, Provincial and Territorial governments collaborating in delivering a common message that abuse of older persons will not be tolerated anywhere in the country.
- **Primary prevention programs** based on research into risk and protective factors would work to develop support networks countering isolation among seniors and caregivers, provide needed information about abuse and also about care giving issues, and finally engage seniors in the wider community, promote volunteering etc.
- **Intervention and Advocacy** is the area of greatest need, with the demand far outstripping the infrastructure available to help abused seniors. With a lack of dedicated services available abused seniors are falling between the cracks. Needs include legal services for low income seniors, emergency safe shelters for short term protection of abused seniors, as well decent long term housing, and adult protection services properly resourced to make effective protective interventions. Also needed are multi disciplinary teams to deal with the complexity of cases. Training of first detectors/responders, as well as ongoing training for adult protective services is a tremendous need.
- **Strengthening the legal response to abuse** is essential if the public is to be aware of the true seriousness of elder abuse. Seldom are abuse cases successfully prosecuted, and when they are, sentences are often a token 'slap on the wrist'. In order to improve prosecution of abuse cases, designated police units are needed, forensic expertise needs to be developed (medical, psychological and financial) to support police in preparing cases, and ongoing training of frontline officers in elder abuse detection and intervention must become standard. Judges, Crown prosecutors, and the wider legal system also need to be educated about elder abuse, and the legal system needs to be more sensitive to the needs of vulnerable victims (seniors, those with cognitive impairments etc.) throughout criminal proceedings.
- The **Restorative Justice** approach can provide an important tool in dealing with less serious abuse cases, in a way that works to repair harm -- with a focus on forgiveness, healing and restoration of relationships, while recognizing the need for true accountability for wrongs done. Restorative justice to be effective requires proper program resourcing, and is not always suitable due to power imbalances between the victim and the abuser.

Financial Abuse:

- A vigorous response to **financial abuse** of seniors is needed, as the asset rich older baby boomers reach retirement age in significant numbers. Their children with some of the highest debt loads in history, and a generalized sense of entitlement, can be tempted to look at their parents' nest egg as a potential source of capital.
- Financial abuse by way of manipulation and undue influence in relation to wills and bequests, fraud or forgery of documents, power of attorney abuse, abuse of joint bank accounts, misuse of funds or property, theft, exploitation, scams, and credit card or debit card theft, (seniors entrusting their pin number to another who does their banking) are becoming very common. Often the perpetrator is a relative or acquaintance.
- Financial abuse is extremely harmful to seniors, with many who are at the end of their earning life being left destitute and dependent on the generosity of friends, family and state support, to survive. Research shows that financial abuse can have far reaching psychological and health effects on seniors, being a significant source of stress for the elderly victim.
- Public Guardian and Trustee offices around the country need sufficient resources to deal with the rising flood of financial abuse cases. The federal government can play a key role in working with the provinces and territories to develop inter-jurisdictional unity across Canada in regards to financial planning and protection laws.
- Financial abuse is difficult to identify and prosecute and will necessitate close working relationships between police, public guardian and trustees, and the financial sector.

Elder abuse is a serious, all too often hidden crime, which affects large numbers of Canadians. Its existence challenges our self understanding as a society of inclusion and respect for all, and requires collaborative work by all sectors of society. A cultural transformation is needed, in which abuse comes to be regarded as absolutely unacceptable. The complexity of elder abuse necessitates action on a variety of fronts, with careful coordination and collaborative effort. It is essential that we as a society take steps to protect and support those who are abused.

Part -- IV. A Disability Perspective on Health Care and Inclusive Community Living:

Due to limited Committee resources the Disability Perspective report is still in progress and will be released on completion, later in the parliamentary session.

Committee Recommendations

Palliative Care recommendations

Recommendation # 1: We strongly urge that the federal government re-establish a **Palliative Care Secretariat**, provided with adequate funding to conduct and support research, and to facilitate communication and collaboration between the various levels of government, and community stakeholders, for the sake of:

- a) Developing and implementing a **National Palliative and End-of-Life Care Strategy**.
- b) Collaborative development and implementation of national standards as a benchmark of quality palliative care.
- c) Coordination and dissemination of palliative and end-of-life research and information resources.
- d) Ongoing coordination and support as the Strategy is implemented in jurisdictions across Canada. (p.31)

Recommendation # 2: We recommend the development of a flexible integrated model of palliative health care delivery, able to take into account the geographic, regional and cultural diversity of Canada; while providing a funding mechanism to help the provinces and territories with implementation. (p.32)

Recommendation # 3: We recommend that the federal government provide stable funding to the **Pallium Project** and the **Canadian Virtual hospice**, two important examples of innovation; while developing an easily accessible venue for funding other innovative programs. (p.36)

Recommendation # 4: We recommend that the federal government either through Health Canada or the recommended Palliative Care Secretariat fund a national public awareness campaign on palliative and end-of-life care. An aspect of this campaign should be to encourage Canadians both to talk about end-of-life care, and go through the process of advance care planning. The Canadian Hospice Palliative Care Association (CHPCA) Advanced Care Planning program is an existing resource which could be utilized in educating the public about advanced care planning. (p.37)

Recommendation # 5: We call upon the federal government to strengthen the home care delivery program for First Nations, Métis and Inuit communities, developing home delivered palliative care resources, sensitive to community, cultural, familial and spiritual needs. Research, training and capacity building, are required for First Nations, Métis and Inuit peoples to receive the high quality palliative and end-of-life care they deserve. (p.39)

Recommendation # 6: We recommend the development of rural palliative care delivery within the primary health care system, utilizing home care services, and local long term care homes; allowing care to be delivered in or close to a person's home community. (p.40)

Pain Control Recommendation

Recommendation # 7: We recommend that the federal, provincial and territorial governments along with the various NGO stakeholders (i.e. The Canadian Pain Society) develop and implement a National Pain Strategy, to provide a unified approach in the delivery of pain control methods. (p.45)

Funding for Home and LTC Services Recommendation

Recommendation # 8: We recommend that the federal government in collaboration with the provinces and territories implement a right to home care, long term care and palliative care, for all residents of Canada, equal to the current rights in the Canada Health Act, to those services defined as “insured health services”, including hospital services, physician services and surgical dental services. (p.51)

Caregiver Support Recommendations

Recommendation #9: We recommend that the federal government expand the provisions of the E.I. based compassionate care benefit to a minimum of 26 weeks coverage. We further recommend that the benefit be given flexibility to allow partial weeks to be covered, allowing caregiver leave for episodic care giving needs i.e. 5 or 6 days a month to allow a parent to stay in hospital with a child as they undergo chemotherapy. We recommend that the qualifying criteria be changed from “significant risk of death” to “gravely ill” so as to allow the hope of caregivers to be kept alive when applying for the caregiver benefit. Finally the government should look at raising the maximum payment cap to a higher amount, more in line with the costs of living and care giving. (p.64)

Recommendation # 10: We recommend that the federal government establish a refundable tax credit for family caregivers, to help families, with the high costs of care giving. The Caregiver credit and the infirm dependent credit could be made refundable for caregivers below a certain income level. (p.64)

Recommendation # 11: We recommend that the federal government set up a Canada Pension credit for family caregivers, so that those who are long term unpaid caregivers receive annual pension credit worth half their average annual salary from the years leading up to full time unpaid care giving. The annual credit could have a maximum capped amount, and a minimum amount for those who had small incomes leading up to the care giving years. (p.64)

Suicide Prevention Recommendations

Recommendation # 1: We urge that the federal government establish a **Suicide Prevention Secretariat**, provided with adequate funding to conduct and support research, and to facilitate communication and collaboration between the various levels of government, and community stakeholders, for the sake of:

- a) Developing and implementing a **National Suicide Prevention Strategy**.
- b) Collaborative development and implementation of a training program with established national standards, for the training of suicide intervention personnel.
- c) Coordination and dissemination of suicide prevention research and information resources.
- d) Development of a national public awareness program on suicide and suicide prevention, including a social media campaign on reducing stigma towards suicide and mental health issues.
- e) Ongoing coordination and support as the Strategy is implemented in jurisdictions across Canada. (p.82)

Elder Abuse Recommendations

Recommendation # 1: We recommend that the federal government establish an **Elder Abuse Awareness and Prevention Office** with a general directive mandate, under the **Minister of State for Seniors**, in conjunction with HRSDC, Public Health Agency of Canada, Justice and the RCMP, for the purpose of facilitating communication and collaboration between the various levels of government, and community stakeholders, with a view to:

- a) Developing and implementing a **National Elder Abuse Prevention Strategy**.
- b) Promoting and funding research on the incidence, and prevalence of elder abuse as well as effective tools and responses.
- c) Coordination and dissemination of elder abuse information resources.

- d) Development of a national public awareness program on elder abuse and elder neglect including elder abuse prevention, detection and response.
- e) Ongoing coordination and support for groups working to prevent elder abuse across Canada.
- f) Working with the Ministry of Justice, Health Canada, Public Safety, the RCMP, and other federal departments, to coordinate an integrated federal response to elder abuse, including the development of a **National Forensic Centre on Elder Abuse**, needed changes to the criminal code, and improved data collection by Statistics Canada. (p.124)

Recommendation # 2: We recommend that the federal government provide core funding to:

- a) The Canadian Network for the Prevention of Elder Abuse (CNPEA), so as to enable CNPEA to promote and coordinate networks for the prevention and detection of and response to elder abuse across Canada.
- b) The National Initiative for the Care of the Elderly (NICE) to continue work of the *Elder Abuse Theme Team* to identify, pilot, and train diverse responders across Canada on evidence based tools for preventing, detecting and intervening in situations of abuse of older adults.

The Committee believes that Core funding for the non-governmental sector is a cost effective way of building needed infrastructure for the reduction of elder abuse. (p.124)

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Introduction:

About a year ago the MPs of the Parliamentary Committee on Palliative and Compassionate care began a journey, seeking ways to improve the care given to vulnerable and dying Canadians. Twenty four hearings, and hundreds of witnesses later, the Committee is ready to release a report of its findings. This was a daunting task. The numerous submissions presented to the committee, exemplify the profound concern Canadians have for compassionate care. The Committee is not a standing committee; but rather an all party group of MPs who conducted these hearings as a response to the deeply felt concerns expressed by Canadians for issues surrounding the way palliative and compassionate care is practiced. No budget was made available to bring people to testify. Despite this, large numbers of Canadians came at their own expense, to provide expertise and share their stories. These are the people who are directly affected by the practice of palliative and compassionate care; either as front line caregivers and the remarkable people for whom they provide care, or as people who already experience the vulnerability of various disabilities. End of life issues can involve suffering, and great hope, discouragement and resilience, creativity and compassion. Everyone will ultimately face their own mortality as we encounter our own fragility, and that of our loved ones. In that way, the issues involved in providing compassionate care are important to every Canadian.

Canadians need to decide together, how we as a nation will care for our citizens facing end of life. The members of the committee were humbled by the calibre of those committed to influencing the practice of care for vulnerable Canadians. We thank each one of you for your commitment to caring, and for sharing your stories with us as we seek to do our part on the federal level to move these vital issues forward.

The Committee dealt with four areas surrounding compassionate care: palliative care, suicide prevention, elder abuse and rights of persons with disabilities.

1) Palliative Care:

The first area is **palliative and end-of-life care**. We have included in this section of the report some reflection on how we as a nation care for persons experiencing aging and chronic illness. The best possible care for those who are dying must flow seamlessly from the best possible care of all Canadians, including persons experiencing aging, mental illnesses, disabilities, chronic illness, and acute and chronic pain. The dignity which must be accorded to a person as they approach death is a dignity which must be accorded at each stage of a person's life. There is an opportunity to offer much better ways of providing this care in the future. Although Canada can be proud of the achievements and efforts made, the task of providing quality end of life care for all Canadians has not yet been achieved.

2) Suicide Prevention:

The second area we dealt with is that of **suicide prevention**. Nearly 4000 Canadians end their lives by suicide each year. Suicide is the second largest cause of death for young men. Many tragic deaths may be prevented, if a national strategy for suicide prevention is developed and implemented that seriously addresses the social and mental health concerns that contribute to this tragedy. Suicide is a major public health concern. Sadly, Canada lags behind much of the developed world in terms of responding to suicide. While most western nations have or are developing national suicide prevention strategies, Canadians have not politically addressed this issue in a comprehensive and systematic way. It should be mentioned that the Canadian Association for Suicide Prevention (CASP) strategy, developed independently of any federal or provincial funding, has been used as a model for developing other national strategies worldwide. The time has come for Canadians to take an effective public health approach that addresses the tragedy of suicide. Proposals for dealing with the prevention of suicide are dealt with in the second part of this report.

3) Elder Abuse:

The third area addressed by the Committee concerned elder abuse. Elder abuse has been described as a silent epidemic in Canada, and although strides to prevent and stop elder abuse have begun, political will is required to consolidate these first steps, and eradicate all forms of abuse against elderly Canadians. Within this report, are guidelines to assist those working on the front lines to get the resources required for intervention, and research. Best practices need to be identified that can assist those who advocate for people experiencing abuse.

4) Rights of Persons with Disabilities:

The fourth area discussed by the Committee concerned the rights of persons with disabilities, particularly in the areas of health care and personal support. As more Canadians age and experience the onset of disability, this topic will have increasing implications for Canada's health and social care systems. We received some very important testimony, but have determined that we require more information before we can write this section of the report. While we will make remarks relating to the disability perspective, it is the hope of the Committee to issue a supplementary report pertaining to disability, in the next session of Parliament.

The Role of the federal Government:

The Committee acknowledges that health care falls under provincial and territorial jurisdiction. At the same time, the federal government has a number of significant roles to play around end-of-life and palliative care.

First, the federal government can offer vital *leadership* in the country by raising awareness of compassionate, end-of-life and palliative care issues and by drawing attention to the needs of both care receivers and caregivers. End-of-life realities represent a complex mix of health, social, emotional, legal and financial pressures. Care receivers and caregivers currently have only a faint voice on the public radar screen. With an aging population, we recognize the need to give voice – to their voice.

Second, while provinces and territories are responsible for the day-to-day delivery of health services, the federal government has a *standard-setting* capacity to ensure comparable access to a continuum of high-quality care for all Canadians. This function involves setting benchmarks for the provision of health services, ensuring accountability and enforcing existing legislation.

Third, the federal government is a significant delivery agent. As the fifth largest provider of health care in the country, it directly serves a substantial segment of the Canadian population including veterans, First Nations and Inuit people, the military, the RCMP and inmates of federal prisons. Like other Canadians, these groups deserve high-quality, community-based compassionate care, palliative and end-of-life care.

Fourth the federal government plays an important role in terms of the *financing* of compassionate, end-of-life and palliative care. There are two dimensions to this financing role. The first involves the direct support of health care services through general taxation and health-related transfer arrangements. The second financing component takes the form of indirect support by helping offset the extended health care and drug costs paid by individual Canadians. Tax measures such as the medical expense tax credit and attendant care credit are examples of this indirect financial support.

Finally, the federal government can play a crucial role in *knowledge brokerage*. This task involves support for research and the collection of relevant data. It also entails the identification and exchange of information around effective compassionate, end-of-life and palliative care interventions. There are many exemplary models throughout the country with neither the means nor methods to scale up their interventions. Canada can save significant time and resources if we build on good practice already tested. We need not start from scratch in every community to develop a robust compassionate care infrastructure.

Compassionate, end-of-life and palliative care affects every citizen in this nation. Both leadership and collaboration are required to advance the practice and delivery of compassionate care. The Committee believes that a coordinated national effort among many key players is essential if we are to attain our goal of quality end-of-life care for all Canadians.

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“We may or may not in our lifetime be accidentally hurt, develop a pathological tumour, or experience cognitive loss, but we will most certainly die. Despite technological advances in health care, we are by virtue of the human condition, all vulnerable. In a society that is increasingly scandalized by any human condition that is not powerful, beautiful and ruggedly independent... it is critically important that the Parliamentary Committee on Palliative and Compassionate Care keep in its view the fundamental moral questions about what kind of society do we wish to live, grow old, and eventually die in. How do we truly care for one another at the end of life? This is not the same meaning as how do we treat, or even cure others. Care speaks to relationship and a shared sense of vulnerability. How then are we vulnerable with one another, and stand with one another in times of need? These are some of the most important social justice issues in our time. The future of palliative and end-of-life care in this country will play an important part in helping shape our answers to these questions.” Covenant Health – Edmonton Alberta¹

Part 1

Palliative and End-of-Life care

“Each of us is fragile, with deep needs for both love and a sense of belonging. We begin and end our lives vulnerable and dependent, requiring others to care for us. ...In our states of dependence, our need cries out for attention and care. If this need is well received, it calls forth the powers of love in others, and creates unity around us, the gifts of the vulnerable to our world. If our cry and our need are unmet, we remain alone and in anguish. ...The danger in our culture of productivity and achievement is that we easily dismiss and ignore as unproductive the gifts and the beauty of our most vulnerable members, and we do so at our own peril, dehumanizing ourselves.” Jean Vanier – Founder of L’Arche²

Palliative and End-of-life Care:

Adequate palliative and end-of-life care becomes more essential as the numbers of Canadians requiring these services grows. Canada is not providing adequate palliative and end-of-life care for all who need it. Depending on where you live, only 16-30% of those who need it receive palliative care.³ 16-30% is a failing grade in any ordinary exam, how much more so in the context of our dying fellow citizens, friends and relatives.

Despite efforts made by palliative care providers, Canadians have a long way to go to meet our goal of quality end-of-life care. Canadians in all parts of our country should be able to get effective palliation of their pain and symptoms, and have their psycho-social and spiritual needs addressed.

“We may have forgotten in our evolution as societies, what communities can provide.” Catherine Yuill -- Colchester East Hants Hospice Society⁴

Palliative care requires the mobilization of persons and communities from coast to coast. Compassion has long been the hallmark of what it is to be Canadian.

“The essence of our caring society is to integrate all programs and services into one seamless system, to meet the health care needs of all citizens, using Health Canada’s social determinants of health as our foundation, and patient-centred care as our model. We need to ensure that the right person is receiving the right care, from the right caregiver, in the right way, at the right time, in the right place, for the right cost and for the right reasons for all Canadians.” Harry van Bommel – Toronto Ontario

The Section of the report concerning palliative and end-of-life care is set within the wider context of a description of the kind of health care system required to provide adequate care for the elderly, those with chronic conditions, those suffering with acute or chronic pain, mental illness, or a disabling condition. We deal first then with:

- 1) The question of patient centred care as a paradigm for all health care. Palliative care is the best existing example of truly patient centred care.
- 2) Health care integration, the development of a system of integrated continual care as a model of health care delivery in Canada, a model best suited for caring for people with long term chronic conditions.
- 3) Palliative care delivered from the perspective of an integrated continual care system.

I -The Context: The Health Care System and the Care of Vulnerable Persons

Canadians are united in their agreement that our health care system needs reform. Almost every presentation to this committee acknowledged the primary importance of having patient-centred care in Canada. The only health care, however, that offers such care consistently, effectively and across all jurisdictions is palliative care.⁵ This is all the more noteworthy in that much of our palliative care infrastructure was developed at the margins of the health care system, with little or no financial support, often as the result of grass roots community endeavour.⁶

Palliative care is based on patient-centred, family-focused, and community-based care of the ‘whole person.’ This philosophy of care already present in programs across Canada looks at the physical, psycho-social, information and spiritual needs of patients, and their families or support networks. Palliative care is, therefore, the chosen example for this committee of what is possible to address the needs of all patients in Canada, in all settings, regardless of their health care needs. This is especially true for our most vulnerable patients: those who have a terminal or life threatening condition, our elders who are too frequently abused physically and emotionally, our citizens with disabilities and those who are suicidal.⁷

Palliative care is not only the best model for caring for vulnerable and dying Canadians; it also embodies truths that could be transformative of our whole health care culture.

Canada has an expanding patient population with a growing number of people, of all ages, experiencing chronic conditions such as diabetes, eating disorders, arthritis and chronic pain. The palliative philosophy of care is needed to meet these needs, in urban, rural, and First nation communities, in the treatment of street people, those with mental illness etc. Patient-centred, family-focused and community-based care must become the fundamental framework for social and health policy decision making. There are proven successes which must be adapted and replicated across the country.

Palliative care provides a philosophy of care to transform that system. **The palliative care philosophy is person-centred, family-focused and community-based. The philosophy moves us from disease or condition specific care to person-centred care.** No longer will we refer to “the cancer patient in bed 4A” or “the heart patient going down to pre-op” or “the broken arm in 6B getting a cast.” As one doctor noted:

“Doctors need to move beyond the model of glorified mechanics changing parts and oil. Science and technique are important, but people are more important, and it is people who get sick. Sickness almost always goes beyond the purely physical, the purely “mechanical”. The mind, the heart, the will, the human, need to be put back at the centre of the doctor’s vocation.” Dr. John Meenan – Kitchener Ontario⁸

A movement away from disease-based models of care invokes an incorporation of Health Canada’s social determinants of health, as defined by the Public Health Agency of Canada. This model emphasizes the interconnected social and environmental components of health and demonstrates why a seamless system is necessary to ensure a citizenry with maximum health outcomes. Awareness that many factors effect human health is important. Simple things like encouraging physical activity via the ParticipAction program, ensuring that people unable to prepare their own food maintain healthy nutrition through programs like Meals on Wheels, and combating social isolation through opportunities to become involved in community activities; can have huge health benefits at relatively low cost. Very important is an awareness of the health literacy of patients, ensuring that healthy life style information, treatment and care instructions are explained in a way that is understandable to the patient and their caregivers. Health information needs to be translated into culturally and socially appropriate language best suited to the understanding of the recipient. The determinants of health are:

- 1) Income and social status
- 2) Social support networks
- 3) Education and Literacy
- 4) Employment/working conditions
- 5) Social environments
- 6) Physical environments
- 7) Personal health practices and coping skills
- 8) Healthy child development
- 9) Biology and genetic endowment
- 10) Health services
- 11) Gender
- 12) Culture⁹

II - The Integrated Continual Care Model:

“In order to undertake a national dialogue, we must use common terminology. For purposes of this brief, continuing care will be defined as: . . . an integrated mix of health, social and support services offered on a prolonged basis, either intermittently or continuously, to individuals whose functional capacities are at risk of impairment, temporarily impaired or chronically impaired. The objective of continuing care is to maintain, and when possible, improve the functional independence and quality of life of these individuals. The continuing care network is composed of a continuum of services available for individuals and their families according to needs.” Canadian Healthcare Association¹⁰

The demographic reality means that a hospital based, acute-care system was never, and is no longer, adequate for dealing with a predominance of chronic care needs; a new paradigm of care delivery is needed. ¹¹ Hospital based acute care is a necessity, but it is a continuum of a larger health care delivery system, that needs to be integrated into the whole. Building a new paradigm will require a concerted effort of all sectors of society. It will also require leadership. The federal government has an opportunity to build consensus between the provinces and territories in a national dialogue on how to meet the increasingly vocal demands of patients for enhanced, integrated and coordinated care. The federal role is vital both in terms of leadership from the pan Canadian perspective, illumined by careful health research (a federal role), and because the Canadian government is the 5th largest provider of health care in the country, providing health care to First Nations, veterans, the RCMP, the Military, and inmates of federal prisons.

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Senator Carstairs has consistently spoken of the problem of health care silos and need for integration. The health care system is fragmented into component parts that may not adequately communicate with each other. A fragmented system leads to fragmented care. People experiencing complex and chronic health problems, aging and disability etc.; are not best served in a disjointed health care system. Hallmarks of fragmentation include difficulties navigating the system; long wait times for medical consultations and diagnostic procedures, and undue hardship being shunted around from place to place. These added stressors have significant impact on persons already experiencing health difficulties, and are made worse when coupled with service overlap, repetition of tests, and difficulties in making transitions to different levels of care.

How delivery systems are organized and structured can have significant impact on how efficient and cost effective they are, and how effective they are at meeting people’s needs.

“It is, in fact, the integration of medical, health, supportive, community and residential institutional care into one system that is the essence of the continuing care model and is why it is such a good fit to the actual needs of people with ongoing care needs. We need to think in terms of integrated and coordinated systems of care, not just one or two services at a time such as home care or residential care. There is essentially no evidence that fragmented systems provide good care or are cost-effective.”¹²

Integrated care delivery includes home care, home support, community services, case management, mental health services, varied palliative care services, residential care and acute care. Being integrated into a coordinated system of delivery, appropriate substitution of more cost effective means of care i.e. homecare instead of more expensive residential care, can be made. It should be noted that home care for example, without administrative coordination may not actually save the system money, as there is no mechanism for cost effective substitution of services. Development of an integrated continual care model needs strong leadership, to avoid a derailment of the process through vested institutional interests.

A successful integrated continual care system needs: a) a single coordinated administrative structure at a regional and local level b) a single funding envelope c) integrated information systems (i.e. electronic health records) d) a single coordinated entry system, or multiple first entry points (i.e. emergency department, doctor’s office, community care clinic) that are immediately coordinated into unified care through common case management e) a system level of assessment (a common tool of assessment) f) a single system-wide client classification system g) ongoing system level case management (same case worker follows client throughout any needed transitions in the system – continuity of case management) h) good ongoing communication with clients and families¹³

The system must be redesigned so doctors are paid to communicate with patients. **“As long as success is measured by tasks completed and not by end results, we will continue to pay for numbers instead of patient centred care.”** Harry van Bommel – Toronto

Integrated Continual Care Systems have been shown to be cost effective

“Opportunities to study the impact of hospital in the home (HITH) service closure on hospital budgets are uncommon in the literature but provide important observational data to inform our understanding of the impact of HITH services on health services delivery costs at the system level. A home hospitalization program operating in Israel was closed following changes in government economic policy. The impact of the closure on hospital utilization rates among 45,000 beneficiaries aged 65 years and over was assessed. Closure of the HITH program resulted in a direct saving of \$US1.3 million dollars but was estimated to cost \$US6.2 million dollars in increased hospitalization; a ratio of direct increased costs to savings of 5:1.”¹⁴

Integrated continual care systems have demonstrated their effectiveness in various parts of the world. Ironically Canada was once a leader in this form of health care delivery, especially in the 1980’s through mid 1990’s. Programs in places as diverse as Italy, Denmark, the United States, Australia, New Zealand, and in our own nation in British Columbia; provide cost effective, and more importantly, care effective means of health care delivery.¹⁵

In Denmark where integrated care has been in place for some time; in the twelve year period from 1985-1997, while the U.S. experienced a 67% increase in per capita expenditures for continuing care, including both community and institutional care, Denmark experienced an 8% increase. For persons 80 years of age and older, the U.S. had a 68% increase, while Denmark had a 12% decrease in costs. As Hollander points out, Denmark reduced its nursing home beds during this period by 30%, while the U.S. increased theirs by 12%. **Savings were made through an increasing proportion of Danish people being cared for in the home.**¹⁶

Non professional home support services i.e. house cleaning and meal preparation, have proven to be cost effective.

British Columbia had a policy to cut back on home support services as a cost saving mechanism. Some health districts did and some did not cut back on these services. Those that cut out or drastically reduced home support services were found to have a significant increase in costs by the second and third year after cutbacks. These increases were not found in those health districts that maintained services. As Dr. Marcus Hollander notes: “Most of the differences in costs were accounted for by increased costs for acute and long term residential care.”¹⁷ A cutback in house cleaning and food preparation services, resulted three years later in an increase in illness and death among those not receiving support services, as well as a decrease in the ability to continue to live in their homes.

“People with ongoing care needs due to functional deficits clearly have ‘health’ problems and require ‘medically necessary’ care. However, the ‘medically necessary’ care services they require to maximize independence and minimize their rate of deterioration are, in large part, non-professional home support services. This does not seem to be recognized in the current policy debate. It is, in fact, the integration of medical, health, supportive, community and residential/institutional care into one system that is the essence of the continuing care model and is why it is such a good fit to the actual needs of people with ongoing care needs.”¹⁸

III – Palliative Care and an Integrated Care System:

The health care system would experience significant benefits through the implementation of an integrated continuing care system. This would include a commitment to provide, person-centred, family-focused, community-based, philosophy in an all encompassing vision of health care.¹⁹ Canadian palliative care programs provide a fine model for this care revolution. Palliative care principles must transform the ethos of the entire system, become the root of all care provided in acute, chronic and ongoing care. Once you don’t need to be dying to get excellent care, then palliative care philosophy will become the health and social care norm, not the poor orphaned cousin.²⁰

“Patients die in hospitals in wet diapers, alone, untouched, unspoken to; as staff work to deal with ‘curable’ patients.” Rose De Angelis, Director of Nursing West Island Palliative Care Residence – Montreal

Palliative care is a revolution in the vision of health care. It returns to a priority of the person, a priority of care; and for people facing a life-threatening or terminal illness, the palliative whole person care principles should be applied upon diagnosis in the disease trajectory. Palliative care delivery could be coordinated to the needs of the client in a much more seamless fashion, with for example the home care team introducing palliative principles from the very beginning of the care relationship. An integrated system makes this possible. Palliative care symptom and psycho/social/spiritual specialists would come into the care plan, as needed, in support of the regular care team. This would mean less disruption with the caregivers the client already knows. Should a person not be able to live at home until they die, palliative care in a LTC facility, or a residential hospice is needed. This could be seamlessly arranged by the client’s integrated continuing care coordinator. Palliative care becomes a gradual and normal transition within the continual care process.

By the nature of the continual care system there would be encouragement to keep the person home as long as possible, and close to home in a residence, or hospice in the patient’s community should a transition be necessary. This approach, so important to caring for people with chronic illnesses; dovetails naturally into palliative care, which is really an extension of good chronic care. In the management of ongoing chronic conditions and in the care for a dying person, palliation of pain and symptoms, as well as

psycho/social/spiritual care of the whole person, in the context of family and community, are the essence of good care.

The mode of delivering palliative care would be multiple, but integrated. There would be:

- a) palliative care in the home, delivered by regular home care staff, supported by palliative care specialist teams.
- b) small community hospices, allowing the person to stay close to home, while offering a full range of palliative care supports.
- c) palliative care delivery within nursing and LTC homes, delivered by a range of in house and visiting specialist staff.
- d) There would even be some need for palliative care expertise within intensive care settings (see below) as those dying from traumatic injury or other conditions in ICU settings likewise have a right to the best possible palliation of their pain, symptoms, and psycho, social, spiritual distress.

Capacity building is required on all fronts, to meet the health care needs of Canadians.

Home care is an important venue of Palliative care delivery. In order to be effective, it must be properly funded, and able to give sufficient support. As one woman from eastern Ontario noted, home care in her rural community offered only one hour of support a day. She wanted to keep her husband at home, but her own health made this impossible, as she had to look after him round the clock, without meaningful help or respite. With no meaningful home care services, she was unable to rest, and broke under the strain. If she had been given a few hours of support per day, she might have been able to keep her husband at home. As it was, her husband ended up spending the last weeks of his life in a ward of their small community hospital.

“Inequitable access to palliative care and home care supports across the country as noted in the Commission on the Future of Health Care in Canada and the recent Canadian Medical Association report card reveals that it does make a difference where one dies, and the kinds of services that will be available. We recognize that for the large majority of the time, palliation can be provided in the community, in the comfort of the patient’s own home. A sustainable and well resourced strategy must also include adequate home care and primary care supports, including pharmaceutical care. It is incumbent upon health policy makers that proportionate funding is dedicated to augment these essential elements of the health care system that has historically been under resourced. Yet it is important that we allocate funding appropriately to the place of care. It is not uncommon that patients earlier on in the disease trajectory when they are feeling relatively well will say they wish to stay at home until the end. However, as their disease progresses and their care needs increase so do their wishes (and those of their caregivers), change. Without giving people options for location of care and location of death as their circumstances change, we may risk over-emphasizing home care, which is counterproductive and potentially harmful. Home care rather needs to be situated as part of an integrated regional service delivery model. Until we are able to promote and develop integrated regional palliative care services in urban and rural areas across Canada we will continue to offer poor national palliative and end-of-life care, with a few isolated areas of excellence.” Covenant Health -- Edmonton AB²¹

The community hospice is an irreplaceable part in the development of integrated regional palliative care services.

“...There are over 200 residential free-standing hospices in the United Kingdom. There are 1300 of them in the United States and there are 30 free-standing residential hospices in Canada” Dr. Fred McGinn, Hospice Society of greater Halifax

Canada needs to develop its capacity for residential hospices. Provinces need to adequately fund the operating costs of these facilities. Hospices across the country spent enormous amounts of time and energy struggling to raise the funds to stay open. This time and energy could be better utilized in care giving, if governments would supply adequate funding. In the long run such funding would save money.

It costs \$600-\$800 per day to have a palliative care bed in the hospital. It costs \$200 a day to have a palliative care bed at home. It costs \$300 a day to maintain a hospice bed. In many provinces people are dying in acute care beds at \$1200 per day or more. It would be a cost effective policy for provinces to fund home and hospice delivered care. It would also move us a long way on our journey towards quality end-of-life care for all Canadians.

“We maintain that funding should be allocated proportionately where patients choose to live and eventually die – be it at home, in hospice settings, shelters, continuing care, or specialized tertiary settings.” Covenant health – Edmonton AB²²

While fully recognizing the importance of a range of palliative care options, the committee wishes to emphasize the ideal of caring for a person as close to their home and community as possible.

IV - Hierarchy of Care Environments:²³

“People need to live until they die. They need support to die as naturally as possible and in their own homes. Whenever someone has to leave this most valued care environment, there are compromises to their physical, emotional, spiritual and informational supports. We must be careful that these compromises do not become the norm. People should not assume that a free-standing hospice is always the most appropriate place to die. The hospice movement began because modern health care had medicalized death to the point that hardly anyone died at home anymore and their care often included unwarranted treatments and a painful, isolating experience for the patient and family alike.” Harry van Bommel – Toronto

The **hierarchy of care environments** identifies different locations where hospice care can be practiced. Level 1 is the most preferred and Level 8 the least. The hierarchy assumes that excellent palliative care can be practiced at levels 1-7. It is not quality of care that determines why level 1 is better. For many people Level 7 is the best location possible for them to receive good physical, emotional, spiritual and informational care. The higher the level, the greater the number of new people who enter a person’s life. The more strangers, the fewer the opportunities for one’s own family, friends, neighbours, colleagues and spiritual community to share in one’s final days. When one leaves one’s own home for care elsewhere, one grieves the loss of familiar people, and places; and begins “a kind of dying” because of this. Whenever we take away what is valued, we increase the expectation that someone will die sooner, rather than later. We increase the expectation that things are ending and there is less time for living, for loving, for sharing and for being a valued member of one’s family and community. Not everyone can stay at home. Each level has consequences that affect the fullness of one’s life until death. These consequences do not prevent us from using the expertise and loving compassion of caregivers at the different levels: but remind us that in the development of services for people who are dying, we should try to begin with levels 1-4, utilizing levels 5-7 as backups if needed. Level 8 must be completely eliminated from the regime of care.

- **Level 1.** The person who is ill lives at home and enjoys the natural supports of family, friends, neighbours, spiritual communities, and others; plus their own family physician and local health care providers. The fewest people necessary should provide basic physical care.
- **Level 2.** The above group with the added help of specially trained homecare staff.
- **Level 3.** Levels 1, and perhaps 2, plus community volunteers who understand the hospice philosophy of care and how to apply it (i.e. Community-based hospice programs).
- **Level 4.** The previous levels plus other community agencies that may provide other physical, emotional, spiritual and informational supports. This may include palliative care professionals from community agencies (extra visiting home nurses) or one’s local hospital.

- **Level 5.** At level 5 the patient cannot be taken care of at home and moves into another location of care: preferably this could be someone else's home, someone who is better able to care for the person with many of the positive aspects of levels 1-4 still available.
- **Level 6.** The person who is ill is moved to a free-standing hospice program where elements of levels 1-4 are still possible but may be under-utilized and replaced by the program's own staff and volunteers. The greater the extent to which one can use one's own community, family, friends and volunteers (and thus less professional staff) the better. [An interesting example is the free standing hospice in Nieuwkoop Holland. This hospice has the goal to be kept empty as much as possible. The philosophy of their local hospice program emphasizes helping people to stay home to as great an extent as is feasible. When a person does need a separate location for their last months or weeks of life, the family physician, home care and community volunteers, take care of the person at the completely volunteer administered hospice building.]²⁴
- **Level 7.** The person who is ill moves to a hospital with a specialized team and/ or palliative care unit. The quality and compassion of palliative care supports are similar, in many cases, as one would receive at home but the providers are mostly new people who share little common history with the person who is ill and, therefore, the naturalness of one's own community is somewhat lost. The caregiver roles that are played by family and friends are often reduced to "visitor" roles. In some cases, level 7 is the best that society and one's community has to offer and can provide many pleasurable days or months of care, however, it is a compromise from level 1 and must be regarded as that. We must never repeat the history of modern health care by medicalizing palliative care to the point where people continue to see their hospital as the best place to die.

Care beyond the pale:

- **Level 8.** Person dies in an acute care hospital, in a hospital without a palliative care program, or elsewhere without special attention to their needs. This is the level that the hospice care movement began to address in the 1970s and it is long past time for it to be stopped.

N.B. Palliative care programs within nursing homes or long-term care facilities may be a necessary compromise, to prevent people from leaving their "home" to go to a hospital where palliative care is not available. Palliative care programs in nursing homes or long term care facilities are not an ideal. An exception to this rule might be in rural and remote communities, where a lack of health care resources makes LTC homes very important local assets for palliative care delivery. A close knit community can offset some of the disadvantages of a long term care facility, through the presence of family, friends and neighbours, both as regular visitors, and as the staff of the facility itself. In a small community, the LTC home, while still an institution, is much more integrated into the wider community.

V - Medical vs. Community model of care:

"Nursing is a bridge to the community/caregiver perspective. Nurses are advocates fighting with the funders for what the patient and family needs." Judith Shamian, President CNA

Distinction is often made between a medical vs. a community model of palliative care. Historically palliative care developed at the margins of the health system, mainly through the efforts of volunteers, and the efforts of local groups to build community hospice programs, and community based home delivered palliative care programs.

The **community model** emphasizes care in the person's home, or in as homelike as possible a setting, in the person's community. The community model places as much care as possible in the hands of family,

friends and non professional volunteers; with professional and community supports as needed. Palliative care professionals whether symptom control specialists, or experts in psycho/social/spiritual care provide support. There should be no expectation that all families will care for their loved ones. This would not be reasonable, given levels of family dysfunction, geographic distances, internal family problems, career and financial considerations, abilities etc. To this end small community hospices are essential as well. In Vancouver for example, the model chosen is to build small five or six bed hospices throughout the metropolitan area. Small, local hospices keep people closer to their communities, closer to the life they knew before they got sick. They are more responsive to people's desire for a homey family atmosphere, in a way a large institution can never be.

The **medical model** emphasizes the central role of professional care teams, and the authoritative role of the doctor. Doctors, nurses, social workers, psychologists, spiritual counsellors, and a range of accredited specialists, become the central actors in the patient's care. While recognizing that whole person care is an ideal which encompasses physical, emotional and spiritual concerns, this medical understanding of whole person care is equated with the multi disciplinary professional team, not with the simple needs of people, most naturally attended to through the day to day interaction with family, friends and community. Accreditation, gold standards, training and certification become central to this perspective. Family and friends are certainly involved with their loved ones, even volunteers may be involved, but the focus of caring is centred in the professional team, and upon medical leadership. The care setting, though it may still be the home, or try to be home like, (i.e. a residential hospice); will still have more institutional professionalized dimensions imposed upon it. Desire to meet accreditation standards, for the sake of funding, health institution standards set by provincial health ministries, along with legal liability issues, are the basic drivers towards institutionalization within the medical model of palliative care.²⁵

There are valid aspects to each model. One wants well trained symptom control specialists. One needs access to the services of palliative care specialist teams for complex care support. Residential hospices are sometimes necessary for patients who can't be cared for at home. The training of palliative care volunteers is important. But each of these aspects of the medical model carries with it a price tag in terms of institutionalization of the process of care. Standards, accreditation, certification of various types, set up a culture which lessens the naturalness, and home like qualities of the dying person's environment; diminishing the role of the family and friends in care giving, and subtly sidelining them in terms of the naturalness of the family relationship.

The value of care for a person in their home, in as comfortable and natural an environment as possible, surrounded by family and friends, with little institutional and bureaucratic overlay, is already practiced successfully throughout the world and in parts of Canada. We need to find these successes and replicate them nationwide. There is a quiet tension between the two models of palliative care, and as the palliative care movement is gradually professionalized and adopted into the system of main stream health care, the virtues of the community model of palliative care risk being lost. These virtues are often hard to describe, because they are so much a part of everyday life that they often go unexamined. They are very real none the less, and their loss would be a tragedy. That said, elements from each vision can be successfully united into a truly patient centred vision of care.

“Dying alone or unloved seems to be a universal human fear. In democratic western societies many people have a sense of loss of family and community: relationships between intimates have been converted into relationships between strangers. That loss has had a major impact on the circumstances in which we die. Death has been professionalized, technologized, depersonalized and dehumanized.” Dr. Margaret Somerville, McGill University, Montreal²⁶

The Role of the federal Government:

The Committee acknowledges that health care falls under provincial and territorial jurisdiction. At the same time, the federal government has a number of significant roles to play around compassionate, palliative and end-of-life care. As stated at some length in the introduction, the federal government has 1) a vital leadership role in raising awareness of the issues, 2) a standard setting role, setting national benchmarks, ensuring accountability and enforcing existing legislation, 3) is the nation's 5th largest health care provider, 4) has a financing role, and 5) has an important role in research, data collection and knowledge brokerage.

End-of-life and palliative care affects every citizen in this nation. Both leadership and collaboration are required to advance the practice and delivery of compassionate care. The Committee believes that a coordinated national effort among many key players is essential if we are to attain our goal of quality end-of-life care for all Canadians.

Our first recommendation, the establishment of a Palliative care secretariat, is of fundamental importance. It was emphasized by virtually everyone who presented before us. A Palliative Care Secretariat encompasses the two things necessary for the advancement of palliative and end-of-life care in Canada. A renewed, adequately funded, **Palliative Care Secretariat** and a **National Palliative and End-of-Life Care Strategy** are the most important aspects of bringing quality end-of-life care to all Canadians. Research, education, national standards, everything else flows from the Secretariat, **working in close collaboration**, and from a strategy, **developed in close collaboration**, with the various levels of government and the many key players.

“Canada desperately needs a National palliative care strategy! Even Georgia, in the former Soviet Union, and Poland have national strategies. We also need a Secretariat to coordinate activities between government and community organizations. Canada once led the world in Palliative care and is rapidly falling behind for lack of coordination and leadership.” Dr. Jose Pereira –Head of Palliative Care Division, University of Ottawa; Medical Chief of Palliative Care, Bruyère Continuing Care and the Ottawa Hospital ²⁷

Recommendations for the Federal Government:

Immediate Priority

Recommendation # 1: We strongly urge that the federal government re-establish a **Palliative Care Secretariat**, provided with adequate funding to conduct and support research, and to facilitate communication and collaboration between the various levels of government, and community stakeholders, for the sake of:

- a) Developing and implementing a **National Palliative and End-of-Life Care Strategy**.
- b) Collaborative development and implementation of national standards as a benchmark of quality palliative care.
- c) Coordination and dissemination of palliative and end-of-life research and information resources.
- d) Ongoing coordination and support as the strategy is implemented in jurisdictions across Canada.

While recognizing the need for national leadership, there is a crucial need for close federal, provincial, and territorial collaboration in implementing good palliative and end-of-life care.

...

Our second recommendation is based on the outcome of collaboration and research. The collaborative effort led by the Secretariat, will involve the provincial, territorial and federal Health ministries, NGOs and relevant professional organizations. Health research is an important aspect of the federal mandate,

and the federal government would provide needed research funding. The Committee has touched on the second recommendation in the sections of the report on integrated continual care, and palliative care delivery within the integrated continual care system. The topic is addressed in the sections on First Nations and rural palliative care delivery. More research is still needed. **A flexible integrated model of palliative care delivery** is needed, a model which can form the basis of a nationwide capacity building campaign.

Recommendation # 2: We recommend the development of a flexible integrated model of palliative health care delivery, able to take into account the geographic, regional and cultural diversity of Canada; while providing a funding mechanism to help the provinces and territories with implementation.

VI - Recruitment, Capacity building, Media, Education, Research, and Knowledge Translation:

“We must commandeer the resourcefulness of our nation to care for the needs of our people.” Dr. Ray Hasel
– Montreal

With an aging population and an increased prevalence of chronic illness, the Canadian health care system finds itself in need of transformation to meet the new challenges. Established as a primarily hospital based acute care system, ordered to treating episodic illnesses, the system of care needs both redesign, and capacity development, if it is to meet the demands of the aging baby boomers. We are meeting less than 30% of the demand for quality palliative and end-of-life care. As the population ages, we will have to increase our capacity, just to maintain the status quo; and significantly increase our capacity, if we are to achieve our goal of quality end-of-life care for all Canadians. Our nation faces a serious shortage of geriatricians, palliative care specialists, pain control specialists, psychologists and psychiatrists specializing in the care of the elderly. We need to encourage students to choose these areas of health care, and to upgrade the training of existing health care professionals to include these skill sets.

To exemplify the urgency of our elder care needs, consider the impact of just one form of illness, Dementia, which is projected to affect a significantly larger percentage of the population in the coming years. We are short of long term care facilities and staff trained to care for persons with cognitive impairments. With the numbers of people with dementia projected to more than double in the next 25 years, these shortages will become critical, if we don't prepare ourselves now. By 2038 some 1,125,200 people are expected to suffer from dementia.²⁸

Dementia is just one issue. The demographic and population health realities must be taken into account in planning public policy if we are to meet these challenges. While the challenges are not insurmountable, they will require cooperation at every level of society, at all levels of government, in close collaboration with the health care stakeholders and the wider public.

“Research is important both in education and in clinical care. Research drives best practices in learning and in patient care.” Dr. Jose Pereira – Ottawa Ontario

Research is vitally needed:

a) at the social policy level, i.e. economic, legal, demographic, system organization, and jurisdictional issues; b) at the level of evidence based medicine, dealing with pain and symptom management, and issues in caring for people experiencing chronic conditions; c) at the public health level, dealing with ways to keep our people healthier longer and minimize patient abuse d) at the mental health level, dealing with the psychological issues impacting the well being of the elderly, including such issues as suicidal feelings, depression, dementia, and delirium. e) at the psycho/social/spiritual level, dealing with issues of grief and bereavement, human dignity, personal sense of meaning, etc and finally f) at the familial and

caregiver level, helping develop resiliency and coping skills in families and informal caregivers, as well as studying ways to give needed supports (financial, emotional, informational, respite etc.), to informal caregivers so they don't burn out, and so their health and well being are not seriously compromised through the care giving role. The Committee heard frequent testimony as to the need to:

- **Set up dedicated research funding for Palliative and End-of-Life care.**²⁹
- Develop a focused research agenda, dealing with the multifaceted aspects of good end-of-life care; including social policy, ethics, mental health, psycho, social, spiritual issues, familial and caregiver support and of course medical research. Research is needed on a broad spectrum of end-of-life issues, not solely medical ones.
- Create a clearing house of Best Practices information (through the Secretariat) so promising family and patient centred pilot programs and practices can be more easily adapted throughout the nation.
- Develop our understanding of health literacy, researching ways to convey health information so it is understandable to patients, caregivers and the general public. Health literacy is a major public health issue, as misunderstandings by the patient leads to non compliance in treatment, tests and appointments, unhealthy behaviour patterns, and difficulties navigating the healthcare system. Health illiteracy costs the system a great deal of money, in increased emergency room visits, poor personal health practices, and corresponding long term increases in chronic disease conditions. At end-of-life health literacy is important in patient and family decision making, as both adequate information and adequate understanding are necessary for long term care planning.

A Canadian Health literacy report found that:

- a) 60% of adult Canadians (ages 16 and older) lack the capacity to obtain, understand, and act upon health information and services and to make appropriate health decisions on their own.
- b) The proportion of adults with low levels of health literacy is significantly higher among certain groups: older adults, non-English/French speakers, aboriginal groups, and those with chronic illness and stress.
- c) Seniors tend to have the lowest level of health literacy suggesting that the aging process amplifies initial levels of education-based inequality.³⁰

Many of our end-of-life and long term care planning problems would be solved by better communication strategies, which make information accessible and comprehensible to patients, families, and health care proxies, during a period of great stress.

Palliative and Eldercare Education and Training:

"Given Canada's current shortage of geriatricians (there are fewer than 200 while the estimated need is for more than 600), it's essential to understand how we can better teach medical students the principles of elder care. As baby boomers move into their senior years, physicians will be spending half their time with patients over age 65." Dr. Laura Diachun – Schulich School of Medicine -- London Ontario³¹

Presenters forcefully urged the government:

- To work in close collaboration with the various medical, nursing and other professional colleges, to develop and implement a strategy for encouraging young people to enter and train in the palliative/end-of-life and elder care professions.³²

"At McGill, undergraduate medical students receive a mere 20 hours (approximately one-half of a three credit course) over 4 years in learning about palliative and end-of-life care. The educational programs for

nursing, social work and other key disciplines that complete the interdisciplinary palliative care team offer equally limited attention to this area of health care.” Dr. Bernard Lapointe, Eric M. Flanders Chair of Palliative Medicine, McGill University³³

Given the need for better palliative care training, presenters to the Committee urged the government to:

- Collaborate with various professional colleges and organizations, to meet the legitimate needs of Canadians; that doctors, nurses, and related professionals receive significantly more palliative/end-of-life and pain control training. The medical schools, nursing schools, pharmacy schools, and related professional schools need to significantly increase the number of hours spent on training in palliative care, pain and symptom management.
- Work for the establishment of protocols, which set substantive, enforceable, national standards of training, to be met by **all** our medical schools. Similar protocols need to be implemented; focusing on nursing, and other health care professionals.
- Fund the medical and other professional schools to transition into new palliative and pain control curricula.
- Work towards improving training of health professionals in communicating in a clear, understandable way, to the many patients, family members and caregivers who have a low level of health literacy.³⁴
- In addition the committee heard that medical colleges and physician organizations in collaboration with the various ministries of health need to develop specialist training in Palliative care, and official recognition of Palliative care as a specialty or sub-specialty.³⁵

As a way of focusing the implementation of palliative care into the training, vision, and research of the entire health system, it would be beneficial to incorporate hospice palliative end-of-life care into Canada's nine national health strategies. The federal government would play an important role in the discussion necessary for implementing palliative care principles into the national strategies on:

- 1) Heart Disease
- 2) Chronic Disease Management
- 3) Seniors
- 4) Canadian Partnership Against Cancer
- 5) HIV/AIDS
- 6) Diabetes
- 7) Lung Health
- 8) Aboriginal Health
- 9) Mental Health³⁶

Palliative care principles have much to offer in the development of each of these health care strategies. As we move towards a future of Quality End-of-life care for all Canadians, this palliative care vision should be extended to all those in need.

“Central to the challenge of providing adequate and equal access to palliative care is the lack of medical expertise available to meet the needs of the growing number of chronically ill people with complex symptoms. Because people are living longer with one or more chronic diseases, the holistic management of their symptoms for a good quality of life has become more complex and often requires specialist care. Palliative medicine provides such specialist care to people who are nearing the end of their life. ... There simply are not enough palliative care experts to provide the care and training needed to meet the needs of our aging population. ...In order to improve access to palliative care, we need to attract physicians to palliative care and ensure that they have the necessary medical expertise to provide much needed specialized pain management, scholarship and leadership. ... It is time to move forward in the development of recognized specialists in palliative medicine. ...Palliative medicine is recognized as a specialty, or subspecialty in many countries

including the United States, the United Kingdom, Ireland, New Zealand, and Australia.” Dr. Bernard Lapointe, Eric M. Flanders Chair of Palliative Medicine, McGill University³⁷

Innovative program trains medical students as hospice Volunteers

Dr. Valerie Schulz of the Schulich School of Medicine in London Ontario has developed a simple and effective way to get medical students interested in palliative care. Each year 12 students from the undergraduate program become hospice volunteers. Undergoing 30 hours of training, each being mentored by an experienced hospice volunteer; they visit clients in their homes. The experience is priceless for the future doctors, as it gives them a chance to meet and converse with people outside the clinical environment, and without the need to bring a clinical perspective to the relationship. They relate to the hospice clients as persons, learning how they feel and react to the prospect of dying. Friendships are formed, and lessons learned, which will be of lifelong value to the future doctors in terms of person centred care. The clients also are transformed, touched that a future doctor would care enough to spend time with them in a companion role. This program is worth emulation, and broader application. If larger numbers of medical and other healthcare students across Canada were able to experience one on one relationships, as hospice volunteers, the positive effects on our medical culture would be immense.

Knowledge Translation and Capacity Building

“Knowledge transfer is moving knowledge into practice. Evidence informed decision making, sounds reasonable and simple enough, yet policies and practices in the health system often lag well behind discovery, or do not take evidence into account in decision making.”³⁸

Knowledge gained through research needs to be translated into the practice of palliative care professionals; as well as into information for patients, families and volunteers. Knowledge translation is focused education. To this end we salute exemplary programs such as the Pallium project and the Canadian Virtual Hospice, as providing knowledge translation, education, and vital information, in a way that is both innovative, and cost effective.

The Pallium project:³⁹

The Pallium project began in 2001 creating innovative educational resources on Palliative care delivery, for remote and rural health care professionals. One of the earliest inter-professional educational initiatives in the country, Pallium sought to build capacity, by providing rural health providers with the tools they needed to build up community palliative care programs. The Pallium project utilizes the most advanced forms of communication technology, doing pioneering work with e-learning, utilizing pod-cast technology, as well as the tried and true hands on approach, through training seminars in remote and rural communities. Materials were developed through extensive collaboration with a wide ranging and interdisciplinary group of palliative care experts.

Between 2004 and 2006 phase II of the project received government funding of \$4.3 million and evolved into a “community of practice” working collaboratively with people across Canada, with the common goal to advance skills and knowledge in hospice/palliative care. Phase II continued to emphasize building up long term system capacity, through a range of local projects advancing outreach, education and professional development; focusing on knowledge management, work place learning, service development and innovative modes of collaboration. Emphasis was placed on improving supports to regional health authorities and community-based voluntary sector partners. 71 projects were implemented between 2004 and 2006. These were strategic investments to boost local capacity, with projects being implemented across the country.

In addition Pallium continued to do innovative research and to develop learning tools for physicians. **The Pallium Palliative Pocketbook** was released in September 2008 as a peer-reviewed, comprehensively-referenced handbook for health care professionals. It has been rapidly adopted as an authoritative

Canadian resource to assist in inter-professional education as well as daily, bedside decision-making about a range of palliative clinical issues. Ten thousand copies of the 2008 first printing are in circulation throughout Canada, with many being used by community practitioners who have limited palliative care resources or back-up. It is also widely-used in Canadian health care education. In late 2010, a second printing was commissioned with 7,000 copies being pre-purchased by institutions in the provinces of British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, Nova Scotia, Prince Edward Island and Newfoundland & Labrador.⁴⁰

The Canadian Virtual Hospice:

Going on line in 2004, the Canadian Virtual Hospice provides support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers, and educators. It uses a web-based platform to address information needs, in terms of palliative and end-of-life care. The Canadian Virtual Hospice gives people access to articles such as managing symptoms, accessing financial benefits, health system navigation and communication with health providers. The Virtual hospice pioneered an online exchange where both ordinary people and medical professionals can communicate with interdisciplinary palliative care professionals, expert in pain and symptom management, psycho/social/spiritual care, grief and bereavement issues, even a bioethicist, to address moral quandaries. Some 40% of the users of the Virtual hospice are medical professionals, who are seeking advice on complex cases; with the Virtual hospice being the largest repository of clinical tools in the world. One thousand people visit the web site every day, while to date the clinical team has answered more than 1200 questions, 40% from medical professionals, and 60% from patients and families. The Canadian Virtual hospice answers questions from all over Canada and around the world, having become a destination of choice for palliative care information. Ontario, Quebec, B.C. and Alberta are the largest users of the service.⁴¹ This cost effective venue for needed information on Palliative and end-of-life care, is an exemplary model of health care innovation.

Our third recommendation is addressed to the federal government, asking that two highly effective, innovative national projects be given the stable funding they need to continue their work. These two exemplary projects supply vitally needed information to people across Canada and around the world. Their irreplaceable work needs to be expanded, and their services advertised widely, so that countless Canadians and health professionals who don't yet know about them, can benefit from their resources.

Recommendation # 3: We recommend that the Federal government provide stable funding to the **Pallium Project** and the **Canadian Virtual hospice**, two important examples of innovation; while developing an easily accessible venue for funding other innovative programs.

National Public Awareness campaign:

Many Canadians think that palliative care is simply for cancer patients, and fear that palliative care is equivalent to giving up on life. **The benefits of palliative care** for any one with chronic, life limiting and terminal conditions need to be emphasized, along with the understanding that palliative care is not so much about dying, as about living the days one has to the maximum, free from pain and symptoms, in an affirming environment, surrounded by family and friends.

Canadians need to be educated about dying, **grief and bereavement**. These are universal human experiences that touch individuals, families and communities. They are primarily human not medical events.

Planning and communicating with one's family about medical and end-of-life decisions is a process that every Canadian should engage in. A public awareness campaign could place special emphasis on the informational needs of patients and families as they engage in care planning, and as they attempt to make informed decisions about care.⁴² Advance care planning must not become a process of bullying families

into the decisions their health care providers, and health care institutions desire, but rather a genuine dialogue on what is best for the patient. At the same time advance care planning requires information to be delivered in a way that is understandable to patients, families and caregivers. Low levels of health literacy means that information needs to be communicated to people in a more accessible manner, avoiding technical jargon, utilizing pictures and diagrams, and asking patients to explain what they have understood, to insure comprehension.⁴³

Supports for caregivers, including information resources, respite care, the EI caregiver benefit, and various tax benefits need to be widely known. Informal caregivers are the backbone of the health care system, and a public awareness campaign needs to make them aware that help is available in carrying out their vital role.

Recommendation # 4: We recommend that the federal government either through Health Canada or the recommended Palliative Care Secretariat fund a national public awareness campaign on palliative and end-of-life care. An aspect of this campaign should be to encourage Canadians both to talk about end-of-life care, and go through the process of advance care planning. The Canadian Hospice Palliative Care Association (CHPCA) Advanced Care Planning program is an existing resource which could be utilized in educating the public about advanced care planning.

VII – Thoughts and recommendations for Palliative care providers:

The following are not formal recommendations, but a list of ideas articulated during the hearings, that are worth reflecting on in the ongoing dialogue for developing palliative care in Canada.

- 1) Palliative care providers should reflect a family, not a disease model, an inter-professional team rather than a medical model.⁴⁴
- 2) Palliative care should not be regarded as an end stage crisis model of care; health professionals should strive to begin introducing palliative care from the point of diagnosis.
- 3) We must identify, establish, educate, and support social networks to help people who are chronically or seriously ill, disabled, dying and or bereaved. Social networks begin with family and friends, supporting this group with neighbours, occupational and community contacts.
- 4) **Health care system navigators** are needed, to guide individuals and families through the intricacies of the health care system. Navigators help with solution identification, decision making in crisis situations, consensus building between the family and care providers, the brokerage, implementation and review of care plans. Navigation is different than case management. It is driven by the family and patient's needs, not the health care system. It is knowledge transfer and translation. It is a family/person not a disease model.⁴⁵
- 5) **Health Literacy of patients and health communication by professionals** must be improved, with health care providers presenting health care information in an accessible manner, sensitive to cultural, social, and educational background. The elderly, minorities, persons with disabilities, persons with little formal education etc. often have a difficulty understanding complex jargon laden explanations of their health and treatment needs. Health communication ordered to communicating information at the level of understanding of the care recipient must become the best practice standard. This standard could perhaps be embodied in a standard protocol through Accreditation Canada.⁴⁶
- 6) We recommend building a national consensus on clear, unchanging terminology pertaining to end of life care. Confusion as to the meaning of terms, and even deliberate obfuscation of end-of-life terminology for political reasons, causes much unnecessary tension in end-of-life discussions.
- 7) We must fund and build capacity in those areas of palliative care that help individuals and families improve their quality of life in the non disease aspects of the dying process. Patients and families need help and encouragement, through the support of occupational and physiotherapists,

homemakers, volunteers, social workers, chaplains etc. These non medical supports help maintain the hope of both client and family during the care giving process.

- 8) It is important to respect the spiritual aspects of Palliative care and the role of spiritual caregivers, in a holistic approach to palliative care. The following thoughts on spirituality and chaplaincy are worth noting.

VIII - On Spiritual Care of the vulnerable:

“The experience of vulnerability at the end-of-life has many faces. Certainly, pain management issues and the myriad other manifestations triggered by the evolving disease pathology can make a person extremely vulnerable. But associated with these physical changes may come emotional and psychological stress in trying to cope with loss. A person may experience or anticipate the loss of dignity, self-esteem, or control. Many persons report a fear of being a burden, and becoming dependent on others. For some, the diagnosis of a terminal illness may be the first time one's sense of immortality may be shattered, representing yet another loss. It is not uncommon that these losses evoke deeper level questioning about meaning, spiritual beliefs, one's legacy in life, and the need for closure. While Canadians have a right to quality palliative care services to attend to their physical, emotional and psychological needs, ensuring this right is grossly incomplete unless hospice and palliative care programs also include access to spiritual care resources. One such resource is chaplaincy. Chaplains are invaluable members of the interdisciplinary health care team, ensuring we are able to provide for the person's total needs at the end-of-life. Together, chaplains, other spiritual care providers and volunteers are able to provide supportive presence and pastoral counselling, to listen to, and validate, the deeper level questions raised.” Dr. Gordon Self – VP Mission, Ethics and Spirituality -Covenant Health Edmonton, Alberta

The end of a person's life often raises profound questions as to the meaning of life, of the place each one of the myriad experiences that make up that life, had within the greater whole. There are questions from the past that were never addressed, relational issues requiring resolution, or perhaps just the respectful openness of a sympathetic ear. For those of religious faith, there are questions of moral fault and forgiveness, brokenness and redemption, hope and its consummation in a coming new life. These are realities that many people have a profound need to broach, particularly as their earthly life reaches its close. While not to be imposed, the right to spiritual support must necessarily be easily accessible for those who desire it.

“One essential support we can always bring to patients when there may no longer be aggressive treatment options available is simple presence, when questions of meaning, existential suffering, and loss may be raised. Doing this may challenge the health care providers own sense of helplessness and requires maturity and self-discipline to be able to enter a person's life at a time of great vulnerability, without proselytizing or imposing one's agenda. Chaplains bring a repertoire of evocative listening skills, non-judgmental, unconditional regard, and clinical experience, to effectively establish trusting relationships with persons, to attend to their deeper spiritual questions and to truly be present.”⁴⁷

In addition to support for the dying person, chaplains support family members through the day to day struggles of the dying process, and the bereavement period following a loved one's death.

“The ongoing presence of the faith community can bring tremendous consolation to persons at the end-of-life, perhaps even for some, giving them a sense of "permission" or freedom to let go. For those who belong to religious communities, chaplains can help connect or reconnect families to those communities, facilitate rituals and sacraments, lead prayers, and help plan funeral services. Many chaplains provide short-term grief counselling and bereavement supports, including memorial services to assist with the bereavement journey.” Dr. Gordon Self – Edmonton

IX - Palliative care delivery for First Nations peoples:⁴⁸

The Committee received several important submissions on First Nations Palliative Care. While enough to give us a sense of some of the problems, we did not receive enough testimony to get a clear picture across all regions of the country. We also did not receive testimony from Inuit or Métis groups. More work is needed on this important topic. We recommend that the re-established Secretariat spend time studying First Nations palliative care delivery in greater depth. Cultural diversity must be carefully taken into account, with a strategy flexible enough to respect cultural and spiritual needs, in the context of family and community.

All peoples in Canada want the choice to be able to die in their home communities. Due to lack of services in their local communities, however, most First Nations people end up being transferred to regional and urban hospitals, dying isolated from family, friends and community; in an environment which conflicts with deeply held cultural, familial and spiritual values.

“Given existing barriers and the lack of targeted funding, access to home and community based palliative care will remain limited for people living in First Nation communities unless palliative care programs are developed and integrated into existing local resources.” Holly Prince MSW. & Mary Lou Kelly PhD. – Lakehead University Thunder Bay, Ontario⁴⁹

By improving home care for First Nations communities, and by instituting first rate palliative care, Canada has an opportunity to become a leader on the world stage, an example to the world, of the kind of treatment that should be accorded to all Aboriginal peoples.

Recommendation # 5: We call upon the federal government to strengthen the home care delivery program for First Nations, Métis and Inuit communities, developing home delivered palliative care resources, sensitive to community, cultural, familial and spiritual needs. Research, training and capacity building, are required for First Nations, Métis and Inuit peoples to receive the high quality palliative and end-of-life care they deserve.

“Inconsistencies exist in how home care services are provided and delivered to First Nation communities across Canada. In addition, significant gaps also exist in the continuum of care when addressing the higher levels of needs, including palliative care, due to jurisdictional issues and lack of funding for these services.” Holly Prince MSW. & Mary Lou Kelly PhD. – Lakehead University Thunder Bay, Ontario⁵⁰

To build capacity for the delivery of adequate palliative care to First Nation people, research and education are required that is sensitive to the cultural uniqueness and resource deficits of these remote and rural communities. It is imperative that Canada dramatically improve health care delivery and chronic and end-of-life care for the elderly members of our rural and remote First Nation communities. We call upon the federal government to give special priority to the various recommendations that were given to the committee in this section:

- The need to fund ongoing research to develop a model of palliative care for First Nations communities that would be applicable across Canada.
- Implement a program of culturally appropriate palliative care education for First Nation community health and service providers.
- Develop a community based training program for local health care providers and community volunteers in First Nation communities for delivering palliative and end of life care. Such a training program would encompass e- learning, written resources, audio learning, and weekend training seminars. Home care professionals would work collaboratively in training volunteers.
- Assist local palliative care providers to develop supportive linkages to regional palliative care experts.

- Facilitate communication between local First Nations health care providers and outside palliative care experts via provision of needed communication technology and infrastructure in remote communities (high speed internet, video conferencing, virtual meeting technology).

“First Nations have grave concerns over the increasing number of Elders who are being placed in facilities outside their communities. First Nations feel isolated in provincial facilities and are often situated long distances from their families. This has a detrimental effect on their health and quality of life. ... First Nations have continually emphasized the importance of culture and tradition in the care of the elderly and disabled. This aspect has not been readily recognized or considered in many of the programs implemented by the various federal government departments. To ensure optimal health, the continuing care program and policies must ensure that clients receive effective, understandable and respectful care provided in a manner compatible with their cultural beliefs, traditions, practices and preferred language.”⁵¹ Assembly of First Nations

X – Rural Palliative Care delivery:

A significant number of Canadians, close to seven million people, live in rural areas and communities of only a few thousand people. If there is a form of “two tiered” health care in Canada it would be the distinction between urban and rural areas in terms of health care delivery. Canada’s health policy has emphasized urban centres, attempting to adopt urban models of health care to rural health care delivery. Certainly as vast an area as Canada, with a widely dispersed population, makes it extremely challenging to deliver health care to rural and remote areas. Creativity is required as we begin to address health care transformation from the rural perspective. Small communities have significant resources to bring about health care transformation. They come together more easily in times of crisis, cooperating together for the common goal. Faith communities, sporting groups, schools, and service clubs, provide powerful venues for action. People know each other and can get organized more quickly than in urban centres. We need to acknowledge this expertise and learn from it, supporting home grown initiatives for rural palliative and health care delivery.

“Rural health services often suffer from a lack of resources, including health care providers. Notwithstanding this lack of resources, rural people have expressed a preference to receive healthcare in their home communities; they do not want to travel to urban centres for care when they are dying.”⁵² Dr. Mary Lou Kelly – Lakehead University

Transportation is a significant factor in rural communities, and not only in remote communities. Consider a typical small town or village in Southern Ontario. If you are young, healthy and drive, a twenty five minute drive to the nearest city doesn’t seem far. Consider though an eighty year old woman, who never had or perhaps lost her driver’s license. If she has to go to a city 20 or 30 minutes drive away, for a medical appointment, or a test, this is a significant challenge. There is almost certainly no public transit, and a taxi, if available, is very expensive. If she has to enter a hospice or LTC home, in that neighbouring city, she is separated from her friends and family, many of whom would also not drive, or do so with difficulty. She may have lived her whole life in that small community, and to uproot her is no small thing. Health care delivery needs to take this into account.

Recommendation # 6: We recommend the development of rural palliative care delivery within the primary health care system, utilizing home care services, and local long term care homes; allowing care to be delivered in or close to a person’s home community.

Creative capacity building utilizing existing resources and health care professionals is important if we are to meet the needs of rural Canadians to good end-of-life care. A capacity building model of palliative care depicts “the process of developing palliative care as building up from the roots. It begins by assessing and strengthening available infrastructure, staff empowerment, the vision for change and collaborative

practice. Health care professionals use localised knowledge and skills to develop integrated palliative care programs that meet the unique needs of their community or long term care home.”⁵³

The stakeholders recommended to the Committee that governments and rural communities collaborate to develop a capacity building model for palliative care delivery. Such a model to be successful requires:

- Ongoing research into rural health care delivery from a systems perspective.
- Research on best practices as applicable to rural and remote palliative care delivery
- Development of hospice volunteer programs which both encourages volunteering in rural and remote areas, and supplies training needed so volunteers can be effective members of the rural palliative care team.
- Development of communication, networking, and information resources so rural health professionals can both link with specialists in urban centres for support on complex cases, and have access to up to date medical, and psycho/social/spiritual resources.
- Communications infrastructure to facilitate remote communication with palliative care specialists.

“Hospice volunteers have a vital role to play in supporting persons receiving palliative care and their families. Palliative care is not primarily a medical event. Volunteers can create a “culture of caring” that ensures that the social, emotional, and psychological aspects of dying are addressed which has an impact on the quality of life for those individuals who are impacted by death or dying. Hospice volunteers are valuable members of the palliative care team whether it is in a rural community or in long-term-care homes because they have time to talk and most importantly to listen.”⁵⁴ Dr. Mary Lou Kelly & Alesha Gaudet – Thunder Bay

- The Committee was told that the government should look at health care funding and revise the process to take account of the fact that dying is not just a medical event but requires enhancing and supporting community capacity.

“The whole community takes part in the dying process and supports the dying person and their family by meeting their social, emotional, spiritual and psychological needs. The need to build rural community capacity to support health services was a key finding of the federal Ministerial Advisory Council on Rural Health (2002)⁵⁵ Dr. Mary Lou Kelly & Alesha Gaudet – Thunder Bay

This aspect of community development through palliative care and appropriate supports from governments can be a stepping stone to addressing other community needs like the minimizing of elder abuse, suicide prevention, poverty etc. Once one model of mutual support is supported, it is easier to expand to other social determinant needs.

XI – Long term care facility Palliative care Delivery:

“Residents of LTC homes represent one of society’s most frail and marginalized populations who often struggle with managing multiple chronic conditions and social isolation. Within LTC, over 75% of residents have cognitive impairment, which creates additional challenges for providing care due to the related communication, functional, and behavioural problems that arise. Thus, people who are dying in LTC homes form a growing population that consists of some of society’s most vulnerable citizens who would benefit by access to palliative care programs that encompass disease management, address the physical, psychological, social and spiritual issues at end of life, issues of loss and grief, and practical end of life/ death management concerns of residents and their families.”⁵⁶ Dr Mary Lou Kelly & Alesha Gaudet – Thunder Bay

Long term care homes form an important part of the health care infrastructure enabling palliative care delivery in rural areas. LTC also plays an important role in caring for persons with dementia. It is necessary to develop high quality palliative care delivery for all persons residing in LTC facilities. It was recommended that:

- The provincial governments develop implementation models, a funding envelope, and capacity building support for palliative care delivery in Long term care homes. The same applies to the federal government in terms of veteran homes, First Nation facilities etc.
- The provincial governments in conjunction with the stake holders develop inter-professional pain management protocols for long term care homes, which address systemic barriers to pain management, educate the staff on pain control issues, and improve pain care communication between staff, families and residents.

Given that long term care facilities provide an important component of palliative care delivery in rural communities, it is necessary to facilitate the development of high quality small LTC facilities in rural areas.

“Small Seniors residences provide an important service, to many who want to live in a smaller homelike environment close to their community. Rural communities need smaller residential care facilities by the nature of their demographics. Yet the Canadian Mortgage and Housing Corporation (CMHC) won’t give loan guarantees for homes of less than 50 people. Without CMHC loan guarantees, banks require a larger down payment and much larger (sometimes double) the interest rate. This makes it difficult to finance small senior residences. CMHC policy is biasing the system against the rural elderly.” David Morris – Montreal Round table Dec. 17, 2010

- A recommendation was made to the Committee that the government of Canada change CMHC policy so as to give mortgage guarantees for senior’s residences of less than 50 persons. Such policy change would correct the systemic bias against the rural elderly, allowing small seniors residences to be more easily built in smaller communities. This would allow elderly people to remain in their home community, rather than being forced to leave to large regional facilities. Such a policy can only be regarded as facilitating legitimate choice for those who prefer to live in smaller residential homes.
- Another interesting recommendation presented to the Committee was that the government fund options for providing in-home services to home owners who will accept one to three seniors to come live with them, whether these are family members, neighbours or strangers who want to remain in an actual house rather than a facility, but can’t live in their own homes anymore. For these home owners there would be costs of renovating their homes to accommodate mobility and health care needs.

XII - Palliative care and the ICU:

“On the surface, Palliative care and Critical care would seem to be polar opposites- one discipline focused on fighting illness and saving lives with aggressive treatments, the other focused on providing comfort to a dying patient as they navigate through the terminal phase of their disease. Yet palliative care is playing an increasingly important role in the care of ICU patients. While we may be able to bridge the gaps in care that patients receive before they become seriously ill, some dying patients will always end up coming to the ICU. For this reason, Palliative Care in ICU must be a part of the continuum of end-of-life care linking community, Long Term Care, and acute care hospitals.” Canadian Critical Care Society⁵⁷

Clearly we must minimize **inappropriate** admissions to ICU. Admitting incurably ill patients to ICU is harmful both for patients and for the healthcare system.

- It is harmful to patients, who prefer to avoid ICU care at the end of life, and who, as a result, experience a lower quality of life when they die in the ICU.
- It is harmful to family members, who suffer higher rates of depression, anxiety, and post-traumatic stress disorder when their loved ones die in an ICU.
- It is harmful to healthcare workers, who suffer higher rates of emotional burnout and compassion

fatigue.

- It is harmful to the healthcare system, which must bear the higher costs of death in the ICU, and the strain of having ICUs working over capacity.

We should not underestimate the harms of dying in the ICU

Even when faced with a dire prognosis, some patients and family members will say that “We have to try life support, because if we do nothing then he/she will die.” The implication is that the patient will lose nothing in the attempt. In fact, most patients who die in the ICU experience very significant symptoms, including shortness of breath (90%), moderate to severe pain (56%) and moderate to severe anxiety (63%). In addition to physical suffering, there is a potential loss of dignity and well-being. Worse still, most ICU patients are unable to communicate; we may be unaware that they are suffering, and inadvertently doing everything we can to prolong it.

To avoid inappropriate ICU admissions the Canadian Critical care Society recommends:

1. Increasing the frequency and effectiveness of advance care planning (ACP).
2. Improve communication between health care providers and patients/families.
 - i) Develop and implement communication training for front-line physicians and advanced practice nurses.
 - ii) Use of communication competence as a quality indicator and a component of recertification.
3. Publicity and education about the limitations of life sustaining treatment, the harms of dying in the ICU, and the potential for comfort-oriented care to *prolong* life.

Palliative Care Teams do have an important but often unrecognized role in ICU

“Although professional organizations recognize the importance of palliative care in the ICU, most Canadian ICUs do not routinely consult Palliative Care Teams. The potential roles of Palliative Care Teams in ICU include advanced symptom assessment and management; appropriate interdisciplinary communication and collaboration with teams and patient/families; patient/family-centred decision-making, aligning treatments with goals of care, and transitioning from acute to palliative care; emotional, spiritual, bereavement and practical support for patients/families; and emotional and organizational support for ICU clinicians. Palliative Care Teams aim to bridge the quality gap between ideal end-of-life care and the reality of intensive care for many dying ICU patients. They blend the cultures of acute and palliative care to meet patients’ needs along their illness trajectory. And notably, they can do this *without* compromising survival or shortening life.”
Canadian Critical Care Society⁵⁸

Given that some Canadians will continue to die in ICU settings, it is important that we formalize the role of palliative care teams in ICU, so that patients may be given appropriate pain and symptom management, emotional and spiritual support. Families need emotional, spiritual practical and bereavement support, both during the ICU experience, and following the patient’s death.⁵⁹

XIII – Pain Management:

“People in pain have a right to fully adequate pain relief treatment. Indeed for the healthcare professional to act unreasonably in leaving a person in pain is a breach of a fundamental human right of the person. Physicians should not fear that giving adequate pain relief treatment is unethical or illegal; in fact, they should fear the ethical and legal consequences of not doing so. To unreasonably leave a person in pain is medical negligence (malpractice); and, I believe, in extreme cases, it should be treated as criminal negligence – wanton or reckless disregard for human life or safety. It is torture by wilful omission. But rights to pain relief treatment will, however, be nothing more than empty words unless treatment is accessible. We have

serious obligations to ensure fully adequate pain relief treatment is readily available to all Canadians who need it.” Dr. Margaret Somerville, Director of the McGill Centre for Medicine, Ethics and Law; Samuel Gale Professor of Law⁶⁰

Important Facts

- Some 6 million Canadians live with unrelenting and under-managed pain.⁶¹
- The risk of suicide doubles for people with chronic pain.⁶²
- Chronic pain is very costly, with estimates of direct health care costs for Canada being some \$6 billion per year.⁶³
- Chronic pain costs more than Cancer, heart disease and HIV combined.⁶⁴
- Canadians are often left in pain after surgery, even in our best hospitals.⁶⁵
- Inadequate control of acute pain is the leading cause of post-discharge visits to the emergency room and early re-admission to hospital.
- 90% of patients could obtain effective pain control yet only 50% get such treatment.⁶⁶
- Only 30% of ordered medication is given, 50% of patients are left in moderate to severe pain after surgery a situation which is not improving.⁶⁷
- Uncontrolled pain, slows the healing process, and depresses the immune system, leading to increased sickness and even shortened life span.⁶⁸
- Family members are deeply affected by the impact of a loved one’s ongoing pain.⁶⁹

“Poorly managed pain creates a pain cycle that spirals downward towards a life experience where people suffer both physically and psychologically. The cycle begins when pain prevents or interrupts sleep. Lack of sleep increases the experience of pain which in turn promotes distressing emotional responses of fear, anger, anxiety and stress. The ability to sleep is further compromised and the cycle begins again. If the pain cycle continues uninterrupted and its mechanisms are further compounded by isolation, global stress related to life and the lack of effective pain care, the person’s ability to cope deteriorates markedly. Their mood becomes gravely affected, they grieve the significant losses in their lives and they may experience depression for the first time in their lives which is directly attributed to their pain. For some this becomes a desperate, dark place where hopelessness and helplessness reign. For some no longer able to bear the life altering assault of pain, suicide becomes an option. The majority of Canadians with pain are neither familiar with the concept of the pain cycle nor have they had access to training in coping strategies that they can use to break the pain cycle.” (Submission of the Canadian Pain Coalition)

Pain affects a large number of Canadians and its effects are far from negligible. Pain, whether acute or chronic, has devastating effects on the quality of a person’s life, and the social and societal costs both economic and relational are immense. Pain control is gravely deficient in Canada. Acute pain is often poorly managed, despite the availability of pain management knowledge and technology. It is critical to treat acute pain adequately, not only to decrease suffering but to minimize the chances of the pain becoming a persistent chronic condition.

People in long term pain encounter stigma and shame, as others judge them as “malingerers and drug seekers”. They encounter work place difficulties when employers and colleagues, through lack of understanding, fail to make accommodations to enable them to remain at work. Insurance companies, Workers Compensation Boards, and other bureaucratic structures can be unsympathetic, presenting further hardships for people already worn down by pain. Health care professionals often fail to take seriously peoples requests for pain control help. Misconceptions about addiction to pain killers, and inadequate training in pain management, leave patients hard pressed to find meaningful help.

Pain Management Training:

Pain control training is inadequate for health care professionals. Professional schools give pain management a low priority, in terms of class room hours. It is a sad irony that veterinarians receive 5 times more education on pain control than do doctors who treat humans.

“A recent survey of pre-licensure pain curricula in health science and veterinary training programs across Canada has identified inadequate training about pain among health care practitioners. This survey included medical schools and faculties for training nurses, dentists, physiotherapists and occupational therapists as well as veterinary medicine programs. Only one third of the programs could identify time designated for mandatory teaching about pain. The mean total number of hours designated for pain teaching over the entire academic training program was 15 for dentistry, 16 for medicine, 31 for nursing, 28 for occupational therapy, 13 for pharmacy, 41 for physical therapy and 87 for veterinarians.”⁷⁰

Given the lack of pain control education, it is not surprising that physicians, nurses and related professionals, are not adequately equipped to deal with people’s pain control needs. This educational lack includes the technical side of pain control, and the complexities of interdisciplinary approaches needed to treat more difficult pain symptoms. It also involves changing a mind set, which refuses to see pain as a matter of utmost urgency. This mindset is found among many of our health care professionals, as well as in health policy circles.⁷¹

“It is disturbing that in Ontario, the largest province in the country, there is not a single interdisciplinary pain management program that is fully funded by the Ontario Ministry of Health. At present wait times for care are greater than 1 year at over one third of publically funded pain clinics in Canada with vast areas of the country having no access to appropriate care. Patients waiting more than 6 months from the time of referral to assessment experience deterioration in health related quality of life, increased pain and increasing depression. In addition to contributing to ongoing suffering, disability and diminished life quality, it has been demonstrated that uncontrolled pain compromises immune function.” (Submission of the Canadian Pain Society).

Pain Control is an area in need of immediate attention. There are a broad range of issues which need to be addressed if Canadians are to receive adequate pain control. Our recommendation is that all levels of government, the Canadian Pain Society, the various professional associations etc. must work together to develop a National Pain Strategy, laying out the blueprint of how we as a country can proceed towards the goal of adequate pain management for all Canadians. This strategy should not distinguish between cancer and non-cancer pain. Pain is pain and must be effectively treated. People with both acute and chronic pain must be included in the dialogue leading up to the development of the strategy. Fears of opioid addiction and drug abuse, while needing to be addressed, cannot derail the right of countless Canadians to receive adequate pain management. A nuanced approach is needed that balances the need to control restricted drugs, with the fundamental right of human beings to adequate pain management. Finally for a strategy to be effective it will require adequate funding over a period of at least ten years.

Recommendation # 7: We recommend that the federal, provincial and territorial governments along with the various NGO stakeholders (i.e. The Canadian Pain Society) develop and implement a National Pain Strategy, to provide a unified approach in the delivery of pain control methods.

- A research program needs to be developed, with the various levels of government working together to provide direct designated funding for pain control research. Such funding must be measured against expected outcome indicators, to ensure accountability and sustainability.⁷²

Our Committee was told of the need for the various levels of government to:

- Work closely with the Canadian Medical schools to assure minimum standards, and sufficient time dedicated to pain control training for pre-licensure medical students. Levels of training

should minimally be equivalent to that of veterinarians who currently receive more than 5 times the number of hours of pain control training as do human doctors. Such training should integrate patho-physiology, assessment and treatment of pain, in a way that prepares physicians to work within an interdisciplinary team context in treating more complex pain conditions.

- Ensure that similar improvements in pain control training are implemented in nursing schools, pharmacy schools, and related health care professional programs.
- That the Royal College of Physicians and Surgeons allow pain control medicine to become a fully accredited program of specialist training. Financial and other inducements should be given to medical students to enter this field.
- That the College of Family Physicians of Canada and the Provincial Colleges of Family Physicians, begin work to develop pain control protocols and training curriculum for the continuing education of primary care physicians. The majority of pain control support will always come from family physicians. Primary care is the key to a sustainable service model.
- That special billing codes and other incentives should be set up by the provinces and territories, to encourage family physicians to spend the needed time to take care of patient's pain management needs. Adequate pain management is often a very time consuming process, a fact which is not reflected in present provincial billing codes.
- A strong recommendation was made to the Committee that the federal, provincial and territorial governments include pain assessment and care in the upcoming 2014 Health Care Accord. The Accord should also contain the requirement that pain become the fifth vital sign, taken and recorded with the other four in the patient's medical chart
- It was also noted that governments must ensure that all health care institutions in the nation meet the **Accreditation Canada** (AIM –Achieving Improved Measurement) standards on pain control.⁷³
- Develop inter-professional pain management protocols for long term care homes, which address systemic barriers to pain management, educate the staff on pain control issues, and improve pain care communication between staff, families and residents. Various international consensus statements exist to guide this work.⁷⁴
- It was strongly recommended to the Committee that the federal government change the definition of medical practitioner under the Controlled Drugs and Substances Act (CDSA) to include **Nurse Practitioners**. This would allow properly qualified nurse practitioners to prescribe narcotic pain control medication. Nurse practitioners would be a great help in facilitating better pain control, particularly in remote and rural areas, LTC homes, and in hospice and other palliative care settings. With the ability to prescribe, nurse practitioners would also be excellent leaders of palliative and pain control interdisciplinary teams, especially in homecare environments.
- That the federal government formally recognize the **Declaration of Montreal** and its acknowledgement of good pain control as a fundamental human right.⁷⁵

The fundamental dignity of the human person should elicit from each of us and from society in general, a compassionate response seeking to alleviate suffering.

“One of the most rewarding things that can happen to a doctor is when you take someone who has been in deep pain for months, not able to sleep, and you take away that pain. When they finally can fall into a deep sleep, one realizes that this has been a great privilege to be involved.” Dr. Ray Hasel – Montreal – Pain control specialist

The following considerations given to the Committee are also worth reflecting on.

1) Official recognition of serious chronic pain as a medical condition or chronic disease. This will promote an attitudinal shift about pain which will resolve issues surrounding access to pain management and promote a greater willingness to invest in pain control. That the provinces and territories ensure chronic pain is integrated into chronic disease management primary care redesign initiatives.⁷⁶

2) Provincial and territorial governments provide adequately funded regional pain control hubs, so that complex pain conditions are assessed and managed in a timely fashion. Regional pain control centres could provide mentoring and technical support to local doctors and nurse practitioners, as they attempt to address pain issues in the local community. More complex cases could be referred to the regional pain control centre.

3) Law reform commissions, medical associations, and other professional bodies might consider what clarifications to our laws, and to the code of conduct of various professional associations, might be necessary, to ensure that physicians who through carelessness, or failure to exercise due diligence, are responsible for patients living and dying in untreated or seriously undertreated pain; can be effectively disciplined.

4) Law reform commissions, legal and public policy experts, as well as pain control clinicians, consider collaborative development of nuanced protocols that deal effectively with prescription drug abuse, while not preventing and discouraging physicians from giving adequate pain medication to patients in need.

5) Health care practitioners were urged to recognize the foundational importance of adequate pain control, an importance based upon the dignity of the human person; a fundamental right of the person to have unnecessary suffering alleviated. We urge health care professionals to treat pain as a “5th vital sign”, and to regard pain management as a central aspect of their vocation.

“To cure sometimes, to relieve often, and to comfort always -- this is our work. This is the first and great commandment. And the second is like it - Thou shalt treat thy patient as thou wouldst thyself be treated.” Anonymous

XIV – Legal and Human Rights Perspectives on Palliative Care:

“Palliative care is part of a movement for fundamental justice and basic human rights for citizens facing the last fragile stage of life. It challenges narrow, impoverished and dehumanizing ways of dealing with dying. It calls for the building of a culture of care, dignity and support for men and women as they pass from family, friends, and wider communities they have worked, loved, struggled, and contributed to in many known and unknown ways.” Dr. Daniel Cere – McGill University – Montreal⁷⁷

Fragility is a universal feature of human life, we all face our fragility at some point, yet it is a reality that most people wish to ignore. When one is young and healthy, successful and at the peak of one’s powers, it is easy to forget about the contingency of human life; and it is common to try to insulate oneself from any reminder of life’s basic uncertainty. Public policy too tends to be insensible to human fragility. Unintentionally, vulnerable members of society often recede to the margins of the consciousness of public officials, civil servants, and policy makers. There are a range of reasons why this happens. Policy makers by definition focus on developing policies that fit the majority of people. Public policy decisions reflect a compromise amongst a cross section of groups, none of whom are particularly vulnerable, and none of whose economic and political interests naturally coincide with those who are. The most vulnerable in society are not part of the day to day experience of policy planners.

“Each of us is fragile, with deep needs for both love and a sense of belonging. We begin and end our lives vulnerable and dependent, requiring others to care for us. Throughout our lives there are other moments of fragility and dependence. In our states of dependence, our need cries out for attention and care. If this need is well received, it calls forth the powers of love in others, and creates unity around us, the gifts of the vulnerable to our world. If our cry and our need are unmet, we remain alone and in anguish. The vulnerable people, whom your committee is called to reflect about caring for; are often in a precarious state mentally or physically or both. They are often in anguish. The old, those living with illness and perhaps near death, those in depression and with a sense of despair, those living with disabilities; these are all people living in a most fragile state. The danger in our culture of productivity and achievement is that we easily dismiss and ignore as unproductive the gifts and the beauty of our most vulnerable members, and we do so at our own peril, dehumanizing ourselves.” Jean Vanier – Submission to the Committee

Human rights Declarations seek to overcome our natural lack of awareness of the needs of vulnerable persons; reminding us that every human being has a fundamental dignity that should elicit from us a response of compassion and a sense of profound identity in our shared humanity. They are a sign post as it were, pointing to a reality which we overlook to our own detriment, stirring us to consciousness of those basic responses that are due to each human person irrespective of their state, condition, or place in the social hierarchy. When the United Nations implemented the universal Declaration of Human Rights in 1948, it did so, with the recent past in mind; with recognition of what can happen when we are forgetful of the vulnerable, when we allow the fragile to slip from our consciousness. The document was not meant so much to be an enforceable code, as an aspirational beacon of what a human being is at their deepest core; of their grandeur and dignity, and what that should entail in terms of the individual and communal response.

Human Rights Declarations and Pain Management:

On December 10, 2008 the UN Special Rapporteur on the Right to Health, and the Special Rapporteur on Torture, noting the inadequacies of Palliative and Pain control care stated:

“The failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman, and degrading treatment. International human rights law requires that governments must provide essential medicines—which include, among others, opioid analgesics—as part of their minimum core obligations under the right to health. Lack of access to essential medicines, including for pain relief, is a global human rights issue and must be addressed forcefully.”⁷⁸ Earlier that year on March 11, 2008 Paul Hunt the Rapporteur on Health had noted:

“Many other right-to-health issues need urgent attention, such as palliative care. Palliative care includes pain relief for the terminally ill. Every year, millions suffer horrific, avoidable pain. Very few have access to pain relieving drugs. As always, those in the developing world suffer much more than those in the developed world. Six countries account for 79% of medical morphine consumption. But this is not just a problem of development. Lack of access to pain relieving drugs is partly due to regulatory barriers. Regulations aim to protect populations from drug dependence. But these regulations do not always strike the right balance between this legitimate aim and genuine medical needs. In short, palliative care needs greater attention.”⁷⁹

These two quotes are examples of clarifications made by UN human rights rapporteurs as they clarify basic human rights accords, including the Universal declaration of human rights which states in **Article 25.1** **“Everyone has the right to a standard of living adequate for the health of himself and his family including food, clothing, housing and medical care and necessary social services.”**

The International Covenant on Economic, Social and Cultural Rights in **Article 12.1** states that **“The state parties to the present covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”** Commenting on the Covenant the UN Interpretive Committee overseeing the ICESCR states in **General Comment #14: “In particular, states are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal**

access for all persons, including prisoners or detainees, minorities, asylum seekers and illegal immigrants to preventative, curative and palliative health services.”⁸⁰ The Committee goes on to note in the section on older persons, that there is a responsibility to give “**attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.**”⁸¹

These references to International Human rights accords and their official interpretation form the basis of a developing understanding of a fundamental right to adequate pain control and palliative care.

In 2003 for example the European Committee of Ministers in Declaration 24 stated that: “**Palliative care is an inalienable element of a citizen’s right to health care.**”⁸²

Earlier in 1999 the Parliament of the Council of Europe promulgated Recommendation 1418 (1999) **Protection of the human rights and dignity of the terminally ill and the dying** This document gave a ringing endorsement for the right to good palliative care. It noted among other things:

“5. The obligation to respect and to protect the dignity of a terminally ill or dying person derives from the inviolability of human dignity in all stages of life. This respect and protection find their expression in the provision of an appropriate environment, enabling a human being to die in dignity.

6. This task has to be carried out especially for the benefit of the most vulnerable members of society, a fact demonstrated by the many experiences of suffering in the past and the present. Just as a human being begins his or her life in weakness and dependency, he or she needs protection and support when dying. ...

9. The Assembly therefore recommends that the Committee of Ministers encourage the member states of the Council of Europe to respect and protect the dignity of terminally ill or dying persons in all respects:

a. by recognising and protecting a terminally ill or dying person’s right to comprehensive palliative care, while taking the necessary measures:

i. to ensure that palliative care is recognised as a legal entitlement of the individual in all member states;

ii. to provide equitable access to appropriate palliative care for all terminally ill or dying persons;”

⁸³

In Canada our Senate recognized palliative care as a basic right when in 2000, the Standing Committee on Social Affairs, Science and Technology titled their final report on Palliative care **Quality end-of-life care: The right of every Canadian.**

In 2011 Canadians must ask themselves what direction do we wish to take?

It is an interesting historical note that the first draft of what would eventually become the 1948 Universal Declaration on Human Rights, was written by a Canadian Law professor from McGill University John Peters Humphrey. Despite this, Canada initially abstained from voting for the declaration, and only at the very end reversed its abstention and voted in favour. As John Peters Humphrey would note at the time: “**This Declaration is the work of hundreds indeed of thousands, of people and it represents a synthesis of the ideas and convictions of the millions of people of all races and nationalities who spoke through them. ...The final judgement of history will be determined by the impact which the declaration has and will have on the actual conduct of states and of individual men and women everywhere.**”⁸⁴

Dr. Harvey Chochinov in addressing the Senate Committee in 2000 reminded each one of us that:

“Unfortunately, in end-of-life care, we do not have a vocal constituency: The dead are no longer here to speak, the dying often cannot speak, and the bereaved are often too overcome by their loss to speak.”⁸⁵

As worthy successors of John Peters Humphrey, let us be that vocal constituency for Palliative care.

Canadian Law and the Question of Palliative Care

Arguments for palliative care and pain control as human rights carry great moral force; yet in reality these rights are aspirational and not legally enforceable. Dr. Yude Henteleff Q.C. presenting before the Committee November 1, 2010 noted:

“The Supreme Court has in recent decisions determined that international treaties are not binding unless implemented in domestic law, and can only be referred to for guidance as to the meaning and interpretation of certain Charter principles.”⁸⁶

Dr. Henteleff contends that action towards better palliative care is best attained through either:

i) a Charter challenge, or ii) a change to the Canada Health Act.

The Canada Health Act (1984) sets the frame of reference for health care delivery in Canada. Its function is to establish the conditions and criteria that provinces and territories are to meet in order to qualify for federal funding under the provisions of the Canada Health and Social Transfer. With the objective of ensuring reasonable access to quality health care for all Canadians, without financial and other barriers, the CHA sets five criteria that must be met for insured health services. These are a) public administration, b) accessibility, c) universality d) comprehensiveness, and e) portability. Unfortunately the Act makes a distinction between medically necessary/insured services, and so called extended services. The medically necessary services must follow the five criteria in their delivery, in order for provinces to receive full federal transfers. Extended services are left up to the Provinces, to determine if and how they will be delivered.

“Extended health services are described in the CHA as services such as a) nursing home intermediate care service, b) adult residential care service, c) home care service, and d) ambulatory health care service. Extended health services encompass that broader “continuum of care” which would include services such as access to home and community care, long-term and palliative care, and are generally not considered as being medically “necessary” or “required”. Thus these services are not protected under the CHA’s 5 principles and the CHA does not require the provinces to provide funding for these services. ... This in turn leads to a patchwork of uncertainty across Canada.”⁸⁷

Original proposals for health insurance as early as 1945, had envisioned a broad range of services covered, including, doctors, hospitals, and home visiting nurses as a first stage. A second stage was to quickly follow with private duty nurses, dental care, pharmaceuticals, surgical appliances, laboratory services etc., being gradually phased in. Home care would have been a part of Canadian Medicare from the beginning, but unfortunately “earlier proposals crashed on the rocks of federal-provincial disputes, (and) a series of political compromises were made, which began with the most expensive parts of the system.”⁸⁸

As hospital and physician services were the most expensive, these became the core of funded services in a series of acts ranging from the 1957 Hospital Insurance and diagnostic Services Act, through the 1966 Medical Care Act, right up to the 1984 Canada Health Act. The Canada Health Act envisioned: “an illness oriented, hospital-dominated health system with a cure focus. Dying requires care but not cure, and it is only cure-focused care that appears to be insured under the CHA.”⁸⁹

Hospitals and physician services became the “medically necessary” insured services of the Canada Health Act, beginning as early as 1945. Technology gradually changed and services that had once been available

only in hospital could now be more cheaply and easily done at home. What began as a temporary political compromise, became an institutionalized philosophy in which acute care, hospital dominated, cure focused health care was seen as the only kind of health care that was medically necessary and insured under the Canada Health Act.

With an aging population and an increasing number of long term chronic conditions, the health philosophy of the Canada Health Act is both outdated and inefficient. We must change the focus of our health system to meet the health care needs of Canadians who require home and long term care, in an integrated continual care system; a vision of health care which does not fit within the Canada Health Act's outmoded criteria of what is insured. Home care, palliative care, and long term care, seem not to fit under the Act because of an implicit distinction between cure-focused care and care without cure. Chronic conditions and certainly the dying person are cared for, palliated, but not ultimately cured.

At this point Dr. Henteleff reminds us:

“A ‘cure’ interpretation of the CHA is arguably a violation of section 15 of the Charter; (the equality section) because of its foregoing limitation. The distinction (cure/care) is based on the nature of the disability giving rise to the need. That in my view is discriminatory under section 15 of the Charter since it is discrimination based on disability. It is my further view that this unjustified distinction lies at the very root of the health care system in Canada resulting in a systemic denial of the right to palliative care. What should replace the “cure” perspective? Quite simply, the provision of services should be determined on the basis of need and its having been so determined as medically necessary by a physician. If caring for a patient is as important as curing the patient (and it should be); palliative care should be included as part of “insured services” under the CHA.”⁹⁰

The Canada Health Act needs to be changed, so care which is not curative; palliative care, care of persons with chronic conditions, home care etc. can be covered. One of Canada's foremost palliative care specialists reminded our MPs at the Montreal Round table:

“When the Canada Health Act was implemented it was so every Canadian could have access to health care without being financially wiped out. Now we are saying that you must go back to charity to receive care when you are most in need. This goes directly against the spirit of the Canada Health Act, and creates a kind of health care apartheid for the dying in this country.” Dr. Bernard Lapointe – McGill University Montreal

Recommendation # 8: We recommend that the federal government in collaboration with the provinces and territories implement a right to home care, long term care and palliative care, for all residents of Canada, equal to the current rights in the Canada Health Act, to those services defined as “insured health services”, including hospital services, physician services and surgical dental services.

Stakeholders reminded the committee that the federal, provincial and territorial levels of government together with the medical and health care professional organizations, need to begin a serious rethinking of the philosophy underlying health care delivery in this country, to update it in light of the need for care as distinct from cure, for the growing number of Canadians with chronic conditions, chronic mental illness, long term disability, and those approaching death. The bias at the root of the Canada Health Act for curative care to the exclusion of care for those who can't be cured needs to be publically repudiated, perhaps in an appendix to the CHA. The inclusion of a philosophy of integrated continuous care would be a valuable supplement to the central document of Canadian health policy.

The Committee was encouraged to remind legal scholars, philosophers, historians, religious thinkers, human rights activists etc. to advance discourse on the dignity of the human person and his or her basic human rights. Writers and scholars need to further develop the human rights discourse in relation to a fundamental human right to adequate palliative and pain control care.

“We should look at palliative care under the rubric of a fundamental human right.” The Honourable Clifford Lincoln – former Quebec Environment minister – Montreal

XV – Home and Long term care and the vulnerable:

“Prolonged hospitalization often has devastating effect. Elderly persons rarely return home at the level of functioning of when they were first admitted. With bed rails up, and intravenous lines in, patients become bed ridden and deconditioned. On admission basic accessories such as glasses, canes or hearing aids are often forgotten, or worse, these articles are lost in the numerous transfers around the hospital that a patient endures. The nutritional status of patients often deteriorates over the course of their hospital stay due to declines in psychological well-being, difficulties in accessing food in sealed containers, or aversion to the taste and presentation of hospital food. A lack of coordination among the staff (e.g. untimely checking of vital signs or transferring patients in the middle of the night) can disturb sleep patterns and make it harder for the patient to function normally. Often the patient is so weakened that they cannot go home even after a medical crisis is resolved. Although attention to these details will help prevent deterioration, the benefits of keeping patients at home or shortening their hospital stay should not be underestimated.”

Dr. Ramona Coelho – Montreal Round Table Dec. 17, 2010

Home Care:

Home care is foundational to transforming Canada’s health care system. In reality it is a paradigm shift in our vision of health care. Allowing patients to stay at home has pronounced benefits for everyone involved, not least of which, the person being cared for in their own home and community. This is important as our nation seeks ways to improve the care of the elderly and vulnerable.

Hospital based acute care service had built up an institutional understanding of providing all encompassing care. This perspective needs to be reconsidered. A continuing care system can relieve burdens on the acute care system, in a way that doesn’t harm quality of care and perhaps even enhances it. This is not to deny the importance of surgical, diagnostic and specialist interventions, clearly the domain of the hospital. We now know that the majority of care that can be delivered to a person with chronic conditions in an institution can be delivered just as well at home. Home, family and community are too fundamental to the identity of the person, to be ignored in the basic care of the chronically ill or dying person.

Allowing patients to stay as long as possible in their home is a wise, compassionate choice, which should become a goal of public policy. The Romanow report noted the importance of developing home care to meet the needs of people for: a) short term post acute care, b) Palliative care, and c) mental health intervention and support. The Committee endorses these recommendations; but adds the important role of long term home care as a support for persons with disabilities and for persons with persistent chronic conditions.

“We need a well-planned expansion of homecare and education of health care workers especially in years to come. Creative collaborative systems of home and institutional care may actually relieve pressure on our public health care system. According to a SIPA research program conducted in Montreal, increasing, homecare services decreases or shortens hospitalizations and improves the patient’s, as well as their families’ quality of life.” Dr. Ramona Coelho – Montreal

In the late 1970s New York State developed an innovative program called Nursing Home without walls (NHWW). “The goal of NHWW is to reduce the human and fiscal costs involved in institutionalizing chronically ill persons while increasing the quality of life for individuals.”⁹¹

The fundamental idea was that NHWW home based programs should replace institutional care. Many argued against this holding that the approach would not be cost effective, would not provide adequate care, etc. Home care it was argued would not fit within the model of economies of scale. As Dr. Paul Sinclair notes however:

“While an institutional system dominates the landscape and a community-based system has to be built up, naturally the institutional system appears most cost-effective. This pretence of economy can then sideline the ethical imperative to address social devaluation, while community support alternatives are portrayed as unproven, simplistic and financially and clinically irresponsible.” He goes on to note that **“those for whom it is claimed institutional care is absolutely essential are the very people who benefit most from non-institutional care. Not only do the smallest improvements in care make the most difference for people with high support needs, but also it is they who suffer most from institutional care, especially via neglect and abuse.”**⁹²

Despite the gainsayers, Miller and Lombardi note that the Nursing Home Without walls program consistently cost about half of traditional institutional care.⁹³

“The practical achievement of NHWW with those with high support needs is impressive. Of NHWW patients, 46% live alone (Miller and Lombardi, 1991, p. 142). Miller and Lombardi describe a couple in their early sixties – the wife with ‘multiple myeloma and bone tumours that caused spontaneous bone fractures’, the husband with cancer of the colon requiring twice weekly chemotherapy. Nursing Home Without walls provided ‘personal care 12 hours a day, 7 days a week, and weekly nursing visits to monitor their physical condition. The NHWW nutritionist assisted with special diets, and a social worker provided supportive counselling’. The wife also received physiotherapy and both had emergency response alarms. ‘The husband and wife were able to remain in their home together despite the seriousness of their illnesses, until they passed away within weeks of each other.’⁹⁴

New York State adopted this innovative approach in 1977. It proved efficient, cost effective, and most importantly good for patients and families. Nursing Home without walls (NHWW) is one of many successful homecare programs found throughout the world, including Canada.

Another story of success was shared with the committee by a woman from Guelph Ontario. Her mother was able to die at home surrounded by her loved ones thanks to the excellent home care system in her native England.

“We were blessed to have the medical and care support that enabled mummy to die at home in her own bedroom. Each day brought its own laughter, tension and tears... These last days were the worst and the best that you could possibly want but the awesome opportunity to care for our mother in this way is a treasure that every child should experience. I had the extra gift of holding my mother’s hand as she died. I kissed her into heaven and my heart was filled with an indescribable peace. Our family spent five hours with Mummy after her death - crying, laughing, sharing stories about the last few days and our childhood. ...Mummy died at 12.25am on December 10th 2007 and we talked together in her room until 5.30am when she was taken from us physically. I think letting her go was the hardest - it finally made it real. ... Dying is a process and families need to be free to be able to make the ever changing arrangements necessary for the best care for the person dying and for themselves. For our family it meant being able to be together to discuss the options with our mother. Mummy was adamant that she should stay at home, yet each of us had professions and families and timetables of our own. We had to learn that you can still care for someone, even if you cannot do the caring yourself. One of my sisters had wanted to look after my mother’s personal care but it became very difficult both for the parent and the child. We thank God that the government covered personal care help in my mother’s home. Care-givers came in three times a day to look after my mother’s personal needs. While my mother was unsure at first she very soon became accustomed and welcomed these wonderful women into her life.”

The family was able to enter more deeply into their mother’s final days because:

- personal in home care was provided

- a 1 800 health help line was available
- the family physician would call on their mother after surgery hours
- a physician was on call every night to assist and give extra pain management if needed
- district health nurse teams would respond as often as needed day or night.
- access to needed drugs was possible at all times.

“Our family was supported and cared for by the whole team. On more than one occasion after some especially gruelling night or day the physician would take me aside and make sure that our family was managing. We experienced what every family should who are going through this difficult time and the reason we survived was because we had the medical and personal support at home. I will remember forever the day that Mummy was told that she would be cared for at home - her smile was angelic! The only bleep came when she had to change her bed for a hospital one - but we soon got over that. If I can personally ask anything of this Committee it would be to ensure that children, no matter how old they are, can remain children when they are losing their parent. While I have performed any and every service that my mother needed willingly - there is a real sense of freedom for patient and family when certain personal care is performed by others. I would wish the system our family experienced in England could be available in Canada.” Jakki Jeffs – Guelph Ontario⁹⁵

It is time that Canada seriously studies the many models of success in home delivered health care, and begins to emulate these successes as we commence the vitally needed transformation of our health care system. Sadly, as with palliative care;

“Home care is not recognized as an essential service in the Canada Health Act – without a federal framework there is a wide variability in eligibility, access and services across Canada. The belief in a social safety net is a unifying value for Canadians; however, there is no national framework to assure access to homecare across the country. The Canadian Home Care Association believes that in order to achieve Canada’s Health policy objective ‘to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers’, harmonized principles that reflect Canadian values of equity and solidarity must be developed for home care. Our elderly and vulnerable populations need to be assured care, and with the growing reliance on home care within our health system, it is time for a nationally defined home care system.” Canadian Home Care Association⁹⁶

Several important recommendations were made to the committee in regards to home care.

- It was recommended that the federal, provincial and territorial governments identify home care as a priority in health care discussions, particularly making the implementation of a comprehensive, national approach to home and community care a major focus of the 2014 National Health Accord.
- It was further recommended that the federal government should establish a five year Health and Social care transition fund to assist provinces and territories in realigning the health care system to meet the needs of an aging population and an increase in chronic disease rates. This funding would be directed towards communities, in the transition process, and towards alternative settings of care; such as residential hospice and home care services.
- In addition the committee heard the recommendation that the federal, provincial and territorial governments in collaboration with the NGO stakeholders establish a working group to develop and implement a comprehensive, national approach to home and community care. This working group would work towards a national strategy, minimum standards and bench marks, to form the basis of a National Home and Community Care Accord to be established by all levels of government.
- Other stakeholders recommended that the federal government establish a University Health Policy research chair in Home and Integrated Community Care, in each of the five major regions of the country. (Atlantic region, Quebec, Ontario, Western provinces, and B.C.) The purpose of

these endowed chairs would be to study the implementation and ongoing continuity of effective home and continuous care programs across the country.

- It was recommended that the federal, provincial, and territorial governments work together to create and implement a technology strategy for the home and community care sector, a strategy which would include:
 - i) Target funding for construction of housing units for low income seniors and persons with disabilities using “smart” technology to enable accessible and efficient home care support.
 - ii) Extending a GST rebate to health care organizations that invest in “point of care” technology (hardware and software) that improves the cost efficiency and effectiveness of care.
 - iii) Expanding broad band coverage in rural and remote communities to ensure access to communication technology to deliver safe and effective remote monitoring and communication, in the home and community care sector.

“Individuals living at home with chronic conditions incur substantial expense and physical stress when they need medical attention. Alternately, health authorities incur substantial travel costs sending staff to visit individuals in their homes. There are a variety of technological supports that can reduce the cost of community supports, such as access to quality health information, remote monitoring of health outcomes, and telephone support. ... Individuals want access to tools to help them manage their own health. VON has successfully implemented pilot projects in other jurisdictions with promising results. Improvements in the health outcomes of the client and reduced health care utilization have produced cost savings to the system. We have found investing in technology can be care-effective as well as cost-efficient.” Victorian Order of Nurses⁹⁷

The committee also heard the recommendation that the government of Canada utilize tax levers to relieve the excessive financial burdens of home based care, including:

- i) Tax credits for care givers
- ii) Establishment of a savings vehicle that will facilitate the ability of individuals to access the services that will allow them to remain at home – i.e. a Registered Chronic Care Savings Plan (RCCSP). Such a plan, with tax benefits and cost sharing considerations similar to the RRSP would allow individuals to share in addressing their future needs. The RCCSP would be introduced as a new program with tax relief on contribution, and not being taxed on withdrawal. Should the individual pre-decease utilization, the funds would form part of the estate and be taxable.

“The current state of the provision of care in home and long-term care falls far short of what Canadians expect and need. Due to a fractured system of services, and the absence of a national strategy and standards, many Canadian seniors, people with disabilities and chronic disease, and those in need of post-acute care are falling through the cracks when it comes to a continuum of care – assisted living, palliative care, home care, long-term residential care, pharmacare, respite care and support for informal caregivers. Gaps in the health system leave those in need of care trying to navigate the system to get the care they need at a time when they are ill and most vulnerable.” Canadian Health Coalition⁹⁸

Nursing Home and Residential Long term Care

“If facility-based long term care is to meet future expectations we must fund it properly and hold homes accountable for excellence. Neither can exist without the other. Resource allocation and accountability are inseparable. There are pockets of innovation in every corner of the country despite the provision of inadequate resources. Many examples of excellence give testimony to the commitment and resourcefulness of those managing and working in facility-based long term care across Canada. But the challenges within the sector will not vanish. Instead, weaknesses will intensify and become more pronounced with the emergence of a demanding baby boomer cohort.”⁹⁹ Canadian Healthcare Association

The Long term care residence provides care for people with complex health needs, requiring continuous on site professional nursing services, personal care assistance, and health service delivery for moderate to

extensive functional deficits and / or chronic conditions. The retirement residence by comparison, does not provide daily, around the clock nursing services.

Nursing Home and LTC are important dimensions of the continuum of care for the vulnerable elderly. While our committee hearings only touched lightly upon the long term care sector, we did receive a lot of input from concerned citizens from across Canada. It is important to put these tragic cases in context. As the Canadian Healthcare Association notes:

“Today, no sector along the Canadian health care continuum is more misunderstood than facility-based long term care. The cultural stigma of long term care is derived largely from historical accounts that described environments for seniors as little more than warehouses of death. ... The tarnished image of facility-based long term care is sustained by periodic accounts that reveal and even dramatize cases of neglect and abuse. The information contained in incident reports, required by provincial regulatory agencies, can be readily accessed by inquisitive journalists through freedom of information legislation. Thus the industry is more vulnerable than publically-funded acute-care hospitals which are not typically subjected to the same reporting requirements. Despite unfavourable media coverage, most facility-based long term care organizations in Canada quietly provide good care and routinely score high grades in annual satisfaction surveys and accreditation reviews. Still, public anxiety about quality of care continues to beleague the industry despite the fact that actual users of the system generally have a high regard for the services provided in long term care homes.” Canadian Health Care Association¹⁰⁰

The Committee agrees that most LTC organizations provide good care. That said there are those tragic exceptions which must be dealt with. The following, are a few typical examples of the kind of concerns that were expressed in correspondence to the Committee. They emphasize certain systemic problems. We record them in the spirit of the recent reports of the Ombudsperson of B.C. and the Ombudsman of Ontario; with the intent of collaboratively seeking solutions. Collaborative action with the industry, government, families and clients is the key for finding a remedy.

...

“Tomorrow morning set a stop watch and see how long it takes you to get up, go to the bathroom, wash yourself and get dressed. Now imagine doing this for a 103 year old woman, suffering from dementia. You’ve got six minutes. Good luck! Frustration and anger are building among health care workers. The provincial government continues to increase the burden of responsibility without providing the necessary funding to meet the demands of caring for Ontario’s elderly. Having six minutes to get a resident ready for breakfast is not an extreme example. It is happening every day in long term care institutions. The situation in the halls and rooms of the provinces long term care facilities continues to deteriorate. Residents are left sitting for 45 minutes or longer on commodes, the health care aids just can’t get to them. If you are trying to give a diabetic their drink and they don’t want it, you obviously should spend more time with the person to get them to drink it, but you don’t have the time, so you give them a couple of spoonfuls and go on to your next resident. Residents are lucky if the health care aid spends an hour a day with them one on one. If the government is serious about ensuring that our families and loved ones living in long term care homes are cared for safely and with dignity, it needs to take a careful look at where care is being provided at the ground level. The ministry of health expects front line workers to wake, toilet, wash and dress a resident in six minutes. How can they dare to call this quality care, when not one of us can meet this standard ourselves. This is nothing but institutionalized abuse, period.” Susanne Staldegger -- Mitchell Ontario¹⁰¹

Nationwide we face great challenges in the area of Residential long term care. Testimonies like that of Ms. Staldegger could be quoted from across the country. Problems presented include: a) Nutritional deficiencies, due to insufficient time for feeding people who can’t feed themselves. b) Patients being left for hours in soiled and wet diapers. c) Problems with the inappropriate use of physical and chemical restraints, sometimes leading to serious injury and even death.

d) Serious problems with untreated bed sores While of course these problems are not found in most LTC homes, they are significant enough that both the BC ombudsperson and the Ombudsman of Ontario have

felt compelled to release reports dealing with issues of long term care.¹⁰² These reports point to the breadth of problems faced.

In the course of receiving testimony and submissions for our own Committee, many people presented accounts which are indicative that these problems are not isolated events. The following testimony to the committee from a man in B.C. is sadly typical of problems faced across the nation:

“My wife is 81 and has Alzheimer’s and Parkinson’s disease and is currently a resident in the (Name excised)¹⁰³ which is an annex of (a large General Hospital), itself a wonderful facility. However, the chronic shortage of staff has turned this wonderful, caring place into a living hell for many of its residents. I am referring to those who are not incontinent but need assistance getting to the bathroom. I visit my wife everyday and on many occasions have seen residents crying out, in tears, because there is no one available to take them to the bathroom. Can you imagine yourself ‘dying to go’ but unable to get out of your wheelchair. You eventually reach a point where you can’t ‘hold it’ any longer and you’re left to sit in your own mess until someone comes to clean you up. Two months ago my wife who isn’t incontinent, was trying to summon help to get to the toilet- only a few feet from her bedside. No one was available; she became so desperate that she tried to make it by herself and fell and broke her hip in the process. The cost of fixing a broken hip is probably about equal to that of a care aide’s annual wage. These elderly people deserve better than this. Most of them have been tax payers for years and have subscribed to the national healthcare program since its inception.” E.M. – British Columbia¹⁰⁴

A Toronto man spoke to us of the problems of accessing good pain control and palliative care in the LTC home.

“My mother passed away a little over a year ago in a nursing home in Mississauga, Ontario. She was 94. ...An infection on her leg took hold and she started to go downhill. She was in constant pain. She started hallucinating – fearful nightmares in broad daylight. She no longer communicated other than through moans and nods. My siblings and I watched in horror and engaged in the games of optimizing care. When you or I get a headache – we go to the medicine cabinet and take a Tylenol. When my mother complained of pain – she was told that the doctor was the only one who could prescribe something -- and she’d be coming on Thursday. Thursday!!!? When we begged for palliative measures to calm her, to free her from pain, to give her comfort -- we got process, process, process. The palliative assessment would happen “next week sometime”. It took about 2 months of this before my mother finally died. I wish she could have seen the peace it brought her.” Philip Edwards – Toronto¹⁰⁵

The problems faced include problems like those described above, which might be termed forms of systemic institutional abuse (to be dealt with at greater length in the Elder Abuse section of this report). They also include issues which are due to bureaucratic inability to deal with individual preferences and needs, for example keeping patients close to home and family. With a shortage of long term care beds, people are often forced to move to regional facilities far from their home and communities. This puts tremendous stresses on patient and family alike, stresses which are compounded still further should a patient be approaching the last days and weeks of life. The following two testimonies to the committee are indicative of this problem.

a) **“Following my mother’s death, my father moved to a retirement home. This home was located in his home community and many of the residents were lifelong friends of my father. It clearly became his new home. His health began to fail, and he was in and out of hospital on numerous occasions, each time returning a little weaker than before. As each hospital stay was extremely stressful for him, his doctor suggested that he not return to hospital unless urgently needed. Instead the family paid for overnight care and we stayed with him during the day when he had pneumonia. His health continued to deteriorate, due to a very weak heart, but he was never identified as needing ‘end of life’ care. Consequently the solution was long term care, rather than any kind of palliative support in his home, although he desperately wanted to stay at the retirement home, which he considered to be his home. Although he had been on the waiting list for long term care in his home community for over 18 months, no bed was available. Rules required that we make other choices, and a bed**

came up in a community an hour away, where he knew no one, and had no personal connection. We had 24 hours to make the decision to move him – clearly this was not a choice, but rather a requirement, as we had no other option. Much as we hated to do it, and much as we knew he did not want to go, we moved him to the designated facility. My father died the morning after the move, with no family, familiar staff or friends with him – he was there less than 24 hours.” Mary Simpson – Guelph Ontario¹⁰⁶

The importance of family, friends, and familiar surroundings is vital for the well being of anyone, how much more for the aged and ailing. When our system of care cannot facilitate care which enables friends and family to surround their loved one, in their final days, such a system is deeply flawed. To be forced to move an hour or more from one’s home and family, in order to receive care, is problematic, a systemic issue that needs to be corrected.

b) “My 58 year old previously healthy brother very recently has been diagnosed with an especially aggressive form of terminal bowel cancer that had metastasized to his lung and liver before he even was diagnosed. He lives alone in Cobourg. My brother wanted to go to Ottawa where his children both live and work, to die there. In spite of his dire situation he was placed on waiting lists in Ottawa for everything including an oncologist and a community care case worker. The window to accomplish this was very narrow because of the nature of his disease and he had about 3 weeks at the very outside for this to be accomplished. Sadly the time has passed for this to happen and we siblings organized everything in Cobourg. His children have managed thankfully, to take time off and put their lives in Ottawa on hold to be with their dad. It is incomprehensible to me that the Ottawa area is so short of the necessary services to deal with situations like this. In spite of assurances from the Ontario government, cancer patients are not getting the services that they require. Cobourg has provided my brother with prompt and compassionate care, but Ottawa felt that this situation could be dismissed as unworthy. I wonder how the decision makers sleep at night!” Anne Thomlison -- Maberly, Ontario¹⁰⁷

Very central to many Canadian’s dealings with long term care and health care in general, is the problem of navigation and advocacy.

“In my experience over the last 8 years as a son and caregiver, I have been an advocate/ proponent for my parents, in attempting to navigate our healthcare system on their behalf. Please listen carefully to this: Assisted living, intermittent diagnosis, RPN, RNA, hospice, dementia, rehab, physio, service care providers, respite ... these are just a smattering of the concepts, acronyms and terminology an advocate has to be familiar with – and these are just a few I heard here this morning!! A web like organizational structure has been allowed to proliferate and grow into a bureaucracy – a lethal bureaucracy – that is impossible to navigate. Full of well meaning mission statements, statements that overlap each other and geographically render impossible any responsibility. National health strategy, Ontario health strategy, OHIP rules and regs, OHIP policies and procedures, LHINS, Community care, CCAC, Health care funding, sector services, geographic jurisdictions – Ontario, Canada, Dufferin, Guelph, Wellington, Waterloo!!!” Christopher Henry – Guelph Round table¹⁰⁸

In a later written submission following up his statement at the public forum, Mr. Henry proposed an important idea to remedy this problem of navigation and advocacy.

“I would respectfully submit for the consideration of (the Committee) a proposal to establish an Office of Ombudsman for healthcare. Regardless of a person’s capacity (legal, cognitive or physical) a prerogative, even duty exists to seek and attain assistance for those who are in distress or not capable of representing themselves. I believe a stand-alone office of an Ombudsman for Healthcare, not affiliated with, thus outside the formal healthcare system bureaucracy, standing separately and answerable to caregivers, advocates and families of patients; would be a valuable asset in the planning and management of healthcare for seniors and disabled clients. ... I would also suggest this office would be ineffective or even doomed, were it staffed by current proponents of our health care system. As you are well aware, there are substantial economic and budgetary challenges in providing any service or assistance. There are clear and obvious business justifications to support this proposal. The budget would be appropriated by the Ministries of Health based

on business benefits, and managed by the Ombudsman's office. Establishing an office void of political conflicts of interest or any partisan impropriety is essential. I propose an independent, apolitical, nonpartisan office comprised of dedicated individuals personally vested in an actual commitment to providing answers and direction to advocates, patients and care givers in need of obtaining the best healthcare possible. ... The primary function of the office is providing answers, assistance and information in a helpful, non-intimidating atmosphere, to negotiate and navigate an overwhelmingly complicated bureaucratic process. The office I propose would act and be managed independently; while being sanctioned, endorsed and empowered by a direct reporting line to the Ministers of Health (federal and provincial)."¹⁰⁹

The preceding stories represent a small sample of the stories we received across the country. Our system, or rather systems; of long term care, and nursing home facilities, requires careful supervision and regulation to mitigate these sorts of negative effects. The vulnerable people who are living in these facilities deserve better. The industry, unions, health care professionals, families and patients want better. It is time to work together to implement needed changes.

“There is growing recognition that the quality of care overall in residential long-term care is problematic. Concerns include the quality and safety of food, avoidable medical problems such as dehydration and falls, lack of time for personal care such as bathing and grooming, and the lack of time for developing the all-important caregiver and care-receiver relationships. Quality of care in residential long-term care is by far the most important consideration for Canadians. Quality of care is integrally linked to standards and regulations for care, and to accountability requirements, such as inspection and monitoring. Regulations to govern staffing levels, the skill mix of caregivers and working conditions are integrally connected to quality of care. According to a 2009 report by the Canadian Union of Public Employees, Residential Long-Term Care in Canada, Our Vision for Better Seniors Care, ‘No Canadian province has meaningful legislated minimum staffing levels; provinces have ‘target levels’ which are not enforceable or their regulated levels are so out of date as to be meaningless...’ Similar to the home care situation, staff reductions and shortages have led to work intensification with all the negative consequences that implies for workers and residents. ... As the registered Nurses Association of Ontario states: ‘Long-term care facilities now have to deal with a patient population of whom 60 percent require heavy care, estimated to be at 3.5 hours per day or more.’ Levels of staffing, skill mix and working conditions matter to the quality of care.”¹¹⁰ Canadian Health Coalition

- The committee heard the strong recommendation that the federal, provincial and territorial governments must collaborate together to develop enforceable pan-Canadian standards for minimum staffing levels in long term care residences.

“The development of pan-Canadian minimum staffing standards for long term care homes in Canada should become a priority of policy makers at the federal level. Health delivery is a provincial/territorial responsibility but since long term care affects all Canadians at some point in their lives, it is appropriate for the federal government to spearhead the development of broad pan- Canadian objectives and principles. ... Establishing minimum staffing ratios is not a panacea. There are numerous factors that contribute to quality of life for long term care residents, but the entire infrastructure of care and service is built upon the foundation of an adequate staff complement. Every home should be required to maintain a basic minimum number of staff in all major categories.” Canadian Healthcare Association¹¹¹

- Testimony was also received of the need for the federal government to establish a “Residential Facility Long term care construction fund” to enable provinces and territories to **build or renovate existing structures**, for urgently needed LTC beds¹¹².

LTC facility infrastructure desperately needs to be developed. The **BC Care Providers Association** in February of 2010 noted that the projected number of Canadians living with dementia, will, more than double in our generation to 1.1 million. “The number of long term care beds will need to increase by over 140% to meet the demand – from 280,000 today to 690,000 by 2038. ... Failure to take action now will

cost taxpayers hundreds of millions of dollars more in the long run and place a crippling financial and personal burden on families.”¹¹³

In addition the committee was told that:

- a) The federal government needs to facilitate provincial and territorial governments, in developing a national set of standards for LTC services, and placing these standards both in some form of National Accord, and in provincial and territorial legislation; so as to ensure Canadians have universal access to comparable levels and quality of services.
- b) The federal, provincial and territorial levels of government need to work together to develop uniform monitoring and accountability mechanisms, including reporting to the government, for LTC.
- c) The federal, provincial and territorial governments need to collaborate together on the possible incorporation of residential LTC services into the Canada Health Act, thereby ensuring that these services become insured health services, subject to the conditions and principles of the Act.
- d) The various levels of government need to work together to develop an integrated continual system of health delivery, unifying home and long term care into a continuum of care in which transitions between levels of care are invisible and seamless.

“Cultures of caring will never materialize in homes or systems that cling to the institutional model of care. The institutional model focuses on tasks, schedules and processes related to illness. It stifles innovation and is associated with poor outcomes for residents, frustration for family members, and an unsatisfying work environment for staff. Cultures of caring will assign greater priority to the psychological, social, and spiritual elements of life. Bureaucratic traditions must succumb to cultural transformation. For this to happen we must devote less energy into creating additional regulations and more attention to processes that will help transform facility-based long term care into desirable places to live and work. Dignity and respect should be two fundamental values on which a pan-Canadian facility-based long term care system is built and maintained. The consumers and baby boomers of today will be the residents and families of tomorrow. They will not accept institutional settings, structured schedules, rigid dining hours and waiting for care. Privacy, respect, flexibility and the right to manage one’s own risk should be the cornerstones of facility-based long term care services.” Canadian Healthcare Association¹¹⁴

XVI – Family Caregiver Support

“One person caring about another represents life's greatest value.” Jim Rohn – Philosopher

- One in four Canadians has cared for a family member or close friend with a serious health problem in the last 12 months.¹¹⁵
- There are at least 2.85 million family caregivers in Canada.¹¹⁶ This number is based on statistics that are more than 10 years old (the most recent available), the actual number today is estimated to be closer to 4 to 5 million.¹¹⁷
- A recent conservative estimate of family care givers economic contribution is \$25 billion.¹¹⁸
- Care giving often results in lost income and increased financial burden.¹¹⁹
- Caregiver economic burden is often over \$1000 a month.¹²⁰
- Many family caregivers (41%) use their personal savings to weather the financial hardships of care giving.¹²¹
- Nearly a quarter of family caregivers miss one or more months of work.¹²²
- Family caregivers provide 80% of all homecare in Canada¹²³
- 77% of caregivers are women.¹²⁴
- About 65% of households with caregivers report a combined income of less than \$45,000.¹²⁵

“Canadian caregivers are the invisible backbone of the healthcare system, providing \$25 billion in unpaid care.” Canadian Cancer Society¹²⁶

The importance of family and friends in the care of persons suffering from chronic conditions, persons with disabilities, and persons who are dying; cannot be over stated. Our medical system would not be sustainable without this massive contribution of time, and resources. Sadly, though, the role of the family care-giver is both misunderstood, and looked down upon, by large segments of our Society.

Caregiving will become the most important issue of social policy in the years ahead. Health care systems are down loading ever sicker patients into the home care setting. This downloading which is done to save the acute care system money presupposes the presence of sufficient family caregivers.

Public policy planners assume that caregivers will always be present in the numbers needed to sustain a homecare/continual care system. We can't, however, simply take this for granted. Demographic changes, social realities such as poverty, migration, changes in family structure, and growing numbers of women in the work force, are factors which must be taken into account as regards family care-giver capacity.

“Noteworthy is the fact that traditional support networks are disappearing. Nuclear families have decreased by 18%. There are three times as many single person households, as households of 5 persons or more. 51.5% of the population was not married in 2006, outnumbering the married population for the first time since the census began. 42.7% of households have no children. For the first time there were more households without children than with children. 1.5 million families, 1 in 4 families with children, is headed by a single parent, up 8%. Single parent families headed by men, increased by 14.6%, more than 3 times the rate of single parent families headed by women. ... In addition Canadian adults are not marrying – just over 51% of adults (15 and over) were unmarried – up from 49.9% in 2001. Two-thirds (65.7%) of Canada’s total of 5.6 million children aged 14 and under lived with married parents in 2006, a decline from 81.2% in 1986.”¹²⁷

These changes could be significant to the future of care-giving, as the vast majority of personal care is presently provided by spouses and children.¹²⁸ Changes to family structure will inevitably impact family care-giver capacity. With fewer family members, there are fewer people to provide care. While social organization will evolve and other sources of caregivers may develop, policy makers must be aware that building up social capital will be needed, and proper care of existing family care-givers will be necessary to enable them to persevere in their role.

“Being a caregiver is the most thankless role in the world. Everyone gives the patient some slack, as they should, but the caregiver has the stress of life and then you put a catastrophic illness on top of it, and the stress goes through the roof.” Marcia Wallace – Actress

Family care-givers face a variety of burdens. It is common for family care-givers to face changes in sleep patterns, decline in overall health, depression, reduction in social activities; guilt that one might not be providing the best care possible, family conflicts and stress of all sorts etc. Research indicates that **“caregivers have higher rates of affective and anxiety disorders than non caregivers and use mental health services twice as much. Care-givers for people with dementia are particularly at risk, and among those, people whose first language is neither English or French are especially fragile. Immigrants may feel particularly isolated and limited in their access to services to meet their needs. This may contribute to depression, with those who have no outside help suffering most.”**¹²⁹

As the population ages and as more people require care, we must look at ways to support and sustain the precious resource of family caregivers; giving them the tools they need to carry out their vital role, while maintaining their health and equilibrium. If we don't we risk the situation where we will have to treat two severely ill patients rather than one.

“A frail elder without the family caregiver won't make it, but if you don't have a sense of who that family caregiver is you don't know what is needed. Assessment is an intelligent step. This identifies the caregiver as a

recipient of care and essentially as much of a patient as the frail elder. That makes perfect sense. Clearly, more and more families are providing care to people at home and are in tremendous need of additional support.” Cynthia Epstein

Support for Caregivers

“Caregiver needs are linked to – but significantly different from – those of care receivers.” Sherri Torjman – Caledon Institute

- 1) Family caregivers need explicit recognition of the value of their care giving role.¹³⁰
- 2) They also need to be engaged as partners, alongside professional caregivers, in the planning process for care receivers.
- 3) Family caregivers need training and information to carry out their care giving role.
- 4) Information needs to be delivered in an accessible manner sensitive to low levels of health literacy among many Canadians
- 5) Family caregivers need support dealing with the stresses and mental health problems that often come with the care giving role. These supports include:
 - i) Improvements to the formal care system especially home care, including attendant services and homemaker services. Also expansion of long term care options, something which is vital, both for the good of the family caregiver and also for the sake of the acute care system which faces backlogs due to the lack of long term care beds.
 - ii) Respite care: Respite as a service gives family caregivers a break, allowing some time off from their care giving role.

“A new and broader interpretation of the notion of respite has emerged in recent years, which recognizes that many different interventions can potentially create a sense of respite for caregivers. The assumption speaks clearly to the importance of flexible and responsive forms of assistance, determined primarily by caregivers themselves. For some caregivers, respite or a sense of relief derives from information from a qualified provider that helps better meet the needs of the care receiver. It is possible that the individual wanders at night or inadvertently risks causing a fire through unsupervised use of the stove. Advice on how to minimize the likelihood of these potentially dangerous behaviours can provide significant relief. Other caregivers experience relief when they are able to have a free night, weekend or even a week. A 24-hour break allows many to get badly needed rest. A weekend or week enables caregivers to take a break or brief holiday if they are able to afford the time and cost. The physical rest helps them “recharge their batteries” in order to carry on with their care-giving responsibilities. For some, respite stems from knowing that there is around-the-clock tele-help in the event of a health-related or behavioural emergency. Caregivers of individuals with various forms of dementia or other mental health problem, in particular, point out that they are often unsure of how to cope with presenting challenges, such as verbally or physically abusive behaviour. This conduct can be especially acute for those with late-stage dementia who may hallucinate or experience delusions, such as mistaking the caregiver for a stranger or attacker.” Sherri Torjman¹³¹

- 6) Family care-givers need support dealing with financial pressures.

Most family caregivers are relatively poor to begin with. As noted above, 2/3 of caregivers have combined family incomes of less than \$45,000 per year. As many persons with disability and senior citizens live on fixed incomes, family caregivers often spend their own money to provide basic needs such as food, electricity, and transportation, for care receivers. They also often cover the costs of medical supplies and disability aids not covered by public or private medical insurance. In fact some 2/3 of family caregivers spend at least \$100 per month on care giving. 40% spend between \$100 and \$300, and 24% spend more than \$300 per month.¹³² More recent analysis based on 2005-2006 estimates by the Cancer society puts the mean cost to caregivers at \$36 per day, about \$1000 a month.¹³³ In addition to the out of pocket expenses, caregivers often have to take significant time off work, sometimes being forced to quit their jobs in order to deliver care. Even when a boss is flexible in allowing the caregiver to work reduced hours, or take unpaid leave, the financial impact of long term leave on pension income can be significant.

Serious financial stress can be experienced by families facing long term care-giving for a seriously ill child. Families, for example, who face the sudden crisis of childhood cancer, are often impacted by ruinous financial pressures. These financial burdens render the stress from the life threatening illness of a beloved child, even more overwhelming. Childhood cancer can involve many months of intensive treatment, sometimes extending into several years. Children facing the regimen of chemotherapy have depleted immune systems, which necessitates long term care at home. In families with mortgages and fixed costs, making their monthly payments based on dual incomes, the withdrawal from the labour force of one or the other parent, for the sake of care-giving can result in the loss of the family home, automobile, etc. The costs of driving back and forth to the cancer hospital over months and years, the costs of home schooling, the countless invisible costs of care, can be overwhelming in themselves. At any given time in Quebec for example LEUCAN (Association for Children with Cancer) is helping more than 2100 families with cancer stricken children.¹³⁴ With more than 10,000 children living with cancer across the country, the pressures faced by families are not insignificant, but a major issue for the consideration of social policy makers.

The Guinea Kid: The Story of a Childhood Cancer Survivor

In May of 2003 six year old Colleen Ruth was diagnosed with an advanced case of non - Hodgkin's lymphoma. With the diagnosis, of their youngest child, a nightmare began, which stretched Sharon and Danny Ruth, and each of their three children to the limit. Day blended into day over the two year ordeal of intensive chemotherapy. Every ounce of the families' strength was needed to support little Colleen through her treatment regimen, helping keep her spirits buoyed, helping keep her hope alive. Sharon and Danny took turns on unpaid leave, while Danny finally had to quit his job in order to be full time caregiver of his baby girl. Sharon a banker, was stretched to the maximum, to support her family financially, keep her older children intact, while attempting to encourage her baby girl, and husband Danny, through the day to day grind of fighting for Colleen's life. The emotional intensity of battling childhood cancer is overwhelming, while the stresses on family relationships are profound. Add to this the pressures of coping financially, while trying to balance work and care-giving, and the situation can overstretch the abilities of even the strongest families.

"How can anyone get by on 100% of the bills and 50% of the income?" Sharon Ruth asked the Committee. Far too many families when faced with the unexpected tragedy of childhood cancer have lost everything, as they fight for their child's life. Employers often don't offer the flexibility necessary for parents to balance care-giving and work, and as a result many parents are forced to leave their job to be there for their child. Government, employers and society, must become more sensitive to the needs of family caregivers, giving flexibility and support, so people facing the catastrophic situation of a gravely ill child, can give their child the care they need, without being forced into destitution.

"Governments must support and invest in families during these tragically difficult times. The long term socioeconomic benefits and returns of supporting families are far greater than the supposed cost savings that result from a politics of inertia. Doing nothing simply raises the toll of broken individuals and families. Colleen is living proof that there are gaps in our social and support systems that need to be updated. I am asking you to extend compassionate leave benefits to at least 26 weeks in a 52 week period. I am also asking that you change the qualifying criteria to "gravely ill" as opposed to "significant risk of death". These changes will keep hope alive for parents, and allow them without any trouble to be away from work and collect their benefits, providing peace of mind, and much needed financial assistance during their time of crisis." Sharon Ruth¹³⁵

Sharon's plea for basic justice is made on behalf of tens of thousands of families who over the years have faced the crisis of child-hood cancer and tens of thousands more who will do so in the future. Happily Colleen is now a teenager in full remission. Like many other young people she made it through the nightmare of childhood cancer. The many children like Colleen, the numerous parents who care for them;

they need the help of society to make it over the difficult period of intensive care giving. Surely Canada can give them this basic help!

“Children with cancer should not have to fight for their lives without their parents 100% attention and support.” Cathy Peyton – Labrador City, NL¹³⁶

Recommendation #9: We recommend that the federal government expand the provisions of the E.I. based compassionate care benefit to a minimum of 26 weeks coverage. We further recommend that the benefit be given flexibility to allow partial weeks to be covered, allowing caregiver leave for episodic care giving needs i.e. 5 or 6 days a month to allow a parent to stay in hospital with a child as they undergo chemotherapy. We recommend that the qualifying criteria be changed from “significant risk of death” to “gravely ill” so as to allow the hope of caregivers to be kept alive when applying for the caregiver benefit. Finally the government should look at raising the maximum payment cap to a higher amount, more in line with the costs of living and care giving.

“There are both direct and hidden costs to care giving. Direct costs are readily itemizable. In some cases, they are offset by provinces or may be partially claimed under the federal medical expense tax credit. But households must be in a secure enough financial position to afford these upfront costs in the first place. Most households incur extra costs, such as technical aids and equipment to enable independent living outside of a hospital or residential care facility, or modification of a primary residence such as the addition of an elevator or ramp. Care giving responsibilities may also include the purchase of additional supports for respite – e.g. a friendly visitor for the care receiver for a short period of time. Hidden costs by contrast, cannot be easily measured though they are very real – the out-of-the-way trip to the accessible store or the wear and tear on clothing. In recognition of the additional costs of care giving and other financial pressures, Ottawa provides some relief through two tax measures – the caregiver credit and the infirm dependent credit. These measures are intended to help caregivers by reducing their federal income taxes. The problem is that these provisions afford no assistance to Canadians too poor to pay income tax. Turning these measures into refundable tax credits would ensure that all households receive some money in respect to their care giving costs.” Sherri Torjman – Caledon Institute¹³⁷

Recommendation # 10: We recommend that the federal government create a refundable tax credit for family caregivers, to help families, with the high costs of care giving. The Caregiver credit and the infirm dependent credit could be made refundable for caregivers below a certain income level.

“Most caregivers believe, correctly in my experience, that their caring is not overly valued, beyond pious lip service, by the community at large. They are financially disadvantaged by a lack of financial support, while care giving, and by a loss of income when it comes time to apply for Canada pension. If you spend 15 years caring for another without pay, those are years where incomes do not accrue towards one’s pension. One answer to recognize familial caring for the real work it is, work that while not necessarily compensated is quantifiable; is to grant a long term caregiver a pension credit of half the annual salary earned in the years prior to care giving, for the years in which care giving was a full time responsibility. If the person has no salary history then a pension credit of say, \$25K could be granted. This would actually cost nothing. Those whom pension plans benefit are persons who would likely require social assistance were this not done. They would be largely indigent and thus on public monies. So what this does for no cost is acknowledge caring as real work and places it in the federal sphere without any real cost to the government of the day.” Dr. Tom Koch -- Toronto¹³⁸

Recommendation # 11: We recommend that the federal government set up a Canada Pension credit for family caregivers, so that those who are long term unpaid caregivers, receive annual pension credit worth half their average annual salary from the years leading up to full time unpaid care giving. The annual credit could have a maximum capped amount, and a minimum amount for those who had small incomes leading up to the care giving years.

Caregiver recognition

“Recognizing the value of informal care giving and enhancing political and economic responsiveness to the care giving role is viewed as vital to the well-being of the caregivers themselves, and their family and friends. One way to increase the value of care giving is to clearly define the role of caregiver. ...by recognition it is meant that the social status of the informal care giving role needs to be acknowledged as a valuable contribution to society, as well as having significant economic value. Such formal recognition has the potential to increase the likelihood of persons taking on a caregiver role and safeguards against a perceived diminished social position. At present, most people are unaware of the economic and social value of informal care giving; this value is neither regularly monitored nor reported for public understanding. There is also no systemic method of trying to accurately capture the less tangible “social value” of informal care giving.”¹³⁹

The following sentiments were expressed by round table participants:

- Care giving today, compares to how motherhood was regarded 35 years ago, when getting pregnant meant leaving work without any paid maternity leave or job security on return.
- Airline passengers have legal rights...prisoners have legal rights...Caregivers need legal rights.
- There needs to be recognition for caregivers struggling to balance care giving and paid work.
- There needs to be recognition and support for full time informal caregivers, who because of the intensity of the care giving role cannot work an outside job.
- A form of reverse discrimination is often evidenced against full time informal care givers; similar to the prejudice sometimes experienced by stay at home mothers.
- These caregivers are too often viewed as “unsuccessful adults” who take care of loved ones to avoid getting a “real job” This stigmatization is profoundly unjust, marginalizing caregivers as they struggle to carry out their difficult tasks.

Caregivers often experience family/relational difficulties due to their care giving role. In dysfunctional family situations, these difficulties can escalate to tragic proportions. The bulk of care giving is usually assumed by one sibling, the geographically closest child to the parent and in the case of intensive long term in home care, often by the one perceived as having the “least successful career”. Jealousies can develop, with other family members accusing the caregiver of taking advantage of the care giving situation for their own financial gain. Parents can also take the caregiver son or daughter for granted, not recognizing the sacrifices they make, and not taking measures to protect them, or to adequately support them in their care giving role. In many families it is actually the “black sheep” who becomes the caregiver. This leaves a long term caregiver vulnerable after their loved one dies. The blunt instrument of estate court litigation may become the only resort of a caregiver, seeking to stave off homelessness and destitution. It is not an effective instrument, being both very expensive, and tending to render an already tense situation still more adversarial. Furthermore, civil courts are necessarily procedural, and not equipped to offer meaningful family mediation.

“It is not uncommon to have a single family member take responsibility for the care of a fragile senior and later to have other family members deny any compensation or assistance to that person. The senior’s will was made while in relative health, and while the fragile senior may wish to provide for the carer, the will often does not reflect these wishes for a variety of reasons. It would be a real material benefit to have a brief pamphlet published that gives adults an idea of how to plan for their fragility and how to plan in long term support for the family caregiver. ... This pamphlet would be a “What to think about before you need to think about it” kind of thing. It would (a) encourage family pre-planning (b) discuss legacies, wills, etc. (c) give practical advice on not only senior care but care and recognition of the caregiver. It would be made available to social workers, to doctors for their offices, in rehab centres, etc. It would go a long way to getting people thinking and planning. The cost would be minimal.” Dr. Tom Koch –Toronto Ontario¹⁴⁰

Following the death of a loved one, the caregiver is left very vulnerable in terms of physical and mental health. They have often been pushing themselves during the intensive care giving phase at the end-of-life, and have depleted their resiliency. They will often develop serious physical and psychological conditions,

shortly after the death of the person they have cared for, rendering them in a poor condition to effectively advocate for themselves in the event of acrimonious relations with siblings and other family members. This is especially true of spouses, but is also true of children and other close relatives.

“In couples over age 65, when one person becomes seriously ill or dies, the risk that the caregiver spouse will also become ill or die significantly increases. And the level of risk for the caregiver depends on the type of medical condition that the ill spouse has. This information comes from a groundbreaking study by the Harvard Medical School, which examined the medical records of more than 500 couples age 65 or older for a period of nine years. During that time, more than two-thirds of the individuals were hospitalized and more than one-third died. Details of the study, reported in the February 16, 2006 issue of the *New England Journal of Medicine*, show that a wife’s risk of death is 61 percent greater during the first 30 days following the death of her husband. If a wife dies, the husband’s risk of death during the first 30 days increases by 53 percent. ...When a spouse is hospitalized, the partner’s risk of death increases significantly and remains elevated for up to two years. The period of greatest risk is over the short run, within 30 days of a spouse’s hospitalization or death. Over this time frame, hospitalization in a spouse can confer to a partner almost as much risk of dying as the actual death of a spouse. A spouse who suddenly needs to provide more care giving may become cut off from emotional, social, economic or other practical support. Stress and lack of social support may also adversely affect immunologic measures, so spousal hospitalization may have physiological effects on partners.”¹⁴¹

- 25% of women caregivers have health problems as a result of their care giving activities.¹⁴²
- Coronary heart disease (CHD) is one physical risk factor of care giving. Women who spend nine or more hours a week caring for an ill or disabled spouse increase their CHD risk twofold.¹⁴³
- Other health effects include elevated blood pressure and increased risk of developing hypertension; lower perceived health status; poorer immune function; slower wound healing; and an increased risk of mortality.¹⁴⁴

As stated earlier, mental health effects from care giving are even greater than physical ones. Depression and related mood disorders, intense grief reactions, and profound exhaustion, leave the caregiver in tremendous need of recuperation, something that can take many months, even years to accomplish. The caregiver is also left very fragile in the face of external stresses such as family squabbles and disputes surrounding the estate. With physical and mental health at a low ebb, with economic resources depleted or gone, in no condition to look for work, much less return to full time employment, the caregiver is extremely vulnerable following the death of the person they were caring for.

Story of a Caregiver in Crisis

Jane cared for her mother for over 20 years.¹⁴⁵ The youngest daughter in a family of four, Jane had begun caring for her mother shortly after completing high school, her mother having been forced to quit her job and go on disability due to ill health. Jane began a successful acting career, which she gradually gave up, as her mother developed more and more serious care-giving needs. Her mother Anne had survived the holocaust and was terrified at the thought of entering a long term care home. At first Jane was able to hold down part time employment while providing home care to her mother, but over the years, as her mother’s needs grew, she had to spend more and more time care-giving. Her life revolved around care for her mother, and her young daughter Mary. Jane has three siblings, all successful health professionals, two of them adjunct professors in major medical schools. Two siblings were far away, one a couple of hours away, so in practice care giving fell entirely on Jane’s shoulders. Her mother’s needs were complex, and Jane’s health too began to deteriorate under the multiple stresses of care giving. Following her mother’s death in 2004 she developed serious heart problems, and began to get seizure like episodes which caused slurring of her speech, and tremendous weakness. These health problems would force Jane onto a disability pension. Jane persevered right till the end in caring for her mother, and her mother’s friends, neighbours, doctors, nurses, home care aids, even the family accountant were glowing in their testimony

to Jane's selfless care. The committee has more than 40 affidavits extolling the persevering and loving care of Jane for her mother Anne.

Upon her mother's death, Jane and her daughter Mary faced almost immediate crisis, as an older sibling, the executor, began proceedings to sell the house they had lived in during all the years of care giving. The siblings even tried to charge Jane back rent, arguing that it was unfair that she had "free" room and board throughout the care-giving years. Jane was paying the home expenses including property tax, insurance and upkeep costs during this period. Faced with being dumped into the street, Jane was forced to litigate. Her argument was simply that her 20 years of care-giving preserved the estate, which would otherwise have been consumed through long term care costs. Surely this was a real financial input that should allow Jane and her daughter to live in the house, at least until Mary could finish her high schooling, and until she could recover her health, find employment, and rebuild her life. It was not to be, however. Seven years of litigation ensued, and early in 2011, a couple of weeks after Christmas, 8 police cars showed up on the front door step, to evict Jane and Mary, leaving them destitute and homeless, cared for by friends of Jane's mother, who took them in. Not content with this, Jane's professional siblings are now seeking to have Mary placed in foster care.

While not able to comment on the complexities of litigation, or even the correctness of judgements made on procedural grounds, a number of issues must be considered.

- 1) Throughout the proceedings, derogatory remarks were made on many sides regarding the apparent lack of value of the care giving role. These remarks were not simply commentary on Jane's care-giving, but manifested an attitude towards caregivers in general. Words were bandied about, even by legal authorities, for example, having had "free" room and board, being an "unsuccessful adult", about having chosen her role of caregiver, and now having to live with the results, etc. words which betray a lack of comprehension about the nature and difficulties of long term care-giving.
- 2) The impact on Mary was hardly considered. Family members seemed hardly concerned about removing a young teenage girl from her friends and neighbourhood, from the only home she had ever known, at an extremely vulnerable time in her life. Mary who had been very close to her grandmother had taken her death very hard, and the stress of what her well to do aunts and uncles sought to do to her and her mother, compounded her vulnerability.
- 3) No real account was taken of the damage to Jane's health physically, and psychologically; in addition to the utter depletion of her savings during the years of care giving. Jane had to undergo heart surgery in 2005, and has been experiencing episodic stroke like conditions since that time. Jane would have needed time to recuperate, time to rebuild her life, free from the ever present threat of litigation and homelessness.
- 4) No consideration was made of the real economic value of intensive care giving. While the will stated that the estate was to be split four ways, natural justice ought to apply a real value to care giving, according a significant portion of the estate to the family caregiver, without the need to go to court to seek remedy. Unfortunately there are no laws in Canada protecting caregivers, or adjudicating how these situations should be handled in an expeditious and just manner. The blunt instrument of civil litigation is a highly ineffective instrument of justice in family matters of this sort.
- 5) The only asset of the estate is the family home, which by community standards is a fairly average house. More important perhaps than the real estate value of the house, was the close community of friends and neighbours that had built up around Anne, Jane and her daughter Mary. Jane and her mother had lived in the home for decades; in fact both Jane and Mary had known no other home. The significant number of affidavits from friends and neighbours in this close knit ethnic community, friends who had known Jane and her mother Anne for many years, attest to the depth of friendship, and family like attitude in the community, an attitude that contrasts markedly to that of certain blood relatives.

- 6) It should be noted that none of the siblings is in financial need. They are all very successful professionals.
- 7) There is tremendous need to develop mechanisms for pre-planning so families can clearly delineate roles, responsibilities, and rights, in relation to care receivers and care givers, and make these clear from the beginning. All too often everyone goes into these situations with preconceived ideas, which may not be so clear to the other people involved. A little discussion and pre-planning at the beginning can save a lot of grief at the end.

This composite sketch of one particular caregiver tragedy is important to consider. A number of experts testified that stories like this are not rare. While not always as extreme as this case, caregivers are often shunted to the side in a variety of ways. Usually caregivers give up early on in the face of the intense pressures of litigation. Many perhaps most caregivers quietly walk away, not even trying to advocate for themselves. Many will face a life of poverty at the margins of society, with no one remembering the injustice done them. Broken in health, broken financially, they are left on the margins solely because they cared for their loved one.

Of course life is never simple, and figuring out how to protect caregivers is not simple either. There are cases of caregivers who do take advantage of the care receiver for financial gain. There are cases of caregiver abuse. Many perhaps even most cases have a mix of motives good and bad on the part of each person involved. None-the-less caregivers must be granted legitimate protection, and injustices against caregivers can no longer be allowed to remain in the shadows.

“How we support the familial caregiver is a tough question. Do we provide monies before the fact or after? How do we balance provincial and federal responsibility? Do we need a Caregivers Act, with a bill of rights protecting those whose principal profession is their unpaid vocation for another? I like to think so. But I’m not sure how this can best be done.” Dr. Tom Koch – Toronto

Research is needed, both to quantify the number of cases like Jane’s, and to clarify the types of abuses caregivers suffer at the hands of siblings, relatives, and uncomprehending bureaucratic and legal institutions. Only recently have we begun to see literature attesting to the fact that caregivers can be abused physically and psychologically by care receivers. We need more extensive insight into other forms of abuse that are being sustained by some caregivers, both during and after intensive long term care-giving.

We also need to clarify our laws in relation to care giving, to protect the legitimate well being of caregivers. Law reform commissions need to begin serious consideration of the many complex issues involved. In the words of one attorney:

“The issue of informal caregivers both in this province and across the country is one which has not been adequately addressed on many fronts. Only one of these is the issue of whether or not family or informal caregivers who, through their actions, enrich the estate or property of the person in receipt of that care deserve an increased consideration in the division of that estate, or some other remedy to adequately redress any unjust enrichment which may have occurred by virtue of their efforts. The law in this area is as yet untested. While constructive trusts have been extended to include both the actions of spouses and common law partners in relation to the property and estates of their spouse, this issue has not yet been considered in the case of non-marital or quasi-marital relationships, such as that of an informal caregiver. It is submitted that this issue is worth adjudication by the courts.” Paul Rochford – Barrister at Law -- Toronto ON¹⁴⁶

The issues of Care-giver support are many and complex. As a country we need to deal with these issues in depth, in order to prepare for a future where family caregivers will be absolutely essential in sustaining our medical and social care net. Many nations have begun the important task of surveying and tackling caregiver issues. The Australian Parliament for example took substantial testimony between 2008 and

2009 on the issue of caregiver support.¹⁴⁷ A Parliamentary inquiry to better support carers resulted in a 324 page report, making care giving an important issue on the social policy radar of the Australian nation. England, Australia, New Zealand, France, Germany, Denmark, the Netherlands, Japan, even the United States, among others have developed extensive policy in relation to care-giving and caregiver support, and in the case of the first three listed, have National Caregiver Strategies. Canada is a long way behind the rest of the G8 on these important issues, but the time has come to make a beginning.

“Aging at home is a major imperative for the formal health care and social services system which cannot adequately address the needs and expectations of growing numbers of older Canadians who must then rely on family and friends. Family caregivers contribute billions of dollars’ worth of unpaid work to ensure their loved ones get the care and support they need to age at home rather than in an institution. The financial and emotional burdens are nearly impossible for some especially lower income Canadians. A comprehensive strategy is needed to support family caregivers and the contributions they will continue to make to the public good. ... Canadian families always stand ready to care for their loved ones and studies have shown that care in the home, properly supported and delivered, contributes to better health outcomes. We would argue that it also contributes to family solidarity and social glue. Public policy can reinforce this contribution to the public good by making sure that family caregivers can afford to take on these duties, that their jobs will be protected and that they have access to information and services from the formal health care and social services system.”
Canadian Association of Retired Persons (CARP)¹⁴⁸

This brings to a conclusion the first section of our Committee Report, the section dealing with Palliative and end-of-life care, and those issues related to the care of the elderly and chronically ill. Hundreds of presentations and submissions have confirmed that for most Canadians these issues are of the profoundest importance. We call upon government and society to work closely to improve the care of the elderly, the infirm, the chronically ill and the dying. The vulnerable and their caregivers are not to be forgotten, in the rush to deal with the pressing issues of the day. The economy, world trade, employment, and national security, are all extremely important, but of equal if not greater importance is how we care for our most vulnerable. Let us add our voice to the call for quality end-of-life care as the right of all Canadians.

“Your committee has a most important task, for it is said that we will be judged as a society by how we treat our most vulnerable members. It is wise to listen to, and learn from them, even as we serve them. ...What I have learned from them, in their humility and their humiliations, is that we are all vulnerable people. Each one of us is important, especially the weakest among us. In our vulnerability we are easily hurt, and we have elaborate systems of self protection which keep us from being open with each other. We need each other, and yet we are deeply afraid of this need. Our fear estranges us from our own weakness, and keeps us from exercising the fullness of our humanity in caring for each other, individually and as a society.” Jean Vanier –
Founder of L’Arche¹⁴⁹

Part 2

Suicide Prevention

“Sudden death, from any cause, and sudden death from suicide are neighbours, and yet worlds apart. Both are devastating losses for families; however, suicide, unlike other causes of death, can infuse the people connected, commonly referred to as suicide survivors, with unrelenting guilt and profound isolation. Survivors are consumed by the "why" of suicide. They look for answers as if trying to unravel a murder mystery they instinctively realize will never be solved. The 'real' reason dies with their loved one, and they are left behind — feeling helpless and guilty and ineffective — to try to put the pieces of an unsolvable puzzle back together.”

Dr. Paul S. Links Psychiatrist, Arthur Sommer Rotenberg Chair in Suicide Studies, University of Toronto

Suicide Prevention Recommendation

Recommendation # 1: We urge that the federal government establish a Suicide Prevention Secretariat, provided with adequate funding to conduct and support research, and to facilitate communication and collaboration between the various levels of government, and community stakeholders, for the sake of:

- a) Developing and implementing a National Suicide Prevention Strategy.
- b) Collaborative development and implementation of a training program with established national standards, for the training of suicide intervention personnel.
- c) Coordination and dissemination of suicide prevention research and information resources.
- d) Development of a national public awareness program on suicide and suicide prevention, including a social media campaign on reducing stigma towards suicide and mental health issues.
- e) Ongoing coordination and support as the Strategy is implemented in jurisdictions across Canada.

(p. 82-83)

The Tragedy of Suicide in Canada

The Facts:

- Latest Canadian Statistics record **3,611 suicides in 2007** 2003 had 3,765, 2004 had 3,613, 2005 had 3,743, 2006 had 3,512¹⁵⁰
- **10 Canadians die every day by suicide:** lives tragically shortened, many of which could be saved by a coherent public health approach to suicide prevention¹⁵¹
- Suicide Deaths are particularly high among young people, *especially* aboriginal and Inuit young people, middle aged men, and the elderly¹⁵²
- Suicide is the second leading cause of death among young people aged 10-24¹⁵³
- Suicide rates among aboriginal youth are five to seven times higher than the rate among non-aboriginal youth.¹⁵⁴
- Quebec and the territories have the highest rates of Suicide in Canada.¹⁵⁵

I – Suicide Impacts Everyone:

"Suicide kills everyone," author Moira Farr writes in After Daniel: A Suicide Survivor's Tale ... Farr writes about her recognition of suicide and survival following the loss of her partner, Daniel Jones. ... I know I could never go back to the old way of seeing, or not seeing." Farr's journey of understanding uncloaks the impact of suicide on survivors and publicly unmask the pain and suffering of those left behind. ... The book follows the author's grief from Valentine's Day 1994, when Daniel took his life, to the point of her durable recovery from the trauma four years later. ... It recounts the raw, disorienting discovery of Daniel's handwritten note on the locked living room door: "Do not come in. Please call the police." Farr's recollection is chest-grippingly painful. She reflects that perhaps it was "that cruel quality of Daniel's" that she recognized as she stood at the closed door, "a quality that might have made him fashion some horrible tableau for the living to find. 'An act like this is prepared within the silence of the heart, as is a great work of art,' writes Camus of suicide in *The Myth of Sisyphus*. And what artful death, I could hardly have dared ask myself, had Daniel silently prepared?" This chilling account will remind physicians that the suicide survivor's response is often a complex combination of post-traumatic features and guilt-laden grief. Both aspects must be worked through during the process of recovery." Dr. Paul Links¹⁵⁶

Suicide is a tragedy that takes its toll in shortened lives, and in grieving families, friends and communities. For every Canadian that commits suicide, there are at least one hundred who attempt to, or who inflict deliberate harm on themselves.¹⁵⁷ These hundreds of thousands of people, struggling with pain and hopelessness, deeply affect those close to them, and so suicide and suicidal behaviour has an impact on many Canadians. Yet suicide is a silent epidemic. Society does not want to talk or even think about it. A profound stigma is attached to both suicide and mental health issues.¹⁵⁸ Because of the stigma, people

struggling with suicidal ideation, or mental health problems, feel further isolated, as do family and friends grieving the loss of their loved one, or struggling to save a loved one still at risk. Traumatic as suicide has been for so many; our society continues to ignore one of the major public health issues of our time.

II -- Suicide Can Be Prevented:

“If it weren’t for my wife I wouldn’t be here tonight. Twenty years ago I was at a place of unbearable pain, grief, and awful loss, to the point that I felt my family would be better off without me. I was not mentally ill, I had however rationalized that suicide was a way forward and I was at peace with that decision. My wife knew something was wrong and she spoiled my plan, I’m glad she did. I’m living proof that suicide prevention and intervention works. In the absence of hope suicide has opportunity, and we must keep pathways to hope open.” Rory Butler – Founder and Director -- Your Life Counts¹⁵⁹

It is important to be reminded that suicide intervention really does work and many lives are saved every year. Despite this fact, Canadian response is mainly due to the efforts of individuals and private groups, who strive against the tide with very few resources. As a nation we have done relatively little to implement a coherent program of suicide prevention. Some provinces have begun to make strides, especially Quebec, yet in general efforts to prevent suicide are still a patchwork, depending on the generosity of individuals, many of whom have been personally impacted by suicide.

An ironic situation exists where some of the foremost experts on suicide worldwide come from, or reside in Canada. Supplying expertise to nations around the world, they receive prestigious awards and research endowments from other countries, while receiving little or no funding or recognition from our own government. Many of these suicide researchers have moved elsewhere, where their work is actually respected and utilized. Groups and individuals have set up innovative programs to reach vulnerable sectors of society, yet without public funding, go about their life saving work with their organizational engine “running on fumes”. Even without resources lives are saved, with funding and a coherent national plan many more could be.

“Most people who die by suicide experience intense feelings of sadness and emotional pain, and feel hopeless about that pain ever diminishing. The many added stressors in peoples’ lives may diminish their capacity to cope, lower their resiliency, and increase their vulnerability to thoughts of suicide. What is especially tragic is that suicide can be prevented with compassion, understanding, and access to appropriate services. In fact, most people who are suffering and at risk for suicide can recover and experience a life that is meaningful, hopeful, and satisfying,” Tim Wall, Executive Director – Canadian Association for Suicide Prevention (CASP)

III – A Public Health Approach to suicide Prevention:

Suicide is a complex phenomenon with multiple often intertwining causes. The complexity of suicide necessitates that solutions cannot be reduced to a mental health approach alone, but must take all aspects of the person into account, including their social and cultural embeddedness.

“Suicide is multi-determined. The common psychological factors (commonalities) are unbearable pain, cognitive constriction or tunnel vision, ambiguities about life and death, a mental health disorder, a weakened ego, a disturbance in a relationship or some other ideal like one’s health or youth, rejection-aggression, and a desire to escape. This complexity calls for diverse suicide prevention strategies. This is necessary to not only solve what is sometimes assumed to be primarily a “medical problem”, but also to address the deep taboo and its stigma, and to address the problem with specific vulnerable groups, such as First Nations and Inuit people, armed services personnel, youth, and elderly (especially those facing end of life issues). The complexity of suicide dictates the necessity of a parallel complexity of solutions. There is never the solution. Therefore not only a mental health approach, but a public health approach, is urgently needed.” Dr. Antoon Leenaars – Psychologist and Suicide Researcher¹⁶⁰

An example of the complexity of Suicide causation is illustrated by research done into First Nations and Inuit youth suicide. The culture of First Nations peoples was thrown into turmoil by the policies of colonialism. Culture, “the whole complex of relationships, knowledge, languages, social institutions, beliefs, values and ethical rules that bind people together and give a collection and its individual members a sense of who they are and where they belong” plays a profound role in mental health and well being.¹⁶¹ Prior to the breakdown of their culture suicide was rare among First Nations people. Today suicide among First Nations youth is at epidemic proportions. The development of a sense of healthy identity is profoundly related to one’s culture, and its ability to reproduce itself in its members.¹⁶² Thus the anthropological and sociological dimensions, can deeply impact upon the psychological. As Dr. Antoon Leenaars notes:

“Prior to the contact with Europe, the culture offered Native peoples a complex and effective system of healing (Vogel, 1970). This healing system was based on a holistic approach of balance between the physical, mental, emotional and spiritual aspects of people (Connors, 1996). For example, the Sweat Lodge of the Ojibway people in Northwestern Ontario fostered a cultural embodied approach to wellness. ... The problem is that many Aboriginal people do not know what the Aboriginal culture was all about (Sinclair, 1998). No culture, no life. Suicide is one posttraumatic response. Many now, once again recognize their Native culture. Sweat lodges, the naming ceremony, trips to the land, the drum dances, the sun dances, lodge gatherings and so on are a healing in a cultural frame.”¹⁶³

While the cultural is just one dimension in the complex of issues to be considered in addressing suicide, it does clarify why a broad based public health approach is needed. The Public Health approach emphasizes a) primary prevention – reducing factors that put people at risk and increasing protective factors that buffer people from suicide risk. b) A surveillance and evidence based response – scientific research on causes, risk, protective factors, and developing and evaluating intervention models must be the basis of a public health approach. c) Multi disciplinary perspective – public health encompasses many disciplines and perspectives making it the best approach to complex problems like suicide. d) A population health approach – focuses on health problems from the perspective of the entire population not just individuals.¹⁶⁴

Dr. John Snow and the birth of the Public Health Approach:

The public health approach was first invented in the mid 19th century by a British Physician Dr. John Snow. In 1854, London was faced by a major cholera outbreak, thousands were hospitalized, many were dying, and health care personnel responded with what they knew, the health care methods of the day. Dr. John Snow, however, began to investigate the cholera outbreak seeking to discover the cause. He questioned patients at great length, where had they travelled, what had they eaten and drunk, what area did they live and work in. After questioning hundreds of patients he began to notice a common link: every one of the cholera patients had drunk water from a particular well in London, the Broad Street pump. At this point Dr. Snow decided to go out into the field and investigate the pump. This was a revolutionary action for a doctor of the day. No one really knew what caused Cholera at this time, but most doctors believed it was an air born disease. Dr. Snow, however, went and studied the pump, studied the water, and concluded that the water had raw sewage in it. He further discovered the sewage line that was contaminating the water. Clearly there must be a link. Next Dr. Snow acted upon his discovery. He intervened by removing the handle of the pump. Though he angered many locals by removing the handle, soon afterwards the cholera epidemic ended. Dr. Snow saved many lives, and became the father of public health in the process.¹⁶⁵

We can note the importance of what Dr. Snow did. He moved beyond what doctors thought they knew about cholera, and investigated the root cause of the epidemic. His approach was research based. His approach thought outside the box of the medical knowledge of the day, and in a real sense was multidisciplinary. His approach moved beyond individuals, and sought to improve the health of the whole population. His approach worked, and saved hundreds and even thousands of lives.

Suicide and the Public Health Perspective:

Dr. David Satcher when he was U.S. Surgeon General in the late 1990s, helped bring suicide into the public eye, and to make suicide prevention an important part of health policy. “...many suicides are already preventable. ...even more suicides could be prevented if this country better focused its resources and its attention on the problem.” That said though “a purely medical approach will not do the job. By the time most people who contemplate suicide come to the attention of our current medical system, it is too late. It is going to take a public health approach, based on the best available science and sensitive to what is happening in individual communities.”¹⁶⁶

As there are many aspects to the complex phenomenon of suicide, there are many aspects to the solution. Many approaches have been taken in various nations, which are aspects of a public health approach to suicide prevention. Three in particular have been shown by social science researchers to be statistically significant in reducing suicide. They provide exemplars of the kind of work to be done in a public health approach to suicide.

- 1) Toning down media reports:
- 2) Control of facilitating factors/ substance availability i.e. alcohol
- 3) Means restriction

1) Media reporting:

The way the media portrays suicide deaths has been shown to impact suicide rates. Reports about celebrity suicides, stories which describe method, give explicit images, or repeat coverage, tend to increase numbers of suicides. The “copy cat” effect was remarked upon in the early 1970s, and dubbed the “Werther effect” recalling Goethe’s 1774 novel The Sorrows of Young Werther, whose fictional suicide set off a spate of “fashionable” suicides among aristocrats of the day. An example of a modern day “Werther effect” was the influence media reports had on the suicide rate in the Subway system of Vienna. A series of suicides were reported in an explicit way with graphic pictures of the victims, repeated stories and front page coverage. Rates of suicide rose sharply. In response, the Austrian Association for Suicide Prevention in conjunction with media representatives, Subway officials, and community groups, developed media guidelines, and began educating journalists in the best ways to present suicide. Suicide reducing strategies for media coverage were implemented in 1987, with dramatic effect. A remarkable 84.2% drop was recorded in the suicide rate. Dr. Antoon Leenaars notes that “**This is intervention at its best! This field experiment demonstrates the fact that ... it is possible to change media reporting. A public health approach allows not only experts to intervene, but all people – reporters, politicians, police, your neighbour, whoever. This is, in fact, a major aspect of effective public health strategies: collaboration.**”¹⁶⁷

2) Control of Facilitating Factors:

Many suicides are linked to various forms of addiction, especially alcohol, drug and gambling addictions. A dramatic example of a successful reduction in suicide rates through reduction in facilitating factors is found in **Gorbachev’s stringent restrictions on alcohol between 1985 and 1990**. As part of the reforms of Perestroika, various measures were implemented to reduce alcohol consumption across the former Soviet Union. The intent of the legislation had not been to curb suicide. Furthermore Russia’s suicide statistics were a carefully kept state secret until after the fall of the former Soviet Union. Keeping in mind that these statistics were not of uniform accuracy, and suicide rates varied from region to region, after the fact study of the data is none-the-less instructive. Dr. Antoon Leenaars summarizes this research:

“The studies by Wasserman and Varnik suggest that indeed, controlling the availability of alcohol may have resulted in reduction of suicide – especially in men. Overall, the data suggest that the alcohol restriction may well have been associated with changes in suicide rate; perestroika resulted in major public change, maybe also reduction of self-directed violence. Between 1984 and 1986-1988, suicide rates decreased 35.2% in the former USSR (Varnik, Wasserman, Dankowicz, and Eklund 1998a)... The

changes in suicide rates observed in the USSR during perestroika (1984-1990) were observed in all regions, but were not uniform. ... There is evidence to suggest that suicide is more correlated to alcohol in men than women (Murphy 2000) Men abuse alcohol more than women. Wasserman, Varnik and Eklund (1994) designed a study to test the impact of the alcohol reduction on male suicides during the Gorbachev years. This study showed that the suicide rates were reduced by 39.9%. (It is of note that they reported that for all the republics, alcohol could explain a large proportion of suicide, and for most republics, more than 50%, at least for the peak year of 1984, before restrictions.) Wasserman, Varnik and Eklund (1998) examined the impact of the alcohol restriction on female suicides. ... The studies showed that the suicide rates were decreased by 17.17% in females. Thus, the legislation seems to have had a greater impact on men than on women. ... The biggest decreases in suicide took place in Russia and Belarus, where male suicide dropped 42% during perestroika. The alcohol restriction, however, affected significant decreases in all republics and for both sexes, but especially for males in the work force ages 25-54. ... Wasserman, Varnik and their colleagues note that not only alcohol restriction, but also liberalization, hope for freedom and democracy, and attitude changes that Gorbachev introduced may have impacted on the suicide rates. There is no question that democratization and liberalization were critical; but so was alcohol restriction.”
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The statistical significance of the reduction in suicides during the years paralleling Gorbachev's stringent limitations on access to alcohol is telling. While there is no way without further research to quantify the precise percentage drop in suicide due to the **single factor** of alcohol reduction, as compared to other factors, the dramatic rate decrease during the years of Gorbachev's restriction policies do point to the effectiveness of this public policy measure as a potent tool in the suicide prevention arsenal. The control of facilitating factors will vary from country to country, both as to factors which are most important to a particular nation and culture's suicide rate, and in regards to the means available for control. As with all aspects of the public health approach, research is very important in determining the most effective ways of controlling facilitating factors.

3) Means Restriction:

A very important approach in the suicide prevention arsenal is means restriction. Means restriction or control of the environment is highly effective especially in the case of impulsive suicides. The predominant method of suicide varies from nation to nation, varies according to culture, and region. In some countries like China and India, death by pesticide intake is a common way of committing suicide. The development of stringent controls on access to and storage of pesticides and industrial poisons has resulted in a reduction in suicide rates in a number of countries, including Sri Lanka.¹⁶⁹ Other examples of means restriction would be detoxification of cooking gas in countries like Britain, and the development of pollution controls for automobiles to render car exhaust less toxic. Means restriction can be as simple as putting up barriers on bridges and high buildings to prevent jumping, or in the case of one community in the Canadian North, where young people were hanging themselves on closet coat bars, installing coat bars that will collapse when a certain weight is applied. Research and creativity are necessary in development of effective environmental controls.

In many countries, including Canada, firearms are the preferred method for committing suicide. The RCMP reports that “Firearm suicides as a proportion of total suicides have remained relatively constant at about 30% over the past 10 years.”¹⁷⁰ Firearms are utilized by a large number of men in committing suicide. Being an extremely lethal means, guns make it less likely that the person attempting suicide will survive, hence less likely that there will be successful intervention. The RCMP goes on to note that “A disproportionate number of young men (age 20-24) and elderly men (80+) commit suicide with fire arms...” and as “... research suggests that many suicides tend to be impulsive acts, often precipitated by stressful life events and facilitated by alcohol or drugs...” especially among young men, restriction of access to firearms can be an effective way of reducing impulsive suicides.¹⁷¹ The RCMP notes that “Case studies have shown that firearms used in suicides tended to be readily available – the victim either owned

the firearm or borrowed it. Firearms are rarely obtained specifically for the purpose of committing suicide. Case-control studies have found that firearms were more likely to have been present in the homes of suicide victims than in the homes of suicide attempters, psychiatric inpatients, or other control subjects. In one study it was found that firearms were twice as likely to have been present in the homes of suicide victims, than in the homes of suicide attempters and the control group.”¹⁷²

There is controversy in the literature, with gun lobbies disputing the data; however it does seem clear that Canada’s 1977 firearm legislation did reduce rates of suicide by firearms. Initially there appears to have been a corresponding shift to other means of suicide, however Lester and Leenaars among others, examining the data for an eight year time frame before and after the passage of Canada’s firearms legislation conclude that there was a significant decreasing trend in the firearm suicide rate in Canada following passage of the legislation. The RCMP will note that “Carrington and Moyer in Ontario concluded that there was a decrease in levels over time of firearm and total suicide rates with no indication of substitution of other methods.”¹⁷³

Because of the complexity of the variables relating to suicide, more research is needed, however, it does seem clear that in Canada gun controls have reduced gun related suicides.¹⁷⁴

Dr. Antoon Leenaars notes that Bill C-51 which required a) acquisition certificates for guns b) restricted some types of guns and persons who could acquire them c) set up rules for the handling and storage of guns d) required permits for those selling guns and e) increased sentences for firearm offenses, seems to have been an effective means of suicide prevention. The study of Leenaars and Lester carefully analysed Statistic Canada’s suicide data for the years before and after implementation of the 1977 gun control laws. With the characteristic caution of a social scientist Dr. Leenaars states:

“The results suggested that strict firearm control laws may well have been associated with changes in suicide rates. The results suggest that the passage of C-51 may have reduced the use of firearms for suicide. To check if individuals may have switched to other methods, Lester and Leenaars (1995) applied a simple regression analysis to examine the trends in the suicide rates. They concluded that after the passage and enforcement of Bill C-51, the firearm suicide rate in Canada and the percentage of suicides using firearms both showed a significant decreasing trend. In addition the suicide rate by all other methods and overall suicide rate also suggested a decreasing trend, but not a significant one. If individuals did switch from firearms to other methods of suicide, this tendency did not increase from 1978 to 1985. Indeed, by 1985, both the firearms suicide rate and the suicide rate by all other methods were at the lowest values since 1977. Lester and Leenaars’ results suggest that stricter firearm control laws may well be associated with changes in suicide rates. Bill C-51 in Canada appears to have had at least one positive effect, namely, lowering the rate of suicide by guns.”¹⁷⁵

In the face of criticism that the above study didn’t take enough account of other factors on suicide rates, Leenaars, Moksony, Lester and Wenckstern (2003) developed a broader based analysis.

“In order to see whether other social changes might have had an impact on suicide rates from guns, time series regressions were run for the period 1969-1985. The social indicators used were birth, marriage and divorce rates as measures of domestic integration [a social variable which Durkheim (1897) argued was critical in determining suicide rates], the unemployment rate [which Platt (1984) has shown to affect suicide rates], median family income and the percentage of males aged 15-24 years as a percentage of the total male population (a group with one of Canada’s highest suicide rates). The data were obtained from the Statistics Canada (annual). The results showed that the passage of Bill C-51 in Canada in 1977, introducing stricter gun control, appears to have been followed by a significant reduction in the suicide rate by firearms, even after controlling for some social variables (such as unemployment rates and the

proportion of young males in the population). Thus, it appears that even if one controls for other social variables, gun control works.”¹⁷⁶

Dr. Leenaars concludes that gun controls were most effective in reducing suicide rates among the young, but that they had an impact on the overall suicide rate as well. Means restriction clearly requires careful research to determine effectiveness, and must be focused on the means used in the given country, region and group being targeted. Means used also can vary over time and hence the public health approach must be dynamic, adapting itself to the particular conditions faced.

Media Reporting Protocols, Means restriction and control of facilitating factors such as alcohol, have all been shown to be effective in combating suicide. Through careful research a public health approach to suicide prevention can find a multitude of ways to work towards the reduction of suicide. Those mentioned above are good examples of some successful public health approaches.

The Public Health Approach and the need for coordinated effort:

The Public Health approach to be effective necessitates a coordination of efforts in all sectors of society, and a coordinating body, which can bring together the various levels of government, NGOs and the private sector. The only body that can coordinate at this level is either a branch of the Federal government, or an organization that is delegated authority by the Federal government to coordinate on these issues. A coordinating body working closely with the Federal, Provincial and Territorial governments, and all sectors of society can develop a coherent public health approach that would save countless lives. It would facilitate the multi-sectoral discussions needed to develop and publish a National Suicide Prevention Strategy.

“A critical element for a national strategy is the formation of a national coordinating body and the provision of executive, financial and technical resources from the national government. The responsibilities of a coordinating body are to mobilize national and regional resources, formulate a culturally appropriate strategy and to activate community based expertise.” Dr. Richard Ramsay -- University of Calgary¹⁷⁷

IV -- A National Suicide Prevention Strategy:

“An analogy for suicide in Canada has been made to that of a jumbo jet crashing every month. If that was to occur month after month – every 30 days, another 340 souls going down on a large aircraft somewhere in Canada – would not reasonable people eventually say, “What is going on here?” Would it not make more sense to put energy into stopping the crashes versus tolerating the aftermath? Suicide is a “stoppable” problem. It is an action, not an illness. In my view, it is appalling that Canada lacks a specific federal direction to reduce the incidence and prevalence of suicide and suicidal behaviours that we experience in this country. Moreover, attempted suicides, where the individual’s actions have been non-fatal, are like the submerged, unseen base of an iceberg; they engender untold suffering to individuals and families and they also consume enormous health care resources.” Diane Yackel – Executive director -- Centre for Suicide Prevention¹⁷⁸

Canada and the History of National Strategies:

Individual Canadians have often taken important leadership roles on the issue of suicide prevention, though the Federal government generally has not. In 1993 Canada played host to an international convocation of experts on suicide, under the auspices of the United Nations, with meetings held in Calgary and Banff. These intensive discussions over five days especially the focused drafting sessions in Banff on the final two days; would form the basis for the 1996 UN document **Prevention of Suicide: Guidelines for the Formulation and Implementation of National Strategies.**¹⁷⁹ Dr. Bryan Tanney Dept. of Psychiatry at the University of Calgary and Dr. Richard Ramsey faculty of Social work University of Calgary were seminal to the drafting process done by the working group, being respectively the Chairman and Rapporteur for the Conference, and editing and publishing the official proceedings.

The role Canadians played in this intensive international effort was foundational. The International Conference was organized on behalf of the U.N. by The University of Calgary Faculty of Social Work, Calgary General Hospital Dept. of Psychiatry, The Suicide Information Centre (Alberta), Living Works Education Inc. (Alberta) and the Calgary WHO Collaborating Centre for research and training in Mental Health. Funding came from Health and Welfare Canada, Alberta Health, Alberta Family and Social Services, Alberta Heritage Foundation for Medical Research, and the Canadian Mental Health Association.

The province of Alberta at this time was recognized as a world leader in suicide prevention initiatives, something implicitly recognized by the United Nations in their choice of Calgary and Banff for this important conference.¹⁸⁰ Out of this conference came the impetus to develop national suicide prevention strategies throughout the world, including six of the G8 members. Ironically while Canadian funding, experts and organizational ability was so important in bringing this UN initiative to fruition, Canada is still ignoring the recommendations of the final document, and unlike our G8 partners, including the United States, we still don't have a National Suicide Prevention Strategy 17 years later.

“Suicide prevention in Canada remains fragmented, disconnected and lacking a national vision. The UN guidelines listed all the things that could be part of a strategy and it was up to jurisdictions to decide what they wanted to do, but at least they started with the whole picture and worked down to their individual parts. In Canada, we’re just starting from our disparate provincial or local parts without any idea of where they fit into the big picture.”¹⁸¹ Dr. Richard Ramsay – University of Calgary

V - Development of CASP Blueprint for a National Suicide Prevention Strategy:

Though the federal government has tended to downplay the need for concerted efforts to prevent suicide, and certainly has failed to act on calls for a National Suicide Prevention Strategy, individual Canadians, under the leadership of the Canadian Association for Suicide Prevention (CASP) once again stepped into the breach, and in October 2004 came out with the first edition of *The CASP Blueprint for a Canadian National Suicide Prevention Strategy*. The Blueprint would be revised in September 2009. The Blueprint was developed by a team of leading experts, who volunteered thousands of hours, and funded the project out of their own pockets.

Backroom feedback from politicians and bureaucrats from a number of countries tell a story of how a document written by volunteers, with no government money or support, formed an important model for a number of national strategies, which though funded in the millions of dollars to develop their own strategies, found the Canadian Blueprint “incredibly helpful” in drafting their national documents. The Blueprint also provided a model for our provinces and territories.

“At the provincial level, Alberta and Nova Scotia have used the CASP Blueprint to complete their own provincial strategies, while in Nunavut, Manitoba, New Brunswick, British Columbia and Ontario communities of concerned citizens are currently using the CASP Blueprint as the catalyst for working towards their provincial strategies. With the Quebec Strategy already in place for many years, Canada as a whole is turning the corner.”¹⁸²

Developing and Implementing a National Strategy is a dynamic process, where many groups work together towards a unified response. The very process facilitates awareness of the issues, activates persons and groups to get involved, and provides a catalyst for original thought and research, as well as effective intervention activity. The goal of CASP in writing the Blueprint for a National Suicide Prevention Strategy is:

“To unite all communities, governments, organizations and resources across Canada with CASP and our stakeholders to work effectively together to prevent death by suicide and to assist, educate and comfort those who have been impacted by suicide-related behaviours.”¹⁸³

The CASP Blueprint sets out certain working categories, with some of the more specific goals needing to be achieved. In doing so it gives a clear direction for dialogue and action. It is a beginning not an end in itself. It provides a basis upon which to begin the national dialogue which would lead to our particular National Suicide Prevention Strategy, one that has been debated, discussed and confirmed by everyone, and one that has the buy-in of all levels of government and of all the stakeholders.

VI - Outline of the CASP Blueprint:

The Blueprint articulates a number of themes and goals, some of which are outlined in what follows.

i) Awareness and understanding of suicide:

Goal # 1 – to Promote awareness in every part of Canada that suicide is our problem and is preventable.

The fact that each one of us has a personal stake in preventing suicide is little known and requires the raising of community awareness. A public awareness campaign is needed; one that is coordinated within each province, territory, region and community, reaching both the general public, as well as vulnerable target audiences, with the basic facts about suicide and the help that is available. In addition to a public awareness campaign utilizing the various forms of social media; conferences and public forums are required for more specific education of potential gatekeepers, while public education about mental health, substance abuse, trauma and grief issues is also needed. A special means of raising awareness about suicide is the development of a *National Suicide Prevention week* in Canada, to coincide with World Suicide Prevention day. Awareness is a key to suicide prevention, and a social marketing campaign would have to be carefully planned for maximum effectiveness.

Goal # 2 – To develop broad-based support for suicide prevention and intervention.

There is a need to increase the involvement of organizations and groups across the social spectrum in suicide prevention activities. This requires a different more direct kind of awareness campaign, with personal outreach to community and organizational leadership.

Goal # 3 – To develop and implement a strategy to reduce the stigma associated with suicide prevention, intervention and bereavement activities.

Stigma in regards to both suicide and mental health issues is a significant obstacle to be overcome in improving our public response to suicide prevention.

Goal # 4 -- To increase media knowledge regarding suicide.

This would include educating the media to be sensitive in the reporting of suicide, so as not to cause suicide clusters. It would also include educating journalists, so as to work collaboratively in educating the public.

It should be noted that in each one of the goals laid out in the Blueprint strategy, implementation necessitates the ongoing interface of research and frontline work. This dynamic interface deepens our insights both at the research and practical levels. As such a strategy is not a fixed thing, but a dynamic constantly improving response to the problem of suicide. The National strategy document provides a starting point, and at its most effective, will be in a state of constant improvement and revision.

ii) Prevention and Intervention:

Goal # 1 – To develop, implement and sustain community-based suicide prevention programs, respecting diversity and culture at local, regional, and provincial/territorial levels.

- **Inuit, First Nations and Metis programs**
- **Programs for persons with various mental disorders**
- **Programs for other high risk groups**
- **Programs for youth, young adults, family, community service providers, employers**
- **School and college based programs**
- **In-home and community based programs for seniors**
- **Military, police and emergency personnel programs**
- **Programs for mental health, medical and other health care providers**
- **To develop training and technical resources for the interveners**

It should be noted that some of these groups i.e. police and emergency personnel, health care providers etc. are both at risk groups, as well as front line interveners. Programs of training must be delivered to police and emergency personnel in a way that both minimizes their own risk of suicidal behaviour, due to high stress levels, and exposure to traumatic situations; as well as helps them to intervene effectively with persons in crisis.

Developing sustainable suicide intervention infrastructure is essential. At present there is a tremendous shortage of long term social support infrastructure, and of specialist mental health providers, especially for groups such as the young and the elderly. Psychologists and Psychiatrists specializing either in youth or geriatric patients are in great demand, and students must be encouraged to enter these fields of the mental health profession. Primary care specialists also need better training in detection and intervention both of persons at risk of suicide, and in terms of assessing and treating various mental health conditions such as depression.

Goal # 2 – Reduce the availability and lethality of methods.

We dealt earlier with means reduction, which is a very important dimension of a suicide prevention strategy. Education and action is required in relation to many possible means including firearms, drugs, poisons, etc. Technology such as firearm locks, carbon monoxide shutoff controls, bridge barriers, medicine safety containers etc. must be promoted so as to save lives. Advocacy is sometimes necessary to achieve necessary protective legislation. Means reduction also requires careful and ongoing monitoring and research.

Goal # 3 – Increase training for risk recognition, and effective intervention of gatekeepers, volunteers and professionals. Suicide risk identification, management and intervention skills need to be developed among:

- Employers
- Health care professionals
- Teachers and counsellors in schools
- Clergy
- Correctional workers
- Home care providers
- Military, police and emergency response personnel
- Mental health providers
- Social workers

(Goal # 4-6 will not be directly discussed in this report)

Goal # 7 – Increase crisis intervention and support.

Training, and certification, for crisis intervention and support networks needs to be expanded. We need to develop a national crisis line network connecting existing crisis lines and providing service where none yet exists.

Goal # 8 – Increase bereavement support for families and friends of persons who have died by suicide.

Postvention and bereavement support infrastructure is vitally needed. Families and friends of persons who have died by suicide are at increased risk of suicide, and require support, the infrastructure for which is presently seriously underdeveloped.

Goal # 9 – Increase Primary Prevention activities.

This includes programs promoting resiliency and protective factors, as well as developing integration between crisis intervention services and various community health and social service organizations. Again these primary prevention activities require continual interface with ongoing research.

Other goals in the second category (Goal # 4-6) would include improvements in the assessment and interventions given to suicidal persons in primary health care settings, improvements in identification of depression and other mental illnesses in vulnerable populations, improvements in ongoing outreach to vulnerable populations, improvements in support for families and social networks of those struggling with suicidal behaviour, improvements to service linkages and continuum-of-care for those dealing with suicidal ideation, self destructive behaviour, etc. in themselves, or family and friends. Social support linkages can be essential in suicide prevention and intervention.

iii) Knowledge Development and Transfer:

Goal # 1—Improve and expand surveillance systems.

A coherent suicide prevention strategy requires ongoing surveillance and research to both plan and determine the effectiveness of various interventions. Suicide statistics at present are not detailed enough, nor timely enough to accurately ascertain the effectiveness of intervention strategies. Statistics are four or five years old when made public. Statistics don't go into the epidemiological detail needed to adequately track and comprehend suicidal behaviour patterns. Details such as the ethnicity, locality, and mental or physical health condition etc. of the person who committed suicide are important data for making epidemiological correlations, and at present our data collection is not this sensitive. We haven't the data sensitivity to accurately map suicide clusters. We have little or no data on non-fatal suicide attempts, much less on suicidal ideation. We need to develop consistent standards and protocols for collecting information on suicide deaths, non-fatal attempts and suicidal ideation. We also require national standards for coroners to assist in accurately determining and reporting on cause of death. Since coroner reporting standards vary from region to region, our suicide statistics are rendered far less accurate.

Means of collecting and preserving suicide notes, psychological autopsy reports and other coroner records in a national research data base would help suicidologists improve the success of suicide intervention techniques. Such records would have to be recorded in such a way as to preserve the privacy of the suicide victim and family.

Goal # 2 – Promote the development of effective evaluation tools.

Intervention programs need to be evaluated on an ongoing basis to assure that suicide prevention efforts utilize the most effective means possible, and adjust on a regular basis to improve effectiveness. To attain this end it is also necessary to develop links and communication between survivors, community resources and researchers to facilitate knowledge transfer and knowledge uptake.

Goal # 3 – Promote and develop suicide-related research.

Research is of tremendous importance to ensure the ongoing effectiveness of a suicide prevention strategy. The complexity of suicide requires ongoing study from a range of disciplinary perspectives. At the same time researchers must be in continuous communication with the intervention side of suicide prevention, to ensure that it is directed to the goal of saving lives and not simply writing academic papers. Research is required in the areas of: risk factors, warning signs, and protective factors for individuals, families and communities.

Goal # 4 – Increase opportunities to report and communicate research information.

There is need to develop a national suicide research database. It is also necessary to expand the opportunities for researchers to share information through conferences, scientific journals, workshops etc. not only with each other, but also to translate this information in a manner helpful for front line interveners.

iv) Funding and Support:

Goal # 1 – Increase funding and support for all activities connected with the CASP Blueprint for a Canadian National Suicide Prevention Strategy.

Adequate suicide prevention initiatives require adequate funding. A funding strategy for a National Suicide Prevention Strategy should include all levels of government, as well as funding from the private sector. A multi-sectoral funding strategy is a way of educating society to the fact that suicide prevention is everyone's responsibility.

Goal # 2 – Ensure access to appropriate and adequate health, wellness and recovery services for all Canadians in keeping with the Canada Health Act.

The preceding summary of the key themes and goals in the CASP Blueprint, gives a sense of the breadth of issues to be dealt with in developing a national strategy. Strategies can be quite detailed with the American National Strategy document as an example, running to a length of 204 pages.¹⁸⁴ The development of a national strategy provides a venue for a national discussion. It provides a means of developing that unity of vision and action which is needed if we are to triumph against the tragedy of suicide.

VII - Recommendations for the federal government on Suicide Prevention:

It is the hope of this Committee that the government of Canada sets up a secretariat to deal specifically with suicide prevention, and to bring together all sectors of society in developing and implementing a national strategy. The CASP Blueprint gives us a great model upon which to base our national deliberations. This secretariat would of course collaborate with the Canadian Mental Health Commission, but would be a distinct entity. A secretariat would be a venue for coordinating and supporting needed research, monitoring and evaluating programs to assure maximal effectiveness, facilitating communication with various departments of the government such as Statistics Canada, the various coroners offices, Canadian Institutes of Health Research, federal, provincial and territorial health ministry's etc. Integration of efforts and communication, of the many departments of government and the various private organizations is essential if a national strategy is to be successful. The secretariat would also be a linkage to the suicide prevention efforts of nations throughout the world, benefitting from the experience of the countries that have already implemented successful strategies.

...

Recommendation # 1: We urge that the federal government establish a **Suicide Prevention Secretariat**, provided with adequate funding to conduct and support research, and to facilitate communication and collaboration between the various levels of government, and community stakeholders, for the sake of:

- a) Developing and implementing a **National Suicide Prevention Strategy**.
- b) Collaborative development and implementation of a training program with established national standards, for the training of suicide intervention personnel.
- c) Coordination and dissemination of suicide prevention research and information resources.
- d) Development of a national public awareness program on suicide and suicide prevention, including a social media campaign on reducing stigma towards suicide and mental health issues.
- e) Ongoing coordination and support as the Strategy is implemented in jurisdictions across Canada.

“The federal government has a very important role in the issue of suicide prevention from many perspectives. You deal directly with some of the people who are at highest risk, people in prison, the military and aboriginal communities; in fact you have direct responsibility for these communities. You provide surveillance on suicide statistics... you provide the lead in health research in Canada where you can really direct this to further attention to suicide. You provide leadership on many health promotion issues. But one place we need leadership is a suicide prevention strategy. Many provinces have undertaken work in this area but we won’t succeed unless we have the leadership of the federal government and the coordination and support of the government.” Dr. Paul Links -- Psychiatrist, Arthur Sommer Rotenburg Chair in Suicide Studies, University of Toronto¹⁸⁵

VIII – A Mother’s Tale: Youth Suicide and the Mental Health System:

“When my daughter was 13 and she wanted to die, I learned to ask questions like: Do you want to hurt yourself? Have you decided how you would do it? What is your plan? Then I would decide if this meant a trip to the Emergency room of a hospital, a call the next morning to the psychiatrist for an emergency appointment, or something that could wait until the next regular appointment. How does a parent, spouse, or child decide when to take action? The answer is usually when you know there is something wrong and you cannot cope with it any more. Time after time, my family has found that hospitals are reluctant to admit psychiatric patients even when they are too sick to be at home under the “supervision” of a family member. This takes a huge toll on the family.” Lynn Morgan – Scarborough Round table¹⁸⁶

The tragedy of mental illness, particularly when accompanied by powerful impulses towards suicide, can turn a family inside out, in a nightmarish world of seeking help for one’s loved one, hoping against hope that one can keep them alive. When the suicidal loved one is a young child, this nightmare takes on a particular intensity. Lynn Morgan spoke poignantly and courageously to the committee. She spoke of the double tragedy of her two children, a son lost to suicide at the age of 15, and a daughter who has been severely suicidal from the age of 7, but who thankfully is still alive.

The tragedy of suicidal impulse among the young is a lonely world for family members seeking help in a time where little help is available. At the age of 7 Lynn’s daughter asked her mother “How do I get to Heaven so I will be safe from the house burning down.” With a history of serious mental illness on her father’s side of the family, Lynn immediately realized that her daughter needed help. Yet help was not readily available. Children’s mental health centres in the GTA were booked years in advance, and a child psychiatrist in private practice was a minimum of 9 months wait.

“Nine months! That’s too long for someone who is thinking death is the answer. I live in Canada’s largest city and I could not get help for my child for at least 9 months. When she was finally assessed, they agreed that she had been suicidal in the past, I wasn’t imagining it, but wasn’t at the moment. (It was August; she’d been on summer vacation for 7 weeks).”

(All quotes in this section are from Lynn Morgan’s testimony unless otherwise stated)

The mental health system is extremely stretched for resources. Mental health services for children and teenagers are unbelievably limited. Families discover this lack of support at their moment of greatest crisis.

“I lost my 15-year old son, Kevin, to suicide 3 years ago. When the girl to whom he told his suicide plan went to the school guidance counsellor about it, the school social worker was called in. She went to the principal about the matter. He in turn called Children’s Aid and the Police asking what they should do. At no time did the school social worker talk to Kevin. She talked to the girl who reported the problem, but not to my son.”

Lynn Morgan

As so often in the response to suicide, those who should know how to intervene don’t, and a crisis is allowed to unfold with no adequate response. Guidance counsellors, school social workers, principals and teachers, need a minimum level of training in suicide intervention. Youth suicide is common enough that training protocols should be in place for all school staff with teaching and guidance roles.

Lynn went to see the principal. It turned out there was **no policy** for dealing with suicidal behaviour in this large GTA school district. A primary gate keeper for young people contemplating suicide was completely incapable of providing help.

“Two weeks later, Kevin took around 200 capsules of over-the-counter medication combined with alcohol. The girl from school worried why he wasn’t at school that day and went to his house on her lunch hour looking for him. I met the ambulance at the hospital at 1 pm where Kevin lay on a gurney in the hallway waiting his turn to be seen by triage. Three hours passed, both of us nervously waiting, me frantic at the wait, and Kevin telling me he wished he really had died as he vomited repeatedly, his blood pressure fluctuating and he wavering in and out of consciousness.” Lynn Morgan

While emergency wards are notoriously over stretched, patients who have attempted suicide are often handled with an extreme lack of compassion, many medical professionals manifesting profound anger and disgust, toward suicidal patients, a manifestation of the strong stigma attached to suicidal behaviour; and a travesty against the compassion health care workers should have for victims of the invisible illness of mental illness, or the crisis of extreme hopelessness.

“It wasn’t until I said I’d had enough waiting and was going to take him myself to Sick Children’s hospital that the hospital took some action. They drew blood. When the lab work came back, he was moved into the Emergency ward. At around 5-5:30 pm, over four hours after he’d arrived at the hospital they finally called the Poison hotline at Sick Kids. Why was a patient who had just attempted suicide left in the hallway of the hospital to wait 4 hours before any action was taken? It was too late to pump his stomach and the concern was around the possible damage to his kidneys from the dose he had taken.” Lynn Morgan

Seriously injured suicidal patients, being left for long periods in emergency wards, is sadly not unusual. The primary care system is disastrously incompetent when dealing with mental illness and especially suicidal behaviour. Lynn experienced the stigma against suicidal persons on a number of occasions.

“When my daughter cut her wrist, after she had been stitched up at around 1:00 am, we were told she would be first to be seen by a psychiatrist in the morning. Angela wasn’t assessed until 2:30 pm the next afternoon after watching one patient after another given priority. Imagine what this did to Angela’s already low self esteem! After the assessment, the psychiatrist on duty told me Angela was not likely to imminently harm herself, but she should not go back to her College Residence. I should take her home to watch over her and get an appointment with her psychiatrist, who was on vacation for the next 12 days.”

Back to Kevin at the hospital; who being 15 years old could not be placed in the regular psychiatric ward with adult patients. Paediatric psychiatric beds are in very short supply, and it took quite a while to place Kevin. Visiting Kevin daily, Lynn, her mother and sister, found Kevin highly agitated, talking of escaping the hospital, and very angry. He couldn’t sit and would pace constantly.

“He was starving. With every visit we brought him a full meal to supplement the pathetically small amounts of food that was served to the patients, but was simply not enough for a sprouting teenage boy. In fact, there was a protocol and expectation that families were to bring and leave snack food for their children. Insufficient food and constant hunger pangs cannot possibly help improve the mental state of a suicidal teenager.”

Can a hospital that doesn't know that teenage boys are always hungry, possibly be expected to know how to adequately treat a suicidal condition? This thoughtlessness to the patient's basic needs is iconic of the condition of too much of mental health care across Canada.

“It took Kevin much longer than the hospital staff expected to respond to the medication. The doctor explained that teenagers experience depression differently than adults. Their metabolism is ferocious and the younger patient can take longer than the 5-8 weeks it would normally take medication to have effect in an adult. Yet in less than that amount of time, Kevin's doctor wanted him released from hospital. It was approaching December and the doctor informed us he wanted Kevin released before he left on vacation.”

Lynn protested that she wanted Kevin kept in the hospital, but her estranged husband pushed to have Kevin released into his care. It is a known fact that holidays and weekends are the worst times for people struggling with suicidal behaviour to be released from hospital, with the holiday period often accentuating their loneliness and depression. Furthermore holidays and weekends are the worst times to get mental health care should they relapse. Ignoring Lynn's protests:

“Kevin was taken off the “form” which is used when a patient is a threat to himself or others and allows the hospital to keep the patient against his will. Kevin was put in a day program which ran on weekdays. So I would leave work early to pick up Kevin from the program mid-afternoon and find excuses to do errands with him so as not to drop him off at his father's house until close to dinner time when his dad would be home shortly. I spent time with Kevin and saw for myself that he was not ready to be released.”

Kevin's father and the doctor accused Lynn of being a fussing mother, the doctor told Lynn that she couldn't protect her child 24/7. They were told that the hospital had developed a release plan for Kevin. The hospital was to arrange for a case worker to meet regularly with Kevin in the community. Kevin would also need to be seen by a psychiatrist in private practice and Lynn was told to make an appointment for this.

“I took Kevin on Tuesday December 11th to a doctor whom Kevin had seen a few years after my marriage fell apart. The visit did not go well. Kevin's anger flared. He talked about killing.”

Clearly Kevin was in an agitated and dangerous state, hardly a candidate for release from the hospital.

“A meeting was arranged at the hospital for early in the morning on Friday Dec. 14th, with the doctor, ward staff, Kevin's dad and I. Kevin joined us in the latter half of the meeting. I reported that I was not happy with the first appointment we'd had with the psychiatrist, that Kevin was still too full of anger and resentment. I did not feel he was ready to be released. There was no return to school plan in place and yet it was less than a month away from the semester's final exams and Kevin had missed at least half of the term. He was fretting about school.”

Over Lynn's objections they released Kevin Friday Dec. 14th. Friday is the worst possible day of the week to release a suicidal patient, and immediately post release is the most dangerous time for a suicidal patient to again attempt suicide.

“Two days later, on Sunday afternoon, December 16th he killed himself.”

Lynn had done everything possible to prevent this tragedy.

- She kept the hospital informed of Kevin's state of mind; Kevin was less likely to fool his mother than the hospital staff.
- She informed the hospital of the complexities of the family situation and was ignored.
- She took care of the portion of the release plan assigned to her.

As to the hospital:

- The hospital delayed making arrangements for the portion of the release plan that they were responsible for arranging. Kevin had not yet had an initial introduction to or meeting with the case worker. That was booked for the week following the suicide.
- They released Kevin on a Friday – never a good idea!
- The rationale around the date of release appeared to be tied to Christmas holidays rather than the needs of the patient.
- Lynn felt ignored and mocked.
- They released Kevin into his father's care in spite of Lynn's insistence that they not do so.

“I feel that I have had to fight tooth and nail to get both of my children the medical help they needed. And despite my best efforts, I lost a child to suicide.”

Lynn Morgan summarizes her experiences and offers suggestions as follows:

- a) The Toronto school board (and likely other boards) does not have a policy in place nor do school staffs have training regarding what to do about a suicidal student on the premises.
- b) Hospitals do not handle the intake of patients well, and there are not enough beds.
- c) The family is stranded by the health care system
 - They are left to cope largely on their own
 - Medical personnel need to listen to parents and spouses – they often know their loved ones best; they deserve to be treated respectfully.
- d) The patient needs to be at the centre of the solution, but the family needs to be very close to that centre, and needs to be educated and supported.
- e) OHIP needs to cover counselling by professionals other than psychiatrists (social workers, psychologists etc.) to reduce waiting lists and make it affordable.

“I have experience with immediate family members suffering from major depression, bipolar and mood disorders, borderline personality disorder and suicidal behaviour. I have experience with adult and paediatric psychiatric hospital wards, with psychiatric day programs, with psychiatrists in private practice and with the George Hull Centre for Children and Families. I am well educated, English is my first language and I am articulate and informed – I've been exposed to and worked with psychiatric health issues for many years. What of a family with poor English skills or little education and no understanding of mental health issues? I cannot change what has happened; I cannot bring Kevin back, but I hope by appearing today before you, I can influence what might happen to others in the future.” Lynn Morgan –Scarborough Round Table October 30, 2010

The case of Kevin Morgan is a text book case of **all that should not happen** in caring for the suicidal person. Sadly Kevin's treatment at the hands of the mental health profession is not unique. If we are to move “Out of the Shadows” of this kind of calloused behaviour towards the suicidal person, we need to make strides on the dual fronts of suicide prevention and mental health care. A national suicide prevention strategy is necessary to prevent suicide from being lost in the politics of mental health issues. Suicide Prevention necessitates the wider perspective of the Public health approach. At the same time the suicidal person also requires a corresponding improvement of the mental health system. Perhaps a story told by Dr. Heather Fiske best defines both our response to the suicidal person, and our response to fixing the system.

“A young man was questioning why he should go on living. He confided in his grandfather about the feelings of despair he was having. His grandfather said, ‘Your despair is a wolf that’s powerful. It will kill you and eat your soul. But hope is also a wolf that’s equally as powerful’. The young man asked his grandfather which wolf would be victorious, to which he replied, ‘The wolf that you feed will win’. Dr. Heather Fiske¹⁸⁷

Let us strive to feed the “good wolf” of an effective national strategy on suicide prevention, while also working to feed improvements to the delivery of mental health care in Canada. They are distinct but related tasks that require concerted effort. The result, however, can be **literally** lifesaving!

National Strategies have made a significant difference in the suicide rates of various countries, including Finland, Norway, New Zealand, Australia, France, Great Britain, and the United States. While there is often a time lag of up to five years after implementation is begun before significant reductions in suicide become evident, national strategies have made significant improvements to suicide rates in almost all countries where they have been implemented.¹⁸⁸

It now lies with the federal government to give the necessary leadership for coordinating and implementing this life saving public health initiative.

IX – Suicide and the Elderly:

“The field of suicide prevention among older adults is relatively young and began with the study of risk factors such as; thoughts of suicide, suicidal behaviours, presence of mental disorders, personality disorders, anticipated or actual medical illness, or declined social , psychological and environmental stressors, losses or transitions. ... My colleagues and I have found that older adults that recognize meaning in life are less likely to endorse thoughts of suicide. And this protective effect seems strongest for those with greater depression symptom severity. Our psychotherapy study with suicidal older adults has shown that focused psychological intervention can significantly reduce or resolve suicidal thoughts and depression symptoms and can enhance perceived meaning in life, well being and social functioning. It’s critical that innovative clinical research continue to develop and test novel therapeutic measures for older adults. Nevertheless the average older Canadian struggling with mental health problems will be hard pressed to access recommended services provided by trained mental health providers. Clinical treatment guidelines for older adults at risk for suicide recommend interdisciplinary care provisions, including access to psychotherapeutic services and medication where necessary, unfortunately many older adults at risk for suicide never receive interdisciplinary care and cannot access recommended psychological intervention.” Dr. Marnin Heisel – Dept. of Psychiatry, Epidemiology, and Biostatistics, University of Western Ontario¹⁸⁹

With the elderly soon to exceed 20% of the Canadian population, and more than 20% of middle aged and older adults struggling with mental health problems, suicide prevention among the elderly will become an ever more significant issue. The elderly, particularly men are already a high risk group for suicide. Sadly though, we face a tremendous shortage of mental health professionals specializing in care of the elderly. We need to build capacity if we are to meet the mental health care needs of this growing demographic group. In addition to the need for specialist providers, primary health care providers also need training in diagnosing and treating depression and other common mental health problems in elderly patients.

“Models of care integrating psychological service providers and other mental health specialists into primary care clinics including the new family medicine teams and into outreach services have been found highly effective and are desperately needed. The role of the hospital psychologist for instance is quickly disappearing and many older adults do not have extended healthcare benefits covering psychological services. In this regard our American neighbours in fact are in better shape than we are. Private psychological services are covered by U.S. Medicare but not by the Canadian healthcare system. Even regional geriatric programs in Ontario and across the country do not typically offer the services of a registered psychologist. This is true despite the fact that psychological service provision for depression and other mental and medical disorders

has been shown to create medical care offsets, in other words reducing the cost to the healthcare system. The Canadian mental healthcare system is two tiered. Those who can afford private practice psychological services in addition to services covered by provincial healthcare systems receive better mental healthcare than those who cannot.” Dr. Marnin Heisel

About three percent of those over 55 will be **diagnosed** with depression. Lifetime estimates for those over 60 is that 10% will **develop** depression. Large numbers of elderly Canadians then will develop depression, and the present health care system is not adequate to the task of diagnosing or treating depression in the elderly. The primary health care system needs to become far more effective at this. Isolation is a tremendous risk factor for suicide. Elderly men who have been left alone after the loss of a spouse are particularly prone to suicide. Two ways of lowering rates of suicide in the elderly would be: a) Improve primary care initiatives to detect and intervene in the case of elderly patients at risk. Patients at risk of suicide go to their family doctors far more often than those not at risk. If primary care providers were more attuned to detect and intervene in the case of suicidal patients, and better trained to diagnose mental health problems, this would have a significant impact on reducing suicide in the elderly. b) A second important way of reducing suicide is to develop creative ways of reducing isolation and increasing connectedness. Examples of this are telephone support services which regularly phone elderly people to see how they are doing. There are also a range of creative community endeavours, senior citizen centres, clubs and organizations, which can help keep elderly people connected. It is necessary for our society to develop its volunteer ethos, particularly in terms of people visiting elderly persons both in their homes and in long term care centres. Social integration is a vital protective factor against suicide.

“There is a very interesting study from Italy in the area around Venice where they had two types of telephone support in the community. One was tele-help which was an emergency response, if a person was in danger they had access to emergency response support. The second telephone support was tele-chat where there was proactive phone contact service to see if the person was okay. They demonstrated that this connectedness through telephone led to reduced suicide rates in the community as compared to other communities without this form of help. It was especially effective for elderly women.” Dr. Paul Links¹⁹⁰

A story of suicide in the elderly – Two parents tragically lost:

Joan Seabrook lost her mother and father to suicide October 30th, 1990. She was home spending time with her 12 year old daughter when the phone rang with the news that her parents had died in a suicide pact.

“In that moment my safe, secure, predictable world as wife, mother, daughter, sister and educator was forever changed. The darkness of suicide had entered my world. I was now a survivor of my parent’s suicide. Initially some family members thought that they had made a rational choice to end their lives. After all they had lived full and productive lives and they were entitled to decide when and how they would die. It was two days later that my sisters and I each received letters from our parents stating that they had quit and that life had become too difficult. We were stunned. How could we not have known? They hadn’t ended their lives because they thought they had accomplished all they had wanted to. They had died in despair, unable to carry on. Their final act was not an act of choice at all.”¹⁹¹

Joan’s father was 69, a physicist who had worked for the National Research Council for many years before becoming a Physics professor at Carleton University. Her mother aged 68 had raised her children and after they had all graduated from university, gone back and received her own BA, then qualifying as a teacher. She had actually taught English to the daughters of the King and Queen of Thailand.

“At the time of their deaths they had no physical health issues and as far as the family knew they were not suffering from any mental illness. They had recently returned from a trip around the world, and then stopped off to visit me and my family in London Ontario on their way home to Victoria. We would never have imagined such a tragic end to their lives.”

Joan spoke of her impressions as she stood in her parents' home before the funeral. There was milk in the fridge, bought the day they died. There was a lovely rose that her father had picked from the garden and put in a vase the morning they died. There were detailed instructions to ensure no complications regarding the funeral. Details about where to find important items, everything was well looked after. However there was also, lying on the garage floor, the mattress where they lay down together for the last time and took their lives.

“Suicide among older people is an issue that has not received a lot of attention. We now know that there are things that can be done to increase the diagnosis and treatment of depression and suicidal behaviour in the elderly. The stigma needs to be lifted. It is easy of course and perhaps unfair to play the “what if” game. Perhaps you will indulge me for just a few minutes. What if my father’s doctor had asked a few simple questions intended to identify an underlying condition of depression as part of a normal medical protocol? What if my parent’s family doctors had brochures in their offices dealing with depression in the elderly? What if there had been a public health strategy to help lift the silence and encourage openness in discussing concerns about a spouse with others; a health care provider, a family member, even a friend. What if my father or mother had shared their thoughts of suicide, shared their psychic pain with a doctor. What if, when my mother said to me, please don’t worry about resuscitation I had said, tell me about that, what do you mean? And what if we had had a real discussion? There is a great deal I know about suicide prevention now that I did not know 20 years ago. Much research has been done and many steps have been taken, and yet our national association CASP is non-funded. It is run by volunteers like myself and the people sitting at this table. Canada has no national suicide prevention strategy, what if?” Joan Seabrook – Survivor Chair -- Canadian Association for Suicide Prevention (CASP)

X - Some recommendations and good ideas heard by the Committee:

We received some significant input on suicide prevention, both in our Ottawa and our local and regional hearings. These recommendations were directed across the spectrum to the various levels of government, and to civil society. **Groups and individuals recommended the following:**

Recommendations heard for the Canadian Government:

- Suicide needs to be formally recognized as a major public health problem in Canada.
- The federal government needs to **set a target date and number, by which it plans to reduce the suicide rate.** i.e. 20% reduction by 2020
- **An appropriate agency** such as Health Canada or CHRI needs to set up an accurate **National registry of suicide statistics and back ground information**, which monitors and records not only basic statistics, but maintains records of coroners reports, suicide notes, and any applicable material needed to help research, into the causes of, and effective interventions for the prevention of suicide. This registry needs to start producing annual statistics, instead of statistics every three years. It also needs to record statistics and information about attempted suicides, to enable researchers to develop more effective intervention strategies. This kind of epidemiological monitoring is essential if this serious public health problem is to be effectively addressed.
- Canada must work towards a **unified coroner reporting form, and unified definitions and investigative procedures**, so that the statistics gathered in the various Provinces and territories are methodologically uniform and hence adequately comparable.
- The federal government needs to **fund ongoing research into suicide, suicide prevention, and best practices for suicide intervention.** Suicide research has a hard time competing with Cancer or Aids research in terms of attracting funding. There needs to be a research budget dedicated to necessary public health related suicide research.
- The federal government needs to **take effective measures to increase the number of mental health care professionals able to effectively intervene to prevent suicide.** These measures may involve encouraging the provinces to develop strategies in their professional schools, and might

even involve federal endowments, and bursaries for mental health training. **Child and youth psychologists and psychiatrists are especially needed!**

- The federal government should **take the initiative in developing effective suicide prevention and mental health intervention among aboriginal groups, the Military, the RCMP, Veterans, and any other groups which fall under federal health care jurisdiction.** Such initiative will provide best practice models for provincial and territorial health care authorities.
- The federal government needs to develop **monitoring and treatment for military, RCMP, and other federal personnel, who are traumatized by violence or other traumatic events witnessed in the line of work, and who are hence at higher risk of suicide.**
- The federal government should consider **changes to the Canada Health Act (or other ways of encouraging the Provinces) that would make home mental health care intervention teams, a central part of our National mental health care approach.**

Recommendations heard for a Suicide Prevention Secretariat:

- The Secretariat needs to develop a **national social marketing campaign** to overcome the stigma attached to mental illness and suicidal ideation, so that people will be less afraid to seek help. This campaign has to use all the major modes of public communication.
- The Secretariat needs to develop **educational tools directed to various groups in society,** outlining warning signs for suicide risks, and basic approaches for getting help for suicidal people
- The Secretariat needs to develop and disseminate **professional resources on suicide intervention** and post-vention. **It can be a national clearinghouse for resources.**
- The Secretariat should coordinate **best practice research and knowledge translation,** to improve the level of training of our crisis intervention experts
- The Secretariat should coordinate with all levels in developing **national standards for crisis intervention,** including credentialing standards for interveners
- The Secretariat should coordinate research and development of **common National Coroner reporting standards and definitions** as regards suicide and self harm, to facilitate effective national monitoring.
- The Secretariat should coordinate a **national conference on suicide research** where Canada's leading experts can prepare a roadmap of the needed research for effective implementation and monitoring of a national suicide prevention program
- The Secretariat should coordinate regional training seminars for suicide intervention trainers. These trainers can in turn develop programs to train interveners at the local level.
- The Secretariat should develop a **National Suicide bereavement strategy.**
- Research needs to be done to assess the real economic costs of suicide, attempted suicide and self harm to the nation.
- **A National Media strategy for reporting on suicide and mental health issues** needs to be developed
- **A National 1-800 Suicide Crisis intervention line** should be funded, widely advertized, and maintained by the secretariat.
- The Secretariat must be a venue for **collecting and widely distributing best practice information** regarding suicide prevention and intervention.

Recommendations heard for the Provinces and Territories:

- The provinces and territories need to develop **provincial and territorial suicide prevention strategies** which implement the National Strategy in the context of their unique regional concerns.
- The provinces and territories need to **allocate adequate resources** for the front line suicide intervention organizations to do their jobs of saving lives.

- The provinces and territories need to mandate that **hospital emergency departments must always have someone on duty capable of doing emergency mental health and suicide intervention.**
- The provinces and territories need to cover treatment by a psychologist under Medicare. This will enable people in crisis to more easily access help.
- The provinces and territories need to mandate **training for all front line emergency personal** i.e. primary care staff, ambulance attendants, fire fighters, and police, so that they have the ability to **do adequate first response mental health and suicide intervention.**
- The provinces and territories need to do **regional suicide prevention and awareness media campaigns**, specifically focused at their own particular high risk groups.
- The provinces and territories should each **set up a well advertised crisis intervention line**, with staff trained to do first response suicide intervention, and resourced to refer callers for more intensive intervention
- The provinces and territories should monitor “suicide hot spots” setting up prevention measures at these hot spots. Further provincial and territorial governments need to work on coherent plans of implementing suicide “means restriction” programs.
- The provinces and territories should develop and implement particular bereavement resources for friends and family of suicide victims, and victims of suicide attempts, resources and supports based on the National bereavement strategy recommendations
- Programs need to be developed to support recently released prisoners, who are at high risk of suicide
- Programs need to be developed to support those recently discharged from mental health facilities, who are at high risk of suicide
- Provincial and territorial suicide intervention and bereavement teams should be available to send into schools and communities which have experienced a recent suicide or cluster of suicides
- Provinces and territories need to develop monitoring and treatment for police and emergency personal, who are traumatized by violence or other traumatic events, witnessed in the line of work, and who are hence at higher risk of suicide
- Provinces and territories should **establish mandatory procedures for follow up support for persons** who have been released from Psychiatric care, have been released after treatment for a suicide attempt, or are deemed at risk of suicide.

General Recommendations:

- **Programs** need to be set up **targeting specific high risk groups** for suicides.
 - a) Middle aged and older men are at high risk for suicide. Social organizations such as Australia’s **Men’s Shed project** (see below) have been shown to be good ways of providing needed social supports to men at risk of suicide.
 - b) Need a special Suicide Prevention strategy for First Nations and Inuit groups
 - c) Need support groups for those who have attempted self harm or suicide
 - d) Need to develop strategies to prevent suicide in federal and provincial prisons
 - e) Need to develop strategies to prevent suicides in mental health facilities
- A not for profit foundation should be set up for the purpose of raising funds from the private sector, to support suicide research, and intervention efforts across the country.

Other Good Ideas:

- Letter and post card interventions, where post cards are sent to persons discharged from mental health care, expressing concern and inviting them to stay in touch, have been effective in some countries in reducing suicide.

- Programs in which telephone contact is made with an elderly person , or a person at risk of suicide, at regular intervals, has been shown effective at reducing loneliness, and reducing suicides.
- In Australia special accommodations for those at risk of suicide, where the setting is more home like, has been shown to be a more effective environment than a regular mental health facility, for those at risk of suicide. An example of this would be **Time Out House**—a community organization offering a safe and welcoming space for those at risk of suicide.
- **Men’s Shed Project** – An Australian project in which comfortable work shop environments, (along with a lounge area, pool tables etc.) provide retired men a place to go, socialize, and contribute to their community, by making useful items which go to improvement of their local region. Has been shown to be particularly effective in giving meaning and purpose to the lives of retired working class men, who are particularly at risk of depression and suicide.
- Ways of reaching out utilizing the popular modes of communication such as Facebook, twitter, and other forms of virtual interaction are highly effective at reaching young people at risk, who tend not to call crisis lines, or meet with counsellors face to face. We need research and creativity at reaching out to various vulnerable groups in a way in which they are most likely to seek help.

“I believe that our young people today are coping with pressures and issues that are way beyond the pressures that you or I ever had to deal with. And that is why we have to go into their world, using the technology that they know, that they are comfortable with. With the online lifeline we have, youth open up to us in ways that you just wouldn’t believe. The old saying that a problem shared is a problem halved, this ability to communicate with people that don’t know you. And really, for youth to speak with someone on the phone is often the hardest thing. Reaching out for help is a real stretch and some of the youth have told us that they would rather die than reach out for help (in the ordinary ways). So we have to steady them ...the work that we do in our agency is to steady youth. We build them up, we build trust, and we build their resilience so that they are strong enough to reach out for the help they need, or if they’re not strong enough themselves, they at least give us the permission to make sure they have the help they need. It might just be calling a doctor. It might be that a girl needs to be tested for an STD, she might just have gone too far down that particular road and she’s worried and she can’t sit down and talk to her mom about it. Some girls die by suicide as a result.” Rory Butler – Your Life Counts¹⁹²

Clearly there is much to be done if we as a nation are to be successful in significantly reducing the incidence of suicide. Examples abound around the world of successful suicide prevention approaches. The time has come that we begin creatively implementing such approaches in Canada.

“It will be important for all Canadians to support the government. In order to maximize the effectiveness of a national strategy, a solid foundation supporting the development and delivery must be in place across our nation. At very least, research, training, and information dissemination are essential structural supports. I want to especially emphasize research. It has been neglected in the past. Research is a must in any effective public health approach to answer basic questions: What is the problem? Patterns? What works? What works with youth? What works with elderly persons? What works with First Nations? Armed Services personnel? What is cost effective? Collaboration across a broad spectrum of people will be necessary, too many to name, but the government is one *essential* community. Our national strategy will not be effective otherwise. Collaboration will guarantee more effective awareness, training, and research. This will be a true national effort. The WHO has identified this as key.” Dr. Antoon Leenaars – psychologist¹⁹³

Part 3

Elder Abuse: Canada's Hidden Crime

“Evils that befall the world are not nearly so often caused by bad men as they are by good men who are silent when an opinion must be voiced. Right and wrong is just that. These issues are not shades of gray.”

Detective Steve Thomas – Boulder Colorado Police Force ¹⁹⁴

Elder Abuse Recommendations

Recommendation # 1: We recommend that the federal government establish an **Elder Abuse Awareness and Prevention Office** with a general directive mandate, under the **Minister of State for Seniors**, in conjunction with HRSDC, Public Health Agency of Canada, Justice and the RCMP, for the purpose of facilitating communication and collaboration between the various levels of government, and community stakeholders, with a view to:

- a) Developing and implementing a **National Elder Abuse Prevention Strategy**.
- b) Promoting and funding research on the incidence, and prevalence of elder abuse as well as effective tools and responses. .
- c) Coordination and dissemination of elder abuse information resources.
- d) Development of a national public awareness program on elder abuse and elder neglect including elder abuse prevention, detection and response.
- e) Ongoing coordination and support for groups working to prevent elder abuse across Canada.
- f) Working with the Ministry of Justice, Health Canada, Public Safety, the RCMP, and other federal departments, to coordinate an integrated federal response to elder abuse, including the development of a **National Forensic Centre on Elder Abuse**, needed changes to the criminal code, and improved data collection by Statistics Canada. (p.124)

Recommendation # 2: We recommend that the federal government provide core funding to:

- a) The Canadian Network for the Prevention of Elder Abuse (CNPEA), so as to enable CNPEA to promote and coordinate networks for the prevention and detection of and response to elder abuse across Canada.
- b) The National Initiative for the Care of the Elderly (NICE) to continue work of the Elder abuse Theme Team to identify, pilot, and train diverse responders across Canada on evidence based tools for preventing, detecting and intervening in situations of abuse of older adults.

The Committee believes that Core funding for the non-governmental sector is a cost effective way of building needed infrastructure for the reduction of elder abuse. (p.124)

Elder Abuse: Canada's Hidden Crime

“Canadian research suggests that between four and ten percent of seniors will experience some form of abuse during their lifetime. However, these rates may represent the “tip of the iceberg” in terms of actual occurrences. Older adults are often reluctant to report abuse. Research suggests that only one in five incidents of elder abuse ever comes to the attention of those that can help.”¹⁹⁵

The Facts:

- Any senior can become a victim of elder abuse regardless of gender, race, ethnicity, income or education.
- Shame or guilt may stop a senior from revealing their abuse. Sometimes victims simply do not have the capacity to report it.
- Some of the barriers to revealing elder abuse include fear, love for the abuser, lack of understanding or impairment, lack of awareness of resource options, or acceptance of abuse or neglect as normal.
- Elder abuse is often committed by someone known to the victim, such as a family member, friend, or caregiver.¹⁹⁶

- Abusers can also include neighbours, paid care providers, landlords and staff, or any individual in a position of power, trust, or authority.

Abuse Statistics:

- Data from the Canadian 2004 General Social Survey (GSS) revealed that almost half of all violent incidents against seniors go unreported.¹⁹⁷
- Family Violence against seniors has increased by 14% since 2004.¹⁹⁸ It likely will increase more quickly as our population rapidly ages over the next couple of decades.
- It is difficult to estimate the prevalence of elder abuse in Canada due to underreporting, limitations in victim surveys and police statistics, general lack of awareness, and lack of clarity as to what constitutes abuse. Nevertheless based on available data, it is estimated that between 4 and 10 percent of older Canadians experience some type of abuse. **(2007 analysis)**¹⁹⁹

...

A problem in understanding elder abuse in Canada is the general lack of good Canadian statistics. The only detailed survey on elder abuse is from 1989; hence prevalence statistics are extremely outdated. We need a large population based prevalence survey of elder mistreatment similar to the U.S. Justice Department sponsored: **National Elder Mistreatment Study**. National Institute of Justice, March 2009.²⁰⁰ It is important to note that the National Initiative for the Care of the Elderly (NICE) has just completed a Defining and Measuring Project for Human Resources and Skills Development Canada (HRSDC), which **has done all the preparatory work** to enable a national prevalence study. This preparatory work puts NICE in a position to lead such a study, if the federal government were to allocate the necessary additional funds.²⁰¹

Based on the 1989 data we note:

- Financial abuse is the most prevalent category, affecting at least 60,000 Canadian elders. **(1989 data)**²⁰²
- Chronic verbal aggression, a component of psychosocial abuse, affects approximately 34,000 Canadian seniors. **(1989 data)**²⁰³
- Approximately 12,000 seniors in Canada have experienced physical abuse. Victims of physical abuse are more likely than non-victims to be married and in most cases the aggressor is the spouse. **(1989 data)**²⁰⁴
- More than 18,000 elderly persons in Canada are subjected to more than one type of abuse. **(1989 data)**²⁰⁵

Without a doubt the 1989 data needs to be updated. Population increase alone implies that elder abuse numbers will have risen substantially. To quantify the severity of our abuse problem Canada requires the completion of a large scale prevalence study similar to the American **National Elder Mistreatment Study**. Such a broad based survey is needed both to increase our understanding of the issues and to better target our efforts at preventing abuse. We encourage the government to implement such a study.

...

“As a society, we’re now far more open to talking about the hidden crimes of spousal abuse and child abuse, now we need to do the same for elder abuse. ... The current law is clearly not robust enough to signal society’s abhorrence for this crime.” Susan Eng -- CARP²⁰⁶

I - Elder Abuse: Ending the Silence:

“... every person in our society, regardless of age is entitled to three things: [to] live with dignity; to live with security; and to live as an autonomous human being.” Right Honourable Chief Justice of Canada Beverley McLachlin²⁰⁷

Case of Elder Abuse

i) A horrible case of Elder Neglect:

(The following abuse cases were widely reported in the national news.)

Canadians were shocked in late February when it became public that a 68 year old Toronto woman had been left to live in a squalid almost unheated garage for four months. Smelling of urine and feces the un-insulated garage was not a place for human habitation, especially for an elderly woman with dementia. A makeshift bed with a single blanket, a pail of water with a half inch of ice on the top to wash in, and a filthy untended portable toilet was all that this elderly woman was given to live with. When police found her she was frostbitten and had no food in her stomach. Her 43 year old son and 28 year old daughter-in-law had two empty bedrooms in their home, yet allegedly left the elderly mother in the garage due to her incontinence. She tottered on the edge of life in a Scarborough hospital for some days. While she was eventually stabilized, she was still recovering from double pneumonia and frost bite weeks after being found. This shocking case drew national attention to the issue of elder abuse, one of the worst cases of elder neglect to come to the attention of the public in recent years.²⁰⁸

Elder abuse is an issue we don't like talking about as a society. Even as horrid a case as the one mentioned above garnered no more than five or six days of media coverage. Yet every year hundreds of thousands of Canadian seniors suffer from one form of abuse or another. Admittedly most cases are not as horrid as the Toronto case, though a number are. But whether the abuse is serious neglect as in the case of this Toronto grandmother, or emotional, psychological, sexual, physical, or financial abuse, the end result is always a wounded person.

ii) Land mark elder abuse case:

The case of Mary Noseworthy a 78 year old Alzheimer's patient who unable to care for herself, was beaten and neglected by her son, was another horrible example of elder abuse in the Toronto area. The woman was at a near starvation level when she suffered congenital heart failure in 2007. She had been left on the floor of her bed room for days until her son, who lived with her, found her dead. "The woman's unbathed body was covered with fecal matter, her hair was matted and her nails were overgrown." A pathologist told the court that "regular beatings and malnutrition accelerated the woman's demise. Accelerating death is a manner of contributing to death." For his part the woman's son "told police that he 'bitch slapped' and 'kicked' his mother, didn't feed her for several days and gave her very little water." He went on to note that he was "frustrated by the ill woman's inability to respond to him, and admitted to the police that he never struck his dog. I could communicate with the dog more he told detectives in an interview."²⁰⁹ The case proved a landmark one as the Toronto judge found that the woman had ultimately died from the stress of being abused. Her 55 year old son Donald was convicted of manslaughter and failing to provide the necessities of life. "Noseworthy is believed to be the first person in Canada to be convicted of manslaughter, in other words an unintentional killing in the case of elder abuse. Crown prosecutors believe the ruling sends a strong message about caring for elderly parents."²¹⁰ The tragedy is that the case itself is not unique. What is unique is that the son received a 7 year prison sentence, though he'll probably only serve 3 ½ years. Seldom are elder abuse cases effectively prosecuted, and meaningful punishments are even rarer than convictions. This is due to a number of factors to be discussed later in the report, including a lack of expertise by police and judiciary in dealing with elder abuse cases, and an

attitude similar to one found in the early days of child abuse and violence against women prosecutions, that abuse of elders is somehow a private family matter not to be dealt with in the courts.

iii) Financial and Emotional Abuse – a caregiver gone wrong:

Dorothy was 92, having moved to Windsor Ontario to spend the last years of her life. Always fiercely independent she would have been the last person to have expected what happened. A live-in caregiver robbed Dorothy of her entire life savings, her home, and her dignity with more than \$82,000 spent on extravagant living in less than three years. It wasn't until the utility bills were \$7000 overdue that the bank manager contacted family members to alert them that their aunt had been defrauded of all her money. Coming to rescue their aunt, two nieces were shocked at what they found. Showing up unannounced at their aunt's trailer, they found her frail, confused and unkempt. She had obviously been in the same clothes for days. Her personal belongings had been ransacked, and the trailer was an utter mess. She had been fed on macaroni, and her "caregiver" had moved her 17 year old son and his girl friend into the trailer without Dorothy's permission. "At times when I ventured out from my room into the living area, her son would say things like – What do you want old lady?" Dorothy recalls. It was a crushing experience for the once indomitable Dorothy. Her nieces rescued her and took her home to Ottawa with them. The caregiver, a 44 year old woman has since pleaded guilty to fraud over \$5000. Yet Dorothy has lost her home and savings, and has experienced firsthand the shattering helplessness of abuse. "I feel so embarrassed that I placed my trust in her" states Dorothy, one of many who have been robbed of everything, by someone who was supposed to have cared for them.²¹¹

"Emotional abuse wears the victim down over time, until the victim has lost her self-esteem, her perspective, and her soul." Laurie Salvador – Notary Public, Sidney B.C.²¹²

iv) Even the famous can succumb to Abuse – Mickey Rooney testifies to the U.S. Senate:

On March 2 American film legend Mickey Rooney testified to the U.S. Senate Special Committee on Aging. The 90 year old entertainer gave an emotional testimony of the financial and psychological abuse he suffered at the hands of a relative; abuse that left him unable to afford a lawyer to defend himself. It wasn't until lawyers from a film company he had once worked for came to his aid, that Rooney was finally able to seek remedy. Rooney spoke of the devastation of abuse. "You feel scared, disappointed, angry, and you can't believe this is happening to you. You feel overwhelmed. The strength you need to fight is complicated. You're afraid, but you're also thinking about your other family members. You're thinking about the potential criticism of your family and friends. They may not want to accept the dysfunction that you need to share. Because you love your family, and for other reasons, you might feel hesitant to come forward. You might not be able to make rational decisions. What other people see as generosity may, in reality, be exploitation, manipulation, and sadly, emotional blackmail of older, more vulnerable members of the American public"²¹³ Rooney notes that if he as a nationally famous communicator can be left so utterly helpless in the face of abuse, anyone can fall victim. His relative emptied his bank account, while marginalizing him, psychologically shoving him down, treating him like a child who had absolutely nothing to say about his life. "You can have control of your life one minute and in the next minute, you have absolutely no control. Sometimes it happens quickly, but other times it is very gradual. You wonder when it truly began. In my case I was eventually and completely stripped of the ability to make even the most basic decisions in my own life. Over the course of time, my daily life became unbearable. Worse, it seemed to happen out of nowhere. At first it was something small, something I could control. But then it became something sinister that was completely out of control. I felt trapped, scared, used, and frustrated. But above all, I felt helpless. For years I suffered silently. I couldn't muster the courage to seek the help I knew I needed. Even when I tried to speak up, I was told to be quiet. It seemed like no one believed me."²¹⁴

But Mickey Rooney didn't give up. He continued to share his story with others until finally someone believed him and came to his aid. He spoke out on his elder abuse case not for the sake of getting sympathy, but for the sake of the millions of seniors who in varying ways experience what he did. "I am here today because it is so important that I share my story with others, especially those who may be watching at home, suffering silently as I was. To those seniors and especially elderly veterans like myself, I want to tell you this: You are not alone and you have nothing to be ashamed of. You deserve better. You have a right to control your own life, to be happy, and not live in fear. Please, for yourself, end the cycle of abuse, and do not allow yourself to be silenced any longer. Tell your story to anyone who will listen and above all, HAVE HOPE. Someone will hear you. If we all stand together and speak up, we can begin to take the necessary steps to end the cycle of elder abuse."²¹⁵

Mickey Rooney's case shows us how easily a lucid, intelligent, senior can be isolated and marginalized by a strong manipulative personality. This kind of abuse goes on more than we realize and the results can be devastating. An Edmonton senior 65 year old Rosanne Paluch who spent years suffering emotional and psychological abuse at the hands of a relative, and often when it got unbearable contemplated ending her own life notes "Not all abuse is physical, I didn't have bruises on my body but my soul was bruised from the abuse I suffered from a close family member."²¹⁶

The handful of cases given above shows us the range of abuse, and shows us that abuse can touch anyone's life. Abuse may be hidden but its effects are real and often terrible.

"The abuse of older people by family members dates back to ancient times. Until the advent of initiatives to address child abuse and domestic violence in the last quarter of the 20th century, it remained a private matter, hidden from public view. Initially seen as a social welfare issue and subsequently a problem of aging, abuse of the elderly, like other forms of family violence, has developed into a public health and criminal justice concern. These two fields – public health and criminal justice – have therefore dictated to a large extent how abuse of the elderly is viewed, how it is analysed, and how it is dealt with."²¹⁷ World Report on Violence and Health, World Health Organization, 2002.

II -- Defining Elder Abuse:

"It is generally agreed that abuse of older people is either an act of commission or of omission (in which case it is usually described as neglect) and that it may be either intentional or unintentional. The abuse may be of a physical nature, it may be psychological (involving emotional or verbal aggression), or it may involve financial or other material maltreatment. Regardless of the type of abuse, it will certainly result in unnecessary suffering, injury or pain, the loss or violation of human rights, and a decreased quality of life for the older person. Whether the behaviour is termed abusive, neglectful or exploitative will probably depend on how frequently the mistreatment occurs, its duration, severity and consequences, and above all, the cultural context."²¹⁸

The World Health Organization adopts a UK definition in its report **Missing Voices**. "Elder abuse is a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person" They go on to note the categorizations typical to the policy literature, with elder abuse having been categorized as:

- physical abuse: the infliction of pain or injury, physical coercion, physical/chemical restraint
- psychological / emotional abuse: the infliction of mental anguish
- financial / material abuse: the illegal or improper exploitation and / or use of funds or resources
- sexual abuse: non-consensual contact of any kind with an older person
- neglect: intentional or unintentional refusal or failure to fulfil a care-taking obligation ²¹⁹

To this of course can be added:

- institutional abuse: abuse in long term care facilities including loss of freedom and control, inadequate care, insufficient diet, misuse of physical and chemical restraints to make the staff's job easier, physical and emotional abuse inflicted by care staff etc.
- medical abuse: elders having their medical care wishes ignored, facing systemic cutbacks in medical support i.e. homecare, being faced with unilateral treatment withdrawal and other forms of medical rationing, inadequate pain control etc.
- abuse by systems: the dehumanizing treatment older people are liable to suffer at health clinics and pension offices, various forms of marginalization by the government and bureaucracy.

It might be noted that a significant and often unconscious form of abuse is the tendency for seniors to be spoken to and treated like children "infantilization". By making seniors (especially persons with disabilities), appear childlike even childish through our use of language, we devalue them while thinking we are acting in the opposite manner. We need to exalt the role of the elder while recognizing that many will be difficult to work with. Elders are no more imperfect than those of us not yet elders. They may at times be grouchy, cranky, depressed, lonely, isolated, etc. like each of the rest of us sometimes is. They may take a little longer to do things and to make decisions, but this doesn't mean they are incapable, or that we should take over their decision making to hurry things along. A society which values success and efficiency can sometimes fail to be patient with a person who takes a little longer to make the same decision they used to make so quickly maybe only five years before. How we socially devalue our elders in these subtle ways is causally related to abuse. If as we often do we tend to environmentally segregate and isolate our elders from the "active community" we send a not so subtle message to the younger members of society. Whether we call it ageism or not, we should be aware of the subtle ways we can marginalize the elderly, and the way this unconscious lack of respect may isolate seniors, and put them at risk of more aggressive forms of abuse.

III – Causes of abuse:

"Most of the early work on abuse of the elderly was limited to domestic settings and carried out in developed countries. In seeking explanations for elder abuse, researchers drew from the literature in the fields of psychology, sociology, gerontology and the study of family violence. To accommodate the complexity of elder abuse and the many factors associated with it, researchers have turned to the ecological model, which was first applied to the study of child abuse and neglect and has been applied more recently to elder abuse. The ecological model can take into account the interactions that take place across a number of systems. The model consists of a nested hierarchy of four levels of the environment: individual, relationship, community and society."²²⁰

Elder abuse like suicide is an immensely complicated multi-causal phenomenon. In intervening to prevent abuse we require research which is sensitive to this complexity, and is able to develop responses which address the multiple causes. The ecological approach is a tremendously powerful research paradigm. The ecological model recognizes the complex interplay of individual factors, relationship factors, community and societal factors. It presupposes a multi- disciplinary perspective, and integrates well with a public health approach to prevention and intervention.

a) Individual factors and abuse:

"The first level of the ecological model seeks to identify the biological and personal history factors that an individual brings to his or her behaviour. In addition to biological and demographic factors, factors such as impulsivity, low educational attainment, substance abuse, and a prior history of aggression and abuse are considered. In other words, this level of the ecological model focuses on the characteristics of the individual that increase the likelihood of being a victim or a perpetrator of violence."²²¹

Recent research in elder abuse has recognized that many abusers especially those who are physically aggressive, have a greater likelihood of having personality disorders, and alcohol and addiction related problems. Mental health and substance abuse problems seem to be disposing factors, at very least risk identifiers, flagging our attention to the possibility for abuse problems among family members and caregivers.

Individual factors can also be found among those at risk for abuse. Persons with cognitive and physical impairments are at greater risk of being abused. Dementia in particular can be a strong indicator of an increased risk of suffering abuse. This may in part be due to the stress dementia imparts to the caregiver relationship. Gender has been hypothesized as a factor in abuse, but when the larger number of frail elderly women is taken into consideration, the proportional rate of abuse of elderly men and women is similar.²²² Financial difficulty on the part of the abuser has been found to be a risk factor, especially in terms of feeding a drug or alcohol addiction.

b) Relationship factors and abuse:

“The second level of the ecological model explores how proximal social relationships -- for example, relations with peers, intimate partners and family members – increase the risk for violent victimization and perpetration of violence. In the cases of partner violence and child maltreatment, for instance, interacting on an almost daily basis or sharing a common domicile with an abuser may increase the opportunity for violent encounters. Because individuals are bound together in a continuing relationship, it is likely in these cases that the victim will be repeatedly abused by the offender. In the case of interpersonal violence among youths, research shows that young people are much more likely to engage in negative activities when those behaviours are encouraged and approved by their friends. Peers, intimate partners and family members all have the potential to shape an individual’s behaviour and range of experience.”²²³

In the first speculative work on elder abuse social scientists theorized that caregiver stress and burnout had a great deal to do with the phenomenon of abuse. While recognizing that care giver stress can play a role, further research has shown that the relationship between the caregiver and care recipient prior to abuse can play a significant role. While stress may be a contributing factor it does not alone account for abusive behaviour. “Work with patients with dementia has shown that violent acts carried out by a care recipient can act as “triggers” for reciprocal violence by the caregiver. It may be that violence is a result of the interplay of several factors, including stress, the relationship between the carer and the care recipient, the existence of disruptive behaviour and aggression by the care recipient, and depression in the caregiver.”²²⁴ It has been noted that living conditions i.e. overcrowded living quarters, and lack of privacy can facilitate family conflict. Dependency and co-dependency can also be factors in an abusive relationship. An example would be adult caregivers who depend on the elderly parent for their home and monetary needs. Often in these care giver situations both the parent and adult child can become isolated, with little outside contact beyond their immediate familial care-giving relationship. This leads to an inability to step outside the pressures of the relationship.

c) Community factors and abuse:

“The third level of the ecological model examines the community contexts in which social relationships are embedded – such as schools, workplaces and neighbourhoods – and seeks to identify the characteristics of these settings that are associated with being victims or perpetrators of violence. A high level of residential mobility (where people do not stay for a long time in a particular dwelling, but move many times), heterogeneity (highly diverse population, with little of the social ‘glue’ that binds communities together) and high population density are all examples of such characteristics and each has been associated with violence. Similarly, communities characterized by problems such as drug trafficking, high levels of unemployment or widespread social isolation (for example, people not knowing their neighbours or having no involvement in the local community) are also more likely to experience violence. Research on violence shows that opportunities for violence are greater in some community contexts than others – for instance in areas of poverty or physical deterioration, or where there are few institutional supports.”²²⁵

Social isolation is perhaps the strongest risk factor for abuse. It is a factor both for the victim and the perpetrator of abuse. An important intervention effort from a community perspective is to consider how best to overcome social isolation in elders, and integrate them in the fabric of their community. The same of course also goes for family caregivers. “Isolation of older people can be both a cause and a consequence of abuse. Many older people are isolated because of physical or mental infirmities. Furthermore, loss of friends and family members reduces the opportunities for social interaction.”²²⁶

Development of a Compassionate City/ Compassionate Neighbourhood model, in which community visiting and strong social links are encouraged, is a vital physical and mental health as well as social policy need. All levels of a person’s health and well being are dramatically improved through social connection.

“On the one hand, millions of dollars are committed to alleviating ill-health through individual intervention. Meanwhile we ignore what our everyday experience tells us i.e. the way we organize our society, the extent to which we encourage interaction among the citizenry and the degree to which we trust and associate with each other in caring communities is probably one of the most important determinants of health”²²⁷

The building of community cohesion, as a public health approach requires more research, and is perhaps the most effective approach to the problem of abuse. Under the rubric of community we might also consider factors such as decent housing, building up community infrastructure and social organizations, and developing a community spirit of looking out for one’s neighbour who might be in crisis.

d) Societal factors and abuse:

“The fourth and final level of the ecological model examines the larger societal factors that influence rates of violence. Included here are those factors that create an acceptable climate of violence, those that reduce inhibitions against violence, and those that create and sustain gaps between different segments of society – or tensions between different groups or countries. Larger societal factors include: Cultural norms that support violence as an acceptable way to resolve conflicts; ... norms that give priority to parental rights over child welfare; norms that entrench male dominance over women and children; norms that support the use of excessive force by police against citizens. ... Larger societal factors also include the health, educational, economic, or social inequality between groups in society. ... Placed within the developmental context, the ecological model also shows how violence may be caused by different factors at different stages of life.”²²⁸

As with all elder abuse research, empirical evidence is often limited due to a lack of in-depth qualitative and quantitative research. Far more statistical sampling is needed, as well as more in-depth qualitative probes of the experiences of those who have been abused. While up to now the research emphasis “was generally on individual or interpersonal attributes as potential causal factors for elder abuse” a shift is beginning to take place with “Cultural norms and traditions – such as ageism, sexism, and a culture of violence also now recognized as playing an important underlying role. Older people are often depicted as being frail, weak, and dependent, something that has made them appear less worthy of government investment or even of family care than other groups, and has presented them as ready targets for exploitation.”²²⁹ As a society we need to become cognizant of the impact of such stereotyping on the way people are viewed and treated. Social marketing campaigns can be a powerful force for change.

“Because violence is a multifaceted problem with biological, psychological, social and environmental roots, it needs to be confronted on several different levels at once. The ecological model serves a dual purpose in this regard: each level in the model represents a level of risk and each level can also be thought of as a key point for intervention. Dealing with violence on a range of levels involves addressing all of the following: -- Addressing individual risk factors and taking steps to modify individual risk behaviours. -- Influencing close personal relationships and working to create healthy family environments as well as providing professional help and support for dysfunctional families. – Addressing gender inequality, and adverse cultural attitudes and practices. – Addressing the larger cultural, social and economic factors that contribute to violence and taking steps to change them.”²³⁰

IV – Canada’s agenda against elder abuse:

An adequate response to elder abuse requires four things, all of which need to occur simultaneously. To date intervention, advocacy and support services for victims of abuse have been least emphasized, and the need for protective services is very great.

First we need to develop a **broad based public awareness campaign** to make everyone fully conscious of the seriousness of elder abuse, and that it is a societal responsibility to see it ended.

Second we need prevention programs, designed to integrate isolated seniors into society, support caregivers, minimize risk factors, increase respect for seniors, and strengthen resiliency in seniors. Prevention programs would include specific education designed to overcome age prejudice, and to raise awareness as to signs of and risk factors for abuse.

Third we need to develop adequate intervention and advocacy services, including senior advocates, specialist intervention teams, needed psycho-social support for persons who are being abused, and short and long term housing enabling abused seniors to be removed from dangerous situations. This requires stable ongoing funding.

Forth we need to develop adequate judicial measures enabling us to successfully prosecute cases of elder abuse. This requires educating judges, prosecutors and police. It also requires developing forensic, psychological and financial expertise in the area of elder abuse, with experts capable of giving effective testimony in court. An attitudinal shift is needed in the legal culture which truly recognizes the seriousness of elder abuse and no longer tolerates it.

All of this requires ongoing education, training, and research. **Specialized education** is needed for professionals who deal with front line intervention in cases of abused seniors. It should be noted that the Public Health Component of the Federal Elder Abuse Initiative did some important work which needs to be broadly applied. An example would be the **Counterpoint Project** of the Canadian Centre for Elder Law (CCEL). This project developed some important tools to help responders, and also did some important analysis of systemic and legal changes needed to address cases of abuse.²³¹

“The first step is education. We need to get to the point where everybody knows what elder abuse is and is aware that it exists. The more we talk about it, the more real it becomes and the more people are shocked by it, and then the more committed we are going to be as a society to do something about it.” Dr. Elizabeth Podnieks–Professor emeritus Ryerson University, Toronto²³²

1) Public Awareness Campaign:

The **Federal Elder Abuse initiative** invested \$13 million dollars over three years beginning in 2008, on the issue of preventing elder abuse. Part of this campaign included increasing awareness through advertising, with an awareness campaign running between June 15-29, 2009 and September 28 to October, 2009; utilizing television, print and internet. “A post- campaign survey showed that 58% of **poll respondents** had heard or read advertising about elder abuse, surpassing the government advertising benchmark of 36% and demonstrating the success of the campaign.”²³³

“The TV ads which are currently running are starting to have an impact. It is my anecdotal experience that people are becoming much more aware of the issue than they were the last time the ads ran. And, they are feeling much more uncomfortable about it – which is a good thing.” Sherry Baker – Executive Director BC Association of Community Response Networks²³⁴

While the initiative did a great deal of good, it ended on March 31st 2011. On every level including public awareness, an ongoing initiative is needed. Social marketing campaigns require long term blanket coverage to truly achieve broad based attitudinal transformation. Marketing specialists recognize the importance of continuity, with even well known corporate giants like Coca Cola, spending hundreds of millions of dollars on ongoing marketing campaigns, despite Coke being a household word almost everywhere in the world. A public awareness campaign requires long term, broad based coverage, in addition to a wider range of media being utilized, with many seniors not using internet, and with many Canadians no longer watching the Canadian networks given the prevalence of satellite television networks. Other forms of broad based advertizing, such as inserting tax bills with an elder abuse pamphlet might be considered. Radio is also a popular venue for seniors, and should be considered in terms of an ongoing information campaign on elder abuse. In addition to the Federal Elder Abuse Initiative, the Provinces of Quebec, British Columbia and Ontario are also to be commended for their public awareness campaigns.

“A public awareness campaign that could be rolled out on a federal, provincial and territorial level would save the time and resources that are expended by parties working in “silos”, independent of one another. If we speak with one strong voice, delivering the message that elder abuse is a societal issue and that the abuse of older persons will not be tolerated anywhere in this country, we have the best chance of reaching the general public and changing perceptions and attitudes on a grand scale.”²³⁵

2) Prevention Programs:

While there is still much research needed on both risk factors and protective factors for persons vulnerable to elder abuse, and how to best strengthen protective factors; “psychosocial measures carry much more weight than case-by-case measures and our efforts should be focused on prevention.”²³⁶ If we can strengthen various protective factors in the broader community of seniors, this is a far more encompassing way to reduce elder abuse than after the fact intervention. This approach is referred to as **primary prevention** in the literature and involves activities aimed at reducing factors leading to health and social problems.

Two exemplary initiatives aimed at primary prevention and produced by the public health component of the Federal Elder Abuse Initiative are: a) *“It’s not Right”—Neighbours Friends and Families for Older Adults*, and b) *Across the Generations – Respect All Ages, an intergenerational approach to prevention.*²³⁷ **“It’s not Right” – Neighbours Friends and Families for Older Adults** is an elder abuse supplement for an important family violence awareness program designed to help family friends and community effectively support and advocate for people suffering abuse. **Across the Generations – Respect All Ages, an intergenerational approach to prevention** is a national educational curriculum designed to bring greater awareness to the issues of ageing, greater respect for older adults, and to encourage on-going community based projects across the generations. There are a series of 21 lessons for children aged 8-13, which can be taught in school, the home or the community.

The Quebec government notes in their strategy on elder abuse that the following psychosocial factors are important to protecting seniors from abuse.

- Adequate social and support networks allowing seniors to counter isolation;
- Healthy physical and psychosocial environments allowing seniors to feel safe;
- Accessible information about elder abuse geared towards seniors and their representatives;
- Personal networks that have been educated about elder abuse;
- Support networks geared towards family caregivers;
- Awareness among family and professional caregivers about the normal process of aging and its outcomes (such as changes in eyesight, hearing, speech, or balance) and an ability to deal with other symptoms associated with age-related illnesses (such as dementia or Parkinson’s disease);
- Proper training for home-based caregivers.²³⁸

There are a wide range of potential preventive measures. A general social awareness campaign reinforcing the dignity and importance of our Canadian seniors, and warning against ageist prejudice, is another important dimension of a preventative program. Many provinces/territories and communities are developing networks with a mandate for primary prevention. Called Community Response Networks or Elder Abuse Committees these networks don't handle "cases", but work to affect the fabric of the community so that when a case arises, the individual gets access to more coordinated assistance through local agencies and interdisciplinary teams. Many such networks have been funded temporarily by the HRSDC New Horizons for Seniors Program, but would require stable long term funding to continue their important work.

Community Based Social Programs:

In concrete terms, Australia's **Men's Sheds Program** is an excellent way to encourage socialization among older and widowed men. The program mentioned in greater detail at the end of the suicide prevention part of this report, sets up a "shed" in a community, where men can go and work in a shop setting on woodcraft and other projects, of assistance to the community, while socializing, perhaps enjoying a pint, playing a game of pool, and otherwise connecting, with other retired men. It was found to be an effective way of reaching out to potentially isolated working class retired men who were not interested in more traditional community organizations. It allows these men to continue to do important work, working with their hands to produce useful and beautifying items for their community i.e. items such as park benches, flower planters and picnic tables. It builds up bonds of friendship, self esteem, and social integration among men who might otherwise become isolated and depressed.

The Canadian federal government's **New Horizon for Seniors Program** is supporting projects similar to Australia's **Men's Sheds Program**, across the country. Since its beginning the New Horizons Program has funded more than 5,000 projects in hundreds of communities across Canada. The program seeks to provide support to meet five objectives:

- promoting volunteerism among seniors and other generations;
- engaging seniors in the community through the mentoring of others;
- expanding awareness of elder abuse, including financial abuse;
- supporting the social participation and inclusion of seniors; and
- providing capital assistance for new and existing community projects and/or programs for seniors²³⁹

One Canadian program similar to the Men's Sheds program is the **Wilmot Seniors Woodworking Club and Craft Shop** in the village of Baden, just west of Kitchener Ontario. This facility offers opportunities for seniors to participate in woodworking, metal working and other craft programs. They can build anything one wants, from birdfeeders to beds. Custom made products can be ordered at reasonable prices which helps cover the costs of the club. This innovative program recently received funding through the capital assistance component of the federal government's New Horizons for Seniors Program. The grant enables the Woodworking Club to replace worn out equipment. The club, open to seniors from Baden, Waterloo, Kitchener, Wellesley and the surrounding area, allows seniors to stay connected and enjoy a shared hobby.

"It's a really great place for seniors. We have fellows here who've had strokes and stuff like that, and it keeps them active and gets them better; people with arthritis, it keeps them going instead of sitting at home and feeling worse. ... The local facility is truly unique, it's well run, it's well looked after ... this is a really good thing." John Gruhl – Baden, Ontario²⁴⁰

Of course all sorts of programs have been developed, and the New Horizons for Seniors Program continues to provide support for innovative community based projects. Primary prevention requires a creative approach to building social capital.

The preventive approach balances important aspects of the ecological model, the public health, and the health determinant framework. Within the public health approach a major emphasis is placed on primary prevention. Likewise research is vital for determining the most effective responses to risk and protective factors. With the Health determinant framework, it is necessary to take into account the many variables and determining factors in an individual's health and social well being. As previously noted at the beginning of the report, the Public Health Agency of Canada recognizes the key determinants of health as follows:

- Income and Social status
- Social support networks
- Education and literacy
- Employment/Working conditions
- Social environments
- Personal Health practices and Coping skills
- Healthy Child development
- Biology and Genetic endowment
- Health services
- Gender
- Culture

“Working on any of these will alter a person's well being. It (the health determinant framework) is a holistic approach that goes beyond seeing health as the absence of disease; or the health system as meaning only ‘acute’ care.” This approach makes efforts to:

- i) prevent the problem before-hand
- ii) improve the health status of the whole society while considering the special needs of vulnerable sub populations
- iii) focus on inter-sectoral cooperation and partnerships
- iv) find flexible multidimensional solutions to complex problems
- v) encourage public involvement and community participation²⁴¹

Elder abuse is a complex phenomenon with a strong social dimension. As such it requires a multi faceted solution, a mindset that thinks in terms of the various levels of the problem in developing creative solutions. While not all the health determinants are directly related to elder abuse, this sort of social understanding is a mindset which makes our efforts to prevent elder abuse ultimately more effective. In concrete terms housing, social connection, caregiver support, a strong connection for seniors with their primary health care providers, and a host of other factors, play an important role in reducing elder abuse in Canadian Society. Elder Abuse can be reduced and prevented.

“Violence is often seen as an inevitable part of the human condition – a fact of life to respond to, rather than to prevent. By contrast, the notion that violence is preventable is a basic tenant of the public health approach. In moving from problem to response, the public health approach has four steps. The first step is to statistically describe and monitor the extent of the problem; to identify the groups and communities at risk. The next step is to identify and understand the factors that place people at risk for violence – to assess which factors may also be amenable to intervention. The third step is to develop and evaluate interventions to reduce these risks, and the fourth is to implement and apply widely the measures that are found to work. By linking ongoing statistical description and monitoring of the problem to the fourth step of widespread implementation, the four steps form a feedback loop through which the effectiveness of violence prevention

programmes can be constantly monitored and improved. The public health approach is population-based. It emphasizes primary prevention – doing something about the problem before it occurs. It draws upon a wide range of expertise across many sectors, and it is based in science. It asserts that everything – from identifying the problem and its causes, to planning, testing and evaluating responses – should be based on sound research and informed by the best evidence.” Dr. Alexander Butchart – World Health Organization²⁴²

...

3) Intervention and Advocacy:

“Since the inception of Ontario’s Elder Abuse Strategy, the Networks have seen a significant increase in the demand for elder abuse services. As a result of public awareness campaigns at the local, provincial and national level, the public is now making more calls to report abuse to agencies and police. But with the lack of dedicated agencies to respond to elder abuse many seniors are not getting the assistance they need. Who takes over after a case is reported? Without adequate services the victim could be more at risk.” Raeann Rideout – Ontario Network for the Prevention of Elder Abuse²⁴³

With an increase in public awareness has come an increase in reporting of abuse, both by seniors themselves, and by persons in the community. Elder abuse help lines around the country are working at or close to capacity. Elder abuse prevention networks are reporting significant increases in their client base. Yet universally groups and agencies dedicated to responding to elder abuse report a tremendous lack of resources. Elder abuse response networks are still in their infancy and capacity building is essential. Provincial and territorial government agencies are little better positioned to intervene. British Columbia, for example, has initiated a mandatory response policy, delegating response to provincial health authorities, while dedicating no proportionate resources to meet the volume of cases. In many other provinces and territories, there isn’t even the commitment to mandatory intervention.

“We require an immediate funding response. The government is being unethical in bringing awareness to this issue which is resulting in more calls and requests for help, yet not offering any support in establishing means of responding. Sustainable funding is required so that those regions who have established some response system can continue to develop these, and those regions who have yet to do so, can begin to develop a response person, team or system.” Inga Thompson – Prevention of Senior Abuse Network, Simcoe County, ON.²⁴⁴

Response to elder abuse involves health, social service, legal and community groups. Slowly networks are being built across the country, with grassroots organizations and various agencies coming together to develop a more effective response to abuse. Important as this is, it leaves a problem of coordination for the disparate groups in their intervention efforts. Who is ultimately responsible for coordinating the complex array of services needed, for following up and determining that an abused senior is kept safe and is not lost in the red tape of overlapping jurisdictions and agencies?

“With the development of a regional network, it became apparent that multiple organizations and ministries involved had a shared interest in the topic of elder abuse, however, there were no clear accountabilities related to roles and responsibilities. The organizations did not understand each other’s scope and there was lack of a consistent approach. If everyone is responsible, nobody is responsible.” Anita Cole – Owen Sound, ON²⁴⁵

The province of British Columbia determined that it would be the provincial health services that would be ultimately responsible for elder abuse intervention. It is important that there be a designated agency responsible and accountable for investigation and follow up on elder abuse complaints. The result in B.C., however, has not been entirely without problems with health care personnel sometimes being put into dangerous situations, forced to take on quasi policing roles which they are not trained for. In addition elder abuse intervention tends to become medicalized, with seniors ending up in acute care and LTC beds, even though they aren’t sick, because these are the only resources available to remove seniors from abusive situations.

The use of acute care beds and LTC beds for adult protective purposes is a waste of health resources. Specialized elder abuse shelters modelled on battered women's shelters would in the end be a cheaper and more effective way to respond to problems of abuse. These types of shelters would likely best be built as joint projects of government and local community organizations. Though a specific agency would be ultimately responsible for case file management and coordination, there would be room for a wide range of agencies, police services, the Public Guardian and trustee, and voluntary organizations, in the multi-sectoral response to abuse. The voluntary sector has played an irreplaceable role up to now, and with funding restraints effecting social service agencies all over Canada, the cooperation of the government and voluntary sectors will continue to be important in efforts to build capacity

“Health care delivery systems were not established to provide Adult Protective services. As a result, many of the rules, eligibility, policies and protocols do not take into account the special circumstances of vulnerable adults experiencing violence and serious neglect. ...When an elder cannot be cared for adequately at home ... the only alternative is to apprehend them for their own protection. This generally leads to an acute care admission, even though the patient may not require acute care treatment. The patient will then wait in the hospital until the appropriate authorization is obtained to admit him/her to a LTC facility. LTC facilities are reluctant to admit patients who don't want to be there or those who have problematic family members as they do not have the expertise or staffing levels to deal with the complex interpersonal, legal and family challenges posed by admitting an adult primarily for protection rather than health reasons. Nor do LTC facilities generally have security to prevent an abuser from visiting, or a vulnerable adult from leaving. In short, there needs to be recognition that Adult Protection is a health, social and legal issue which does require special expertise and access to services that the general population receiving health care services does not require.” Amanda Brown – Vancouver Coastal Health²⁴⁶

Elder abuse requires a specialized agency, along the lines of an adult protection service, with a mandate similar to that of child and family services which can be the responsible government agency for elder abuse intervention. This is the only way to overcome the fragmentation that has led to duplication of services, waste of scarce resources, and most importantly ineffective response with clients “falling between the cracks”. The role of this specialized elder abuse protective service is to serve as the case manager with ultimate responsibility to organize and integrate the range of organizations and services needed in the ongoing intervention process. The specialized agency would also be the responsible agency for keeping careful documentation on behalf of the abused senior. While working closely with health professionals and various organizations and agencies, the adult protection agency would be staffed by social workers; with some expertise in the legal dimensions of abuse. Adult protective services have traditionally worked with persons who lack capacity to make decisions for themselves. While incapacity can be present in the case of persons suffering abuse, many if not most abused seniors are quite capable of personal decision making. An agency set up to manage elder abuse would have to take into account the right of competent adults to make their own decisions.

“In general adult protection legislation provides for both emergency and more gradual intervention in the lives of abused or neglected adults so that a range of health, social and other services may be provided, preferably on a voluntary received basis. Interventions under adult protection laws are the responsibility of a statutorily designated service, usually a provincial health and social service department. Services may include the kinds of short-term financial management services provided by a provincial public guardian and trustee service without the need to go through the expensive, time consuming and stigmatizing process of applying to a court for a guardianship order. As a last resort, health and personal care services may be imposed upon an abused or neglected adult for a limited period of time (usually up to 12 months). These services must be needed, the adult has to be mentally incapable of making decisions about the services, and a court must grant an order for the services to be provided without consent. The orders may include provisions that restrain the person responsible for the abuse of a mentally incapable adult, and may require adult children to pay maintenance to their abused parent.”²⁴⁷

What is required in terms of a coherent system of intervention for elder abuse?

It needs to be recognized from the outset that a consistent and effective intervention strategy is vital to prevent serious harm to seniors. If abused seniors are allowed to “fall between the cracks” in the system the results can be catastrophic. With increasing age, injuries that would be minor in a younger person can have very grave health outcomes in a fragile senior.

“For older people the consequences of elder abuse have system-wide impacts, especially in health care. Any injury to an older person runs the risk of further deterioration of health status and wellness. Even minor injuries can cause serious and permanent damage due to brittle bones and fragile health status, convalescence can take longer, and outcomes can result in hospitalization, or placement in a long term care home.” Anita Cole – Owen Sound, ON²⁴⁸

This is true of all forms of abuse. Psychological abuse can also have grave health outcomes in an elderly person, and financial abuse can leave a senior destitute, with no way to recoup their savings through ongoing participation in the labour force. Furthermore the longer abuse is allowed to continue, the worse it often becomes.

“Abuse if not addressed, can escalate with an increasing seriousness of harm. Physical abuse can go from ‘minor’ neglect through to abuse where medical treatment is necessary, on through to death. We also must remember that older adult victims are vulnerable to complications resulting from physical violence which can affect their ability to function independently.” Agnes Soulard – Lampton Elderly Outreach, ON²⁴⁹

In order to effectively intervene in abuse cases we need to develop a range of services including:

a) A first line of communication with people suffering abuse.

A national elder support hot line is an effective way for seniors to make initial contact with support services. Qualified staff would be trained to address a broad range of concerns for seniors, including intervention and support for victims of abuse. Such a national phone line would provide initial support and advice, while putting the person in contact with provincial and regional help lines, and local support networks, for continuing intervention. Service would be available in a range of languages, and staff would be trained to be sensitive to cultural differences. It is important that this national toll free number be widely advertized. It should be in the emergency numbers section of all phone books. It should be displayed prominently in social marketing campaigns, whether in newspapers, TV ads, or magazines. A fridge magnet with the number could be sent out with pension cheques. Seniors need to be made aware that there is a number they can call for help and support. At present seniors are often unsure who to call for help, and how to get in contact with the right organization.

b) A designated agency for response and intervention is essential.

When elder abuse is reported a designated agency is essential to make the assessment as to the truth and seriousness of abuse claims. All situations of suspected or reported abuse, neglect and self neglect need to be dealt with. Determination must be made as to whether the person needs support or assistance, and as to whether the person is capable of seeking support and assistance on their own. The seriousness of the situation must be determined and appropriate action taken to ensure the senior’s safety. If a crime has been committed appropriate authorities need to be involved. Determination needs to be made as to the appropriate designated responder to follow up and manage the client’s case. A care plan needs to be developed and set in place. Assessment may actually require several visits, to gradually build up a relationship of trust with the client.

It is important that the designated responder:

- Carefully document each step of the intervention
- Interview the adult, privately if possible so as to avoid the abuser being present at the interview
- Assess the urgency of the situation

- Coordinate the assessment of the abuse situation, including the interdisciplinary team members needed for specialized assessment i.e. Psychiatrist, gerontologist, financial expert etc.
- Coordinate assessment of clients capacity to make decisions (if needed)
- Determine who is power of attorney (as needed)
- Coordinate development and implementation of a care plan to provide support and assistance
- Advise the client’s responsible physician of the situation and actions taken
- Report as necessary to the Public Guardian and Trustee
- Report crimes committed against vulnerable adult to the police
- Ensure that responders in other sectors are kept informed
- Determine who will take lead responsibilities for investigation and follow up in terms of type of abuse i.e. Public Guardian in case of financial abuse
- Provide full documentation to any new designated responder
- Do not “hand off” an investigation until another designated responder has taken responsibility²⁵⁰

At the same time that there needs to be a designated responder to assure continuity in response, elder abuse intervention at its most effective is multi disciplinary and multi-sectoral, involving a range of professionals, organizations and specialties. There are analogies to integrated continuous care systems, with a need for common case management, and common accessible records to avoid unnecessary overlap and assure continuity between the various interveners.

“One of the primary challenges for older adults seeking help is constantly having to repeat details to yet another service provider in the hope that someone may be able to help. Consequently, many Canadian communities are taking a coordinated community response to providing support and assistance to seniors experiencing abuse and neglect. It begins with the proposition that the responsibility for addressing abuse and neglect does not lie with one agency (alone) – it is a general social responsibility in which many community partners have complementary roles and responsibilities. To a large extent it is a community development approach involving mapping community resources, building common understandings of abuse, building trust among agencies and organizations, and knowing what each is able or not able to do. The process is collaborative and, over time, leads to the development of interagency protocols and coordination of prevention and intervention efforts. The coordinated community approach also creates a supportive network for the service providers.”²⁵¹

c) Network building – Building a multidisciplinary team:

It is vital to build a network among groups, organizations, agencies and professionals, to ensure an integrated multidisciplinary response. An elder abuse network enables cross disciplinary learning, building trust between different professions and specialties, and developing the kind of relationships which facilitate cross-sectoral action. Silos are only bridged through relationship building across organizations and specialties.

“Multidisciplinary teams, based in part on those used in child abuse and domestic violence, ought to be created for the purposes of evaluation and treatment as well as prevention. The teams must address the perpetrator as well as the victim. All attempts must be made to bridge the cultural divide between healthcare providers, social workers, scientists, law enforcement, and the judicial system. Until these teams are formally in place, we will continue to have a fragmented system that leaves some of our most vulnerable citizens without decent care.” Laura Mosqueda, M.D.²⁵²

d) Setting up a community of “First detectors / responders

Many seniors never report abuse for a range of reasons. Physicians, community health nurses, home care staff, pharmacists, dentists, ambulance and fire fighters, police, and other community based professionals must be trained in detecting signs of abuse, and initiating intervention for abused seniors. This will necessitate ongoing professional education, and also facility with user friendly intervention tools. The

National Initiative for the Care of the Elderly (NICE) with funding from the federal New Horizons for Seniors Program has developed some important elder abuse intervention tools including:

- Indicators of Abuse (Pamphlet)
- Caregiver Abuse Screen (CASE)
- Elder Abuse Suspicion Index
- Brief Abuse Screen for the Elderly (BASE)
- Elder Abuse: Assessment and Intervention Reference Guide²⁵³

These tools provide screening tools for various professionals from health professionals (Elder Abuse Suspicion Index) to Police (Elder Abuse Assessment and Intervention Reference Guide). There is also a tool for screening caregivers for potential signs of Abuse, the Caregiver Abuse Screen (CASE). These tools are essential for giving various professionals clear guidelines for detecting and intervening in elder abuse cases. A chart outlining the complete range of tools is found in the preceding endnote.

“All professionals and service providers in contact with older adults and their families should know about aging and should have a good understanding of abuse of older adults. They include professionals such as physicians, lawyers, clergy, social workers and nurses, and also seniors’ organization staff, speech therapists, Meals on Wheels, home support and many more. An example can be seen in faith communities. A survey in Ontario revealed that two-thirds of faith leaders were aware of elder abuse among their congregants. Although clergy are one of the most likely groups of caregivers to encounter cases of abuse of older adults, they are the least likely to refer cases to helping agencies and have not been effective at intervention. Barriers to their effective involvement include lack of training, increased workload, and unfamiliarity with social and health care systems. ... Education and training takes time, money, and resources ... in a time of fiscal restraint, education and training are often treated as luxuries. When they occur, they tend to be a “one shot deal”. Community educators find that basic awareness information is not enough, and increasingly service providers are seeking practical strategies, sets of indicators, helpful resources, and local contacts.”²⁵⁴

e) Emergency short term shelter, and long term housing for abused seniors.

In an emergency intervention for abused seniors it is sometimes necessary to remove the person to a place of safety. For elderly women, battered women’s shelters have sometimes been used, but these are not ideal, as elderly women feel out of place with the much younger women and their small children, and often find it difficult to rest in such a noisy fast paced environment.

“If you’re an 85 year old woman who has been experiencing abuse, you’re looking for peace and quiet, not a really rambunctious house.” Charmaine Spencer – Simon Fraser University, Victoria, B.C.²⁵⁵

For elderly men of course the battered women’s shelter is no option at all. All too many abused seniors end up in acute care wards and LTC homes, because there is nowhere else to send them. Aside from the waste of money in utilizing expensive acute care beds for people who are not sick, acute care hospitals and long term care facilities don’t provide the support abused seniors need. Seniors who have suffered abuse require a supportive environment where they can feel safe. They require a calm home like environment. They may need counselling or perhaps just trusted people they can talk to. Neither a hospital nor a LTC facility can provide the right environment for effective support to a person traumatized by abuse.

Canada has a tremendous shortage of emergency shelters for abused seniors. Still Calgary was the first city in North America to set up an emergency shelter for victims of elder abuse. The Kerby Centre has provided emergency housing for abused seniors since 1999.²⁵⁶ The Centre is run by seniors for seniors, with the board of directors being comprised entirely of seniors. Assisting the board in running the shelter and other senior related programs are 50 professional staff and over 400 volunteers.

Edmonton began the Edmonton Senior Safe Housing project in 2000. Initially they began with seven apartment units. About 30 percent of the people housed in apartment suites are elderly men.

Toronto began Pat's Place in September 2008 with one apartment unit. It is a short term living place for a senior in crisis. Seniors with major security needs or inability to live independently cannot be accommodated. This one apartment is still the only designated emergency shelter for abused seniors in the Toronto area. Clearly we have a long way to go before adequate emergency housing is available for abused seniors across the nation.

“Throughout the country, there are significant gaps between need and capacity to meet it in terms of crisis, short and intermediate term housing for abused older adults. This in part reflects the overall lack of affordable housing across the country. As a result of the shortages, staff in many programs are forced to prioritize daily which abused older adults they can help. Older men and older adults with complex needs, such as mental health or substance use problems, are more likely to ‘fall through the cracks’.”²⁵⁷

In addition to the problem of short and intermediate term emergency shelter, another great need in addressing abuse against seniors is long term housing. There are many cases where the good of the senior is best served by their taking up independent residence. In many areas of the country, especially larger metropolitan areas, affordable/decent housing can be impossible to find. This lack of affordable rental accommodation becomes even greater if the person needs assisted living accommodation. Due to lack of affordable accommodation people who could still live independently are often forced to enter nursing homes.

“There is little new affordable housing available. This in addition to the fact that increases in pension income have not been consistent with the increases in rental costs, creates a particularly vulnerable state for older persons. As one group noted, some of the current housing options that exist for older persons are only available to those who can afford to pay. To address this gap, more affordable housing, priced at fixed rents, or larger increases in pension income are necessary. ‘There are many older people among the homeless ... the lack of accessible low cost housing and the removal of rent controls has left many seniors fearful of eviction. There is no place to go.’ (Canadian Pensioners Concerned) (p.44)... The ideal housing option for older persons is linked housing developments that would include supportive housing, nursing homes, subsidized seniors only housing and some market rent options in addition to amenities such as health clinics, and recreational and educational programs (United Senior Citizens of Ontario). (p.48)”²⁵⁸

The lack of affordable housing becomes particularly acute when it is necessary to find accommodation for a person who needs to be removed from an abusive situation. People are being left in potentially traumatic situations every day, because there is simply no place to go.

4) Revamping the Justice system to effectively prosecute elder abuse:

“Elder Abuse cases are notoriously difficult to prosecute and often result in what many see as insufficient deterrence. Part of the problem lies in the legal interpretation of existing criminal offences and another part lies in the lack of sufficient investigative support to pursue the prosecutions. And even when significant sentences are meted out, the justice system can fail us. A Moncton woman was recently paroled after serving 8 months of a 4 year sentence for letting her mother die of neglect while living under the same roof.”²⁵⁹

Susan Eng – Canadian Association of Retired Persons (CARP)

The case referred to above is that of Margaret Grant a 48 year old Moncton New Brunswick woman who in 2007 left her mother 78 year old Kathleen Grant to rot in a chair. On receiving a 911 call, ambulance personnel found Kathleen with gangrene in her legs, having lost the ability to walk, malnourished, with sepsis after some five months sitting in her chair.

“When the paramedics got out of the ambulance and entered the building they were immediately struck by a stench of feces, urine and rot. Kathleen Grant was sitting in a living room chair and had been there so long the chair had formed around her body. The chair was covered in human waste and the floor around it was littered with garbage, dirty bandages and used diapers. One of the paramedics, Julie Martin, later told police there was a pool of liquid on the floor under the woman oozing from the rotting flesh on the woman’s legs that was so advanced, bone and tendons were exposed. ... ‘There was a hamster cage on the table and the hamster was the cleanest of all the family’ Martin told police. The elderly woman was taken to hospital where medical staff were shocked by her poor condition, with two doctors later telling police it was the worst case of senior neglect they had ever seen. She died four days later of heart failure.”²⁶⁰

In December of 2009 Margaret Grant was released to a Moncton halfway house. She had applied for an early leave from jail for non-violent, first-time offenders, a request which was granted. Grant was eligible for day parole after serving one sixth of her sentence, in her case eight months. Day parole allows the person to function in society under the condition that they return each night to a half way house. The Parole Board stated:

“Your crime resulted in the ultimate of tragedies. Notwithstanding the seriousness of your offence, there is no evidence of past violence, no indication of any threatening behaviour to the degree which could lead to an offence of violence. Details of your offence are now fairly well known in your area to professionals and the community in general. It is therefore highly unlikely that you will ever be in a position for a similar offence to occur.”²⁶¹

This situation is troubling. On one hand Margaret Grant did have some limitations to her intellectual capacity, which may come into play when figuring out how to deal with her punishment. It might for example have been the best to put her in a facility which specialized in dealing with persons with intellectual limitations for the duration of her sentence, rather than keeping her in a regular prison. Her intellectual limitations were not, however, that significant, and she did have a part time job and a fairly extensive network of friends. To simply release her into a half way house after only eight months sends a message to the community that severe abuse and neglect is not really a serious crime. Perhaps prison was not the place for Margaret, but release back into the community seems not to be in the interest of either Margaret (one questions her ability to care for herself given her horrendous lack of care for her mother) or of justice. Without focusing on the complexities of the Margaret Grant case, it must be stated that elder abuse cases often find abusers receiving at best token punishments, with the message being sent to the community that abuse of the elderly doesn’t really matter, or doesn’t matter as much as abuse of younger people.

“Punishment is now unfashionable... because it creates moral distinctions among men, which, to the democratic mind, are odious. We prefer a meaningless collective guilt to a meaningful individual responsibility.” Dr. Thomas Szasz – Professor Emeritus of Psychiatry SUNY Health Science Centre, Syracuse N.Y.

A 2001 article interviewing Dr. Elizabeth Podnieks notes that:

“In the last three years (1999-2001), there were only five criminal charges laid in connection to elder abuse across Canada. To make matters worse, charges were stayed in all five cases. Some factors that complicate such cases include problems with a senior’s mental abilities, an attitude of ageism where it is assumed that seniors are less reliable, and a reluctance to involve other people in family problems.”²⁶²

The law is an educator, and until elder abuse is treated with the seriousness it deserves by the courts, it will be difficult to make a significant shift in public perception. Of course there is a two way influence, with the prevailing cultural perception of a nation often being embodied in the law and the way the law is prosecuted.

"Law is the embodiment of the moral sentiment of the people."-William Blackstone -- 18th century British Jurist

With some 400,000 seniors being abused annually in Canada, there should be a significant number of cases serious enough to warrant prosecution. Of course many cases of abuse and neglect do not fall under the domain of law, and should be dealt with by way of social intervention. In the case of serious physical, psychological sexual and financial abuse, however, the law must be involved. As in the case of spousal battering and child abuse, a shift in public perception and a shift in the perception of the legal system, is essential. It is not that long ago that both child abuse and spousal abuse were essentially ignored by both the law and society.

“We need to put elder abuse on the same footing as child abuse. Both are egregious criminal acts.” Dr. Marjan Abbasi – Covenant Health, Edmonton, AB²⁶³

The shift in public and legal perceptions of violence against women and children took many years. We are now at the beginning of a similar shift in attitudes towards violence against seniors. It is essential that Canada comes to the point where violence and abuse against elderly persons is no longer tolerated even tacitly.

“We need to keep the issues of abuse on the forefront so that it becomes socially unacceptable to abuse older adults (just as it is now with children). This will mean a judicial system that prosecutes and sentences offenders to more than just a ‘slap on the wrist’. Many judges say ‘there is no precedent’ for a stiffer sentence – but we need to start somewhere.” Agnes Soulard -- Lambton Elderly Outreach²⁶⁴

Prosecuting Elder Abuse:

That elder abuse cases can be complex to prosecute cannot be denied. Most police forces do not have staff with expertise in elder abuse. Collecting evidence requires an understanding of the unique health and social context of elderly Canadian’s lives. Even in the few cities that have a designated elder abuse officer, departments tend to move officers every five years, so that the designated officer will just be acquiring the requisite expertise when they get moved to a different assignment. Continuity of law enforcement expertise in elder abuse becomes a problem. You can’t hand on five years of hard won experience in a two week training period with the succeeding officer.

“From a law enforcement perspective, elder abuse investigations pose numerous challenges, which often result in criminal prosecutions being difficult if not impossible to pursue to conclusion. In many cases the Elder Abuse Intervention Team pursues alternative intervention strategies aimed at harm reduction. While often preferable and ultimately beneficial to the individual senior, this approach reduces the number of files, which are successfully prosecuted and the associated exposure, which would raise awareness of what are very real criminal issues frequently associated to elder abuse cases.” Constable Jared Buhler – Edmonton Police Services²⁶⁵

There are a number of factors involved. For one thing police officers are often relatively young, and find it difficult understanding and communicating with seniors. For their part seniors often find it difficult in confiding in police officers they view as being ‘kids’.

“Like many other entry level workers, most police academy students are in their mid 20s and have difficulty sympathizing with and understanding older adults. Somebody needs to teach them about the process of aging. ... They need to know how this works, that not everybody who is 85 is impaired, and a lot of my officers think they are. Many of their complainants will be elderly and could be good witnesses if the officers knew how to work with them. I have certainly seen a 23 year old recently promoted detective conduct a photo ID with an 85 year old mugging victim in a way that was obviously not going to lead to a useful result just because of a lack of knowledge about the kind of person the detective was dealing with. ... Older adults are not always eager to work with young officers, either, often commenting ‘send me back a real adult’.” Randolph W. Thomas – Police Investigator, Law Enforcement Instructor²⁶⁶

In addition collecting forensic evidence in elder abuse cases is often challenging. Most medical professionals have little experience in the forensic side of medicine, and even less experience testifying in court. As a result vital evidence may not be properly identified and documented, and even when it is, medical professionals without court room experience can often be flustered by aggressive defence attorneys. The forensic expertise needed also includes forensic psychologists and psychiatrists, in addition to “forensic accountants”.

“Effective case building in the emerging field of elder abuse and neglect must have effective forensic medical evidence. The ability of a law enforcement investigator to bring a case to successful resolution relies on a combination of experience and the ability to reach out to others who have the necessary expertise to assist in determining what happened and how it happened. Access to the medical community is imperative. It should also be clearly stated that the medical community must have the training and exposure to the forensic aspects of elder abuse and neglect to be of value to the criminal justice system. Consistent interaction between those two functions can produce the evidence necessary to hold an offender accountable. The fundamental problem often lies in the difficulty between identifying those medical facts that indicate abuse, and not those that are just the normal process of aging. The complex medical issues associated with aging, such as nutrition, use of medications, pressure sores, bruising, fractures, and other all too common conditions, can present the criminal justice system with difficult issues to present to a jury. Ultimately, any evidence collected by medical professionals might require presentation to a jury that often cannot grasp the complex issues. For example, it is difficult in many neglect cases to make a direct connection between medical fact and criminal intent. The relationship between nutritional deficits and the intent to deprive someone of food can be tenuous to a jury, thereby creating the reasonable doubt that defence attorneys utilize to their advantage. It is imperative that the medical community and law enforcement develop a multidisciplinary approach to elder abuse and neglect. This concept has been successfully applied to child abuse and, lately, to financial exploitation of the elderly. This concept can include the development of a medical protocol, joint training, and joint staffing of complex cases. ... Elder abuse and neglect cases present some of the most complex medical issues encountered by the criminal justice system. Unless we find an effective way to build bridges to the medical community that can provide the level of expertise necessary, we will always have major problems building effective cases.”
Randolph W. Thomas -- Police Investigator, Law Enforcement Instructor²⁶⁷

It should be noted that two distinct though overlapping multidisciplinary team efforts might be necessary, one focussed on intervention and harm reduction, and one focused on criminal prosecution. The mind set needed for elder abuse intervention is not necessarily the same as the one needed to collect forensic evidence. Even coroners and medical examiners apparently don't often take into account forensic markers pointing to elder abuse.

“Medical examiners infrequently determine elder mistreatment as a cause of death in older decedents. Chronic diseases and features of old age confound the picture. Medical records and other information, including scene investigation reports, are often inadequate. ... Scene investigation is not geared to the detection of forensic markers and risk factors. Training of investigators in elder mistreatment may be helpful. We should consider the use of standardized investigation forms that prompt investigators to look for signs of elder mistreatment.” Dr. Carmel Dyer—Associate professor of medicine Baylor Medical College²⁶⁸

The Federal Government would have an opportunity of helping the Provinces and Territories in investigating and prosecuting elder abuse cases by developing a **centre of expertise in the Forensic investigation of elder abuse**. This centre could be a branch of the RCMP, which is the major police force in most provinces and territories. Employing forensic pathologists, forensic gerontologists, forensic psychiatrists, forensic accountants etc. such a centre could both assist in providing expertise in elder abuse investigations, and help train local medical and other professionals in forensics so as to develop forensic expertise for provincial, regional and local police forces.

“No one favours casualness on the part of police investigators, but it would be a shame if the older among us, after long lives of supporting others, should be left beyond the reach of legal protection in their declining years by reason of investigative difficulty. There is a large difference between judicious care in the search for

the truth and presumption that such cases are hopeless.” The Honourable Mr. Jack Watson – Alberta Court of Queen’s Bench – Commenting in his decision in R. v Morin.

Improving the quality of forensic investigations, improving the ability of specialist witnesses to present effectively before the court, and training police investigators to prepare strong cases are all very important. Equally important is the need to educate prosecutors and judges on the issues surrounding elder abuse. Both specialized knowledge and a change in legal culture are necessary.

“Training for crown attorneys and judges is a challenge due to the difficulty in accessing time to provide the training/education on the dynamics of elder abuse. Often the sentencing is too lenient and there are limited precedents of sentencing set to discourage elder abuse.” Manon Thompson – Ontario Network for the Prevention of Elder Abuse²⁶⁹

While all prosecutors and judges should receive comprehensive training on elder abuse; special prosecution teams and special elder abuse courts would be the fastest way to ensure the level of expertise needed to effectively prosecute abusers. This approach of special courts is similar to the approach taken on other family abuse issues. Such an approach also enables the court to be sensitive to the unique needs of seniors as they participate in abuse trials. The court system needs to become more sensitive to cultural and language issues as well as the unique difficulties seniors have in implicating abusive children in criminal proceedings.

“Although seniors cannot be stereotyped as vulnerable, the criminal justice system must be more attentive to power imbalances and the possibility that the system may be continuing the victimization of seniors.”²⁷⁰

Seniors in some cases require a slow paced, less intensive process to effectively present their testimony. The effects of the aging process may be further complicated by language difficulties, culture shock, isolation, in addition to the effects of the abuse itself. The court system needs to be sensitive to these diverse needs, and innovative in finding ways to facilitate senior’s involvement in the legal process. **In addition older adults need access to legal information and legal advocacy.** Abuse of older adults isn’t covered by most legal aid programs. There are only two programs in Canada that are funded to provide legal advice to older adults who are experiencing abuse. The **Advocacy Centre for the Elderly (ACE)** in Toronto was for a long time Canada’s only community based legal clinic for low income seniors. The **BC Centre for Elder Advocacy and Support** in Vancouver now does similar work to ACE. It is necessary that appropriate, affordable legal advice and advocacy be available to **all** older and vulnerable Canadians wherever they live. It is also necessary that this legal help be available in a range of languages, sensitive to the fact that many elderly Canadians who have immigrated to our country may revert back to their first language as they age, and require services that are linguistically and culturally appropriate.

“Age appropriate services and supports (need) to be developed within the criminal justice system. Assigned crowns and court rooms would be helpful (as would be training to accompany the assignments). In some cases of elder abuse, restorative justice approaches should be fully considered and used where appropriate as they may provide better outcomes than responses within the formal justice system.”²⁷¹

V. - Restorative Justice:

“Elder abuse is a ‘community issue’ that requires a cohesive plan of action by local agencies and justice partners working collaboratively. The shift to rehabilitation is necessary to help mitigate or reduce the impact of harm once abuse has occurred.” Dr. Marjan Abbasi – Covenant Health, Edmonton²⁷²

Elder Abuse is a crime, but also is often a form of family violence that rends families and communities. As such an important part of dealing with the abuse of seniors is to attempt to restore family relationships, rehabilitate abusers and achieve a just resolution without permanently tearing a family apart. The

restorative justice approach seeks to shift the way we approach less serious/non dangerous abusive situations. The following section focuses on one model of restorative justice. It is important to note that there are various approaches to restorative justice, and that such approaches will only be effective if initiatives are properly resourced. This section explores one approach to restorative justice for the sake of highlighting relational aspects of the abuse dynamic and the need to mend relationships. Another model which carefully designs processes around the needs of the people involved is described at www.nsrj.ca/services.html

“Restorative justice is a response to conflict that brings victims, wrongdoers, and the community together to collectively repair harm that has been done in a manner that satisfies their conception of justice. According to Judge Bria Huculak of the Saskatchewan Provincial Court ‘scholars ...have meticulously searched out their [respective] religious and spiritual traditions and found Restorative justice resides in [them] all.’ This approach with its focus on forgiveness, healing, and restoration of relationships provides hope that positive solutions can be found to these complex situations. It is an approach that resonates with the Judeo-Christian tradition.” Arlene Groh R.N. – Community Care Access Centre of Waterloo Region ²⁷³

Restorative justice is an important approach to keeping families whole. It is a response which allows action to be taken in the significant number of cases where a senior doesn’t want criminal charges laid against their child. Arlene Groh sets out the following case as the basis for explaining how the Restorative Justice approach works.

“Mrs. Smith is an 89 year old widow living alone. The assistance of private and publicly funded services, as well as that of her family, has made it possible for her to continue living in her home. One day, she discloses that her son has withdrawn \$40,000 from her bank account. Mrs. Smith is given information about various community resources, including the option of calling the police to report this theft. She refuses these options, saying that her son is a good man who probably needs the money more than she herself does. Furthermore, she needs him to buy her groceries, run errands, and take her to Church each Sunday. The relationship with her son and his family is more important to her than the \$40,000.”²⁷⁴

The Restorative justice approach focusing on forgiveness, healing and restoration of relationships, could be an acceptable way to deal with a situation like that of Mrs. Smith. It provides an opportunity for change and healing of people who have been abused, abusers and the wider family.

“Justice ... means achieving a situation in which the conduct or action of individuals is considered fair, right, and appropriate for the given circumstances. It reflects a sense of right and wrong. It is called into question when our understanding of what is right is offended and is restored when wrongs are addressed. Our laws list a series of behaviours that are considered unjust and establish a process of labelling, detecting, and repressing these behaviours. These laws are in place to control socially inappropriate behaviour.”²⁷⁵

In the traditional approach of the justice system Mrs. Smith’s son would have been charged with theft for stealing her money and if found guilty would have faced punishment, most likely imprisonment. Retributive justice places the emphasis on punishing the guilty person for their crime. Punishment is seen as a deterrent to further criminal activity, as a control mechanism for inappropriate behaviour. This emphasis **“seeks punishment rather than accountability and the victim plays a minor role. It does not consider the fact that abuse occurs for a complex series of reasons, with a complex series of results. Furthermore retributive justice provides no opportunity for healing and reconciliation.”**²⁷⁶

To work effectively, however, Restorative Justice necessitates a pre-existing familial or communal bond, and a desire for change. It does not work in the case of a crime crassly committed by a complete stranger, and it doesn’t work in the case of serious crimes of violence such as rape, or attempted murder. That said even in the case of serious crimes committed by strangers, elements of the approach are useful, as restitution and rehabilitation can and should be made a part of retributive criminal proceedings.

“A restorative justice approach considers abuse primarily as a violation of people and relationships and secondarily as a violation of the law. This holistic approach focuses on a wider range of considerations, including the need of speaking the truth, giving equal voice to all affected individuals, healing and restoration of relationships, respect for individual values and preferences, and the prevention of further harm. It is not simply an alternative to the criminal justice system. Nor does it amount to an avoidance of justice. There is a clear message that particular actions are unacceptable. At the same time, however, support is given to the person who has done the harm.”²⁷⁷

To achieve Restorative justice mediation, community conferencing, healing circles and sentencing circles can all play a part, depending on the particular crime to be addressed, and following certain important principles. **In a situation of power imbalance great care needs to be taken not to put the person who has been harmed at greater risk.** Arlene Groh outlines the principles of Restorative justice as follows:

- a) **Safety:** Everyone involved needs to be safe and secure throughout the restorative process. Means must be taken to ensure a proper balance of power amongst everyone involved, and to ensure that the solution devised by the process prevents any further abuse.
- b) **Confidentiality:** Participants must determine what personal information can be shared with the other members of the restorative process.
- c) **Dignity and Respect:** The culture, values and preferences of participants must be respected. Individual stories as told by the people involved are to be received by participants and legal and professional staff with a respectful non-judgemental attitude.
- d) **Autonomy:** Participants have the right to determine and control their own affairs, with participation being voluntary, and all participants having an equal voice in the process.
- e) **Access to information:** Participants must be given the information necessary for making meaningful decisions. This includes information on the restorative justice process, the legal process, community resources, and how to access them.
- f) **The least restrictive interventions:** Interventions should be the least restrictive possible of the individual’s rights, abilities, and personal liberties.²⁷⁸

The Restorative Justice Process:

The process taken to achieve Restorative justice is illustrated using the case of Mrs. Smith and her son. An initial referral can be made by anyone involved in the abuse case. It will be necessary to begin a screening process to determine that a) all parties feel safe to proceed, b) the abuser accepts responsibility for his or her abuse, c) all parties are willing to participate, and d) whether the senior involved is capable of understanding and participating in the process.

Two facilitators are assigned to handle the case. One facilitator carefully listens to Mrs. Smith to hear her story and to develop an understanding of the case. Mrs. Smith will speak of her understanding of what took place. She may speak of:

- her sadness and anger that her son took her money
- her disappointment that she couldn’t trust him
- the fact that her son has been unhappy and angry, yelling more than usual and drinking a great deal since he took the money

The second facilitator contacts Mrs. Smith’s son to hear what he has to say.

- he speaks about how badly he feels about what he did
- he says he loves his mother and how things got out of hand
- he tells how difficult it has become to care for his mother and how she refuses to go into a nursing home
- he speaks of the long hours during both the day and night he has to spend in caring for her
- he tells how his business has suffered as he has less time to pay attention to it during the care giving process

- he tells how his son has had to move home, unable to find a job
- he talks of how financial pressures and the long hours of care giving have put stress on his marriage
- under great stress he has begun to drink too heavily and doesn't know how to get his life back on track

Next the facilitators contact family and friends of Mrs. Smith and her son to get a wider perspective of the situation. Their findings include:

- Mrs. Smith's minister doesn't know how to help the family who are all active church goers
- Mrs. Smith's sister doesn't trust the son
- Mrs. Smith's daughter doesn't consider her brother a criminal
- Mrs. Smith's daughter-in-law doesn't know of the theft of money and is fed up with the long hours of care her husband provides his mother

As Arlene Groh notes, these cases are usually quite complex. It is important for the facilitators to come to a good understanding of the complexity. They may also have to work with the various parties to prepare them for the process. It may take months before everyone is ready to come together to participate in a restorative justice circle.

When the facilitators are finally ready to bring the parties together to discuss the situation, each party comes with a group of persons supportive of them. They discuss together what happened, why it happened, how to repair the harm, and how to prevent future harm. The circle is opened with a prayer; and following First Nations practice people are instructed to speak one at a time, and only when holding a "talking piece" a symbolic object that gives the person the floor to speak. They are told to speak truthfully and from the heart.

"Mrs. Smith talks about her love for her son and how sad she is that he has stolen money from her. She admits that she is sometimes afraid of him. She speaks of prior abuse she has suffered, and of her husband having abused her son. She is sorry she was not able to prevent it. The son apologizes to his mother. He knows that he has taken his frustration out on her, but wants to get his life back on track. He will continue with AA, and agrees to a plan to repay the funds he misappropriated. Various supporters indicate ways in which they will be able to help. For example, church visitors will provide care giver relief hours for the son each Friday and for the grandson each Saturday. The sister will assume the power of attorney."²⁷⁹

As Arlen Groh notes in her summary, justice is realized when the persons affected by the abuse reach consensus about:

- i) Why the abuse happened (e.g. caregiver burnout, alcohol abuse, financial stresses, previous family violence, marriage stresses, care giver need for respite etc.)
- ii) Meaningful reparation for the harm done (i.e. repayment schedule, community service work, formal apology etc.)
- iii) Plans to prevent further harm (i.e. respite care, home care support, change of power of attorney, a business plan, AA meetings etc.)

Upon successful resolution the circle closes with prayer and is followed with refreshments.

The facilitators make sure that the group stays focussed throughout the process. They make sure that everyone is heard, that a final agreement addresses the real needs and is workable, that the group while disapproving of the offender's behaviour also offers support for the individual. The facilitators do not contribute to the content of the group discussion. They do however follow up regularly to ensure that the abuse has stopped, the agreement is followed, and that there is improvement in the well being of the parties involved.

Faith Community Response:

Arlene Groh invites various faith communities to consider the following questions:

- To what extent does your community embrace the philosophy of restorative justice, a philosophy of peace both between people and God and between people themselves on a variety of levels?
- Is your community committed to accountability and restitution or repair of harm?
- Would your community be able to support the Smiths on their path to reconciliation?
- Is your community able to listen to their various stories without passing judgement?
- Is your community able to walk with the older adult who has been abused?
- Is your community able to support the person who has caused the harm?
- How might your community assist these people as they attempt to reintegrate into the church community?
- Is the community silent, or does it speak out against the harmful behaviour that is often a hidden crime?

“The faith community is an integral part of the complex network of supports required to meet the diverse needs of an older adult who has suffered abuse. Its role is to provide support both to the individual who has been harmed and to the person who did the harm, as well as addressing the underlying causes of abuse, in the interests of long-term prevention. Participation by faith communities is essential to sustaining a restorative justice approach to elder abuse. Indeed, I believe that the faith community is pivotal to the prevention and resolution of elder abuse in general.”²⁸⁰

...

Restorative justice is an important contribution to elder abuse intervention in those situations where there is a strong familial and/or community bond, and a real desire on the part of both the abuser and the abused to achieve reconciliation. It also provides a venue for addressing abusive situations that don't have adequate means of resolution under present criminal laws.

“Psychological abuse often does not fit under the criminal code as an offence so many seniors suffer emotional trauma by family and others due to a lack of intervention services available and limitations of the law to protect them.” Manon Thompson²⁸¹

A legal approach to elder abuse should where possible include aspects of Restorative justice. This will require ongoing research, education, and adequate funding for community based restorative justice initiatives. For more serious forms of abuse a stronger legal basis is required.

“Consideration of legislation (is needed) to introduce changes to the criminal code so that consideration is given in sentencing to the nature of crimes committed against vulnerable adults. This consideration is necessary as deterrence against crimes, which by the nature of the victim are more difficult to investigate and prosecute.” Const. Jared Buhler²⁸²

In crimes committed against the elderly, age should be considered an aggravating factor in sentencing, with stricter sentences being given out for crimes committed against seniors. Changes are required to the criminal code ensuring that serious cases of elder abuse are punished with sufficient severity.

VI—Financial abuse of seniors:

“You have an asset rich older generation and a debt ridden younger population struggling to make ends meet ... relatives use the senior's money for supplementing their own accounts, or they may use the money to invest in their home. ...There are a lot of myths like...that's really my money. I'm just going to inherit it anyway, and she doesn't need that money now. ... Many baby boomers carrying debt loads among the highest in

history are looking to their parents' nest eggs for a bailout. I think it (financial abuse) is going to be one of the most significant issues in the next 10 years.” Laura Watts – Canadian Centre for Elder Law – Vancouver, B.C.²⁸³

Conditions for a “perfect storm” of financial abuse are becoming more obvious as the first of the baby boomers begin to retire. The boomers are the wealthiest generation in history, the largest demographic of seniors in history, and all this is coinciding with a down turn in the economy, and the first generation in many years to be less well off than their parents. In addition a sense of entitlement is all too common in a culture which has been very prosperous and very consumer oriented. Financial abuse of the elderly is on the rise, as is the range and sophistication of frauds and scams being perpetrated against seniors.

Financial abuse is most often perpetrated by family members and close family friends, though at the same time criminal elements are becoming more aggressive and sophisticated in defrauding seniors of their money. The dramatic demographic shift towards an aging population, the increase in various forms of dementia, especially among the oldest seniors, as well as a wide spread financial illiteracy; these are all factors in the coming tsunami of financial abuse.

Financial abuse is being perpetrated in a number of ways:

- Abuse of a power of attorney
- Abuse of joint bank accounts
- Misuse of funds or property
- Theft, exploitation and scams
- Fraud or forgery of documents
- Manipulation and undue influence in relation to wills and bequests
- Credit card and debit card theft (specifically with seniors entrusting their pin number to another person who banks for them)

“Approximately 10% of seniors experience some form of abuse, with most financial abuse being initiated by family members. The abuse may be a deliberate single act such as a transfer of a major asset into a joint tenancy or a sale of a home and redirection of the proceeds. Or, it may be a series of calculated actions designed to redirect income to the abuser. Sometimes, the abuser does not see the error of the actions. It may be viewed as compensation for the care and support being provided. Others may believe that the person will not need the money and expect it as an inheritance in the future. The senior may not realize abuse is occurring because the necessary information contained in statements and other mail is kept from them, or they may have simply trusted the person and not thought to ask questions. Other times they may know but feel powerless to stop it. They may not know their rights and/or where to go for assistance. They may feel ashamed or fear the consequences if it is reported and action taken. They may fear loss of access to grandchildren or their home. They may fear that the abuser will be sent to jail, causing hardship on the remainder of the family. In order to prevent, detect and respond to financial abuse effectively, one must look at the range of players who are involved, understand their roles, responsibilities, and constraints, and understand their points of interaction. When prevention fails, systems for detection must be in place and the responses must be timely and appropriate.” Jay Chalke – Public Guardian and Trustee of British Columbia²⁸⁴

It should be noted that financial abuse can be extremely harmful to the effected senior. A senior who loses a significant portion of their retirement income is in no position to replace it, having come to the end of their earning life. As such they can be left destitute, dependent upon the generosity of their family, or upon the support of the state. The stress of such a situation can deeply affect their emotional and physical wellbeing. Douglas Melville Ombudsman for Banking Services and Investments notes: **“Research shows that seniors suffering financial crises have a significantly elevated rate of death within a short period.”**²⁸⁵ The health and emotional effects of the financial loss can be further compounded because financial abuse of seniors is often accompanied by a range of other abusive behaviours, rendering a senior extremely vulnerable.²⁸⁶

“Abuse and neglect are a major source of stress and can have long-term effects on the health and well-being of older adults. The stress of abuse may trigger chest pain or angina, and may be a factor in other serious heart problems. High blood pressure, breathing problems, stomach problems (ulcers), and panic attacks are common stress related symptoms among older people who experience abuse. ... As a result of abuse and neglect, older adults often experience worry, depression, or anxiety. These signs may be mistaken for memory loss or illness, when really they are the effects of stress or worry. ...Some abused older adults may start to eat less, use more medications or drink more alcohol to help cope with the emotional and physical hurt. They may have difficulty sleeping or sleep too much. Some abused or neglected older adults may lose interest in life or become withdrawn. Some have suicidal thoughts. ...Many older adults who experience financial abuse also face emotional abuse. Stolen or forged income cheques can leave a low-income senior without money for food, medications, or transportation. ...When abusers steal or control older adult’s money or other property, older adults may have fewer resources to take care of their own health, housing, good nutrition, and activities.”²⁸⁷

Financial abuse has serious consequences both for the health and wellbeing of the senior, and for our broader society. The misappropriation of an elderly person’s financial resources, while devastating, and all too common; is often not prosecuted often not even detected.

“Of particular concern is the lack of reporting of cases of financial abuse of seniors, who are often in arrangements of enduring power of attorney. It has been the experience of this team that financial institutions are reluctant to report suspected financial abuse, even when the sums of money involved are large, and the impact to the senior severe. The team has further witnessed a lack of knowledge from front-line staff to management and legal departments of major financial institutions with respect to legislation relevant to dealing with such matters.” Constable Jared Buhler – Edmonton Police Service²⁸⁸

There is a great need to educate financial personnel as to the indicators of financial abuse, and how best to intervene when faced with a suspicious case. There is also need for legislative clarity so that financial institutions don’t have to have an undue fear of privacy regulations when dealing with cases of financial abuse.

“The federal *Personal Information Protection and Electronic Documents Act* (PIPEDA) has caused difficulties for federally regulated companies including banks. Financial institutions have responsibilities to their clients to maintain privacy. However, they are also in a good position to see financial abuse occurring. If they see that a client is being mistreated or suspect mistreatment, they need assurance that they will be protected if they report their suspicions to the appropriate authorities in good faith. Proposed amendments to PIPEDA currently before the House of Commons (Bill C-29) are crucial to removing this barrier. C-29 would allow organizations subject to PIPEDA (such as banks) to proactively report concerns of financial abuse to provincial authorities. While C-29 is a step forward, we would support amending Bill C-29 to explicitly recognize neglect and self-neglect as well.” Jay Chalke – Public Guardian and Trustee of B.C.²⁸⁹

In addition the federal government could do a great deal to develop inter-jurisdictional unity across the country as regards financial planning and protection laws. There would also be a need to develop coherent national standards for Public Guardianship laws, power of attorney legislation etc. Formal dialogue between the provinces, territories and the federal government would be an important first step. **“Internationally, Canada could facilitate inter-jurisdictional recognition of guardianship orders and other protective measures through ratification of the Hague Convention on the International Protection of Adults.”²⁹⁰**

There is also a great need to develop education and awareness of powers of attorney, joint accounts, beneficiary designations, care agreements, and general financial literacy among the general public as well as more specialized awareness among professionals and service providers. The financial sector could do a great deal to increase education and awareness, as well as detect abuse early on.

- Financial institutions could offer seminars and brochures to customers, informing clients of issues surrounding fraud and financial abuse.

- Financial staff could be trained in basic protocols of screening customers through simple questioning for financial abuse.
- Financial institutions could develop monitoring protocols for transactions in joint accounts
- Financial institutions could develop formal company policies which disallow the POA from acting unilaterally in the case of major transactions such as the sale of a senior's home.
- It might be valuable to develop a mandatory Power of Attorney (POA) registry
- It would also be valuable to require disclosure of fundamental information to customers; before allowing a joint account, or an account managed by a POA.
- There is a need for in-depth education of (POAs) on their duties. This could be accomplished both in mandatory discussions of these duties, and through written materials given out by financial institutions. A short test might be administered before allowing a person to be a power of attorney, making sure they read the applicable materials.

“POA and joint accounts are powerful instruments and ... both the person issuing it and the person trying to act on behalf of it often have very little guidance. Family members are often unaware of their duties as an appointed attorney. Most attorneys haven't a clue, really what their legal obligations are. Some of the statutes aren't particularly well articulated and even for the ones that are, it's complicated stuff.”²⁹¹

The general public also needs to be much more aware of financial fraud and the potential risks of various financial products and services.

“Financial fraud remains a real danger to many Canadians. Those at particular risk of becoming victims of financial fraud include people living on low incomes, those with high levels of debt and immigrant communities. Elderly Canadians are especially susceptible, as they are often targeted by scams and fraudulent behaviour. Age related loss of mental capability adds to the vulnerability of seniors. ... By continuing to bolster the financial literacy of Canadians, particularly those at risk, these (educational) efforts will enable vulnerable Canadians to be more informed, more vigilant and better able to detect and prevent fraud. Among the existing Government of Canada initiatives in this area that can be expanded or built upon are Fraud Awareness Month (held each March), the Federal Elder Abuse Initiative (administered by *Human Resources and Skills Development Canada*), and the work of the Competition Bureau in collaborating with federal, provincial, private sector and non-profit sector organizations involved in financial fraud issues.”²⁹²

It is not only the financial sector that needs training in financial abuse. The policing sector also has to develop a deeper understanding of the issues. It is surprising how many police officers believe for example that abuse of a power of attorney can only be remedied by civil action, unaware that it is a violation of the criminal law.

“This past spring I was invited to speak in the Lower Mainland by a credit union, on the financial abuse of seniors. During the week long series of presentations I continually heard the same grievance from those in attendance. ‘We have reported the matter to the police, but they say it's not criminal, but civil. Go see a lawyer.’ The abuse of powers by an appointed attorney acting as power of attorney is not civil; it's criminal. The police are wrong. Section 331 of the Criminal Code of Canada clearly sets out the offence, *Theft by Persons Holding Power of Attorney*. This section has been in existence for many decades now, and yet very few police officers have heard of it. One of the reasons for this may be the fact this section is not a charging section, but what is referred to as a descriptive section. When someone is charged with stealing funds from a senior, the charge is section 336-Theft, not 331ccc. This causes confusion, however, no matter how it's viewed, a theft is a theft, and an investigation needs to be undertaken by the police.” Sgt. Brian Trainor – retired Saskatoon police detective.²⁹³

Improving response to financial abuse of seniors will necessitate closer working relationships between police and the financial sector. Multi-sectoral collaboration is essential for the successful prosecution of financial abuse. Financial experts will have to be included as multidisciplinary elder abuse intervention teams are developed across the country. The role of the “forensic accountant” in police investigations is

an important one, and governments need to allocate resources to develop this expertise and place it at the disposal of police forces.

“Financial abuse can be difficult to identify or recognize. It is often a pattern rather than a single event, happening over a long period of time. ... [never-the-less] there needs to be a willingness and a corresponding resourcing of police units to pursue POA theft by family members [and other forms of financial abuse]. ...If police took an active role in vigorously investigating POA theft, would-be thieves might be deterred. As well, those acting under a POA document might be more aware of the potential consequences of misusing their powers because of publicity surrounding police investigations and arrests.”²⁹⁴

VII - Recommendations for Action:

Responding to elder abuse requires collaborative work by all sectors of society. A cultural transformation is needed, in which abuse of seniors comes to be regarded as absolutely unacceptable. The complexity of elder abuse necessitates action on a variety of fronts; social media, the judiciary, law enforcement, education, psycho-social support, healthcare, the financial sector, research and statistics. To be effective it requires careful coordination, and collaborative effort.

“The complex and multi-faceted issue, mandate, and response to abuse of vulnerable and older adults must be positioned firmly in a ministerial portfolio, with collaboration with other ministries who have a role. For example, in BC the Ministry of Attorney General led the Adult Guardianship Legislation reform, and has an ongoing role for some of its implementation. However, the responsibilities for the Adult Protection provisions are delegated to agencies who report to other ministries, in our case the Ministry of Health. There are no reporting requirements to the AG. In fact there are no monitoring, reporting, quantifying requirements of any of the Designated Agencies to their own ministry or to any other provincial body. As a result, there is no reliable data on incidence, intervention, or outcome, and no provincial coordination that is recognized and sanctioned by a provincial/federal body, and no provincial oversight to implementation.” Amanda Brown – Vancouver Coastal Health²⁹⁵

Each province and territory requires a ministry to have ultimate responsibility for overseeing the response to elder abuse. This is certainly true at the level of intervention which is within provincial jurisdiction; as it is of the domain of prosecution and law enforcement.

The federal government too has an important role to play, a role that requires a responsible ministry to oversee action at the federal level. The federal government oversees needed changes to the criminal code, various banking regulations, research, the gathering of health and social statistics etc. The federal government can also play an important role in developing a national social marketing campaign to continue the advances that were made through the *Federal Elder Abuse Initiative*.

There is a profound need for research (a federal domain) and to effectively advance our understanding of elder abuse the federal government needs to work towards national standards of collecting statistics so that we can begin to collect accurate information about the prevalence and scope of abuse.

“The majority of agencies do not keep statistical information on cases reported / responded to. There is no standardized tool for collecting statistics in Canada. With the lack of factual data it is difficult to determine the prevalence of abuse. This information is necessary to validate the seriousness of the issue among seniors.” Raeann Rideout – Ontario Network for the Prevention of Elder Abuse²⁹⁶

On any other health or social issue of importance, a lack of statistics would be regarded as great imprudence. A nation that would not keep statistics on infectious diseases for example, would be regarded as acting blindly in the area of public health. In addition a National Prevalence study is desperately needed. Given that HRSDC funded the National Initiative for the Care of the Elderly (NICE) to do all the

preparatory work for a national prevalence study, (work that was just completed) it only makes sense that additional funding be granted for NICE to carry out the prevalence study itself.

Recommendation # 1: We recommend that the federal government establish an **Elder Abuse Awareness and Prevention Office** with a general directive mandate, under the **Minister of State for Seniors**, in conjunction with HRSDC, Public Health Agency of Canada, Justice and the RCMP, for the purpose of facilitating communication and collaboration between the various levels of government, and community stakeholders, with a view to:

- a) Developing and implementing a **National Elder Abuse Prevention Strategy**.
- b) Promoting and funding research on the incidence, and prevalence of elder abuse as well as effective tools and responses.
- c) Coordination and dissemination of elder abuse information resources.
- d) Development of a national public awareness program on elder abuse and elder neglect including elder abuse prevention, detection and response.
- e) Ongoing coordination and support for groups working to prevent elder abuse across Canada.
- f) Working with the Ministry of Justice, Health Canada, Public Safety, the RCMP, and other federal departments, to coordinate an integrated federal response to elder abuse, including the development of a **National Forensic Centre on Elder Abuse**, needed changes to the criminal code, and improved data collection by Statistics Canada.

Recommendation # 2: We recommend that the federal government provide core funding to:

- a) The Canadian Network for the Prevention of Elder Abuse (CNPEA), so as to enable CNPEA to promote and coordinate networks for the prevention and detection of and response to elder abuse across Canada.
- b) The National Initiative for the Care of the Elderly (NICE) to continue work of the *Elder Abuse Theme Team* to identify, pilot, and train diverse responders across Canada on evidence based tools for preventing, detecting and intervening in situations of abuse of older adults.

The Committee believes that Core funding for the non-governmental sector is a cost effective way of building needed infrastructure for the reduction of elder abuse.

“The Federal government can help support multi-sectoral collaboration, education, research and allocation of financial resources to ensure we are better equipped to meet the needs of our aging society. Government is uniquely positioned to help champion the needs of the elderly who helped build our country, and to promote a compassionate society that meets the needs of all Canadians.” Dr. Marjan Abbasi – Covenant Health, Edmonton, AB

Elder Abuse recommendations made to the Committee:

(It should be noted that the following recommendations can apply to various levels of government, and sometimes to non-governmental stakeholders for their implementation.)

A number of individuals and organizations made recommendations to the committee which are worth consideration. These include the following:

#1 -- National Strategy and Federal Initiative

- The federal, provincial and territorial governments in coordination with the Canadian Network for the Prevention of Elder Abuse and the various provincial networks need to implement a **National Elder Abuse Strategy** with federal coordination, to prevent and respond to abuse, neglect, and self neglect of vulnerable and older adults. National leadership is needed to

accelerate national results. A national strategy would be developed in conjunction with provincial strategies, and would recognize abuse, neglect and self neglect of older adults as a health mandate as well as a legal, justice, and social issue.

- The federal government needs to continue the work done in the Federal Elder Abuse Initiative, including continuing the work of the National Institute for the Care of the Elderly (NICE) in developing elder abuse intervention tools, and the CNPEA in continuing and expanding the Elder abuse social marketing campaign, supporting Elder abuse networks across Canada, and developing educational tools and materials.

“In 2008, the Government of Canada launched the first Federal Elder Abuse Initiative, investing \$13 million over three years to help seniors and others recognize the signs and symptoms of elder abuse and to provide information about support that is available. With funding for this initiative set to end this year, we can only hope that MPs will advocate for continued funding. The initiative has raised the expectations of seniors seeking help, and to allow the initiative to end may leave seniors in a worse situation than before, with the expectation of help being available, but without adequate means to meet these expectations.” Laura Watts -- Canadian Centre for Elder Law²⁹⁷

#2 – Government Over-sight and Cooperation

- There is a need to create a single government ministry at both federal and provincial levels to oversee and coordinate elder abuse prevention. The complexity of elder abuse requires a single coordinating ministry working in collaboration with other ministries and the not for profit sector.
- Need to establish a comprehensive adult protective service in each province to ensure universal access to protection for all Canadians rendered vulnerable due to age, illness, incapacity or other condition. A strengthened adult protection infrastructure is necessary to provide monitoring for cognitively and functionally impaired adults, protecting them from abuse both in home and institutional settings. Strengthening Public Guardian and Trustee offices, giving them adequate resources and a wider mandate may be part of the solution.

“Older adults who are cognitively and functionally impaired and require care are particularly vulnerable to being abused by privately hired caregivers. Some unscrupulous caregivers move in with the vulnerable older adult and ‘takeover’ the older adult, not allowing access to family members, and taking control of finances, sometimes by claiming common law status. There is little protection for older adults in these circumstances. Problems and short falls at the institutional level include: lack of understanding of the rights of older adults and of residents of institutions, institutional culture, focus on task completion rather than on the individual for whom the task is being done, inadequate staffing levels, and inadequate staff training. Improving education and training of care giving staff to improve their understanding of residents, their health conditions and care needs would go a long way to strengthening the caring bond with the older adults they are providing care to – as would adequate staffing. The Older Adult Abuse Task Force believes abuse free environments in care facilities can be achieved only if staff is trained and supportive. ... Light care facilities are of necessity providing care to individuals with increasingly heavy needs. Lack of training is a key issue and is becoming more so. Caregivers who do not know what dementia is and how it affects behaviour cannot care adequately, let alone compassionately, for people with dementia. Caregivers who do not know about diabetes can misjudge the needs of residents with diabetes. ... Improvement in staffing levels in care facilities – and in public Home Care programs – requires government and societal commitment. The care of frail elderly citizens is worthy of our tax dollars.” Elliot Paus Jenssen – Saskatoon Council on Aging²⁹⁸

#3 -- Legislative Reforms

- There is need to develop a mandatory reporting policy for elder abuse, combined with a mandatory intervention policy. (This presupposes the need of adequate resources to respond to all cases of abuse.)

“Peel Elder Abuse Prevention Network (PEAPN) is asking for federal and/or provincial legislation on mandatory reporting of abuse and the establishment of mandatory adult protection services to deal

comprehensively and effectively with elder abuse and vulnerable adults with a disability who may be at risk. Such legislation would need to account for situations where seniors or vulnerable adults are capable/incapable and/or willing/unwilling to come forward and report abuse and neglect. While the legislation must be supportive and responsive to diverse situations of elder abuse, it should establish a broad national framework to guide communities in their development of local protocols, policies, reporting guidelines and standards.” Peel Elder Abuse Prevention Network²⁹⁹

- Need to pass Bill C-29 the proposed amendment to the *Personal Information Protection and Electronic Documents Act* (PIPEDA), to remove legislative barriers which prevent financial institutions from reporting financial abuse due to privacy concerns.
- To investigate whether the Canada Health Act might be amended to include adult protection as an insured health service.
- To introduce minimum mandatory sentences for violence, abusive behaviour, and financial crimes targeting seniors and vulnerable adults.
- To work with the provinces and territories to develop harmonized “Power of Attorney” legislation/documents. To review legislation concerning the threshold of negligence for a power of attorney and the liability of the attorney who abuses his/her powers.
- To protect Canadian seniors from financial abuse by foreign nationals Canada should consider ratifying the *Hague Convention on the International Protection of Adults*.

#4 – Research and Statistics

- An appropriate Agency such as Health Canada, Statistics Canada, or CIHR needs to develop an accurate national registry of elder abuse statistics, as well as develop a uniform method/template for statistical collection, for use throughout Canada.
- The federal government needs to fund vitally needed research especially a large scale prevalence study for elder abuse. Also needed is research into risk factors and protective factors, research into best practices in elder abuse intervention, and careful follow up research to determine the effectiveness of various approaches to elder abuse intervention.
- Canada has a great need of up to date studies on institutional abuse, both to determine prevalence and develop means to reduce abuse of vulnerable persons under institutional care.

“Perhaps the most disturbing observation made was the frequently noted lack of sensitivity of nursing home staff to the gravity of the assaults on the residents. Responses ranged from cynical disbelief that anyone would sexually assault an elderly individual to what can be described as a perverse sense of amusement. There is a well-known pattern of bystander apathy and bystander inaction in response to crime, and the same pattern appears evident in this case. However, one major difference is that these ‘bystanders’ are not strangers who happen on a victim in the street. These bystanders are professionals charged with the care and protection of these residents.” Dr. Ann W. Burgess – Professor of Psychiatric Nursing--University of Pennsylvania³⁰⁰

- We require substantive qualitative and quantitative research on all aspects of elder abuse.

“Although speculative discussions of elder abuse abound, rigorous research evidence is still relatively scarce. The lack of scientifically credible research is not just an academic concern. The paucity of firm findings regarding elder mistreatment makes it difficult to develop practical solutions to the problem, including methods of identifying persons at risk of maltreatment, preventing abuse, and treating victims when abuse and neglect occurs. Research on elder abuse has been inconsistent due to the sources of data on the problem. Most studies are small, non-random, unrepresentative, and largely exploratory in nature. The majority of studies have relied on surveys of professionals and/or reviews of agency records. It is widely recognized that

these are highly selective samples and that there is a large reservoir of unreported and undetected cases about which very little is known.” Dr. Karl Pillemer – Cornell University³⁰¹

#5 – Funding

“Peel Elder Abuse Prevention Network (PEAPN) would like to see a greater financial commitment from the federal government in terms of core funding available to non-profit organizations that serve seniors who have experienced abuse. Existing funding is short-term and has been provided through grants. ... In order to succeed as a region in dealing with elder abuse, sustainable funding is needed.” Peel Region Elder Abuse Prevention Network³⁰²

- Funding is badly needed to build up infrastructure to intervene and support seniors who are victims of abuse, to train first responders, to train law enforcement personnel, lawyers and judges, as well as to educate the public on elder abuse.

“While significant funding has been dedicated to the development of screening tools and public education, it would seem that a response capacity is limited and /or absent in many jurisdictions. This lack of capacity becomes a source of frustration for those persons attempting to report such cases to authorities.” Cst. Jared Buhler – Edmonton Police Service³⁰³

- Core funding of not-for-profit groups is a cost effective way to advance social policy initiatives in the area of elder abuse intervention. Especially important is developing and funding federal, provincial and regional coordinating networks.

“Provide core funding for community based coordinating networks which can build healthy, consistent and respectful change in the culture of the community. This does not have to be a large sum of money but should recognize the work needed to administrate and coordinate the response, prepare materials and produce and distribute them.”Sherry Baker– Executive Director -- BC Association of Community Response Networks, October 26, 2010

#6 – Education, Social Media and Training

- The elder abuse resources of the National Clearinghouse on Family Violence need to be updated and expanded.
- We need to develop a social marketing campaign on the value and dignity of seniors and the dangers of ageism.

“We need to address ageism in our society that views elderly persons as non-productive, and less worthy. This is evident even when consulting other physician colleagues who may be reluctant to get involved because of their own biases of what ‘a 94 year old’ signifies when providing the consultant the patient’s case history. We need to shift referencing the elderly as ‘vulnerable’ to ‘valuable’.” Dr. Marjan Abbasi – Covenant Health, Edmonton, AB³⁰⁴

- Implementation of an elder abuse/bullying of seniors curriculum in elementary and secondary schools to enhance awareness and understanding of abuse, and to help overcome ageist attitudes and restore respect for seniors.
- Special training for police, legal professionals and the judiciary is needed to increase awareness and expertise in dealing with elder abuse.
- Special training for doctors, dentists, nurses, pharmacists, emergency response workers, etc. in detection and first response intervention in cases of elder abuse.
- Provide training for front line staff working with seniors, including cross cultural training. There is need for generic training of all professionals and para professionals who provide health and social care or other services to seniors, not just on the job training, but continuing education.

- Develop the use of interactive media for the exchange of information and for ongoing training of front line professionals

#7 -- Intervention and support

- A **National 1-800 elder abuse line** should be set up as a first line of contact, directing people in crisis to local and regional elder abuse networks.
- There is a profound need to develop an infrastructure of transitional housing and safe shelters for abused seniors. Other alternative care options include foster families, transition houses, crisis stabilization units, emergency respite services etc.
- There is a profound need for adequate housing for low income seniors.
- There is a great need to develop caregiver support programs, to prevent caregiver burnout and stress triggered abusive behaviour.
- There is a need to develop programs for the rehabilitation of elder abusers.
- It is important that means be developed to overcome isolation among seniors. Creative social capital development would include social clubs, seniors supporting seniors groups, telephone connection/support, cultural projects etc.
- There is a need to engage multicultural and faith-based organizations in elder abuse prevention and intervention.

“Create opportunities for choices – choices for living arrangements, for supports, for care needs. A ‘buffet’ system which can be tailored to meet the individual’s needs based on their specific circumstances.” Inga Thompson – Prevention of Senior Abuse Network Simcoe County Ontario – November 16, 2010

#8 – Canada’s Multicultural Society

- To protect immigrant seniors from abuse; both judicial and intervention/support services must become sensitive to cultural and linguistic needs. Many immigrants revert to their first language as they advance in age. Others never developed fluency in either of Canada’s official languages. These seniors are at high risk of social and linguistic isolation, and are often unsure of where and how to seek help.
- Elder abuse materials need to be translated into a wide range of languages beyond French and English.
- Social marketing efforts need to target cultural and linguistic groups beyond French and English. Elder abuse affects all cultures and language groups, and intervention and response needs to be available to everyone.
- Collaboration with diverse cultural communities is necessary to identify needs, develop resources, and ensure that immigrant seniors are safe and respected.

#9 – Financial Literacy and Financial Abuse

- There is a need to educate all Canadians and especially seniors in the basics of financial literacy, especially the nature and responsibilities of Power of attorney documents, joint bank accounts, beneficiary designations, and care agreements. Specialized training and awareness is needed among professionals and service providers. The financial sector could do a great deal to increase education and awareness, as well as detect abuse early on.
- Financial institutions could offer seminars and brochures to customers, informing clients of issues surrounding fraud and financial abuse.
- Financial staff could be trained in basic protocols of screening customers through simple questioning for financial abuse.
- Financial institutions could develop monitoring protocols for transactions in joint accounts
- Financial institutions could develop formal company policies which disallow the POA from acting unilaterally in the case of major transactions such as the sale of a senior’s home.
- It might be valuable to develop a mandatory Power of Attorney (POA) registry

- It would also be valuable if mandatory disclosure of basic information to customers; were necessary before a joint account, or an account managed by a POA, were allowed to be opened.

“Many Canadians don’t understand that once you add your adult children to your account, it’s legally as much their money as it is yours.” Douglas Melville – Toronto, ON: Ombudsman for Banking Services and Investments.

- There is a need for in-depth education of (POAs) on their duties. This could be accomplished both in mandatory discussions of these duties, and through written materials given out by financial institutions. A short test might be administered before allowing a person to be a power of attorney, making sure they read the applicable materials.
- There is a tremendous need to develop and fund collaborative policing/public guardian/financial industry/judicial resources to deal with the complexity of financial abuse.

“Awareness of financial abuse, neglect and self-neglect is increasing at the same time that Canada’s senior population is increasing. The combined effect of heightened awareness and demographics will severely strain, if not overwhelm the capacity of agencies with the statutory responsibility to respond to such matters. Addressing the question of the capacity of jurisdictions to respond to increased reporting of abuse, neglect and self-neglect is essential if awareness initiatives are to have any real meaning.” Jay Chalke Q.C.—Public Guardian and Trustee of BC-- Ottawa hearing, October, 25, 2010

#10 – Capacity Assessments and Advanced Directives

“Loss of capacity is a major fear of older adults and a major factor in abuses experienced by some older adults. Competent capacity assessment is crucial. (At present) means of capacity assessment vary from practitioner to practitioner, within jurisdictions as well as between jurisdictions.” Elliot Paus Jensen – Saskatoon Council on Aging³⁰⁵

- There is a need to develop common national standards for capacity assessment procedures and medical decision making vehicles. Inter provincial/ territorial differences in power of attorney (for medical decision making), and advanced directives, leads to confusion due to variances in terminology and legal concepts. Common standards need to be developed through a substantial federal/provincial/ territorial dialogue, and the ongoing work of the various Law Reform Commissions across the nation.
- Resources need to be devoted to the evaluation of methods of capacity assessment, and the development of best practice standards for those responsible for making such assessments.

“Issues surrounding a senior’s competency are frequently encountered during investigations undertaken by the Elder Abuse Intervention Team. In Alberta these matters are governed by the Adult Guardianship and Trustee Act (AGTA), which enacted in 2009 replaced the Dependant Adults Act. The underpinning of the AGTA is the assumption that a senior is competent until determined otherwise, and the Act sets out provisions for competency assessment, which in the majority of cases must occur on a voluntary basis. While competency/incompetency is a black and white distinction under the Act, it is self-evident that the age related loss of competency occurs gradually and on a broad spectrum. While in agreement with the philosophical basis of the act, it is the experience of the Elder Abuse Intervention Team that the application of the act, with respect to competency, frequently leaves seniors who remain technically competent at high risk of continued abuse. Our team has been witness to numerous occasions, where a senior not recognizing their own vulnerability and unwilling to submit to competency assessment, or intervention services chooses to remain in at risk situations, which eventually result in adverse consequences. In these instances family members, friends, and concerned professionals are often left powerless to act until the situation reaches a crisis point sufficient to allow protective mechanisms to be enacted. Constable Jared Buhler – Edmonton Police Service³⁰⁶

- Legislative changes have to be thoughtfully considered that balance senior's rights and freedoms against putting seniors at risk, with consideration also to the health and well being of the whole family.

At the same time it should be remembered that:

“Most elderly people value autonomy above personal safety and comfort, and would rather have inadequate care with families than the best of institutional care.” Dr. Anne Sclater³⁰⁷

- The complexity of capacity assessment also needs to be kept in mind. Capacity can be assessed in a variety of domains with the person possibly losing capacity in some domains but not others. Capacity may be different for different types of decisions and at different times. There is not a single test that determines capacity for all times and for all purposes.
- Capacity assessment is often difficult to get done particularly in the community. A legal capacity assessment can be prohibitively expensive.
- There are both legal and ethical issues surrounding capacity judgements. A capable person has the right to take risks. There is a danger of protective service professionals utilizing “incapacity” as an excuse to make decisions for people who are actually mentally capable, assuming that they (the professionals) know what is best for the person. In practice person's can be judged “incapable” precisely because they desire to take a risk.

“Watch out for a ‘best interests test’ – a capable person has a right to risk. Although people say that they believe any abuse response should be from the point of view of the older adult, when the time comes where the service provider faces a tough situation – best interests rather than support (often) occurs; someone decides FOR the senior despite the fact that the senior is mentally capable; someone else assumes that they know better. We need to understand what victims WANT and NEED as opposed to what service providers and others want and need. We also need to understand why people refuse help.” Judith Wahl – Advocacy Centre for the Elderly -- Toronto ON³⁰⁸

While the intent of capacity assessors is usually benign, in fact they are usually seeking the “best” for a person based on a paternalistic concept of “best interest”; the results can often be far from benign. Take the case of Tony Argieri.

“Argieri has a neuromuscular disease; he’s wheelchair-bound, deaf, and recently lost speech. But with the aid of specialized computer communication tools, he’s lived alone and worked as a government accountant for years. In some unclear sequence participants disagree on, Argieri apparently was hospitalized for a thigh operation last year, a hospital doctor declared him mentally incapable even though Argieri could communicate in slow, awkward handwriting, he was sent to Glengarry nursing home, Vancouver Island Health Authority (VIHA) stored his belongings, the Public Guardian and Trustee (PGT) took control of his money, and his landlord stopped receiving rent and sued. Eventually, clumsily clutching a pencil and pushing one computer key at a time, Argieri contacted Paul Gilbert, an old friend. Gilbert says Argieri seems like ‘pretty much the same guy’ he’s always known. He’s been trying to unravel what happened and help Argieri regain control of his life, but has been stonewalled. Authorities are reluctant to communicate with Gilbert, protecting patient confidentiality. Argieri signed a letter designating Gilbert as his representative, but Glengarry staff countered Argieri wasn’t mentally capable of making that decision. Gilbert asked for documents establishing Argieri was incapable, but no one has produced any. ‘I was murdered,’ Argieri types to me.”³⁰⁹

Cases like this are not uncommon. People can find themselves divested of their autonomy at the stroke of a pen, and facing an intransigent bureaucracy, in an uphill battle to regain control of their lives.

“The root problem is provincial legislation covering guardianship of people with diminished mental capacity. Canadian Centre for Elder Law (CCEL) lawyers analyzed guardianship laws in 2006. These experts say BC laws ... have ‘remained virtually unchanged’ since 14th century Kings were dictating to lunatics and idiots. BC

laws are ‘paternalistic,’ they state, ‘breach procedural fairness standards,’ and ‘threaten Charter rights and freedoms.’ In summary, the laws affecting ... Tony are a ‘disgrace’ to democracy says Laura Watts, CCEL national director. ‘You flip a switch and you have no rights.’ The ‘switch’? If you are deemed ‘incapable’ by a health professional control of your life is handed to a court appointee, usually a family member or the Public Guardian and Trustee (PGT).”³¹⁰

It should be noted that capacity assessment is a problem in many Canadian jurisdictions. The *Elder Advocates of Alberta Society*, for example, presented a large number of cases in their brief to our Committee, which raise questions about abuse of capacity assessments by at least some professional assessors.³¹¹ They recommend that:

- Capacity assessments should be recorded and transcribed.
- In addition there should be a clear, affordable and easily accessible process for appealing assessments of incapacity.

“A physician has a powerful quasi-judicial position in society by virtue of the reliance on his assessments by the judicial system, in that his assessment can lead to the detaining of lawful citizens behind locked doors, and removal of property and human rights. The current standards required for a physician in the performance of his assessment are not well defined. We believe that if the judiciary is to rely on a physician’s assessment, specific standards and criteria must be developed for the exercise and documentation of a physician’s assessment, as well as practical avenues for the appeal and review of that assessment. Far too many seniors are being abused through this process that declares them incompetent to look after their finances and personal decisions. We have documented a litany of flawed, implausible, inaccurate assessments, assessments which have stripped seniors of all monies and all rights. They are carried out in secret. No one is allowed to witness the assessment. Most of the time, the victimized senior is not allowed access to the assessments. We have appealed to the Minister of Justice, Minister of Seniors and Minister of Health, that all capacity assessments be transcribed. We have called on our Government to legislate that all capacity assessments be recorded and transcribed. The proposed legislation should require that, a certified real time reporter must be present, to transcribe each and every assessment. When completed, the reporter should make a certified transcription directly available to the assessed senior, without delay. It is no longer acceptable, that seniors are being stripped of all rights in an unmonitored, secret process.”

Elder Advocates of Alberta Society – Edmonton Alberta³¹²

Certain attitudes are leading to serious problems for seniors, who risk being stripped of basic rights by well meaning staff. Without the time to address complex cases with the attention they deserve, protective staff can intervene too quickly, and in lockstep conformity to generalized protocols. They attempt to do what they think is best for a client, but don’t always take individual circumstances into account. The result is a systemic attitude that is deleterious to seniors with complex needs. Systems don’t deal with unique circumstances well, but operate based on generalized conditions. These generalized conditions often don’t reflect the real needs of a large section of those who find themselves within the system. This systemic attitude clearly affects competency assessment, which by its very nature must carefully judge the unique situation of the person being assessed.

“ Many systems and institutions are not senior friendly; people do not take time, use appropriate language, or consider sensory issues such as vision and hearing, and they are not accessible to mobility issues etc. ... Right’s advisors, advocates and Ombudsmen should be available to help seniors navigate through the system and help them access the supports when they need them, where they need them. ... (For its part) the complexity of privacy and confidentiality is both legal but also an ethical issue. Not everyone who is abused wants ‘systems’ intervening and interfering into their personal business.” Inga Thompson – Senior Abuse Network—Simcoe County, ON³¹³

Strengthening of the language of adult protection legislation, to provide adequate safeguards, is necessary to avoid tragic cases of seniors being improperly divested of their most fundamental rights. A balance

must be struck which protects vulnerable people from abuse, while respecting their most basic rights. Intervention should always maintain as many of even the incompetent person's basic rights as possible.

“There is widespread confusion even among lawyers and health professionals, the Canadian Centre for Elder Law (CCEL) writes, because incapability is ‘vague’ and ‘appears to differ in different contexts.’ Health professionals often use a Mini-Mental State Examination, CCEL notes, ‘erroneously’ presuming that its 10 to 15 cognitive challenges – to count backwards by seven, spell backwards, and say noifsandsorbutts – can effectively determine your right to liberty. Many health professionals, CCEL states, simply dole out ‘informal,’ ‘on the spot’ judgements and then testify authoritatively, ‘in my opinion, this person is incapable.’ CCEL adds that due process rights are often ignored by health professionals who ‘perceive doing law as contrary to doing health’. Typically, you’re not even notified you’re losing your rights, in order to ‘avoid unnecessarily upsetting’ poor, incapable you.”³¹⁴

A declaration of incapacity has far ranging consequences, and must be utilized with utmost care. The consequences for the person erroneously declared incapable can be devastating.

“It must be clearly understood that to be declared incompetent, a senior is stripped of rights. Rights such as access to monies/bank account, birth certificate, identification papers, (choice of) whom to associate with, the key to one’s own house, phone calls, mail (Christmas cards), right to financial statements, determining where to live, self determination, and personhood. The guardian determines if you have a non-resuscitation order, which means that in a nursing home, when very ill, you will probably not be sent to hospital for treatment. The guardian/agent may restrict or ban friends and neighbours from visiting.” Elder Advocates of Alberta Society³¹⁵

Clearly developing adequate protective laws is a complex process. On the one hand laws are required that allow for effective protective intervention in the case of serious abuse. On the other hand basic protection of fundamental rights is needed, to protect seniors from well meaning interventions that have the unintended consequence of erasing basic rights in the name of safety. By its very nature, an overworked, understaffed bureaucracy will tend to follow protocols in a strict fashion, sometimes not allowing for the nuance necessary for dealing with particular circumstances. Of course most protective staff will try to be careful, however, even an occasional intervention, where an overworked case worker misjudges and takes a capable senior into protective custody unnecessarily, or declares a client incapable, can have tremendous negative consequences. A form of independent advocacy and oversight is necessary to ensure that individuals don't find themselves inappropriately stripped of their rights and freedoms, by the very system designed to protect them. Even persons, who have genuinely lost capacity and are in need of protective intervention, deserve to be granted as much freedom as is possible under the particular circumstances. Interventions should be the least intrusive possible to protect an incapable adult, while ensuring their safety and comfort.

VIII - Conclusion:

“We are seeing increasing signs of elder abuse in our clinical practice, and we believe this trend will only continue to increase as our society ages.” Dr. Marjan Abbasi – Department of Geriatrics – Covenant Health, Edmonton, AB.

Elder abuse is a serious, all too often hidden, crime which affects large numbers of Canadians. Its existence challenges our self understanding as a society of inclusion and respect for all people. We are the inheritors of a national patrimony that was defended and handed down to us by our seniors. Grateful for this legacy of freedom, the least we can do is protect the dignity of our elderly citizens, ensuring that no Canadian, however vulnerable, suffers abuse. It is necessary that elder abuse become unthinkable, an unacceptable injustice. It is essential that as a society we take steps to protect and support those who are abused. A society that fails to respect its elderly has lost touch with itself in a way that ultimately destroys

respect for the dignity of every human being. The future of Canada as we know it is weighed in the balance, let's not be found wanting.

“We live in a society where there will always be a fraction of people who prey on the vulnerable. ... Demographically our society is getting older which is going to result in many changes; there will be more seniors to potentially be victims of abuse, equally there will be more seniors to stand up to abuse and demand a response.” Inga Thompson -- Prevention of Senior Abuse Network – Simcoe County, ON.

Report Appendices:

Appendix #1:



WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

Appendix #2:

Problems in the health care system underscore need for person centred care:

The committee recognizes the difference between the levels and types of care, and understands that there are necessary differences in how care is delivered at each level. We also recognize and affirm the work of the countless committed health providers; who work to deliver the best possible care. That said, there are countless stories, and also many personal experiences, that have been shared with the committee as regards less than exemplary care, at all levels of the health care system; care which failed to respect the basic dignity of the people seeking medical assistance. In adopting the palliative care philosophy to the medical system at large, we imply that systemic tendencies that isolate and dehumanize patients must be consciously overcome, so that patients feel valued and not simply numbers in a queue. Institutional culture, various economic and staffing pressures, are not excuses for ‘systemic indifference’, for treating people as ciphers. Canadians have accepted depersonalization for too long in health care delivery. The following true stories from different parts of Canada, illustrate a tendency within the health care system that needs to be overcome:

a) Customer service workshop for diagnostic imaging department in an Ontario hospital.

“In the early 1990s I was asked to do a ‘customer service’ workshop for staff in a university teaching hospital’s diagnostic imaging department. This is the department where x-rays, CT Scans and ultrasounds are performed. To give the staff an idea of what it “feels like” to be a patient, I asked each to wear 2 patient gowns (so both their fronts and backs were covered) and to go for a half-hour to a waiting room of any other department in this large hospital where they did not know the staff. Some walked to the waiting rooms while others went by wheelchair or on a gurney. When they came back they were absolutely livid. I’ve never had such an extreme response in any of my workshops. They were not livid because not one of their colleagues in these other departments asked them who they were, why they were there, whom they were waiting to see, whether they were in the right place or not, and certainly not offered a welcoming cup of water or tea. They were not livid at the response of their colleagues. They were livid with me. “How dare you dehumanize us that way!” was their unanimous response. They could not generalize that what they felt during only a 30-minute experience was what many of their own patients felt like every day.

While they were off visiting other departments, I put on the same kind of gowns and sat in their waiting areas. I say ‘areas’ because they had a waiting room and a hallway where patients were expected to wait. The waiting room was always empty because it was not wheelchair accessible and patients are always brought to this department in either a wheelchair or gurney. So the official waiting room with the lovely fish tank meant to calm patients during their wait was actually only used by staff for their breaks. The patients were lined up in a cold hallway each facing the same direction along the wall. In other words, each patient saw only the back of the patient in front of them in the line-up so there was no possibility of conversation to ease the worry or boredom of those waiting their turn. They were cold, scared or bored and none of the staff could empathize with them having gone through a similar experience of being ignored for only 30 minutes. The health care environment turned many otherwise compassionate staff people into unresponsive people. They could not empathize, nor sympathize with the experiences of their patients. The workshop failed because the empathy bridge would not be crossed – it would be too frightening to accept that what they were doing to their patients was what they experienced in other departments. If they feel dehumanized in their own hospital after only 30 minutes, what must patients feel like over the course of days, weeks or months?”

Harry van Bommel – Testimony to Scarborough Round table, October 30, 2010

b) Elderly Montreal woman and the acute care setting

“Amy (name changed to protect her privacy) is a healthy 84 year old woman who suffers from osteoporosis (poor bone integrity). She had an elective hip surgery but unfortunately had a fall and broke her wrist. During her convalescence she developed diarrhea secondary to c.difficile and on her way to the bathroom, fell and broke her other hip. On returning to the hospital, the house staff (including physicians, nurses and aids) clearly perceived Amy’s quality of life as poor and gave her little attention. When I came to visit her, this was painfully clear to me. The attending staff was surprised she knew someone as young as I was and, with a note of pessimism, lamented her declining health. In fact, Amy’s quality of life was anything but poor. She had been a volunteer at a hospital in Montreal for over twenty years since her retirement. She had been the former principal of an outstanding school in Westmount. Until her recent series of medical problems, she had a very active social life. Unfortunately, the house staff made assumptions about Amy’s life based on her acute illness and current deteriorating state. One day, I phoned Amy to talk after she was admitted, only to find her short of breath and in terrible pain. I rushed to the hospital to find her near death. The nurse had taken her vital signs but had not alerted anyone to her condition and had not given Amy any pain medication. After an hour of arguing with the nurse, calling the resident and talking to the internal medical staff on call, Amy was taken to the operating room for a surgery that saved her life. She is now recovering and planning for her elective hip surgery. She still has a dynamic social life and is very happy to be alive. The house staff clearly had misjudged her quality of life and her potential for recovery. They decided to presumptively stop caring for her acute issues. As well, they were ignoring her pain.”

Dr. Ramona Coelho is a Montreal based family physician whose practice includes home care. She is affiliated with McGill University. Both Amy and Tom, the subject of the next story, are patients. These accounts come from her September 30th 2010 written submission to the Committee. She also presented at our Montreal Round table December 17, 2010.

c) ER visit of 44 year old Montreal man a distressing experience.

“Tom (name changed) is a 44 year old patient whom I visit at home. He has myotonic dystrophy and he is disfigured from his disease (he has little muscle mass). Physicians, like others, don’t like to see this kind of deterioration, especially when we have no effective treatment. However, despite his appearance, Tom himself is happy to be alive and constantly says he would like to live as long as possible. He speaks to his family daily although they are in Ontario, and his mental capabilities are normal. Recently, Tom had increasing weight loss so I sent him to the hospital for an evaluation. He spent a long time in the emergency room (ER) despite my multiple attempts to discuss his case with the staff physician in the ER and having personally asked my husband (a physician at that hospital) to intervene. In short, no one wanted to admit Tom. Not that he did not deserve or want investigations. Put bluntly, beds are tight and he looked like a long admission. In the end, Tom signed out of the ER because he felt he was treated as a non-entity. This kind of callous attitude is commonplace in our hospital system. Tom tells me that he would rather die than go back to the hospital. The lack of compassion he experienced at the hospital was unreal. As a vulnerable person, it seems he was not considered the treating team’s priority.”

Dr. Ramona Coelho – Montreal

d) Tragedy in Winnipeg ER as 45 year old man dies after 34 hour wait for medical care

Brian Sinclair died sitting in his wheel chair in a Winnipeg hospital ER waiting room, Sept. 21, 2008, after nurses left him waiting for 34 hours to receive care. A bladder infection, which could have been easily treated with antibiotics and a new Catheter, unnecessarily ended a young man's life. A whole host of people were involved in the tragedy, including several nurses, security staff, and orderlies etc., who had been continually alerted to the man's poor state by other people waiting in the emergency room.

“Brian Sinclair sat vomiting in the Health Sciences Centre emergency room as security guards tried to alert triage staff to the ailing double-amputee's urgent need for care, the province's chief medical examiner told the Free Press. Dr. Thambirajah Balachandra's latest revelation sheds new light on Sinclair's tragic 34-hour wait for medical treatment. Balachandra said hospital security staff tried "many times" to get the attention of triage and "other staff" because Sinclair needed help. His investigation reviewed hospital security tapes and involved interviews with security staff. The 45-year-old legless man was found dead by a horrified member of the public in the hospital's waiting room Sept. 21, 2008. An autopsy showed he died of a bladder infection, which could have been treated with a catheter change and antibiotics. "The security guards tried to talk to the hospital staff," Balachandra said Friday. "But to no avail." Winnipeg Regional Health Authority officials have never disclosed Sinclair was seen vomiting during his final hours, and up until Thursday, maintained that Sinclair never approached the triage desk for care. Officials allege Sinclair "fell through the cracks" of the medical system due to systemic gaps. The Free Press obtained an internal email circulated Friday by WRHA CEO Dr. Brian Postl in response to the "dissection of information" about the inquest into Sinclair's death. Postl's email stated the WRHA clearly said Sinclair took all the appropriate steps to obtain care in HSC's ER. "Regrettably, despite Mr. Sinclair's efforts to obtain that care, systems in place at that time did not facilitate his being connected to the proper medical care," the email said.” Jen Skerritt and Gordon Sinclair Jr., ‘Security sought care for man’ Winnipeg Free Press –Online edition 02/7/2009

Though this is an extreme case it illustrates clear systemic problems. Brian Sinclair was an aboriginal person, had a disability (a double amputee), was unable to vocalize, (communicated by printing in a note book), and was poor. Medical sociological literature is clear that medical personnel do tend to stigmatize patients based on perceptions surrounding each of these categorizations. Perceptions of a person being in a less socially valued role tends to get less prompt and less effective medical intervention. The website www.resultsnotintentions.com contains interesting links to peer reviewed medical literature pertaining to inequalities in medical delivery based upon such things as age, disability, mental illness sexual preference etc. In the websites own words: “This site is designed to inform and bring about health care change. It is an interactive site in that we want you to participate in collecting data that demonstrates the inequalities in health care and how we can change the system and the people within it so that everyone receives equal care and support everywhere.”

How many Canadians can report similar stories? While the Brian Sinclair cases are thankfully rare, stories like those of Amy and Tom are much less so. Many persons with disabilities would tell similar stories to Tom's, stories of having to fight for the most basic medical care. So too, far too many Amy's are written off, when medical professionals presume to judge their quality of life. As to being treated brusquely, left to sit in cold waiting rooms for long periods, and rushed through appointments with minimal human communication and less human warmth, the answer here would be that most people who have had experience with the health system, have experienced this. People in general, and sick people in particular deserve better. The Ontario Medical Association in their Policy paper **Patient-Centred Care**; is extremely forthright in noting:

“At all stages of the system, the capacity of physicians and other health-care professionals to respond to patients as individuals is at risk. There is an inherent conflict between the ability to cope daily with

strangers who are partly dressed, sick, suffering, in pain, or dying, and the ability to remain sensitive to these individuals as people. The natural human defense in these situations is to depersonalize people in distress so that the health-care professionals can continue to cope. This creates practices that protect health-care professionals, but are insensitive to patients. From the patient's perspective, events that are unique, profoundly important, and personal are transformed into matters of routine, and patients become one of 'this group of patients,' 'this type of problem,' or 'this procedure.' Depersonalization is probably more prevalent at acute care settings where patients are sicker, but all care settings have the potential to depersonalize patients." (p.38) <https://www.oma.org/Resources/Documents/Patient-CentredCare,2010.pdf>

Clearly while the Committee recognizes the difficulties faced by health professionals, steps must be taken to help these care givers to cope with the stresses involved, while enabling them to provide the very best in person centered care to their patients.

"We need to encourage caregivers to enter into appropriate but real relationships with those they serve, relationships which both validate the client and transform the caregiver. We must help carers to recognize and welcome their own weakness. We need to create places of safety where caregivers can share with each other the anguish which rises up within from time to time, evoked by a client's anguish. They need also to be able to share together their feelings of helplessness, inability, anger, frustration, violence and grief. These feelings are within each of us, and sharing them constructively as a group will encourage growth towards unity and maturity in the individual and within the group, and will help to prevent burnout." Jean Vanier – Submission to the Committee

Whether this requires supportive counseling for our health care personnel, support groups to share frustrations, or other means, it is imperative that the OMA definition of patient-centered care become normative in health care delivery.

"A patient-centered care system is one where patients can move freely along a care pathway without regard to which physician, other health-care provider, institution or community resource they need at that moment in time. The system is one that **considers the individual needs of patients and treats them with respect and dignity.**" Ibid. (p.34)

Person centered care must become the norm, not the exception. The welfare and comfort of the patient must be put at the centre of the health care endeavor. This is imperative from a moral perspective, but also would ultimately save the system money, reducing medical errors, improving diagnostic success, improving patient outcomes.

Appendix #3:

Health Burden of Dementia for Canada: 2008-2038

(From: **Rising Tide: The Impact of Dementia on Canadian Society**)

- Incidence of Alzheimer's disease and related dementias in Canada:
 - 2008 - 103,700 new cases per year (1 every 5 minutes)
 - 2038 - 257,800 new cases per year (1 every 2 minutes)
- Prevalence of Alzheimer's disease and related dementias in Canada:
 - 2008 - 480,600 people with dementia (1.5% of Canada's population)
 - 2038 - 1,125,200 people with dementia (2.8% of Canada's population)
 -
- Hours of informal care provided annually for people with dementia in Canada
 - 2008 - 231 million hours
 - 2038 - 756 million hours

Economic Consequences of Dementia for Canada: 2008-2038

The Economic Burden of dementia doubles every decade, increasing from \$15 billion in 2008 to a startling \$153 billion in 2038.

- Economic Burden of Dementia (in future dollars)
 - 2008 - \$15 billion
 - 2018 - \$37 billion
 - 2028 - \$75 billion
 - 2038 - \$153 billion
- The full report can be accessed at:
http://www.alzheimer.ca/docs/RisingTide/Rising%20Tide_Full%20Report_Eng_FINAL_Secured%20version.pdf

Appendix #4:

DECLARATION OF MONTREAL

(Promulgated May 3rd, 2010 at the First International Pain Summit Montreal Canada).

Declaration that Access to Pain Management Is a Fundamental Human Right

We, as delegates to the International Pain Summit (IPS) of the International Association for the Study of Pain (IASP) (comprising IASP representatives from Chapters in 64 countries plus members in 129 countries, as well as members of the community), have given in-depth attention to the unrelieved pain in the world,

Finding that pain management is inadequate in most of the world because:

- There is inadequate access to treatment for acute pain caused by trauma, disease, and terminal illness and failure to recognize that chronic pain is a serious chronic health problem requiring access to management akin to other chronic diseases such as diabetes or chronic heart disease.
- There are major deficits in knowledge of health care professionals regarding the mechanisms and management of pain.
- Chronic pain with or without diagnosis is highly stigmatized.
- Most countries have no national policy at all or very inadequate policies regarding the management of pain as a health problem, including an inadequate level of research and education.
- Pain Medicine is not recognized as a distinct specialty with a unique body of knowledge and defined scope of practice founded on research and comprehensive training programs.
- The World Health Organization (WHO) estimates that 5 billion people live in countries with low or no access to controlled medicines and have no or insufficient access to treatment for moderate to severe pain.
- There are severe restrictions on the availability of opioids and other essential medications, critical to the management of pain.

And, recognizing the intrinsic dignity of all persons and that withholding of pain treatment is profoundly wrong, leading to unnecessary suffering which is harmful; we declare that the following human rights must be recognized throughout the world:

Article 1. The right of all people to have access to pain management without discrimination (Footnotes 1-4).

Article 2. The right of people in pain to acknowledgment of their pain and to be informed about how it can be assessed and managed (Footnote 5).

Article 3. The right of all people with pain to have access to appropriate assessment and treatment of the pain by adequately trained health care professionals (Footnotes 6-8).

In order to assure these rights, we recognize the following obligations:

1. The obligation of governments and all health care institutions, within the scope of the legal limits of their authority and taking into account the health care resources reasonably available, to establish laws, policies, and systems that will help to promote, and will certainly not inhibit, the access of people in pain to fully adequate pain management. Failure to establish such laws, policies, and systems is unethical and a breach of the human rights of people harmed as a result.
2. The obligation of all health care professionals in a treatment relationship with a patient, within the scope of the legal limits of their professional practice and taking into account the treatment resources reasonably available, to offer to a patient in pain the management that would be offered by a reasonably

careful and competent health care professional in that field of practice. Failure to offer such management is a breach of the patient's human rights.

Note: This Declaration has been prepared having due regard to current general circumstances and modes of health care delivery in the developed and developing world. Nevertheless, it is the responsibility of: governments, of those involved at every level of health care administration, and of health professionals to update the modes of implementation of the Articles of this Declaration as new frameworks for pain management are developed.

Footnotes

1. This includes, but is not limited to, discrimination on the basis of age, sex, gender, medical diagnosis, race or ethnicity, religion, culture, marital, civil or socioeconomic status, sexual orientation, and political or other opinion.

2. International Covenant on Economic, Social and Cultural Rights (ICESCR) (1966). The State parties of the ICESCR recognize “the right of everyone to the highest attainable standard of physical and mental health” (Art. 12), creating the “conditions which would assure to all medical service and medical attention in the event of sickness.”

3. Universal Declaration of Human Rights (1948): Rights to Health (Article 25); Convention on the Rights of a Child (Article 24); Convention on the Elimination of All Forms of Discrimination Against Women (Article 12); Convention on the Elimination of All Forms of Racial Discrimination (Article 5(e) (iv)).

4. The Committee on Economic, Social and Cultural Rights. General Comment No.14, 22nd Session, April-May 2000 E/C 12/2000/4. “Core obligations” of all signatory nations included an obligation to ensure access to health facilities, goods, and services without discrimination, to provide essential drugs as defined by WHO, and to adopt and implement a national health strategy.

5. Committee on Economic, Social and Cultural Rights. General Comment No.14, 22nd Session, April-May 2000, E/C 12/2000/4, para. 12. General Comment No. 14 stated that health accessibility “includes the right to seek, receive and impart information and ideas concerning health issues.”

6. Appropriate assessment includes recording the results of assessment (e.g., pain as the “5th vital sign,” can focus attention on unrelieved pain, triggering appropriate treatment interventions and adjustments). Appropriate treatment includes access to pain medications, including opioids and other essential medications for pain, and best-practice interdisciplinary and integrative nonpharmacological therapies, with access to professionals skilled in the safe and effective use of these medicines and treatments and supported by health policies, legal frameworks, and procedures to assure such access and prevent inappropriate use. Given the lack of adequately trained health professionals, this will require providing educational programs regarding pain assessment and treatment in all of the health care professions and programs within the community for community care workers delivering pain care. It also includes establishment of programs in pain medicine for the education of specialist physicians in pain medicine and palliative medicine. Accreditation policies to assure appropriate standards of training and care should also be established.

7. Failure to provide access to pain management violates the United Nations 1961 Single Convention on Narcotic Drugs declaring the medical use of narcotic drugs indispensable for the relief of pain and mandating adequate provision of narcotic drugs for medical use.

8. The UN Universal Declaration of Human Rights (1948) (Article 5) states: “No one shall be subjected to torture or to cruel, inhuman or degrading treatment...” Comment: Deliberately ignoring a patient’s need

for pain management or failing to call for specialized help if unable to achieve pain relief may represent a violation of Article 5.

9. The UN Special Rapporteur on the Right to Health and the UN Special Rapporteur on the question of torture and other cruel, inhuman, and degrading treatment stated: “The failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman and degrading treatment.”

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Appendix #5:

Accreditation Canada Pain Management Standards

(N.B. The **Canadian Council on Health Services Accreditation** is now referred to as **Accreditation Canada**.)



Accreditation Canada has new offices from the former Canadian Council on Health Services Accreditation.

- **Head office**
1150 Cyrville Road
Ottawa, Ontario
K1J 7S9
613-738-3800
1-800-814-7769 (within Canada)
613-738-7755 (fax)
- **Québec office**
533 Ontario East #330
Montreal, Quebec
H2L 1N8
514-499-6996

Canadian Council on Health
Services Accreditation



Conseil canadien d'agrément
des services de santé

1730 St. Laurent Boulevard, Suite 100, Ottawa, Ontario, Canada K1G 5L1
Tel.: (613) 738-3800 Fax: (613) 738-1244 www.cchsa.ca

Inclusion of pain management in the AIM¹ standards

CCHSA has enhanced the concept of pain management in its AIM standards:

Pain focused criteria are enhanced in the upcoming version of our Standards Document to be used in 2005. In the revised standards, a pain-focused criterion contains specific actions to meet the standard. Actions relate to assessment, management, related monitoring, organizational responsibility, and includes assessment measures. Criteria that incorporate pain management are now more evidence-based and have a greater emphasis on the organization's accountability to train and update staff, patients and families on pain management options and strategies.

Sections where reference to "pain management" in the standards can be found:

New reference to pain management can be found in Acute Care Standard 13.0, under the sub-section Delivering Services, which covers the topics delivering services, medications, and clients' responsibilities. Criterion 13.11 specifically addresses the team's processes for assessing and managing the client's pain. This criterion is included in all care sections of the standards where appropriate for the

management of pain, from Cancer Care, Maternal/Child, Rehabilitation and Long-Term Care, to Acquired Brain Injury, Ambulatory Care and Critical Care. Processes addressed in this criterion are as follows:

- The team knows how to assess pain using standardized clinical measures
- All clients receive a pain assessment on admission and routinely for those with painful procedures and/or conditions
- The team knows how to implement pain management strategies appropriately and routinely monitors their effectiveness
- The organization trains and updates staff on pain relief strategies that are evidence-based and that guide them to minimize risk factors to reduce or prevent adverse consequences e.g. unrelieved acute pain can have consequences such as persistent pain.
- The team documents findings and communicates with colleagues as appropriate
- The team identifies and consults with experts in pain when a complex problem occurs
- The team educates patients and families on pain management options and strategies for appropriate relief

How pain management has been considered in the context of patient safety:

Increasingly, pain management is being discussed in relation to patient safety because of inadequate pain relief, under-medication and related interference in activities for patients who have been discharged after surgery. Currently, the safe use of medication practices address the use of opioids. To reflect this, our medical standards also include reference to opioids when needed in our guidelines.

¹Achieving Improved Measurement

May 21, 2003 statement to J. Watt-Watson from Duyen Nguyen for the CPS General Meeting

Appendix #6:

Persons and Groups Presenting at the Ottawa, Special, and Regional Hearings:

June 15, 2010 Palliative Care Hearing:

- 1) Harry van Bommel – founder of *Legacies Family and Community Resources Inc.*
- 2) Sharon Ruth – Mother of a childhood cancer survivor, author and caregiver support advocate
- 3) Edwina Eddy – Mother of a childhood cancer victim, founder of *Candle lighters Canada*
- 4) Vickie Viens – Family services officer for *Leucan: Association for children with Cancer*
- 5) Dan Demers – National Director of Public Issues, *Canadian Cancer Society*
- 6) Denise Page – Senior Policy analyst, *Canadian Cancer Society*
- 7) Sharon Baxter – Executive Director, *The Canadian Hospice Palliative Care Association*
- 8) Dr. Melody Isinger – Ethicist for the *Canadian Medical Association*
- 9) Jennifer Kavanagh – Communications officer for the *Canadian Hospice Palliative Care Association*

June 16, 2010 Disability Rights Hearing:

- 1) Rhonda Wiebe – *Council of Canadians with Disabilities*, Policy analyst Disabilities Issues Office Province of Manitoba
- 2) Jim Derksen -- *Council of Canadians with Disabilities*
- 3) Dr. Tom Koch – author, researcher, adjunct professor of Gerontology
- 4) Krista Flint – executive director of *Inclusive Humanity*

October 19, 2010 Health Providers and Advocates Hearing:

- 1) Dr. Mary Lynch – President of the *Canadian Pain Society*
- 2) Lynn Cooper – President of the *Canadian Pain Coalition*
- 3) Dr. Gordon Self – Vice President Mission, Ethics and Spirituality *Covenant Health*
- 4) Karen MacMillan – Senior Operating Officer *Grey Nuns Community Hospital*
- 5) Dr. Barry deVeber – President of the *deVeber Institute for Bioethics and Social Policy*
- 6) Jean Echlin – Nurse Consultant in Palliative Care/ Researcher *deVeber Institute for Bioethics and Social Policy*
- 7) Sr. Nuela Kenny MD – President of the *Canadian Catholic Health Alliance*
- 8) Gloria Hovey – *ALS Society of Canada*
- 9) Leny Van Ryn Bolland – *ALS Society of Canada*
- 10) Donna Rietschlin – Community Leader *L'Arche Ottawa*
- 11) Jim Cassidy – Senior Core member *L'Arche Ottawa*
- 12) Raphael Amato – Executive Director *L'Arche Ottawa*
- 13) John Rietschlin – Associate member *L'Arche Ottawa*

October 20, 2010, Suicide Prevention Hearing:

- 1) Marc Kajouji – *Your Life Counts*
- 2) Rory Butler – *Your Life Counts*
- 3) Joan Seabrook – *CASP Survivors Committee*
- 4) Dr. Paul Links – *Dept. of Psychiatry University of Toronto*
- 5) Dr. Marnin Heisel – *Dept. of Psychiatry /Epidemiology/ Biostatistics University of Western Ontario*
- 6) Dr. Antoon Leenaars – Clinical psychologist/Suicide researcher

- 7) Tim Wall – executive director *Canadian Association for Suicide Prevention (CASP)*
- 8) Renee Ouimet – *CASP*

October 25, 2010, Elder Abuse and Disability hearing:

- 1) Dr. Jeff Turnbull – President of the *Canadian Medical Association (CMA)*
- 2) Anna MacQuarrie – director of policy and programs *Canadian Association of Community Living*
- 3) Louise Bergeron – National director *Independent Living Canada*
- 4) Krista Flint – *Inclusive Humanity*
- 5) Barbara Farlow – Patient Safety advocate
- 6) Manon Thompson – *Ontario Network for the prevention of Elder Abuse*
- 7) Ruth Maria Adria – *Elder Advocates of Alberta Society*
- 8) Jay Chalke – *BC Office of the Public Guardian*

October 26, 2010, Care giver hearing:

- 1) Sherri Torjman – Vice president of the *Caledon Institute*
- 2) Dr. Michele Chaban – Prof. social work *University of Toronto*
- 3) Don Fen – President of *Caregiver Omnia Media*
- 4) Peter Aarssen – Elder care Specialist/ *London Life* executive
- 5) Marilyn Pytka – caregiver advocate
- 6) Bill Innes – Canadian Homecare Association
- 7) Michael McBane – Canadian Health Coalition
- 8) Cindy Wiggins – Canadian Health Coalition

Oct. 27, 2010, Palliative Care hearing:

- 1) Susan Eng – Vice president advocacy *Canadian Association of Retired People (CARP)*
- 2) Dr. Larry Librach – professor of pain control and palliative care *University of Toronto*
- 3) Dr. Ingrid De Koch – President of the *Canadian Society of Palliative Care Physicians*
- 4) Dr. Valerie Schultz – *Canadian Society of Palliative Care Physicians*
- 5) Dr. Romaine Gallagher – *College of Family Physicians of Canada*
- 6) Dr. Francine Lemire – *College of Family Physicians of Canada*
- 7) Darby Chandler – executive director *Elliot Lake Palliative Care*
- 8) Sylvie Ferland – *Elliot Lake Palliative Care*
- 9) Holly Prince – *Lake head University Centre for Education and Research on Aging and Health (CERAH)*
- 10) Dr. Mary Lou Kelly -- *Lake head University Centre for Education and Research on Aging and Health (CERAH)*
- 11) Dr. Allison Williams – *McMaster University*
- 12) Dr. Jose Morais – Director of Geriatric Medicine *McGill University Health centre, Catholic Organization for Life and Family (COLF)*

Oct 28, 2010, Elder Abuse Hearing Annual Canadian Conference on Elder Law Toronto:

- 1) Judith Wahl – Executive Director /Senior lawyer, *Advocacy Centre for the Elderly (ACE)*
- 2) Douglas Melville –*Ombudsman for Banking Services and Investments*
- 3) Dr. Lynn MacDonald – *National Initiative for the care of the Elderly (NICE)*
- 4) Prof. Charmain Spencer – research professor Gerontology Research Centre Simon Fraser University, President of the *Canadian Network for the Prevention of Elder Abuse*
- 5) Laurie Joe – *West end Legal Services Ottawa*
- 6) Ann Soden – *National Institute of law Policy and Aging, Montreal*
- 7) Laura Watts – National Director of the *Canadian Centre for Elder Law*

Special hearings:

- 1) May 12, 2010, Ottawa meeting --Neurological Health Charities of Canada
- 2) Sept. 24, 2010, Ottawa meeting -- Alison Leaney – National project coordinator for the *Elder Abuse Knowledge to Action Project*
- 3) Sept. 28, 2010, Ottawa Meeting -- Shelly Cory – Executive Director *Canadian Virtual Hospice*
- 4) Nov. 1, 2010, Ottawa meeting – Dr. Yude Henteleff *Q.C.* – *Pitblado LLP*
- 5) Nov. 16, 2010, Ottawa meeting – Denis Strangman -- Chair of the International Brain Tumour Alliance -- Consumer representative Australian Federal Government Palliative Care Medications Working Group (PCMWG)
- 6) Nov. 25, 2010, Ottawa meeting -- Judith Shamian, President, Michael Villeneuve, scholar in residence, Barb Wright, Parliamentary relations coordinator – *Canadian Nurses Association (CNA)*
- 7) Nov. 26, 2010, Ottawa meeting – Dr. Jose Pereira -- Head of the Division of Palliative Care at the University of Ottawa and Medical Chief of the Palliative Care programs at Bruyère Continuing Care and The Ottawa Hospital in Ottawa. , *Pallium Project leader*
- 8) Nov. 30, 2010, Ottawa meeting – Pamela Fralick, President, Karl Samuelson Senior Health Policy analyst, Teresa Neuman, Communications specialist – *Canadian Health Care Association*

Local and Regional Round Tables:**1) July 26, 2010, Owen Sound Ontario – Hosted by Larry Miller MP****Palliative care**

- a) Mary Winkler – Victorian Order of Nurses
- b) Marie Palmer – Victorian Order of Nurses
- c) Dr. Hilli Huff – palliative care physician

Elder Abuse

- d) Anita Cole – Regional Manager South West CCAC
- e) Donna Ladouceur – South West Regional CCAC --Community Care Access Centre Disability Issues
- f) Marg Johnson – Director of Housekeeping Services -- Home and Community Support Services of Grey Bruce
- g) Joanne Cook – Programs Director (north) -- Home and Community Support Services of Grey Bruce

Suicide Prevention

- h) Constable Sue Macpherson – Grey County OPP
- i) Marie Lerant – Canadian Mental Health Association Grey-Bruce

2) August 11, 2010, Kitchener, Ontario – Hosted by Harold Albrecht MP**Palliative care**

- a) Betty Posendorf, -- Cancer patient
- b) Irena Borg -- Hospice of Waterloo Region
- c) Connie Dwyer -- Lisard House
- d) George Hekman -- University of Waterloo

- e) Sheila Ainsworth
 - f) Andrea Martin
- Elder Abuse
- g) Brad Lawrence -- General Manager for The Village of Winston Park
 - h) Liz Nieson -- Community Care Access Centre

Suicide Prevention

- i) Rory Butler – Your Life Counts
 - j) Marietta Wagler – SAWW-Wilmont Family Resources Centre
 - k) Bob Prankard
- Disability issues
- l) David Kuhn
 - m) Bill Smith – Independent Living Centre

3) August 24, 2010, Strathroy, Ontario -- Hosted by Bev Shipley MP

Palliative Care

- a) Cecilia Palmer – Coordinator Client Services, Hospice Volunteer program Victorian Order of Nurses (VON)
- b) Sarah Klaver – Coordinator Alzheimer Community Support Program, VON
- c) Paul Cavanaugh – Palliative Care Network, Southwest Director – Erie and St. Clair
- d) Wendy Boyle – Palliative pain and symptom management

Suicide Prevention, Disability and Elder abuse

- e) Hilary Hendley – Canadian Mental Health Association, Suicide prevention and Disability Issues
- f) Staff Sergeant Campbell – Strathroy-Caradoc Police Services, Elder Abuse and Suicide Prevention
- g) Karen Gilbert – Social Worker, Strathroy Medical Clinic, Suicide Prevention
- h) Kelli Russell – Executive Director, Victim Services, Elder abuse and Suicide Prevention

4) August 25, 2010, Wallaceburg , Ontario – Hosted by Bev Shipley MP

- a) Mari Cole – Hospital Auxiliary, Palliative Care
- b) Beth Lambie –Coordinator, End of Life Network, Palliative care
- c) Ron Sheppard – Local Health Integration Network, Palliative care and Elder abuse
- d) Diane Lozon – Chatham Kent Health Alliance, Palliative Care, Elder abuse and disabilities
- e) Sergeant Gabe Tetrault – Chatham Kent Police, Elder abuse and Suicide Prevention
- f) Amy Davis – Canadian Mental Health Association, Suicide Prevention and Persons with Cognitive Disabilities

5) Sept. 3, 2010, Sarnia, Ontario – Hosted by Pat Davidson MP

Palliative Care

- a) Dr. Glen Maddison MD – palliative care physician St. Joseph’s hospice and Bluewater Health
- b) John Taylor – resident St. Joseph’s hospice

Elder Abuse

- c) Agnes Soulard – Lampton Elderly Outreach

Disability issues

- d) Dave Schaller – Pathways centre (provided written brief)
- e) Warren Robertson – Community Living Sarnia – (provided written brief)

Suicide Prevention

- f) Tim Wall – Canadian Association for Suicide Prevention CASP (provided written brief)

6) Sept. 8, 2010, Windsor, Ontario – Hosted by Joe Comartin MP

Palliative Care

- a) Dr. Abu Zahra – Hospice of Windsor
- b) Judy Lund – Canadian Cancer Society
- c) Cathy Shanahan – Family respite
- d) Betty Kuchta – CCAC Windsor/Essex
- e) Sungee John – caregiver
- f) Marion Overholt – Legal Assistance Windsor

Suicide Prevention

- g) Dr. Antoon Leenaars –Clinical Psychologist/ researcher
- h) Pam Hines – Canadian Mental Health Association Windsor

Elder Abuse

- i) Deana Johnson – Council on Aging

Disability Issues

- j) Dr. Brad Burke – Brain Injury Association

7) Sept. 17, 2010, Guelph, Ontario – Hosted by Frank Valeriote MP

Palliative Care

- a) Senator Carstairs – Canada’s leading palliative care advocate
- b) Rosslyn Bentley – Executive Director, Hospice Wellington
- c) John Oosterhuis – Executive Director, Hopewell Children’s Home
- d) Nancy Collett – Hospital Chaplain
- e) Paul Visschedyk – Executive Director, Alzheimer Society
- f) Dr. Deb Robinson – Palliative care physician
- g) Dr. Steve Abdool – Director, Centre for Excellence in Ethics
- h) Marianne Walker – CEO, St. Joseph’s Health Centre
- i) Karen Fisher – Director of Care, Hospice Wellington
- j) Jane Hatton-Bauer – Director of supportive care, Grand River Hospital
- k) Andrea Martin – Waterloo Wellington Hospice Palliative care Network, Director and Co-chair of the Provincial End-of-life Care Network

Disability Issues

- l) Bob Butella – Executive Director, Community living Guelph Wellington
- m) Janet Redman – Manager Guelph Independent Living

Elder Abuse

- n) Sheli O’Connor – System Co-ordinator, Seniors at Risk Wellington County

Suicide Prevention

- o) Sandy Parkinson – Coordinator Community Development and Education, Canadian Mental Health Association Wellington, and representative of the Suicide Resource Group of Wellington Dufferin
- p) Cathy Sturdy-Smith – Psychogeriatric resource consultant, Trellis Mental Health and Development Services

8) **September 17, 2010, Moncton New Brunswick – Hosted by Brian Murphy MP**

Palliative Care

- a) Dr. Julie Wildish – Palliative care physician, Horizon NB
- b) Dr. Lorraine Arsenault – Palliative care physician, Vitalite NB
- c) Dr. Pamela Mansfield – Palliative care physician Moncton Hospital, Association Hospice du NB
- d) Mariette LaFrance – Extra Mural-Vitalite NB
- e) Ellen Snider – Canadian Cancer Society

Elder Abuse

- f) Conrad LeBlanc – Federation des Aines du NB

Disability Issues

- g) David Webb – Association Canadienne des lésés cérébraux Association de NB
- h) Marita Webb -- Association Canadienne des lésés cérébraux Association de NB
- i) Harry Zarins – National executive director, Brain Injury Association of Canada

Suicide Prevention

- j) Ginette Vautour Curin – Sante Mentale et Prevention des suicides NB

9) **Sept. 30, 2010, Brockville Ontario – Hosted by Gord Brown MP**

Palliative Care

- a) Margaret George – Director, Southeastern Ontario Palliative and End-of-Life Care Network
- b) Sherry Anderson – Director, Complex Continuing care, rehabilitation and palliative Care Brockville General Hospital
- c) Joan Schwarze – Coordinator Brockville and District Hospice Palliative Care Service
- d) Sharon Baxter – Executive Director, Canadian Hospice Palliative Care Association
- e) Denise Page – Senior Health Policy Analyst Canadian Cancer Society
- f) Dawn Rodger – Executive director Beth Donovan Hospice
- g) Dr. Gerry Ashe – Palliative Care physician
- h) Doug Struthers – Mayor Merrierville-Wolford

10) **Oct. 12, 2010, Halifax N.S. – Hosted by Megan Leslie MP and Mike Savage MP**

Palliative Care

- a) Dr. David Henderson – Past President NS Hospice Palliative Care Association, Board of Directors and Medical Director of palliative care Colchester East Hants Health Authority
- b) Dr. Fred McGinn – Chair, Hospice Society of Greater Halifax
- c) Dr. Paul McIntyre – Head, Division of Palliative Medicine, Dalhousie University
- d) Ann McKim – Palliative care nurse, Colchester East Hants Palliative Care Program
- e) Sharon Reashore – Executive Director, Caregivers Nova Scotia Association
- f) Catherine Yuill – Executive Director, Colchester East Hants Hospice Society

Disability Issues

- g) Steve Estey – Chair, International Committee Council of Canadians with Disabilities

11) **Oct. 13, 2010, Brampton Ontario – Hosted by Andrew Kania MP**

Palliative Care

- a) Susan Harris – Clinical Director, Catholic Family Services Peel-Dufferin
- b) Theresa Greer – Executive Director, Heart House Hospice
- c) Gabrielle Coe, Executive Director, Hospice Caledon

Elder Abuse

- d) Maureen Etkin – Central West Region Consultant, Ontario Network for the Prevention of Elder Abuse
- e) Nellie Sheppard – Chair, Peel Elder Abuse Prevention Network
Suicide Prevention
- f) Linda Gerger – Executive Director, Distress Centre Peel
- g) Vanita Varma – Executive Director, Spectra Community Support Services

Disability Issues

- h) Gail Jones – Director of Community Supports, Kerry's Place Autism Services

12) **Oct. 17, 2010, Sault St. Marie – Hosted by Tony Martin MP**

Palliative care

- a) Christianne Monico – North East Community Care Access Centre
- b) Rodney Buzdygan – Canadian Cancer Society, Algoma Unit
- c) Karen Bishop
- d) Vicky Roy – Alzheimer Society
- e) Lena Robertson – VON
- f) Valerie Durnford – VON
- g) Helen Ross – Algoma Residential Community Hospice
- h) Jessica Boyer – Indian Friendship Centre -- Lifelong Care Program
- i) Lynn O'Hara -- Indian Friendship Centre -- Lifelong Care Program
- j) Evelyn Theriault – Seniors Health Advisory Committee

Disability

- k) Diane Morell – Canadian Parapelegic Association
- l) John Bothwell – Person with a disability
- m) Sharon Candido – Ministry of Community and Social Services – Integrated Children's Services

Interested citizens

- n) Pastor Gene Monin
- o) Margaret Dupont
- p) Gloria White
- q) Rita Mannarino
- r) Elaine Comrie

13) **October 23, Edmonton Alberta – Hosted by Tim Uppal MP**

Palliative care

- a) Gordon Self – Vice President Mission, Ethics and Spirituality, Covenant Health
- b) Karen MacMillan – Senior Operating Officer, Grey Nuns Community Hospital

- c) Nancy Brook – Government of Alberta appointed Public Member for Health Professional Disciplinary Hearings
- d) Karen Gayman – Executive Director, Palliative Care, Alberta Health Services
- e) Halina White – Program Coordinator and Consultant Health Care Apostolate RC Diocese of Calgary

Elder Abuse

- f) Dr. Marjan Abbasi – Geriatric Site leader, Misericordia Hospital, Covenant Health
- g) Cst. Jared Buhler – Edmonton Police Services Elder Abuse Unit
- h) Pat Power -- Edmonton Elder Abuse intervention Team, Social worker Community Services Department
- i) Jodie Kelloway – Older adults services specialist, Strathcona County Family and Community Services

14) October 30, 2010, Scarborough Ontario – Hosted by Michelle Simson MP

Palliative Care

- a) Ron Lirette – Executive Director, Dorothy Ley Hospice and Perram House, Spokesman -- Toronto Central Hospice Palliative Care Network
- b) Sonia Johnson– Central East Hospice Palliative Care Network
- c) Eric Hong -- Central East Hospice Palliative Care Network
- d) Rick Firth – Executive Director, Hospice Association of Ontario
- d) Dan Demers – Director of Public Issues (National), Canadian Cancer Society
- e) Jacquelyn Saad --Vice President, Willow Breast Cancer Support
- f) Dr. Hung Der -- Local Dentist
- g) Josi Perotto – Social Worker and Psychotherapist
- h) Harry van Bommel, Executive Director, Legacies

Suicide Prevention

- i) Lynn Morgan – Suicide prevention activist

15) November 9, 2010, Saskatoon SK – Hosted by Kelly Block MP

Palliative Care

- a) Dr. Ken Stakiw – Medical Director, Saskatchewan Hospice Palliative Care Association
- b) Corinne Sandstrom – Palliative Care Coordinator, Estevan, Saskatchewan Hospice Palliative Care Association
- c) Carla Carlson – President, Saskatchewan Hospice Palliative Care Association
- d) Sandra Kary – Secretary Treasurer, , Executive Director, Catholic Health Association of Saskatchewan
- e) Jean Morrison – President and CEO, St. Paul’s Hospital

Elder Abuse

- f) Lenora Andres – President -- Families Advocating for Compassionate Environments in Special Care Homes (FACE Saskatoon Inc.)
- g) Eliot Paus Jenssen – Board member, Saskatoon Council on Aging
- h) Sandra Chassk – Executive Director Saskatoon Council on Aging
- i) Sandy Pitzel – Prince Albert Community Against Family Violence (PAIR)
- j) Peggy MacLeod – Older Adult Abuse Taskforce, Saskatoon Council on Aging
- k) Pat Humenny – National Seniors Council

Disability Issues

- l) Allen Hall – Vice president, Community Living Association Saskatoon Inc.
- m) Heather Kuttai – Saskatchewan Abilities Council

Suicide prevention

- n) Rita Field – Executive Director, Saskatoon Crisis Intervention Service
- o) Dr. Gerald Block – Psychologist, Saskatoon Health Region , Mental Health and Addictions
- p) Dr. Fern Stockdale – Psychologist, Saskatoon Health Region, geriatric psychologist

16) November 9, 2010, Victoria BC – Hosted by Denise Savoie MP

Palliative Care

- a) Dr. Michael Downing – Research Director, Victoria Hospice, Clinical Associate Professor Palliative Care UBC
- b) Wayne Peterson – Executive Director, Victoria Hospice
- c) Michelle Dale -- Inpatient Unit Counsellor, Victoria Hospice
- d) Dr. Kelly Stajduhar -- Professor Nursing University of Victoria

Elder Abuse

- e) Dr. Gloria Gutman – Director, Simon Fraser University Department of Gerontology
- f) Prof. Charmaine Spencer – Lawyer, Researcher Associate in Vulnerable populations, Gerontology Research Centre Simon Fraser University
- g) Alison Leaney – National Project Coordinator, Elder Abuse Knowledge to Action Project, National Initiative for the Care of the Elderly (NICE)

Health Economics and Health System Design

- h) Dr. Marcus Hollander – President Hollander Analytical Services Ltd. Health Services researcher
- i) Dr. Neena L. Chappell – Canada Research Chair in Social Gerontology, Professor of Sociology, Centre on Aging, University of Victoria
- j) Dr. Robert Evans -- Internationally renowned health economist, UBC Centre for Health Services and policy Research

Advocacy groups

- k) Wanda Morris – Executive Director, Dying with Dignity

17) December 17, 2010, Montreal Quebec – Hosted by Francis Scarpaleggia MP

Palliative Care

- a) Dr. Bernard Lapointe -- Chief of the Division of Palliative Care, Jewish General Hospital, Eric M. Flanders Chair Palliative Medicine, McGill University.
- b) Dr. Justine Farley – Director Palliative Care, St. Mary's hospital Montreal, Assistant Professor of Palliative Medicine in the Departments of family Medicine and Oncology, McGill University
- c) Dr. Patrick Vinay – Former Dean of the Faculty of Medicine at the University of Montreal, internationally renowned medical researcher, Palliative care specialist
- d) Dr. Robin Cohen – Psychologist, Post Doctoral Fellow and Director of Research Division of Palliative Care, Dept. of Oncology, McGill University
- e) Teresa Dellar – Executive Director, West Island Palliative Care Residence
- f) Rose De Angelis – Director of Nursing, West Island Palliative Care Residence
- g) Marie France Juneau – Executive Director, NOVA West Island
- h) Judy Tellier – Executive Director, NOVA Hudson

- i) Marla Stovin – Executive Director, NOVA Montreal
- j) Debbie Magwood – Executive Director West Island Cancer Wellness Center
- k) Denise Page – Senior policy analyst, Canadian Cancer Society
- l) Doreen Edward – President and founder, Venturing Out Beyond Our Cancer (VOBOC)
- m) Andre Hupe – President Accompagnement Benevoles de L’Ouest – Volunteer Assisted Services
- n) Suzanne Turmel – Executive Director CSSS O’est Isle
- o) Peter Eusano – President, Comfort keepers Eastern Canada and Comfort Keepers Quebec
- p) Dr. Chitra Chopra – President, Montreal Lakeshore University Women’s Club
- q) Dr. Ray Hasel – CEO HappyDurals Clinic, Assistant Professor, Department of Anaesthesia McGill University, Anaesthetist Lakeshore General Hospital
- r) Dr. Ramona Cohelo -- family physician, CLSC Metro Montreal
- s) Dr. Danial Cere -- Researcher in Law, Ethics and Religion, Professor Religious Studies, McGill University
- t) Hon. Clifford Lincoln – President of the English Speaking Catholic Council
- u) Martin Murphy – Past President of the English Speaking Catholic Council
- v) David Morris – Former seniors residence operator, Beaconsfield Quebec
- w) Dr. Allen Dawn – Researcher McGill University (in attendance)
- x) Dr. Elizabeth Kofron –Montreal Neurological Institute (in attendance)
- y) Dr. Pedro Mejia – Jewish General Hospital (in attendance)
- z) Dr. Philippe Violette (in attendance)

Written Submissions from Persons and Organizations that did not present before the Committee at hearings or Round tables:

- a) Alliance for Life Ontario
- b) Ashpole, Mr. Barry R. – media specialist
- c) BC Association of Community Response Networks
- d) Canadian Breast Cancer Network
- e) Canadian Caregiver Coalition
- f) Catholic Civil Rights League
- g) Canadian Critical Care Society
- h) Christian Governance
- i) DAWN-RAFH Canada
- j) DeMarco, Dr. Donald – Philosophy Professor Emeritus
- k) Elder Abuse Prevention Network Haliburton Kawartha Lakes
- l) Elliot Lake Seniors at Risk Committee
- m) Erie St. Clair Local Health Integration Network
- n) Ferrier, Dr. Catherine – Department of Family Medicine, McGill University, Montreal General Hospital
- o) Kelly, Dr. Alvin -- Palliative Care Physician
- p) LeBlanc, Mrs. Louise
- q) Medical Safe guards Project
- r) National Initiative for the Care of the Elderly Palliative Care Submission
- s) NAV Care
- t) Ney, Dr. Philip -- Psychiatrist
- u) Ontario College of Family Physicians
- v) Somerville , Dr. Margaret,-- **Founding Director, McGill Centre for Medicine, Ethics and Law, Samuel Gale Professor of Law**
- w) Tumeinski, Dr. Marc -- Social Role Valorization Implementation Project
- x) Vancouver Costal Health Elder Abuse Submission
- y) Vanier, Dr. Jean – Founder L’Arche
- z) Victorian order of Nurses (VON)

Also several hundred e-mail and letter submissions.

End Notes:

Part 1 – Palliative and End-of-Life Care:

¹ Submission to the Parliamentary Committee Sept. 1, 2010 pp. 3-4.

² From the letter of Jean Vanier to the Parliamentary Committee on Palliative and Compassionate Care: October. 15, 2010.

³ Canadian Institute for Health Information, *Health Care Use at the End of Life in Western Canada* (Ottawa: CIHI, 2007). The 16-30% statistic is quoted regularly by the Canadian Hospice Palliative care Association. The Canadian Cancer Society in their submission to the Committee uses the 16% statistic as representative of Palliative care delivery for Canada as a whole. 16% of people needing it being able to access palliative care is probably more reflective of the patchwork of palliative care services in Canada as a whole, with 30% coverage being attained only in certain metropolitan areas.

⁴ Testimony to the Halifax Round Table October 12, 2010.

⁵ Palliative care is consistently patient centred, and hence a great model of patient centred care. Of course it is not consistently available across all jurisdictions.

⁶ The Committee is glad to note that the CMA and other major medical groups in Canada are beginning to focus on patient centred care.

“The concept of “patient-centred care” is taking hold in other developed countries which are also in the process of reforming their health care systems. The essential principle is that health care services are provided in a manner that works best for patients. Health care providers partner with patients and their families to identify and satisfy the range of needs and preferences. Health providers, governments and patients each have their own specific roles in creating and moving toward a patient-centred system. Patients have consistently emphasized the importance of being respected, having open communication and confidentiality of personal information, in addition to quality medical care. While building a patient-centred system is clearly better for patients, it is also better for physicians and all health care providers and administrators. In a patient-centred system, physicians are provided the optimal environment to give the best possible medical care. From the perspective of health administrators, recruitment and retention of providers who are satisfied with their work and their environment can have many tangible benefits. For instance, hospitals employing patient-centred care principles have found improvements in patient outcomes in areas ranging from decreased length of stay and fewer medication errors to enhanced staff recruitment.” Canadian Medical Association, *Health Care transformation in Canada Change that works Care that lasts.* (2010) p.8. The CMA Charter for Patient centred care is a promising development in Canadian medical culture. See report: http://www.cma.ca/multimedia/CMA/Content/Images/Inside_cma/Advocacy/HCT/HCT-2010report_en.pdf

It should be noted that the essence of patient centred care is treating the patient as a person, with the dignity and respect due a person. This implies relating to the patient as a person, and not as a collection of organs, or a carrier of a disease. Patients want to be treated in a friendly, respectful manner, professional and polite. Far too many patients are not so treated which is why this issue comes up for discussion in the first place.

⁷ The Committee presupposes the WHO definition of Palliative care throughout; please see Appendix # 1 for the WHO definition.

⁸ Dr. John Meenan is a General Practitioner in Kitchener Ontario.

Similar in sentiment are two statements of Canada’s most famous physician Dr. William Osler (1849-1919). “The good physician treats the disease; the great physician treats the patient who has the disease.” And again “It is much more important to know what sort of a patient has a disease than what sort of a disease a patient has.”

⁹ Public Health Agency of Canada: accessed December 13, 2010 <http://www.phac-aspc.gc.ca/ph-sp/determinants/index-eng.php#determinants>

¹⁰ Canadian Healthcare Association, (2009) New Directions for Facility-Based Long Term Care. Ottawa, Ontario: CHA Press. P.29.

¹¹ The Victorian Order of Nurses (VON) note in their submission to the Committee, that by 2020, one in ten Canadians will have diabetes, costing the country almost \$17 billion per year in health costs. Among Canadians aged 65 and older, about 80% have one chronic disease, and of those approximately 70% suffer from two or more chronic diseases. Seniors are the fastest growing group in the population, and by 2031 the number of seniors will almost double to nine million, representing close to a quarter of Canada's population. By 2015, it is estimated there will be more seniors than children.

¹² Power point presentation of Marcus J. Hollander, PhD President, Hollander Analytical Services Ltd: Providing Integrated Care and Support for Persons with Ongoing Care Needs: Policy, Evidence, and Models of Care. Ideas to Action Integrating Community Support Services within Regionalized Models: Innovations and Best Practices from Across Canada Conference of the Canadian Research Centre for Care in the Community, Ryerson University, Toronto, Ontario, Oct. 23, 2006 p.41, 61

¹³ Note: Marcus J. Hollander et al. "Providing Care and Support for an Aging Population: Briefing Notes on Key Policy Issues" Healthcare Quarterly 10(3) 2007: 34-45, also: Marcus Hollander and Michael J. Prince, "Organizing Healthcare Delivery Systems for persons with ongoing care needs and their families." Healthcare Quarterly 11(1) 2007: 2-13.

¹⁴ DLA FOX, "Report on evaluation of Hospital in the Home Programs.", Victoria Department of Health, Australia, 2009, p.71. HITH programs of course form only one part of a continuous care program, that of post acute homecare delivery. That said this data is indicative of savings possible through continuing integrated care, in this case via home care delivery. The Israeli data was given in the article of: Jacobs J. "Closure of a home hospital program." Archives of Gerontology and Geriatrics 2007; 45:179-89.

¹⁵ See: Marcus Hollander, et al, "Providing Care and support for an aging population: briefing notes on key policy issues." Healthcare Quarterly 10(3) 2007: 34-45

More detailed analysis of cost savings specifically in light of Veterans Affairs Canada Continuing care research project can be found in Margaret MacAdam, Marcus Hollander, et al. "Increasing Value for Money in the Canadian Healthcare System: New Findings and the case for Integrated Care for Seniors" Healthcare Quarterly Vol. 12(1) 2009: 38-47.

Dr. Marcus Hollander is a world leader in health system integration research and Integrated Continuous health care delivery. His website for **Hollander Analytical Services** <http://www.hollanderanalytical.com/Hollander/Home.html> has all the listed articles archived, along with numerous in-depth reports done for Health Canada, Veterans Affairs, various provinces etc. on this and related health care delivery topics. The committee highly recommends that political leaders, public policy experts, health care professionals, journalists, and interested citizens, take the time to carefully read Dr. Hollander's important work, so as to take part, in an educated fashion, in the needed national debate on health care delivery.

¹⁶ Marcus Hollander, et al, "Providing Care and support for an aging population: briefing notes on key policy issues." Healthcare Quarterly 10(3) 2007: p. 40

¹⁷ *ibid.* p.39

¹⁸ Power point presentation of Marcus J. Hollander, PhD President, Hollander Analytical Services Ltd: Providing Integrated Care and Support for Persons with Ongoing Care Needs: Policy, Evidence, and Models of Care. Ideas to Action Integrating Community Support Services within Regionalized Models: Innovations and Best Practices from Across Canada Conference of the Canadian Research Centre for Care in the Community, Ryerson University, Toronto, Ontario, Oct. 23, 2006 p.40-41

¹⁹ The Saskatchewan government issued an important report in October of 2009. **“For Patients’ Sake”**. Tony Dagnone, Commissioner of the **Patient First Review**, made a strong case that health care needs to be transformed from its present focus on health professionals, and institutional interests, to the needs of patient and family. This report is the first government document to state this truth so forthrightly. <http://www.health.gov.sk.ca/patient-first-commissioners-report>

“Patient First’ must be embedded as a core value in health care and ingrained in the “DNA” of all health organizations. The health system has lost its focus on the patient and lost sight of the fact that health care is a service industry. The best interests of patients and families must be the primary driver of policy decisions, collective agreements, priority setting and resource allocation decisions, and the operation of workplaces. ... Only a well-integrated system can respond to patients as whole people rather than parts that need fixing. (p.6) ...Care is delivered in silos, and new care models are resisted by providers guarding their own interests – to the detriment of patients. (p.7) ...Patient–and–family centred health care considers the patient’s needs and interests first and foremost. Patients...want their needs, values, culture and spirituality respected. They want support during times of illness and trauma, and effective, compassionate communication that can help to relieve fear and anxiety. They want complete information about care and treatment options. (p.11) ...The entire health system must share a common patient-and family-centred vision and direction, and systematically implement actions to achieve this vision. “Patient First” cannot be a mere lapel pin, button, or logo; it must be a way of doing business for all those associated with health care, regardless of their role, title, or tenure.” (p.14)

The Committee can only applaud these sentiments, and hope that this report will be the beginning of a ground swell demanding change in our health system nationally.

The Ontario Medical Association also recognizes that the health system is not patient centred.

“In many systems today, including Ontario’s, health care is not patient-centred. Rather the patient is required to adapt to the system and to navigate through its many intersections.” (p.34)

The OMA Policy paper **“Patient-Centred Care”** is well worth reading, and another hopeful sign, that the medical profession is also recognizing the importance of transforming the system in favour of patient and family focused care. <https://www.oma.org/Resources/Documents/Patient-CentredCare,2010.pdf>

²⁰ **Problems in the health care system underscore need for person centred care:**

For a sample of cases that exemplify problems in health care delivery, and the need for a renewal of Patient centered care see: Appendix #2.

²¹ Submission to the Parliamentary Committee, Sept. 1, 2010 p.10.

²² Covenant Health Submission Sept. 1, 2010, p. 10.

²³ **The Hierarchy of Care Environments** were first developed by Harry van Bommel in 1994 for a Dec. 7th submission to the Senate Committee on Euthanasia and Assisted Suicide. The version in this report is based on the adaption of the original presented to the Parliamentary Committee Round table in Scarborough ON, October 30th, 2010.

²⁴ The greater the level of government funding, the more bureaucratic a free-standing hospice must become and the greater the demands that patients die within a certain period of time (e.g., 3 months) or they will be moved to a different facility. This moving of people from one place to the other is disorienting and increases the death expectancy placed on patients. The expectation becomes, “Don’t take too long to die or it will cost you money or a transfer.” This becomes a terrible burden on both the patient and their family. Excellent hospice palliative care often extends life, as it should. Patients must not be punished for living longer because they are getting better care.

²⁵ Though dealing with long term care centres, the following quote has applicability.

“Facility-based long term care has traditionally been committed to the institutional model of care by focusing first and foremost on the completion of tasks: feeding, dressing, medicating and documenting. Unfortunately, the institutional model is still evident today though few homes will admit it. Mission, vision and values statements speak about individualized approaches to care and empowering stakeholders, but when you strip away the language and move past the colourful drapes, pets, and carefully-placed personal belongings, little has changed in some long term care environments. (p.24)

Creating a dignified living environment for residents and a quality working environment for staff goes well beyond finishings and rhetoric. Cultures of caring will never materialize in homes that cling to the institutional model of care. Many organizations have made lasting improvements in the culture of their homes through their own ingenuity and sense of purpose. Others have been inspired by methodologies such as the *Eden Alternative*, the *Wellspring Nursing Home Learning Collaborative* model and *Gentlecare*. While each of these concepts has merit, none of them have a monopoly on compassion. There is no preferred methodology for all homes. (p. 25)

Each home has its own culture. Therefore, each home should develop its own pathway toward a social model, and away from the institutional model. Creating a “home” is a journey, not a destination. To prescribe ways to create a home could strip away one of the greatest benefits of the quest: to stimulate curiosity and transform the home into a learning organization. (p. 25)

Bureaucratic traditions must give way to cultural transformation. For this to happen we would be well advised to devote less energy into creating more regulations or devising new ways to enforce strict compliance and direct more attention to processes that will help transform facility-based long term care into desirable places to live and work. (p.25-26)

Canadian Healthcare Association, (2009) New Directions for Facility-Based Long Term Care. Ottawa, Ontario: CHA Press.

Dr. Paul Sinclair the Australian Sociologist gives food for thought when he notes:

“Palliative care assumes that a non-hierarchical team or community can be developed while retaining the fundamental hierarchical team structure and composition of the acute setting. This type of incoherence allows devaluation to be imported unconsciously from the hospital model. ...Importing aspects of the acute care model to the chronic care context, such as palliative care, must introduce significant incoherence. ...Palliative care uses mostly medical structures, processes, language and symbols because the medical model dominates palliative care. So there are ward, nursing station, patient, patient history, diagnosis, prognosis, symptom management, progress notes, clinical care, nursing rosters, shifts and so on. Palliative care, via its medical expression, cannot avoid carrying over role and status differentials operative within the medical system, such as those between consultant and GP, as well as medical imperatives such as demand to conduct research and teaching in an institution. ... The interdisciplinary palliative care team and its processes are a direct transposition from the hospital ward, even though this transposition is overlaid with nuances from other contexts and models.” (p.122-123)

“Palliative care advocates (promotes) client self-determination and client-directed care; yet its structures, such as the interdisciplinary team, tend to compromise these goals. The shift from patient centred to object centred medical cosmologies, which includes the hospital becoming medical workshop, allowed the decision making power in care to shift from the patient to the doctor and the hospital. Object centred medical cosmologies emphasise the body as a visible conglomerate of parts as the central fact of the process of care. The medico-psychological cosmologies likewise somatise, individualise and objectify the soul or mind as being revealed by deviant behaviours, issues, problems, symptoms or biochemistry of the brain. Palliative care imports much of the object oriented cosmology of medicine not only via its medical and medico –psychological concepts but also via its importation of wide ranging hospital /medical structures, processes and terms. With the importation of key aspects of the hospital/medical model into palliative care comes the decision making power of the hospital as institution and the whole symbolic meaning of the hospital, and an institution in general. Object oriented principles oppose person centred principles. ... The interrelationship between doctors’ and nurses’ roles and, more importantly, the symbolic implications of these

roles are fundamental features of the medical model that, therefore, change only very slowly. Doctors and nurses mean medicine, illness, hospital, authority, care towards cure and a hierarchical, paternalistic role system.” (p.74-75) Paul Sinclair, (2007) Rethinking Palliative Care: A Social Role Valorisation approach. Bristol, UK: The Policy Press, University of Bristol

The impact of these medical symbolic structures upon dying persons, while often subtle, is real even within our best palliative care programs. A dichotomy between the palliative care philosophy of person centred whole person care, and the institutional structures with their implicit cultural assumptions, is a constant if unconscious tension within palliative care practice.

²⁶ From the written submission of Dr. Margaret Somerville, to the Parliamentary Committee.

While the institutionalization of care is difficult to define it is something everyone understands intuitively. “No valued person chooses to live his/her normal, day-to-day life in institutional care. Therefore, institutional care is self-evidently an abnormal and unnatural way to live. If institutional care is an abnormal and unnatural way to live then, self-evidently, it must be an abnormal and unnatural way to die, because people live until they die. Since institutional care lies at the heart of the social organization of palliative care, its influence must permeate the entire system.” *ibid.* Paul Sinclair, p.3.

²⁷ November 26, 2010 meeting between Dr. Jose Pereira and four Committee MPs in the Government Lobby, Parliament Building, Ottawa.

²⁸ For a summary of the pertinent facts from the Alzheimer Society of Canada report **Rising Tide: The Impact of Dementia on Canadian Society** see appendix #3

²⁹ Research is needed, on the medical side of palliative care, to improve such things as pain control and symptom management. Evidence based Palliative care research has had a hard time competing with the prestige accorded to curative/ pharmaceutical research. The dedicated research fund should be administered by a board which includes representative members of the palliative care research community, as well as family and client members, to ensure that a family and patient centred perspective is kept at the heart of the research agenda.

³⁰ See the important article by Dr. Romyne Gallagher, “How to improve our patient’s health literacy” BC Medical Journal (2008) Vol. 50, no. 9, p. 525-526.

As pertains to Health Literacy in Canada see: Rootman, I Gordon-El-Bihbety, D. A Vision for a Health Literate Canada: Report of the Expert Panel on Health Literacy. Canadian Public Health Association, 2008

³¹ Dr. Laura Diachun is director of undergraduate geriatric education at the University of Western Ontario Schulich Medical School in London. See article: <http://www.sjhc.london.on.ca/our-stories/we-care-aging>

³² Geriatric nurses, gerontologists, palliative care and pain control specialists, geriatric psychiatrists and psychologists, personal support workers, home care personnel, both medical and non medical support aids etc. will be needed in growing numbers in the very near future. Standards of training, accreditation by some form of professional organization and accompanying recognition will be needed for personal support workers (PSWs), who furthermore, will need to be more fairly remunerated for their labour.

³³ Dec. 17, 2010 Submission to Committee in Montreal

³⁴ “*Health literacy is the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions. But health literacy goes beyond the individual.*

*It also depends upon the skills, preferences, and expectations of those health information providers: our doctors, nurses, administrators, home health workers, the media, and many others. Health literacy arises from a convergence of education, health services, and social and cultural factors, and brings together research and practice from diverse fields.” Health Literacy: A Prescription to End Confusion, *Institutes of Medicine* (2004)*

Rootman, I Gordon-El-Bihbety, D. A Vision for a Health Literate Canada: Report of the Expert Panel on Health Literacy. Canadian Public Health Association, 2008

Dr. Angelo E. Volandes et al, "Health Literacy not race Predicts End-of-Life Care Preferences" Journal of Palliative Medicine (2008) Vol. 11, no. 5 p. 754-762.

³⁵ At the same time we must be cognizant of the risk of palliative care being seen as something that only specialists do. All family doctors, cancer specialists, and other disease-focused specialists must be well prepared to deal with pain and symptom control issues that arise with their patients. Only in a rare situation would they require a palliative care specialist. The people who already know the patient need to develop the skills to care for them including effective palliative care. Patients should be introduced to new professionals only when absolutely necessary. The palliative care specialists need to be there to consult with their colleagues rather than to create a new medical industry.

³⁶ Emphasis is needed to develop palliative care strategies in all areas of health care. Renal (kidney) care and care for persons with motor-neuron disorders like MS, and ALS are examples of other palliative care strategies that need development.

³⁷ Dec. 17, 2010 Submission to Committee in Montreal

³⁸ Knowledge Transfer: Raising the Stakes for System Change. Oct. 1-3, 2007 Conference: http://www.ahfmr.ab.ca/rtna/doc/adv_pro_final_2007.pdf

³⁹ **"The term Pallium is a Latin word which means cloak or shelter. We used this to describe how the guiding aspiration underlying the Pallium Project is to develop networks, tools and resources that ultimately help to cloak patients and families with comfort and support while living with a life-threatening or life-limiting illness."** Michael Aherne – Edmonton
See Michael Aherne speech Oct. 3, 2007 at: <http://www.ahfmr.ab.ca/rtna/doc/Aherne.pdf>

⁴⁰ For more information on the Pallium project see their website at: <http://www.pallium.ca/>

⁴¹ At present the entire limited budget of the virtual hospice comes from health organizations in the province of Manitoba. Due to budgetary restraints this funding is about to be discontinued. The Virtual hospice reaches Canadians coast to coast, hence the committee calls upon the federal government to provide regular funding, so this cost effective venue for needed information on Palliative and end-of-life care, can continue, can expand its capacity, and advertise its services, to the countless Canadians who need informational support, but don't yet know the Virtual Hospice exists. For more information on the **Canadian Virtual Hospice** please see their website at: http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx

⁴² Planning and good communication is needed in advance, but many decisions can only be made in light of actual circumstances. No one can envision all possible circumstances, nor be certain how they would actually want to respond to future events. People often have a very different perspective of treatment options when they actually are sick, then they had years before from the perspective of perfect health. Hence an **advance directive** can bind health providers to treatment options a patient would no longer desire, or would not want given unforeseen particular circumstances, not outlined in the document. A **power of attorney for personal/medical care** is a very effective way to address these concerns, should a patient no longer be competent to make decisions themselves. Presupposed is good **ongoing communication** of one's beliefs, values and desires, with one's attorney for personal care.

Definition of Advanced Care Planning: (Canadian Hospice Palliative Care Association)
http://www.ubccpd.ca/_shared/assets/hanvey_20103727.pdf

"Advanced Care Planning (ACP) is a process of reflection and communication in which a person with decision-making capacity considers options about their future health and/or personal care in the event that they become incapable of consenting to or refusing treatment or other care. Through this process a person identifies what his/her wishes are. The process may involve discussions with healthcare providers and family and friends. Advance Care

Planning involves making choices about end-of-life health care based on a person's priorities, beliefs and values and sharing his or her wishes. It is therefore:

- A process of reflection and communication about values, beliefs and goals of care.
- A process of planning for a time when a person cannot make their own medical decisions.
- A process that involves discussions with healthcare professionals and significant others.
- A process that may result in an advance directive.”

**The Committee notes with interest the Canadian Hospice Palliative Care Association
National Advance Care Planning Day:**

The Canadian Hospice Palliative Care Association has established a **Canadian ‘National Advance Care Planning Day/Campaign.’** This campaign provides an annual opportunity for individuals to discuss their wishes with family, friends and health care professionals while raising overall awareness of the importance of advance care planning. The ACP day will launch on **April 12, 2011**, and will help organizations and individuals to promote ACP in their communities. There will be a variety of resources and tools available that organizations and individuals can use to facilitate ACP in their communities. The National Advance Care Planning Day will be an annual reminder that Canadians need to discuss health care choices with family, friends and the health care team. It will result in an increased awareness among professionals and the public across Canada about the importance of discussing end of life wishes.

For more information contact:

Canadian Hospice Palliative Care Association
Annex B, Saint-Vincent Hospital
60 Cambridge Street North
Ottawa, ON K1R 7A5
Tel: 613-241-3663 or 1-800-668-2785

Fax: 613-241-3986

Email: info@chpca.net

⁴³ Dr. Romyne Gallagher sets out 6 principals to improve patient comprehension.

- a) Slow down when speaking to patients.
- b) Use plain, non-medical language.
- c) Show or draw pictures – a visual picture with an explanation is best.
- d) Limit the amount of information provided and repeat it.
- e) Confirm that patients understand by asking them to repeat instructions to you.
- f) Be open to patients asking questions.

In addition Dr. Gallagher suggests that doctors “look for information pamphlets that provide essential information only, and are written at a grade 6 level. Ideally, before using it in your office present it to a few patients to test read it for you and explain what it says. Look on the Internet for videos or diagrams that can be used with an explanation.”

Dr. Romyne Gallagher, “How to improve our patient’s health literacy” BC Medical Journal (2008) Vol. 50, no. 9, p.525-526.

⁴⁴ **“Medicine is a science based model emphasizing disease, pathology, pharmacare, reductionism, and objectification. While science based thinkers offer their own versions of compassion – it is not their strength. Science based thinkers are trained not to feel too deeply, and to think reductively. Medicine’s emphasis eventually rests in their comfort zone of physical pain and disease management. Both are often accomplished with pharmaceuticals. Canadian development of palliative care speaks to medicine’s primacy. Progressively, since palliative medicine (rather than palliative care) funding came in, we have seen a broadening of the billing of medicine to include many of the skill sets of other disciplines. The costs of palliative medicine rather**

than inter-professional palliative care teams, is significantly higher. Physician billing for what others do must make end of life care more expensive than need be. That said no inter-professional model wants to work without medicine. Inter-professionalism includes medicine. Yet too often when medicine agrees to a model of inter-professionalism it means physicians speaking to other physicians. If you want good compassionate care, fund the disciplines that are family based to balance out more medicine.” Dr. Michelle Chaban, University of Toronto

Dr. Michelle Chaban is a professor of Social Work at the University of Toronto, a Thanatologist, and a long time practitioner of palliative care in the interdisciplinary team context. This quote is from her written submission to the Parliamentary Committee, supplementing her oral presentation October 26, 2010.

It should be noted that a family and inter-professional team model, to work, would require legal changes. Under the present practice of the health system it is the doctor and health facility that is liable to be sued if something goes wrong. **As long as doctors are worried about litigation they cannot be fully engaged in an inter-professional team.** Palliative care doctors do this better than other specialties but the risks for them are still there in ways that social workers, nurses, chaplains, etc. do not have. **Laws of litigation need to be changed to safeguard doctors from prosecution in performing recognized and approved approaches to effective pain and symptom control.** Until that happens, the buck stops with the doctor. Why? Because they have the best insurance to protect themselves -- hospitals are sued for the same reason. A nurse or social worker does not have that kind of liability insurance.

⁴⁵ See Navcare website: http://www.navcare.org/navCare_website_Oct_2009/HOME.html

⁴⁶ Rootman, I Gordon-El-Bihbey, D. A Vision for a Health Literate Canada: Report of the Expert Panel on Health Literacy. Canadian Public Health Association, 2008

⁴⁷ Dr. Gordon Self presented before the Committee in both Ottawa and Edmonton. These insights come from part of an ongoing correspondence on the nature of Spiritual care of the vulnerable. For more information on this topic see:

[Professional Chaplaincy: Its Role and Importance in Healthcare](http://www.cappe.org/publications/whitepaper/index.html)

<http://www.cappe.org/publications/whitepaper/index.html>

The Pallium Project

http://www.cappe.org/dacum/download/Pallium_DACUM_HPCSpiritCarePro_March2005FINALA.pdf

⁴⁸ The Committee is deeply indebted to the work of Holly Prince and Dr. Mary Lou Kelly from the Centre for Education and Research on Aging and Health (CERAH) at Lakehead University in Thunder Bay. Their input both oral and written on First Nations as well as rural palliative care delivery was invaluable.

⁴⁹ Submission to the Committee p.6

⁵⁰ Submission to the Committee p.11-12

⁵¹ **First Nations Action Plan on Continuing Care**, June 2005, p.8. Document archived on the web at: <http://64.26.129.156/cmslib/general/CCAP.pdf>

⁵² Dr. Mary Lou Kelly, “Developing Rural Communities’ Capacity for Palliative Care: a Conceptual Model” Journal of palliative Care (2007) 23(3):143

⁵³ Quoted from the Submission on Rural palliative care delivery by Dr. Mary Lou Kelly, and Alesha Gaudet from the Centre for Education and Research on Aging and Health, CERAH – Lakehead University, Thunder Bay Ontario, p. 9.

⁵⁴ *ibid.* p. 10.

⁵⁵ *Ibid.* p. 10.

⁵⁶ Ibid. P. 11.

⁵⁷ Submission of the CANADIAN CRITICAL CARE SOCIETY, by Dr. James Downar, Dr. Valerie Schulz, and Dr. John Granton. Received: January 18, 2011, p.1.

⁵⁸ Ibid. P.6.

⁵⁹ **“Birth and death are certainties for all of us. However, our healthcare system is far better adapted to birth than death. Canadians require an integrated palliative care program to address our psychological, physical and spiritual needs as we age or move through the natural progression of a terminal illness. We hope that our recommendations will help to bridge the gaps in a comprehensive palliative care model that has failed our patients and contributed to the strain on our acute care resources.”** Canadian Critical Care Society p.10.

⁶⁰ From the written submission of Dr. Margaret Somerville to the Committee.

⁶¹ Chronic pain can result from injury or illness as well as be a symptom of many conditions.

These conditions include fibromyalgia which affects 1.2 million Canadians, arthritis which affects 4.5 million Canadians and neuropathic pain which affects one million Canadians. Over half (56 per cent) of people living with chronic pain symptoms said they were frustrated that they have yet to find a solution that works for them and 53 per cent felt that they receive conflicting information from healthcare professionals. **Press release of the Canadian Pain Coalition** http://www.canadianpaincoalition.ca/media/report_on_pain_media_release_final_en.pdf re: *The Report on Pain* commissioned by the Canadian Pain Coalition, with support from Pfizer Canada Inc., released January 10, 2011

⁶² Tang, N. And C. Crane, “Suicidality in chronic pain: review of the prevalence, risk factors and psychological links.” Psychological Medicine. (2006) 36: 575-586

⁶³ Costs due to lost work days, reduced productivity and job loss would be several times that of health care costs, with the Canadian Pain Coalition estimating these costs at \$37 billion per year. Schopflocher, D., R. Jovey et.al., “The Burden of Pain in Canada, results of a Nanos Survey.” Pain Research and Management Journal of the Canadian Pain Society (2010) -- In Press

⁶⁴ Phillips, C. J. and D. Schopflocher “The Economics of Chronic Pain.” Health Policy Perspectives on Chronic Pain. (2008) S. Rashiq, P. Taenzer and D. Schopflocher. UK, Wiley Press.

⁶⁵ Watt-Watson, J.B. Stevens, et al, “Impact of preoperative education on pain outcomes after coronary artery bypass graft surgery.” Pain (2004) 109: 73-85

⁶⁶ Frank Brennan, D.B Carr, Michael Cousins, “Pain Management : A Fundamental Human Right”, Pain Medicine (2007) 105(1): 205-221

⁶⁷ Watt-Watson, J.B. Stevens, et al, “Impact of preoperative education on pain outcomes after coronary artery bypass graft surgery.” Pain (2004) 109: 73-85 and Watt-Watson, J., M. McGillon, et al, “Prevalence, characteristics and risk factors of persistent post-operative pain after cardiac surgery.” (2010) World Congress on Pain Montreal, Quebec

⁶⁸ Liebeskind, J.C., “Pain can kill”, Pain (1991) 44: 3-4

⁶⁹ Families of those is severe pain grieve their own losses, and experience anger related to their loved one’s pain. Children grieve the “absence” of their parent, who may no longer be able to hold them, or who may have grown emotionally distant, sapped of affective energy through their struggle to cope with the pain.

⁷⁰ Watt-Watson, McGillion et al. "A survey of pre-licensure pain curricula in health science faculties in Canadian universities." Pain Research and Management (2009) 14(6): 439-444. [Quoted in Canadian Pain Society Submission]

⁷¹ Dr. Chitra Chopra president of the Montreal Lakeshore University Women's Club spoke to the MPs at the Montreal round table December 17, 2010, of the need to look at the selection process for medical students. Until recently marks was the sole determinant of acceptance to medical school. High marks in sciences and math, while important; does not necessarily predispose the student to empathy. "It is time to begin looking at characteristics of medical school applicants beyond marks. The personality characteristics necessary for empathetic, holistic approaches to medicine cannot be learned. Empathy has its roots in the personality and character of the prospective doctor."

⁷² Australia was the first country to develop a National Pain Strategy, published in March of 2010. This detailed 100 page document could provide a model as we develop our own. <http://www.painsummit.org.au/strategy/Strategy-NPS.pdf>)

⁷³ see: Appendix # 5

⁷⁴ On the assessment of pain in the elderly see: Hadjistavropoulos T, Herr K, Turk DC, et al. "An interdisciplinary expert consensus statement on assessment of pain in older persons." The Clinical Journal of Pain. (2007); 23:S1-43. On management of pain see: **American Geriatrics Society Panel on Persistent Pain in Older Persons**. "Clinical practice guidelines: The Management of persistent pain in older persons." Journal of the American Geriatrics Society. (2002); 50:S205-24. A more recent article would be Hadjistavropoulos T, Marchildon G.P., Fine P.G., et al. "Transforming Long-Term Care Pain Management in North America: The Policy-Clinical Interface." Pain Medicine. (2009); 10(3):506-520

⁷⁵ http://www.iasp-in.org/Content/NavigationMenu/InternationalPainSummit/2010Program/Program_09162010.pdf
See: Appendix # 4 for the full text of the Declaration of Montreal. (First International Pain Summit May 3, 2010)

⁷⁶ Professor Harald Breivik of the **WHO** states:
"Chronic pain is one of the most underestimated health care problems in the world today, causing major consequences for the quality of life of the sufferer and a major burden on the health care system in the Western world. We believe chronic pain is a disease in its own right."
Quote taken from Statistics Canada Article by Pamela L. Ramage-Morin "Chronic Pain in Canadian Seniors" February, 2008 <http://www.statcan.gc.ca/pub/82-003-x/2008001/article/10514-eng.pdf>
Accessed January 13, 2011.

⁷⁷ Submission to the Montreal Round table December 17, 2010

⁷⁸ Special rapporteurs on the question of torture and the right of everyone to the highest attainable standard of physical and mental health. Letter to Mr. D. Best, vice-chairperson of the commission on narcotic drugs. Dec. 10, 2008.
Available at: <http://www.ihra.net/Assets/1384/1/SpecialRapporteursLettertoCND012009.pdf>.

For human rights texts and analysis, related to palliative care see: L. Gwyther, F. Brennan, and R. Harding, "Advancing Palliative Care as a Human Right". Journal of Pain and Symptom Management (2009) 38(5):767-774

⁷⁹ UN Human Rights Council. Statement by Paul Hunt, special rapporteur on the right of everyone to the highest attainable standard of physical and mental health. 2008. Available from http://www.hospicecare.com/resources/pain_pallcare_hr/list.html. Accessed January 15, 2011.

⁸⁰ Committee on Economic, Social and Cultural Rights. General comment no.14. Twenty-second session. Geneva, April 25-May 12, 2000. Available from: <http://www.unhchr.ch/html/menu2/6/cescr.htm>. or at: [http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/40d009901358b0e2c1256915005090be?Opendocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/40d009901358b0e2c1256915005090be?Opendocument)

⁸¹ Ibid.

⁸² Council of Europe. Recommendation (2003)24 of the committee of ministers to member states on the organisation of palliative care and explanatory memorandum. Was available from:

[http://www.coe.int/T/E/Social_Cohesion/Health/Recommendations/Rec\(2003\)24.asp](http://www.coe.int/T/E/Social_Cohesion/Health/Recommendations/Rec(2003)24.asp).

(Link not working at the moment) Quoted by: L. Gwyther, F. Brennan, and R. Harding, “Advancing Palliative Care as a Human Right”. *Journal of Pain and Symptom Management* (2009) 38(5):767-774

⁸³ **Recommendation 1418 (1999) Protection of the human rights and dignity of the terminally ill and the dying** (Extract from the Official Gazette of the Council of Europe – June 1999) Parliamentary Assembly of the Council of Europe The full document can be accessed at:

http://www.hospicecare.com/resources/pain_pallcare_hr/docs/recommendation_council_of_europe_1999.pdf

⁸⁴ **John Peters Humphrey 1905 to 1995**, <http://humanrightsmuseum.ca/exhibits/jph>

⁸⁵ Dr. Harvey Chochinov, Winnipeg, Manitoba – Address to the Standing Committee on Social affairs, Science and Technology. **Quality end-of-life care: The Right of every Canadian**. Ottawa, ON: Senate of Canada 2000. This final report was an update of the report of the Special Senate Committee on Euthanasia and Assisted Suicide which issued **Of Life and Death**, in 1995.

⁸⁶ Dr. Yude Henteleff Q.C. is a senior partner at the Winnipeg law firm Pitblado LLP. Specializing in corporate and estate law, Dr. Henteleff also has extensive experience in human rights law, especially as related to disability law, rights of children with intellectual disabilities, and more recently palliative care.

⁸⁷ Henteleff submission p. 11.

⁸⁸ Canadian Nurses Association, A National Approach to Home and Community Care: Through the Lens of the Canada Health Act, March 2000, p. 15.

⁸⁹ Henteleff submission p. 8.

⁹⁰ Henteleff submission p.9.

⁹¹ Miller, J. and Lombardi, T. (1991) “The Nursing home without walls”, in: J. Miller (ed.) Community-based long term care: Innovative models. Newbury Park, CA: Sage Publications, p.138.

⁹² Paul, Sinclair, (2007) Rethinking Palliative Care: A Social Role Valorisation approach. Bristol, U.K.: The Policy Press, University of Bristol. p.170.

⁹³ Ibid. Miller, J. and Lombardi, T. (1991) p.147.

⁹⁴ Paul, Sinclair, (2007) Rethinking Palliative Care: A Social Role Valorisation approach. Bristol, U.K.: The Policy Press, University of Bristol. p.171.

⁹⁵ The personal testimony of Jakki Jeffs, about her experiences, during her mother’s death at home, surrounded by her children; is a powerful testimony to the importance of a strong home care system. The British home care system which provided care for her mother, really was compassionate care at its best, and is a powerful model to be emulated in Canada. From the submission of: Jakki Jeffs, Alliance for Life Ontario, Oct. 21, 2010.

⁹⁶ Presentation of the Canadian Home Care Association October 26, 2010

⁹⁷ Submission of the Victorian Order of Nurses November 2010, p.7.

⁹⁸ From the Submission of the Canadian Health Coalition, Oct. 2010, p.3.

⁹⁹ Canadian Healthcare Association, (2009) New Directions for Facility-Based Long Term Care. Ottawa, Ontario: CHA Press. P. 11.

¹⁰⁰ Ibid. P.24.

¹⁰¹ Susanne Staldegger is a recently retired health care aid from Mitchell Ontario. She is dedicating her retirement to advocacy on behalf of vulnerable patients in her local long term care facility. This quote is from Ms. Staldegger's e-mail correspondence with the Committee.

The Canadian Healthcare Association express similar concerns noting:

“Inadequate staffing has major implications for the preservation of dignity and quality of life, as well as the guarantee of adequate basic physical care for residents. An expert panel in the United States has recommended that 4.55 hours per resident day of total nursing time (which includes administrative nursing, direct and indirect care) is required (Kovner et al., 2002). Most Canadian long term care homes would fall far short of this standard.

Ontario doesn't have minimum staffing ratios, having abandoned them in 1995. New Brunswick has a model of funding for care staff based on 3.1 hours of care per resident. But New Brunswick doesn't simply assign a number. It is committed to a strong professional nursing presence in their homes by establishing that 2.5 of the assigned hours are based on a ratio of 20 percent RN, 40 percent licensed practical nurse (LPN) and 40 percent PSW. The balance is assigned to LPN Rehabilitation (0.08 hours per resident); clerical support for nursing (0.13 hours per resident) and PSW peak workload hours (0.39 hours per resident).

Low staffing correlates with inadequate operating budgets. Provincial long term care associations have repeatedly called for increased levels of government funding to improve staffing. Many long term care homes have identified that current levels of funding are insufficient to provide the actual amount of care and level of health service required by residents. It is no secret that in facility-based long term care there are not enough resources 'on the floor.'” Canadian Healthcare Association, (2009) New Directions for Facility-Based Long Term Care. Ottawa, Ontario: CHA Press. P.95.

¹⁰² BC Ombudsperson Kim Carter issued her 1st report on the state of Long term care in B.C. in December 2009. **The Best of Care: Getting it Right for seniors in British Columbia (Part 1)**. This preliminary 60 page report identified serious concerns including: a) inadequate access to information b) lack of available and appropriately trained staff c) inadequate personal care d) poor quality food e) long delays in responding to call buttons f) long delays in help with going to the washroom g) long delays in changing soiled diapers and linens h) inadequate laundry services i) errors in dispensing medications j) inadequate complaint resolution mechanisms k) inadequate recreational and therapeutic activities l) inadequate inspections by provincial regulators m) inadequate information on the quality of various residences The report can be accessed at: http://www.heu.org/~DOCUMENTS/2010%20seniors/Ombudsman%20Report_The%20Best%20of%20Care_1.pdf

It should be noted that the BC Ombudsperson continues to investigate. “Part II of the report is broader in scope. It deals with general home and community care issues, as well as home support, assisted living and additional aspects of residential care. This investigation has become one of the largest that the Ombudsperson's office has ever undertaken. ... The investigation process has included the analysis of a large volume of documents obtained from the authorities, as well as meetings and consultations with the health ministries and health authorities, individual seniors and their families, advocacy groups, academics, service providers, facility operators, unions and professional associations. The public input received through the questionnaire that was posted on the Ombudsperson's website has been an invaluable aid to the investigation. The systemic team also visited 50 individual residential care and assisted living facilities.” August 24, 2010 update on investigative process. <http://www.ombudsman.bc.ca/seniors/seniors-care-investigation/update-status-of-ombudspersons-investigation-of-seniors-care-issues>

Similarly the Ontario Ombudsman launched an investigation of the Ontario Ministry of Health and Long term Care in relation to its oversight of LTC residences.

“TORONTO (December 21, 2010) – Ontario Ombudsman André Marin today released his findings in his investigation of the province’s monitoring of long-term care homes. The probe identified several serious systemic problems that the Ministry of Health and Long-Term Care is working to correct, Mr. Marin said.

The extensive investigation, conducted by the Special Ombudsman Response Team, was launched in July 2008 after the Ombudsman received more than 100 complaints (a further 450 complaints were received after the investigation was announced). During and after the investigation, “significant organizational transition” occurred in the Ministry with respect to the monitoring system, Mr. Marin noted. Among other things, it opted to adopt entirely new “quality indicator” methodology in early 2009, while regulations under the new Long Term Care Homes Act, 2007 were being developed. The Act and regulations did not come into effect until July 1, 2010, and the Ministry’s reform process is ongoing.

The Ombudsman identified four areas of concern in his letter:

1. The standards being used to monitor long-term care homes were inconsistently interpreted and applied. With 450 different criteria to check, ranging from minor to serious, the Ministry’s compliance staff were often overwhelmed, the Ombudsman found. Largely due to inadequate and inconsistent training of staff, serious deficiencies tended to be lumped in with less serious ones and follow-up was spotty, as was enforcement. “Inconsistency in the application of standards can result in dangerous situations continuing unchecked,” Mr. Marin warned the Ministry.

2. The Ministry failed to ensure the timely conduct of inspections. Some facilities went for 18 months without follow-up inspections after problems were identified, and, due to a lack of specialists such as environmental health or dietary advisors, several homes “had not seen a specialist advisor in more than 15 years,” the Ombudsman reported.

3. The complaint investigation process lacked rigor and transparency. The call centre handling complaints about resident care provided sketchy and at times inaccurate information and the Ministry routinely referred complainants back to the homes, Ombudsman investigators were told. Residents and family members who complained about conditions or treatment in homes feared reprisals – some “were threatened with being banned from the home,” Mr. Marin said. Investigations of complaints were often delayed, less than thorough, and complainants were given little information about the evidence gathered or the basis for any findings.

4. The public reporting of compliance findings was inadequate. The Ministry posted inspection data on its website, but it was incomplete, practically incomprehensible and grossly outdated, the Ombudsman said. “All that was available was a partial, incomplete and, at times, inaccurate snapshot of compliance.” The results of specialty inspections were not even included, meaning “serious issues discovered during specialty reviews remain shielded from public knowledge,” he wrote, noting that similar websites in other jurisdictions, such as those in Florida and the U.K., were far superior and more transparent. Press release from the office of the Ombudsman of Ontario (Dec. 21, 2010): <http://www.ombudsman.on.ca/en/media/press-releases/2010/ombudsman-finds-delays-inconsistencies-and-lack-of-transparency-in-monitoring-of-long-term-care-homes.aspx>

A 30 page summary of his findings can be accessed at:

<http://www.ombudsman.on.ca/media/161447/ltc%20for%20web-en.pdf>

While the Ontario investigation focused more directly on the Ontario Ministry of health and problems in investigation and regulation, problems were remarkably similar to B.C.

¹⁰³ The name of the LTC home and hospital were excised by the committee to protect the identity of the patient.

¹⁰⁴ E-mail correspondence to the Committee Sept. 2010

“Research shows that the level of staffing in a care facility has a direct correlation with positive outcome measures and quality care,” expressed Ed Helfrich, CEO of the British Columbia Care Providers Association. “We know a facility with six care aides per shift cannot provide comparable care to a similar site with 10 care aides per shift” (BCCPA, 2009).” Canadian Healthcare Association, (2009) New Directions for Facility-Based Long Term Care. Ottawa, Ontario: CHA Press. P.95.

¹⁰⁵ From an e-mail submission September 17, 2010: to the parliamentary Committee; from Mr. Philip Edwards, Toronto Ontario. Submission was sent in response to a web story asking for submissions to the Committee by CARP. (Canadian Association of Retired Persons)

“A cross-sectional survey of 426 directors of care (known in some other jurisdictions as directors of nursing) assessed the current practice of end-of-life care in Ontario long term care homes. Staffing levels were viewed by a majority of the respondents as being inadequate to provide quality end-of-life care (Brazil et al., 2006b). A similar survey was completed by 275 medical directors representing 302 long term care homes in Ontario with identical results. Most medical directors (67.1%) reported insufficient staffing levels as an impediment to the provision of palliative care. Further barriers to effective end-of-life care included the heavy time commitment required and a lack of needed equipment (Brazil et al., 2006a). p.113.

Health care professionals have historically recognized the need for increased education in palliative care and have expressed a lack of competence in the delivery of end-of-life care. In spite of the emergence of palliative care leading practices and advances in pain and symptom management, front line staff concur that there is still a need for more training in palliative care (Kortes- Miller et al., 2007). A strong palliative care approach can be realized through committed leadership, complete staff and management involvement in decision-making, and implementing changes in manageable segments (Peacock, 2008).

Long term care homes should become palliative care centers of excellence given that 39% of all deaths occur in facility-based long term care in Canada and there is a growing preference among residents to remain there among family and friends during their last days rather than being transferred to a hospital.” (p.114.) Canadian Healthcare Association, (2009) New Directions for Facility-Based Long Term Care. Ottawa, Ontario: CHA Press.

¹⁰⁶ This tragic story comes from e-mail correspondence, following the Guelph Ontario Round table Sept. 17, 2010.

“George Lattery, Mayor of Strathmore, expressed concern in the *Calgary Herald* that couples have been separated and are living in facilities in different communities because of the local shortage of long term care beds. (2009)” Canadian Healthcare Association, (2009) New Directions for Facility-Based Long Term Care. Ottawa, Ontario: CHA Press. P.67.

¹⁰⁷This e-mail submission to the Parliamentary Committee was sent by Anne Thomlinson, September 27, 2010. The problem identified by Anne Thomlinson in terms of movement between health regions in the same province becomes even more acute between provinces.

“Canadians are not free to move to their location of choice for long term care services, should they choose, because provincial or territorial residency requirements and waiting periods vary considerably. This becomes an issue of the portability of services. A province cannot be expected to open its doors indiscriminately to individuals seeking facility-based long term care. But there should be reasonable and humane provisions for the transfer of citizens across jurisdictional boundaries when care is needed. If federal funding of facility-based long term care was linked to compliance with pan-Canadian objectives or principles such as reciprocity, residents could move to a long term care home in another province, pay the local accommodation fee, and be reunited with family. Currently, residency requirements for admission to facility-based long term care cause unnecessary stress on Canadian families.” Canadian Healthcare Association, (2009) New Directions for Facility-Based Long Term Care. Ottawa, Ontario: CHA Press. P.114.

¹⁰⁸ Guelph Round table Sept. 17, 2010.

¹⁰⁹ From the September 22, 2010, letter of Mr. Christopher E. Henry, Guelph, Ontario, to the Parliamentary Committee on Palliative and Compassionate Care.

¹¹⁰ Canadian Health Coalition brief to the parliamentary Committee p. 7.

“Long term care workers know there is a gap between the care they want to provide, and the care they can give. Low levels of funding, staff shortage, poor working conditions, pay inequities and profit taking have created a human resources crisis in the LTC sector. ... This sector has high rates of staff turnover as does the home care sector. The reasons are similar: low pay and benefits, onerous workloads, insufficient time for needed care, no access to decision-making, on-the-job injury, lack of access to on-the-job education and training, and difficult work schedules. Front line workers bear the brunt of the frustration and anger of care recipients who know they need and deserve better care.” *ibid.*

¹¹¹ Canadian Healthcare Association, (2009) New Directions for Facility-Based Long Term Care. Ottawa, Ontario: CHA Press. (p. 95-96)

¹¹² The Canadian Medical Association in their 2010 report Health Care Transformation in Canada: Change that works, Care that Lasts. recommend:

“Construction should begin immediately on additional long-term care facilities. With the senior population projected to increase to around 24% of the population by 2031, and with 3.5% of seniors currently living in these facilities, in order to simply maintain the same occupancy rates, we will need roughly 2,500 additional homes by then. The Building Canada Fund is an ideal source of initial infrastructure funding.” (p.18)

¹¹³ BC Care Providers Association, Response to BC Ombudsperson’s First Report on Seniors Care, February 2010 <http://www.bccare.ca/pdf/2010-Feb%20Response%20to%20Ombudsman's%20Report%20.pdf>

“Ensure Adequate and Sustainable Funding for Facility-based Long Term Care. The federal government must show leadership and establish a Facility-based Long Term Care Fund. The precedent has been established with the federal government directing funding to the provinces to address common priorities through the Infoway Fund in 2001, the Primary Health Care Transition Fund in 2000 and the Health Resources Fund in 1966. Additional federal funding must be linked to pan-Canadian principles to ensure Canadians have access to comparable facility-based long term care.”Canadian Healthcare Association, (2009) New Directions for Facility-Based Long Term Care. Ottawa, Ontario: CHA Press. (p.119)

¹¹⁴ *Ibid.* p.124-125

¹¹⁵ In a 2006 Pollara survey, one-quarter (26%) of Canadians said they had cared for a family member or close friend with a serious health problem in the preceding 12 months, with 22% of these people missing one or more months of work and 41% using personal savings.
Pollara. (2006). Health Care in Canada Survey. www.hcic-sssc.ca

¹¹⁶ Statistics Canada, *General Social Survey. Cycle 16: Aging and Social Support* (Ottawa, Ont.: Statistics Canada, 2002).

¹¹⁷ 4-5 million is the estimate of the Canadian Caregiver Coalition

There are at least 2.85 million Canadians providing care for a family member with long-term health problems (*Cranswick, K. 1997 "Canada's Caregivers," Canadian Social Trend*). As this statistic is derived from 1997 data, it is believed that 4 - 5 million would more accurately reflect the number of caregivers today. <http://www.ccc-ccan.ca/content.php?doc=43>

¹¹⁸ M. J. Hollander et al., “Who Cares and How Much?,” *Health Care Quarterly* 12, 2 (2009): pp. 42–49.

¹¹⁹ More than one third of caregivers report extra expenses due to their caregiving responsibilities (*Cranswick, K. 2003, General Social Survey, Cycle 16: caring for an aging society*). Two-thirds of these caregivers are spending more than \$100 per month on caregiving (*Health Canada 2002, National Profile of Family Caregivers in Canada - Final Report*). This is conservatively translated to an annual cost to Canadians of \$80 million. <http://www.ccc-ccan.ca/content.php?doc=43>

¹²⁰ Dumont S., Jacobs P., Turcotte V., Anderson D., Harel F. “*The trajectory of palliative care costs over the last 5 months of life: a Canadian longitudinal study.*” *Palliative Medicine*; 2009; 1-10.

Dumont S, Jacobs P, Fassbender K, et al. *Costs associated with resource utilization during the palliative phase of care: A Canadian perspective.* *Palliat Med* 2009; 23 (8):708-717.

¹²¹ 10th Annual Health Care in Canada Survey: A national survey of health care providers, managers, and the public, 2007

Dumont S, Turgeon J, Allard P, et al. *Caring for a loved one with advanced cancer: determinants of psychological distress in family caregivers.* *J Palliat Med* 2006;9:912-921.

¹²² Canadian Caregiver Coalition, *Caring for the Family Caregiver*, p.2.
<http://www.ccc-ccan.ca/media.php?mid=271>

¹²³ Caregivers provide more than 80 percent of care needed by individuals with ‘long-term conditions’ and it is estimated contribute more than \$5 billion of unpaid labour annually to the health care system (Fast, J., Niehaus, L., Eales, J., & Keating, N. 2002a, *A profile of Canadian chronic care providers*). The changing demographics and aging population are expected to place further burdens on caregivers. <http://www.ccc-ccan.ca/media.php?mid=124>

¹²⁴ “*Burden of home care borne by women*” *CMAJ-JMAC* (2003) 168(11): 1459
<http://www.cmaj.ca/cgi/reprint/168/11/1459>

¹²⁵ CanadianCancerSociety, *Success-stories*.P.3.
http://convio.cancer.ca/site/PageServer?pagename=GEN_CAN_fight_success_stories Accessed, Feb. 3, 2011

¹²⁶ CanadianCancerSociety, *Success-stories*.P.3.
http://convio.cancer.ca/site/PageServer?pagename=GEN_CAN_fight_success_stories Accessed, Feb. 3, 2011

¹²⁷ Ontario Ministry of Health and Long-Term Care, *Caring about Caregivers: Caring for the future of Ontario – Long-Range Scenario Planning Supporting Care giving into 2033*, Nov. 27, 2009. p. 9.

¹²⁸ Janice Keefe, Jacques Legare, Yves Carriere, “Developing New Strategies to Support Future Caregivers of Older Canadians with Disabilities: Projections of Need and their Policy Implications” *Canadian Public Policy* (2007) Vol. XXXIII, Supplement, p. S73

It is noteworthy that for the period from 2001 -2021 females aged 85 and over have fairly large numbers of children, hence in theory there should be enough care givers for most of this vulnerable group. “ **For the following period (2021-2051) the pressure on formal homecare services should increase as the baby boomers gradually join the oldest old, causing the proportion without surviving children to increase to 20% in 2031 (and 28% in 2051).**” Janice Keefe, Jacques Legare, Yves Carriere, “Developing New Strategies to Support Future Caregivers of the Aged in Canada: Projections of Need and their Policy Implications” (2005) *SEDAP Research Paper No. 140*, p. 4.

¹²⁹ Pat, Armstrong and Olga, Kits, *One Hundred Years of Caregiving*, Law Reform Commission of Canada, April 2001, p.16.

¹³⁰ A number of nations including Australia have passed Caregiver Recognition Acts. The *Australian Carer Recognition Bill* (2010) is an important example of this kind of legislation.
http://parlinfo.aph.gov.au/parlInfo/download/legislation/bills/r4450_adopted/toc_pdf/10205b01.pdf;fileType=application/pdf#search=%22carer%20recognition%20act%202010%22

“**The Bill creates a *Statement for Australia’s Carers* which includes ten key principles regarding carers and how they should be treated by Commonwealth public service agencies and their funded providers. However, the Bill does not establish carers’ rights or create legally enforceable obligations for carers, public service care agencies or associated providers.**” <http://www.aph.gov.au/library/pubs/bd/2010-11/11bd008.pdf> p.2.

While not creating enforceable rights, the Bill expresses the importance of informal care giving, and aspirational goals of how caregivers should be supported in this role.

¹³¹ Submission to the Parliamentary Committee Caledon Institute, Oct. 26, 2010, p. 3.

¹³² Health Canada (2002) National Profile of Family Caregivers in Canada, Ottawa www.hc-sc.gc.ca
“A significant proportion (44%) of caregivers are paying out-of-pocket costs to provide care to their family member, with the most common expenses being for transportation (81%), non-prescription medications (71%), medical supplies (54%), prescription medications (43%) and other equipment (41%). Four in ten report spending between \$100 and \$300 per month on such expenses, with another quarter (24%) spending in excess of \$300.” p. 5.

¹³³ Canadian cancer statistics 2010, Special topic: End-of-Life care, p.77 and Table 7.7, p.85.
http://www.cancer.ca/Canada-wide/About%20cancer/Cancer%20statistics/~/_media/CCS/Canada%20wide/Files%20List/English%20files%20head ing/pdf%20not%20in%20publications%20section/Canadian20Cancer20Statistics2020102020English.ashx

¹³⁴ Submission of Leucan : Association for Children with Cancer Annex #3 June 15, 2010
“Cancer in children represents 1% of all cancers in the general population. The presence of parents is essential in the administration of certain treatments such as chemotherapy due to risks involved. During the diagnosis period, the parents must be present. In the first six months, this required presence averages 45 to 60 days. During the treatment period, many children require hospitalization every three to four weeks, for four or five days each time. Treatment lasts one to three years. When children no longer respond to treatment, the presence of the parents is indispensable to the child in the terminal phase.

The diagnosis of cancer in a child is one of the worst possible sources of stress for parents. It is essential that the parents be able to maintain their psychological stability. They must be able to control their level of stress produced by the initial diagnosis, the decisions to be made, and the impact of these decisions on their family life and financial situation. The concentration of all of their energies on the sick child has a significant impact on the child’s siblings. The emotional load carried by each family member affected by the illness must therefore be taken into account. The duration of treatments and uncertainty with regard to prognosis most often transform this acute stress into chronic stress. Maintaining the ability to absorb professional or financial difficulties becomes practically impossible.” Ibid. p.10.

¹³⁵ Submission to Committee June 15, 2010
The story of Colleen Ruth, a story which is representative of the cancer struggles of so many young people and their families, is told powerfully in: Sharon Ruth, (2008) The Guinea Kid: The True Story of a Childhood Cancer Survivor. Kemptville, ON: North Grenville Press

For a poignant presentation on the need for support for the families of children with cancer see **“John’s Cause”** the story of little John Peyton diagnosed with Cancer Oct. 31st 2008 at the age of one. : http://www.youtube.com/watch?v=3AQIF_f7G7M This is a powerful presentation that needs to be watched by all Canadians.

¹³⁶ **“It is easy enough to believe that when your child has cancer that one parent will continue to work and the other will stay at the hospital/home and take care of the child. What about single parent families out there? How will they do it? Family dynamics are changing and we need to keep up. Also for the majority of families, (especially in rural areas) a cancer diagnosis means moving to another area which has a specialized children’s hospital for treatment. Financial worries put additional stress on families in their darkest days! Your life just got very expensive just to keep your child alive. EI benefits should be available to provide assistance. Let’s make these days a little easier on the parents of the children that will be diagnosed in the future.”** Cathy Peyton – mother of baby John Peyton (child cancer patient) – Labrador City NL

¹³⁷ Submission to the Committee October 26, 2010, p. 5.

¹³⁸ From correspondence with Toronto Gerontologist Dr. Tom Koch re: caregiver support July 6, 2010.

¹³⁹ Ontario Ministry of Health and Long-Term Care, Caring about Caregivers: Caring for the future of Ontario – Long-Range Scenario Planning Supporting Care giving into 2033, Nov. 27, 2009. p. 21

“We have an elephant in the room, and it is care giving of the elderly-in-need. Standing quietly now, this elephant is going to rebel against the load it has to carry, or simply collapse under the strain, and then-look out! There are not enough professional care providers, care facilities, or hospital beds to meet the growing demand as populations age throughout the developed world. Without the millions of dollars in care that is given so freely by family caregivers the system will collapse, but the strain is growing. It is time for the community, employers, and government to share the elephant's burden. The burden on family caregivers can only increase as the population ages. The good news is that most family caregivers want to care for their loved ones. The bad news is that extended periods of care giving are unsustainable without significant and meaningful support. The world has changed. Our economy has changed. Our families have changed. The ways that women work outside the home have changed. Women, who form the majority of caregivers, are having fewer children to support an ageing population. And never, in the history of mankind, have so many people lived to such a ripe, old age. Unfortunately, the load is going to get much heavier, with the number of persons over 65 doubling to 22 percent of our population by 2030. As the number of seniors increases and those seniors advance to ever greater years, the need to share the load will grow. Regardless of gender, the growth of care giving for seniors is no longer a role that can be borne alone. We need to figure out the best ways of sharing the elephant's heavy load before it collapses from exhaustion.” Marian Sherratt, Executive Director, Bermuda Council on Ageing October 23, 2007 THE ROYAL GAZETTE, Hamilton, Bermuda

¹⁴⁰ From correspondence with Toronto Gerontologist Dr. Tom Koch re: caregiver support July 6, 2010.

¹⁴¹ Sharon O'Brien, “Caregiver Burden and the Widower Effect: Caregiver’s Risk of Death Increases When Spouse is Hospitalized.” February 16, 2006 (Accessed Feb. 9, 2011) http://seniorliving.about.com/od/healthnutrition/a/caregiver_risk.htm
Nicholas A. Christakis, Paul D. Allison, “Mortality after the Hospitalization of a Spouse” New England Journal of Medicine. (2006) 354(7):719-30.

¹⁴² **“In aggregate, the caregivers reported poorer physical health and took more medications than non-caregivers. The study found a nine per cent greater risk of health problems in caregivers and a 23 per cent higher rate of stress hormones than for non-caregivers. Other results showed caregivers had poorer antibody production, a higher incidence of sleep problems, less adequate diets and more sedentary behaviour. The health impacts were greater for older caregivers. The authors suggested two possible explanations of their findings. Firstly, chronic stress and distress may lead to elevated stress hormones, primarily through the hypothalamic-pituitary and adrenal axis, causing repeated arousal and inefficient control of physiological responses. Secondly, distress may trigger risky health behaviours such as poor diet, sedentary behaviour and substance abuse. Individual differences and dispositions moderate the impacts of caregiving.”** (Vitaliano et al. 2003;2004)

Vitaliano P, Young H et al (2004) Is caregiving a risk factor for physical illness? *Current Directions in Psychological Science* vol 13(1) pp13-16

Vitaliano P, Zhang J et al (2003) Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, vol 129(6) pp946-972

“Older caregivers, people of low socioeconomic status, and those with limited support networks report poorer psychological and physical health than caregivers who are younger and have more economic and interpersonal resources. ... Outcomes have been linked to primary stressors, such as the duration and type of care provided and the functional and cognitive disabilities of the care recipient, as well as to secondary stressors, such as finances and family conflict. As a result of these stressors, the caregiver may experience effects such as psychological distress, impaired health habits, physiologic responses, psychiatric illness, physical illness, and even death.” Richard Schulz, and Paula R. Sherwood, “Physical and Mental Health Effects of Family Care giving: Adverse—and even positive—outcomes in a chronic stress experience.” American Journal of Nursing. (2008), 108(9) Supplement, p. 24.

¹⁴³ Lee, S. L., Colditz, G. A., Berkman, L. F., & Kawachi, I. (2003). Caregiving and risk of coronary heart disease in U.S. women: A prospective study. *American Journal of Preventive Medicine*, 24(2), 113–119.

¹⁴⁴ Ibid.

¹⁴⁵ The following is a composite sketch based on a number of submissions made to the committee. The facts are based on true cases, but the names are fictitious to protect people’s identities.

¹⁴⁶Quote is from an application to the Test Case Committee, of Legal Aid Ontario, in the possession of the Committee.

¹⁴⁷ The Australian House of Representatives Standing Committee on Family, Community, Housing and Youth, inquiry into the better support for carers issued its report **Who Cares...?** in April of 2009. With 15 hearings across the country and more than 1300 written submissions from both individuals and organizations the inquiry represents a massive initiative to understand better the needs of caregivers. <http://www.aph.gov.au/house/committee/fchy/carers/index.htm>

¹⁴⁸ CARP Submission to the House of Commons Standing Committee on Finance August 15, 2008 <http://www1.carp.ca/12-ATTACHMENT/Caregiver%20Strategy.pdf> p.1-2.

¹⁴⁹ From the letter of Jean Vanier to the Parliamentary Committee on Palliative and Compassionate Care: October. 15, 2010.

Part 2 -- A National Suicide Prevention Strategy:

¹⁵⁰Statistics Canada data found at: <http://www40.statcan.gc.ca/101/cst01/hlth66a-eng.htm>

Suicides and suicide rate, by sex and by age group (Both sexes no.)					
	2003	2004	2005	2006	2007
Both sexes					
number of suicides					
All ages¹	3,765	3,613	3,743	3,512	3,611
10 to 14	27	28	43	31	33
15 to 19	216	210	213	152	185
20 to 24	306	270	296	265	290
25 to 29	245	275	228	237	282
30 to 34	295	316	283	243	235
35 to 39	434	390	381	318	325
40 to 44	463	409	495	418	403
45 to 49	454	446	476	459	486
50 to 54	404	393	407	369	410

55 to 59	292	275	294	328	307
60 to 64	187	174	166	209	203
65 to 69	142	121	138	145	115
70 to 74	105	108	99	104	102
75 to 79	85	88	113	113	103
80 to 84	53	63	66	62	76
85 to 89	34	36	31	39	42
90 and older	23	11	13	20	14

1. "All ages" includes suicides of children under age 10 and suicides of persons of unknown age.
Source: Statistics Canada, CANSIM, table [102-0551](#) and Catalogue no. [84F0209X](#).
 Last modified: 2010-11-16.

¹⁵¹ Stéphanie Langlois and Peter Morrison, "Suicide Deaths and Attempts" [Health Reports](#), Statistics Canada, (2002) vol. 13, no. 2 p.20 <http://www.statcan.gc.ca/pub/11-008-x/2002002/article/6349-eng.pdf>

¹⁵² Ibid. p.21.

¹⁵³ "Each year, on average, 294 youth die by suicide. Suicide is the second leading cause of death for youth aged 10-24, following motor vehicle collisions. Although suicide rates for 10- to 19-year-olds have remained consistently below the overall suicide rates, suicides in this age group began to rise in the early 1960s and tripled by the late 1970s. In recent years, the rate for 15- to 19-year-olds has begun to approach the general population's rate of 13 per 100,000. Suicide rates for 10- to 14-year-olds have also increased, but remain below 2.5 per 100,000. Studies show a significant percentage of adolescents contemplate, plan or attempt suicide without seeking or receiving help. Males are less likely than females to seek help from any source. To put the issue of suicide in perspective, research shows that in Alberta, for every death by suicide:

- approximately 50 people will engage in some kind of suicidal behaviour, and
- at least 1,000 people will have thought of suicide at some point in their lives.

Taking all non-fatal suicidal behaviours and deaths by suicide together, the incidence of suicide becomes a significant public issue that requires everyone's involvement in prevention." Information from the Centre for Suicide Prevention

<http://ww3.suicideinfo.ca/youthatrisk/ForProfessionals/TrendsInYouthSuicide/tabid/710/Default.aspx>

Despite its growing significance, most Canadians are unaware of the problem of youth suicide, and its impact on families, schools and communities.

Your Life Counts, Canada's leading organization saving young people from the tragedy of suicide, found that: "83% of Canadians did not know that suicide is the second leading cause of death among our youth." Your Life Counts National Poll; Harris Decima, August, 2010. <http://www.yourlifecounts.org/>

¹⁵⁴ "Suicide rates are now five to seven times higher for First Nations youth than for non-aboriginal youth, according to Health Canada, and among Inuit youth, suicide rates are 11 times the national average. Some aboriginal bands have suicide rates over 800 times the national average." Am Johal – "Native Youth Suicides in Canada Reach Crisis Rate" IPS Inter Press Service, Vancouver, Dec. 12, 2007 (IPS) <http://ipsnews.net/news.asp?idnews=40448>

"In northern British Columbia, in the rural Hazelton region, the Wrinch Memorial Hospital has seen 111 suicide attempts since Jan. 1, 2007. There were also unreported suicide attempts, so the number is believed to

be much higher. In November, there were seven suicide attempts in one week alone.” Reported in December of 2007. (ibid).

¹⁵⁵ Chart sourced from: <http://fathersforlife.org/health/cansuic.htm>

Canadian Suicide Rates

Province	Sex	1950	1960	1970	1980	1990		
Newfoundland	Male	3.9	4.8	8.7	6.3	15.8	Graph	
	Female	0	0.5	0.8	0.4	4.5		
P.E.I.	Male	6.1	15.3	21.6	21.2	21.7	Graph	
	Female	0	0	0	1.6	0		
Nova Scotia	Male	10.5	11.6	16.0	20.8	21.7	Graph	
	Female	3.5	4.2	2.6	2.3	4.4		
New Brunswick	Male	9.6	7.4	8.3	20.5	19.6	Graph	
	Female	2.0	1.7	3.5	2.9	3.8		
Quebec	Male	5.2	7.7	13.3	23.1	27.2	Graph	
	Female	2.1	2.2	4.6	6.8	5.9		
Ontario	Male	13.6	13.4	16.2	18.9	14.1	Graph	
	Female	4.1	3.8	8.2	7.4	4.3		
Manitoba	Male	17.6	18.7	19.7	16.0	20.7	Graph	
	Female	2.7	3.4	5.9	7.7	5.2		
Saskatchewan	Male	12.4	14.3	18.2	24.9	24.9	Graph	
	Female	2.5	1.6	4.8	6.9	5.6		
Alberta	Male	14.0	15.5	20.1	26.7	25.7	Graph	Article
	Female	3.5	2.4	6.4	9.3	6.9		
British Columbia	Male	26.5	15.4	22.4	23.1	19.4	Graph	
	Female	9.2	4.6	9.6	6.7	6.2		
N.W.T.	Male	44.4	16.1	17.2	38.4	57.4	Graph	
	Female	14.3	0	0	0	7.6		
Yukon	Male	61.2	25.3	97.7	84.8	36.7	Graph	
	Female	0	0	51.2	9.5	0		

Source: Suicide in Canada (1994), Mental Health Division, Health Services Directorate, Health Canada Tables 2.1 and 2.2

A description of the report is available at <http://www.utoronto.ca/chp/hcu/families.html>

The full report is available as a PDF document at

<http://www.hc-sc.gc.ca/hppb/mentalhealth/problems.htm#Suicide>

It should be noted that while Quebec still has the highest suicide rate among the provinces, the rate of suicide dropped 32 % between 1999 and 2008. In 1999, Quebec had a high of 1,620 suicides, by 2008 this had dropped to 1,103, this according to the Institut national de santé publique du Québec. <http://www.theconcordian.com/suicide-rate-in-quebec-drops-32-per-cent-in-10-years-1.1121303> Quebec has concentrated intensely on suicide prevention efforts in the province, and has been showing significant progress. The Suicide rate among Quebec youths aged 15-19 has been reduced substantially decreasing by about 12 % per year between 1999 and 2008.

“Suicide should become unacceptable to society, in much the same way drunk driving has become unaccepted, where most "friends don't let friends drive drunk," said Herman-Lemelin, pointing to parallels between government action toward drunk driving in 1980s, and current actions toward dealing with suicide rates. The AQPS used this year's Suicide Prevention Week, which drew to a close Feb. 6, to set some new projects in motion. One such project, called "Ajouter ma voix," encourages Quebecers to help erase the stigma around suicide by signing the group's "declaration of solidarity," talking to neighbours, initiating fundraisers and, in essence, raising awareness. So far, over 6,000 people have signed up. Also helping spread the word last week was MusiquePlus. The Montreal-based television station gathered 50 young Quebec hip-hop artists to produce and record Désarmé jusqu'aux dents. The song denounces suicide and aims to spread knowledge about alternatives. This effort proves how far the province has come over the past decade, Herman-Lemelin said, noting that this amount of effort would not have happened 10 years ago. Quebec has over 33 helplines throughout the province, with one main line (1-866-APPELLE) that hooks callers up to a call centre in their area. Helplines are open to people experiencing thoughts of suicide, friends and family members concerned for a loved one, and to people who have lost someone to suicide. Quebec's 24-hour call centres have trained counsellors on hand to help during a crisis.”

Kathy Yuck, “Suicide rate in Quebec drops 32 per cent in 10 years: New programs will help province claw its way out from the highest rate in Canada” [The Concordian](http://www.theconcordian.com/suicide-rate-in-quebec-drops-32-per-cent-in-10-years-1.1121303) Feb. 9, 2010

<http://www.theconcordian.com/suicide-rate-in-quebec-drops-32-per-cent-in-10-years-1.1121303>

¹⁵⁶ Dr. Paul Links, “Suicide and survival After Daniel: a suicide survivor's tale”, *CMAJ* • August 24, 1999; 161 (4)

¹⁵⁷ **“Almost 4000 Canadians die by suicide each year, and many more—perhaps 100 times as many—deliberately harm themselves (1). In 1998–1999, 22 887 hospital discharges for suicide attempts or intentional self-inflicted injury were recorded (1). More than 90% of suicide victims are known to have one or more psychiatric disorders at the time of their death, so psychiatric disorders may be considered a necessary, although not sufficient, cause of suicide (2). Despite more than 100 years of study since the time of Durkheim’s seminal research, suicide continues to be a terrible tragedy that must disturb all psychiatrists.”**

Dr. Paul Links -- Arthur Sommer Rotenberg Chair in Suicide Studies and Professor, Department of Psychiatry, Faculty of Medicine, University of Toronto, Toronto, Ontario. *Can J Psychiatry*, Vol 51, No 3, March 2006

¹⁵⁸ **“Stigma**, in general terms, refers to a 'mark of shame or discredit' (Canadian Alliance on Mental Illness and Mental Health, 2000). For an individual who is being stigmatized, this translates into feelings of being negatively or unfairly differentiated because of a particular condition or state. Suicide-related stigma has its origins in powerful religious and legal sanctions and continues to be fuelled by societal misunderstandings about the nature of suicide (Arboleda-Flórez, 2001). Some of the long-standing beliefs about suicide include the idea that being suicidal is a sign of weakness, that suicide is sinful or immoral, and that if one is suicidal, he or she must be mentally ill (Domino and Leenaars, 1995). Research demonstrates that stigma leads to negative outcomes for the individuals affected, impacting both their physical and mental health. Despite the fact that effective interventions do exist, the stigma surrounding suicide often prevents people at risk from seeking assistance or openly communicating suicidal

thoughts or plans with service providers or family members and friends. In some cases, vulnerable and stigmatized individuals may come to view suicide as a solution, making stigma an important precipitating condition in their suicide (Arboleda-Flórez, 2003; Pompili et al, 2003; Rogers and Soyka, 2004). At the societal level, the stigma associated with suicide prohibits open discussion and a coordinated approach to solutions for the people who need them the most (Canadian Alliance of Mental Illness and Mental Health, 2000). Some researchers also argue that the uncomfortable feelings suicide engenders in laymen, professionals, and politicians may contribute to inadequate funding for research and prevention services, both historically and in the present day (US Department of Health and Human Services, 2001; Wasserman, 2004).”

Quoted from: Centre for Suicide Prevention, Alert # 62, July, 2006. <http://www.suicideinfo.ca/csp/assets/alert62.pdf>

¹⁵⁹ From testimony at the Suicide Prevention Hearing, Oct. 20, 2010, Ottawa Ontario.

¹⁶⁰ From the submission of Dr. Antoon Leenaars to the Round table in Windsor Ontario Sept. 8, 2010. p. 3-4.

“Suicide and Suicidal behaviour are multi-faceted events. There are biological, psychological, intrapsychic, interpersonal, cognitive, conscious and unconscious, sociological, cultural and philosophical/existential aspects in the event. Thus, suicide cannot be reduced to a single factor; this complexity dictates the necessity of parallel complexity of solutions.”

Dr. Antoon Leenaars, National Suicide Prevention Strategy and Canada: Researchers and All of Us Lecture presented at Research Day, Canadian Association for Suicide Prevention Conference, Ottawa, October 16-19, 2005. p.2.

¹⁶¹ The Royal Commission on Aboriginal People (1995). Choosing Life: Special report on suicide among aboriginal people. Ottawa: Supply and Services, Canada p.25.

¹⁶² **Cultural reproduction** is the transmission of existing cultural values and norms from generation to generation. Cultural reproduction refers to the mechanisms by which continuity of cultural experience is sustained across time. Cultural reproduction often results in social reproduction, or the process of transferring aspects of society (such as class) from generation to generation. (Glossary of Sociological Terms - School of Sociology and Anthropology - University of Canterbury - New Zealand, 1997)

¹⁶³ Dr. Antoon Leenaars, National Suicide Prevention Strategy and Canada: Researchers and All of Us Lecture presented at Research Day, Canadian Association for Suicide Prevention Conference, Ottawa, October 16-19, 2005. p.5.

¹⁶⁴ **By definition, public health is not about individual patients. Its focus is on dealing with diseases and with conditions and problems affecting health, and it aims to provide the maximum benefit for the largest number of people. This does not mean that public health ignores the care of individuals. Rather, the concern is to prevent health problems and to extend better care and safety to entire populations.**

The public health approach to any problem is interdisciplinary and science-based (1). It draws upon knowledge from many disciplines, including medicine, epidemiology, sociology, psychology, criminology, education and economics. This has allowed the field of public health to be innovative and responsive to a wide range of diseases, illnesses and injuries around the world.

The public health approach also emphasizes collective action. It has proved time and again that cooperative efforts from such diverse sectors as health, education, social services, justice and policy are necessary to solve what are usually assumed to be purely “medical” problems. Etienne Krug, Linda Dahlberg et al, World Report on Violence and Health. (2002) World Health Organization (WHO), p.3-4.

¹⁶⁵ Dr. Antoon Leenaars, National Suicide Prevention Strategy and Canada: Researchers and All of Us Lecture presented at Research Day, Canadian Association for Suicide Prevention Conference, Ottawa, October 16-19, 2005. p.10.

¹⁶⁶ Dr. David Satcher, “Suicide and Public Health” (1999) Public Health Reports March/April vol. 114, p. 198.

¹⁶⁷ Dr. Antoon Leenaars, “Effective Public Health Strategies in Suicide Prevention are Possible: A Selective Review of Recent Studies” *Clinical Neuropsychiatry* (2005) 2(1): pp.21-31. The quote was from p. 28.

See this important article: http://www.clinicalneuropsychiatry.org/pdf/04_leenaars.pdf

Data on media strategy and the dramatic reduction in suicide rates is found in:

Etzersdorfer E and Sonneck G (1998) “Preventing suicide by influencing mass- media reporting. The Viennese experience 1980-1996.” *Archives of Suicide Research* 4, pp. 67-74.

Etzersdorfer E, Voracek M, and Sonneck G (2001) “A dose-response relationship of imitational suicides with newspaper distribution.” *Australian and New Zealand Journal of Psychiatry* 35 p.251.

¹⁶⁸ Dr. Antoon Leenaars, “Effective Public Health Strategies in Suicide Prevention are Possible: A Selective Review of Recent Studies” *Clinical Neuropsychiatry* (2005) 2(1): p. 27-28.

See this important article: http://www.clinicalneuropsychiatry.org/pdf/04_leenaars.pdf

Wasserman D and Varnik A (1998). Suicide-preventive effects of *perestroika* in the former USSR: the role of alcohol restriction. *Acta Psychiatrica Scandinavica*.98, Suppl 394, 1-44.

Wassermann D, Varnik A, and Eklund G (1994). “Male suicides and alcohol consumption in the former USSR.” *Acta Psychiatrica Scandinavica*. 89, p.306-313.

Wasserman D, Värnik A, Eklund G. “Female Suicides and Alcohol Consumption during Perestroika in the former USSR.” *Acta Psychiatrica Scandinavica*. 1998;394(Supplement):26–33.

Wasserman Danuta, Värnik Airi. “Reliability of Statistics on Violent Death and Suicide in the Former USSR, 1970–1990.” *Acta Psychiatrica Scandinavica*. 1998;394(Supplement):34–41.

¹⁶⁹ **“Pesticide ingestion is one of the leading suicide methods. Worldwide, an estimated three million cases of pesticide poisoning occur every year, resulting in an excess of 250 000 deaths. This mortality, accounts for a substantial fraction of the 900 000 people who die by suicide every year. Reports suggest that it is particularly significant in rural areas, especially in some Asian countries. It is estimated that in the last decade between 60% and 90% of suicides in China, Malaysia, Sri Lanka, and Trinidad were due to pesticide ingestion. More recently, WHO has received reports of a growing number of suicides due to pesticide ingestion in many other countries in Asia, as well as in countries in Central and South America. WHO recommends control of access to pesticides, which are all too often easily accessible and stored without any precautions in most households of rural areas. Ongoing pilot studies indicate that interventions to control access to pesticides are effective and work better when integrated into more comprehensive community education programmes as well as pesticide management programmes. WHO advises that in places where pesticide poisoning is frequent, there is an urgent need to train and equip primary health care personnel to manage these cases.”**

“Pesticides are a leading suicide method”, 9 September 2006, Geneva - The World Health Organization (WHO)

<http://www.who.int/mediacentre/news/notes/2006/np24/en/index.html>

“Professor David Gunnell of the University’s Department of Social Medicine and colleagues from the South Asian Clinical Toxicology Research Collaboration in Sri Lanka found that Sri Lanka’s import restrictions on the most toxic pesticides were followed by marked reductions in suicide.

Between 1950 and 1995 suicide rates in Sri Lanka increased 8-fold to a peak of 47 per 100,000 in 1995. By 2005, rates had halved. The researchers investigated whether restrictions on the import and sales of the most highly toxic pesticides in 1995 and 1998 coincided with these reductions in suicide.

They found that 19,800 fewer suicides occurred in 1996-2005 compared with 1986-95. Other factors that affect suicide rates such as unemployment, alcohol misuse, divorce and war did not appear to be associated with these declines. Pesticide self-poisoning is thought to account for an estimated 300,000 deaths in Asia – over a third of the world’s suicides. Professor Gunnell said: “Changes in the availability of a commonly used

method of suicide may influence not only method-specific but also overall suicide rates. “Pesticides are readily available in most rural households in low income countries and are commonly used by young people who impulsively poison themselves in moments of crisis. Our research suggests that restricting the availability of toxic pesticides should be prioritised. We propose that other countries such as China and India where pesticide self-poisoning is a major health problem follow Sri Lanka’s example in comprehensively regulating pesticide imports and sales.” *ScienceDaily* Sep. 22, 2007 “Restricting Pesticides Could Greatly Reduce Suicide Rates Worldwide”, <http://www.sciencedaily.com/releases/2007/09/070918122124.htm>

¹⁷⁰ RCMP, *Research Summary Firearm Suicide*. p. 1. <http://www.rcmp-grc.gc.ca/cfp-pcaf/res-rec/suicide-eng.htm>

¹⁷¹ *ibid* p.1.

¹⁷² *ibid*. p.2.

¹⁷³ *ibid*. p.2

¹⁷⁴ *ibid*. p.2.

“The Department of Justice undertook a sophisticated statistical analysis of the 1977 legislation to assess the effects of the initiative on the incidence of firearms deaths. The exploratory and time series analyses suggested that the legislation has had a positive impact on the reduction of firearm suicides in Canada while the structural analysis did not. Independent assessments of the study conducted by academics suggested that the inclusion of different variables in the suicide analysis may have yielded a different result.”

Department of Justice Canada, (1996) *A Statistical Analysis of the Impacts of the 1977 Firearms Control Legislation*.

Carrington and Moyer, (1994) "Gun Control and Suicide in Ontario", *American Journal of Psychiatry*, 151:4, 606-608.

¹⁷⁵ Dr. Antoon Leenaars, (2005) “Effective Public Health Strategies in Suicide Prevention are Possible: A Selective Review of Recent Studies” *Clinical Neuropsychiatry*. 2(1), 25.

¹⁷⁶ *Ibid*. p.26

See: Leenaars A, Moksony F, Lester D, and Wenckstern S, (2003) “The impact of gun control (Bill C-51) on Suicide in Canada” *Death Studies* 27, 103-124.

¹⁷⁷ Dr. Richard Ramsay, “When will Canada Recognize Suicide as a Major Public Health Problem and Develop a National Suicide Prevention Strategy?” Canadian Association of Suicide Prevention (CASP), 11th Annual Conference, Vancouver, BC, 2000. p. 7.

¹⁷⁸ Diane Yackel as quoted from an address given to Senate Standing Committee on Social Affairs, Science and Technology. <http://www.suicideinfo.ca/csp/assets/ExcerptsStandingCommittee.pdf>

¹⁷⁹ For a short history of the Alberta conference and the subsequent UN document see: Dr. Richard Ramsey, *United Nations Impact on the United States National Suicide Prevention Strategy (NSPS)* Speech given to the American Association of Suicidology 34th annual conference, Atlanta Georgia, April 18-21, 2001. <http://www.livingworks.net/userfiles/file/20010421.pdf>

The UN document itself also contains some pertinent history of the Canadian involvement.

¹⁸⁰ Dr. Paul S. Links, president of the Canadian Association for Suicide Prevention has described Alberta as, “...a beacon for initiatives in suicide prevention and has impacted the development of suicide prevention strategies nation-wide and worldwide.” Quoted from the website *Suicide Prevention History*: <http://www.suicidepreventionhistory.com/> This website provides an important archival resource of documents pertaining to the history of suicide prevention in the province of Alberta, and is the most extensive project to preserve the history of suicide prevention efforts in the world.

¹⁸¹ Dr. Richard Ramsay, as quoted by Lauren Vogel in: “Canada suicide prevention efforts lagging, experts say” CMAJ (2011) 183(1):E27-E28 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3017278/>

¹⁸² *The CASP Blueprint for a Canadian National Suicide Prevention Strategy*. Second Edition, September 2009, p.4. <http://www.casp-acps.ca/Publications/blueprint%20final%20september.pdf>

¹⁸³ *The CASP Blueprint for a Canadian National Suicide Prevention Strategy*. Second Edition, September, 2009. p. 3. For a copy of the Blueprint see: <http://www.casp-acps.ca/Publications/blueprint%20final%20september.pdf>

¹⁸⁴ The United States Department of Health document, National Strategy for Suicide Prevention: Goals and Objectives for Action can be downloaded at: <http://store.samhsa.gov/shin/content/SMA01-3517/SMA01-3517.pdf>

¹⁸⁵ From Dr. Paul Links’ oral testimony to the Parliamentary Committee, Ottawa Suicide Prevention Hearing, October 20, 2010.

¹⁸⁶ Submission of Lynn Morgan to the Scarborough Round Table October 30, 2010.

¹⁸⁷ Quote of Dr. Heather Fiske taken from article “Suicide prevention is everybody’s business October 22, 2008. <http://www.flamboroughreview.com/news/article/214294>

¹⁸⁸ For a careful analysis of the effectiveness of national suicide prevention strategies in a number of countries see: Dr. Graham Martin and Dr. Andrew Page, *National Suicide Prevention Strategies, a Comparison* (2009) The University of Queensland. [http://www.health.gov.au/internet/mentalhealth/publishing.nsf/content/70A18138437EEA87CA2577B5007B7783/\\$File/NSPS%20%20-%20A%20Comparison-%20UQ.pdf](http://www.health.gov.au/internet/mentalhealth/publishing.nsf/content/70A18138437EEA87CA2577B5007B7783/$File/NSPS%20%20-%20A%20Comparison-%20UQ.pdf)

¹⁸⁹ Dr. Marnin Heisel is a research Psychologist affiliated with the department of Psychiatry at the University of Western Ontario in London. A specialist in mental health care and suicide prevention in the elderly patient, Dr. Heisel presented to the Committee in Ottawa October 20, 2010.

¹⁹⁰ From the testimony of Dr. Paul Links in Ottawa October 20, 2010.

¹⁹¹ Quotes in this section come from the testimony of Joan Seabrook in Ottawa October 20, 2010.

¹⁹² From the testimony of Rory Butler -*Your Life Counts* - in Ottawa October 20, 2010.

¹⁹³ From the testimony of Dr. Antoon Leenaars at the Windsor Round table September 8, 2010.

Part 3 – Elder Abuse: Canada’s Hidden Crime

¹⁹⁴ The quote is from the letter of resignation of Detective Steve Thomas from the Boulder Colorado Police Force August 6, 1996. Detective Thomas was one of the lead investigators in the Jon Benet Ramsay murder case, and resigned the Police Force because of intense political obstruction which prevented a fair investigation of the murder. The quote is highly applicable to elder abuse, our own hidden crime, which is too often allowed to continue due to the silence of Canadians, who are both uncomfortable thinking about abuse, and uncertain how to intervene to help the victims. Elder abuse is kept hidden in the dark corners of society, too heinous to think about. The time has come to shine a light on it, so that Canadian seniors can live their golden years free from fear and abuse. Det. Thomas’ letter of resignation can be accessed at: <http://www.documentingreality.com/forum/f181/resignation-letter-det-steve-thomas-8224/>

¹⁹⁵ Federal, Provincial, Territorial Elder abuse working forum, **Summary of Proceedings**. Vancouver , British Columbia, Nov. 8, 2007. p. 3. Accessed April 8, 2011 http://www.seniorsbc.ca/documents/pdf/fpt_elder_abuse_forum_2007_EN.pdf

¹⁹⁶ According to the 2004 General Social Survey in eight in ten violent incidents (82%) involving a lone accused, the senior victim stated knowing the perpetrator as a spouse, other family member, friend, acquaintance or other caregiver.

¹⁹⁷ Selina Lai. M.A., Community Mobilization Empowering Seniors Against Victimization --Elder Abuse and Policing Issues: A Review of the Literature. Submitted to: National Crime Prevention Centre of Canada, Public Safety Canada. p. 4.

¹⁹⁸ Statistics Canada, Family Violence in Canada: A Statistical Profile, January, 2011, p.27.

¹⁹⁹ Based on analysis, prepared for the National Seniors Council; August 2007. **Report of the National Seniors Council on Elder Abuse** November 2007 p.5.

Various earlier studies had indicated that between 4 and 8% of older adults in Canada (or approximately 157,000 to 393,000) are likely to experience one or more forms of abuse or neglect at some time. (1989 data)
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“Definitive data on the abuse of older adults is limited. Various studies indicate that between 4 and 8% of older adults in Canada (or approximately 157,000 to 393,000) are likely to experience one or more forms of abuse or neglect at some time. The rate may be higher among certain groups of older adults, such as those with cognitive disabilities, and those who are socially isolated. Fewer than one in five abuse situations involving older adults ever comes to the attention of authorities.”

Marie Beaulieu, Robert Gordon, Charmaine Spencer, **An Environmental Scan of Abuse and Neglect of older Adults in Canada: What’s Working and Why**, Report prepared for the Federal/Provincial/Territorial Committee of Officials (Seniors) September 2003

http://www.seniorscouncil.net/uploads/files/For_Service_Providers/Senior%20Abuse%20Enviromental%20Scan.pdf

It should be noted that prevalence increased from a high of 8% in 2003 to a high of 10% in 2007. As statistical gathering improves prevalence rates are found to be higher. In the United States for example the most recent prevalence study puts elder abuse rates at a high of 14.1%. This statistic is based on the largest scientific phone sample to date, some 6000 community dwelling adults aged 60 and older, identified through national random digit dialing. **“An estimated 14.1% of adults age 60 and older experienced physical, psychological, or sexual abuse; potential neglect; or financial exploitation in the past year.”** The study did not include self-neglect, nor did it include highly cognitively impaired individuals, factors which would have increased the prevalence rate still more.

For quote see: Report to the Chairman, Special Senate Committee on Aging, U.S. Senate, **Elder Justice: Stronger Federal Leadership could Enhance National Response to Elder Abuse**. March, 2011, p.9. Accessed March 18, 2011 <http://aging.senate.gov/events/hr230kb2.pdf>

The 14.1% prevalence rate is derived from Ron Acierno et al, **The National Elder Mistreatment Study**. National Institute of Justice, March 2009. Accessed March 18, 2011 <http://www.ncjrs.gov/pdffiles1/nij/grants/226456.pdf>

²⁰⁰ Elizabeth Podnieks et al. (1990) National Survey on Abuse of the Elderly in Canada: The Ryerson Study. Toronto: Ryerson Polytechnical Institute. The research for this study was conducted in 1989.

²⁰¹ On the HRSDC funded Defining and Measuring Project towards a national prevalence study on elder abuse, done by the National Initiative for the Care of the Elderly (NICE) see: <http://www.nicenet.ca/detail.aspx?menu=52&app=234&cat1=651&tp=2&1k=n0>

²⁰² “The National Survey on Abuse of the Elderly in Canada: The Ryerson Study, conducted in 1989 found that financial abuse was reported most often and accounted for over 50% of the documented elder abuse cases. The study estimated that at least 60,000 senior Canadians in private dwellings were victims of financial abuse.” **Health Canada, Financial Abuse of Seniors**. February, 1993. p. 2. http://www.phac-aspc.gc.ca/ncfv-cnivf/pdfs/age-finance_e.pdf

Accessed March 18, 2011.

Elizabeth Podnieks et al. (1990) National Survey on Abuse of the Elderly in Canada: The Ryerson Study. Toronto: Ryerson Polytechnical Institute.

It should be noted that Canada needs an up to date and in-depth prevalence study concerning elder abuse. 60,000 cases estimated in 1989 would likely have increased substantially by 2011. General consensus is that financial abuse has been on the rise; however, good statistics are required to quantify the extent of the problem.

²⁰³ Ibid. **National Survey on Abuse of the Elderly in Canada: The Ryerson Study**.

²⁰⁴ Ibid. **National Survey on Abuse of the Elderly in Canada: The Ryerson Study**.

²⁰⁵ Ibid. **National Survey on Abuse of the Elderly in Canada: The Ryerson Study**.

Approximately 4% of elders in Canadian private dwellings (approximately 98 000 people) have been abused. (1989 data)

It should be noted that in all of the above the 1989 data needs to be updated. Canada requires a large scale prevalence study similar to the American **National Elder Mistreatment Study**. National Institute of Justice, March 2009.

²⁰⁶ Susan Eng is the Vice President of Advocacy for the Canadian Association of Retired Persons (CARP). She appeared before the committee, and has continued to correspond with us, sending useful material on a regular basis.

²⁰⁷ This quote of Chief justice McLachlin is from the keynote address for the 3rd Annual Canadian Conference on Elder Law, November 10, 2007. As quoted in: Federal, Provincial, Territorial Elder abuse working forum, **Summary of Proceedings**. Vancouver, British Columbia, Nov. 8, 2007. p. 3. Accessed April 8, 2011 http://www.seniorsbc.ca/documents/pdf/fpt_elder_abuse_forum_2007_EN.pdf

²⁰⁸ “Son and Daughter-in-law face charges after woman removed from unheated garage.” **Globe and Mail** February 28, 2011. <http://www.theglobeandmail.com/news/national/toronto/son-daughter-in-law-face-charges-after-woman-removed-from-unheated-garage/article1923491/>

See also: Nicole Baute, “Bail denied in elder abuse case” **The Toronto Star** April 8, 2011.

<http://www.moneyville.ca/article/971998--bail-denied-in-elder-abuse-case>

Sam Pazzano, “Son of alleged elder abuse victim not granted bail”, **Toronto Sun** April 8, 2011.

<http://www.torontosun.com/news/torontoandgta/2011/04/08/17927846.html>

²⁰⁹ “Son gets seven years in ‘despicable’ elder-abuse death” Can West News Service, March 21, 2007.

http://www.canada.com/story_print.html?id=ac80d03a-8b74-4cd4-a17c-70c7d5b35c0b&sponsor=

²¹⁰ John Lancaster, “Man sentenced in landmark elder abuse case” CTV News, March 20, 2007.

http://www.ctv.ca/CTVNews/mar/20070320/elder_abuse_sentence_070320/

²¹¹ Doug Hempstead, “Nieces rescue elder abuse victim.” (QMI Agency -- Sun Media) November 12, 2010.

<http://cnews.canoe.ca/CNEWS/Crime/2010/11/12/16102911.html>

²¹² Laurie Salvador, “Elder Abuse in our Communities: First of a Series”. **The Scrivener**. Vol. 16 No. 4, Winter 2007. p.58.

²¹³ Testimony of Mickey Rooney Senate Special Committee on Aging March 2, 2011

<http://aging.senate.gov/events/hr230mr.pdf>

²¹⁴ *ibid.*

²¹⁵ *ibid.*

²¹⁶ Clara Ho, “Senior abuse unacceptable” **Edmonton Sun**, June 15, 2010.
<http://www.edmontonsun.com/news/edmonton/2010/06/15/14402421.html>

²¹⁷ Etienne G. Krug, et al. **World Report on Violence and Health**. World Health Organization, Geneva 2002, p. 125.

²¹⁸ Ibid. p. 126.

²¹⁹ Missing Voices: Views of older persons on elder abuse. (2002) World Health Organization, p.3.
http://whqlibdoc.who.int/hq/2002/who_nmh_vip_02.1.pdf

²²⁰ Etienne G. Krug, et al. **World Report on Violence and Health**. World Health Organization, Geneva 2002, p. 130.

²²¹ Ibid. p.12 - 13.

²²² “Older men are at risk of abuse by spouses, older children and other relatives in about the same proportion as women.” Rory Fisher, Madeline D’Arpino, Tracy Dion, Sherry Glazier, Rola Moghabghab, Elizabeth O, Anna Stephans and Lynn Zimmerman. “An Elder Abuse Workshop for Healthcare Providers”. **Geriatrics and Aging**. June 2003 Vol. 6, No. 6. p.62.

²²³ Ibid. p. 13.

²²⁴ Ibid. p. 131.

²²⁵ Ibid. p. 13.

²²⁶ Ibid. p. 131.

²²⁷ Quoted from: Vic Health “Opportunities for social Connection” p.1.
http://www.vichealth.vic.gov.au/~media/ResourceCentre/PublicationsandResources/Social%20connection/opportunities_for_Social_Connection_Summary_Nov10.ashx

Originally found in: Whiteford H, Cullen M and Baingana F, “Social Capital and mental health”, in: H Herrman, S. Saxena and R. Moodie (eds.) 2005, **Promoting mental health: concepts, emerging evidence, practice**. World Health Organization, Department of Mental Health and Substance Abuse, in collaboration with the Victorian Health Promotion Foundation and the University of Melbourne, Geneva. Pp. 70-80.

²²⁸ Etienne G. Krug, et al. **World Report on Violence and Health**. World Health Organization, Geneva 2002, p. 13.

²²⁹ Ibid. p. 131-132.

²³⁰ Ibid. p. 16.

²³¹ On the Counterpoint Project of the Canadian Centre for Elder Law see:
<http://www.bcli.org/ccel/projects/counterpoint-project>

²³² Dr. Elizabeth Podnieks as quoted by: Kirstin Gabriel, **Elder Abuse: a Deepening Current Social Issue Problem** April 3, 2011
<http://www.seniorsos.com/resources/articles/elder-abuse-a-deepening-current-social-issue-problem>

²³³ See: The Treasury Board of Canada Secretariat, **Federal Elder Abuse Initiative**, Results achieved in 2009-2010.
<http://www.tbs-sct.gc.ca/hidb-bdih/plan-eng.aspx?Org=0&Hi=89&Pl=292>
For a copy of the federal government sponsored T.V. ad on elder abuse see:
<http://www.seniors.gc.ca/c.4nt.2nt3col@.jsp?lang=eng&geo=106&cid=161>

²³⁴ The Quote is taken from the written submission of the **BC Association of Community Response Networks** to the Parliamentary Committee on Palliative and Compassionate Care, October 26, 2010.

²³⁵ Federal, Provincial, Territorial Elder Abuse Working Forum: **Summary of Proceedings**. Vancouver British Columbia, November 8, 2007. p. 30. http://www.seniorsbc.ca/documents/pdf/ftp_elder_abuse_forum_2007_EN.pdf

²³⁶ Government of Quebec, **Government Action Plan to Counter Elder Abuse 2010-2015**. p. 32. http://www.mfa.gouv.qc.ca/fr/publication/Documents/Plan_action_maltraitance_en.pdf

²³⁷ See: <http://www.neighboursfriendsandfamilies.ca/about-us/its-not-right.html> and <http://www.intergenerational.ca/images/stories/pdfs/AcrossGenerationsEnglish.pdf>

²³⁸ Ibid. p.32-33.

²³⁹ 2011 updates to the New Horizons for Seniors program:
http://www.hrsdc.gc.ca/eng/community_partnerships/seniors/nhsp/faq.shtml
For projects approved to date see:
http://www.hrsdc.gc.ca/eng/community_partnerships/seniors/nhsp/ca/ap/index.shtml

²⁴⁰ Marc Miquel Helsen, “Coming out for the Woodwork” Woolwich Observer. April, 17, 2009,
<http://observerxtra.com/2/featured/coming-out-for-the-woodwork/>

²⁴¹ The Public health and health determinant framework explanations are based substantially on the work of the Canadian Network for the Prevention of Elder Abuse, **Draft Framework for a National Strategy for the Prevention of Abuse and Neglect of Older Adults in Canada**. August 8, 2007. pp. 14-16.
<http://www.cnpea.ca/Strategy%20Framework%202007.pdf>

²⁴² Dr. Alexander Butchart, “Violence and Public Health: An integrated, Evidence-Based Approach to Preventing Violence and Child Abuse”. 130th International Training Course Visiting Expert’s Paper, Resource Material Series No. 69, p. 68. Accessed April 12, 2011. http://www.unafei.or.jp/english/pdf/RS_No69/No69_10VE_Butchart.pdf

²⁴³ Submission of the **Ontario Network for the Prevention of Elder Abuse** to the Parliamentary Committee on Palliative and Compassionate Care October 12, 2010. p.11.

²⁴⁴ Inga Thompson is Chair of the Prevention of Senior Abuse Network – Simcoe County. The quote is from her written submission to the Parliamentary Committee, October 16, 2010.

²⁴⁵ Anita Cole and Donna Ladovceur presented to the Owen Sound Round table of the **Parliamentary Committee on Palliative and Compassionate Care** July 26, 2010. Both work for the Community Care Access Centre in Grey Bruce and spoke on behalf of the **South West Ontario Regional Elder Abuse Network**.

²⁴⁶ From the submission of Vancouver Coastal Health -- Adult Abuse and Neglect Response Resource, to the Parliamentary Committee on Palliative and Compassionate Care, November 10, 2010. p.4.

²⁴⁷ Marie Beaulieu et al, **An Environmental Scan of Abuse and Neglect of Older Adults in Canada: What’s Working and Why**. Sept. 2003, p.20
http://www.seniorscouncil.net/uploads/files/For_Service_Providers/Senior%20Abuse%20Enviromental%20Scan.pdf

²⁴⁸ Anita Cole – South West Ontario Region Elder Abuse Network – Presentation to the Parliamentary Committee on Palliative and Compassionate Care -- Owen Sound Ontario Roundtable, July 26, 2010

²⁴⁹ Agnes Soulard -- Lampton Elderly Outreach: Presentation to the Parliamentary Committee on Palliative and Compassionate Care -- Sarnia Ontario Roundtable, September 3, 2010

²⁵⁰ **Re:act, Recognize and Report, Act on Adult Abuse and Neglect: A Manual for Vancouver Coastal Health Staff.** pp. 8-10.

http://www.vchreact.ca/attachments/react_manual.pdf

²⁵¹ Marie Beaulieu, Charmaine Spencer, et al., **An Environmental Scan of Abuse and Neglect of Older Adults in Canada: What’s Working and Why.** September 2003, p. 32.

²⁵² Dr. Laura Mosqueda, University of California, is director of Geriatrics and Associate Professor of Family Medicine at the Irvine College of Medicine. She is one of the United States foremost specialists on Elder Abuse. She is quoted from a paper presented October 18, 2000, to an Elder Justice Roundtable hosted by the National Institute of Justice. <http://www.nij.gov/nij/topics/crime/elder-abuse/roundtable/short-papers.htm> p. 28.

²⁵³ These important elder abuse intervention tools can be accessed at:

<http://www.nicenet.ca/list.aspx?menu=43&app=197&cat1=570&tp=9&lk=no>

The Elder Abuse Knowledge to Action Project has an overall tool kit for Prevention, Detection and Intervention in the case of abused seniors. A foundational project of the *National Initiative for the Care of the Elderly (NICE)* the project has developed a range of tools, funded through the Federal Elder Abuse Initiative and listed in the chart below.

Prevention	Detection	Intervention
<u>Coordinated Community Response</u> – CCR - a tool for local networks or elder abuse committees to use to prioritize their work. Based on 15 years of community development experience in BC – piloting version	<u>Elder Abuse Suspicion Index – EASI</u> (physicians) – complete with French and English on one pocket card – recently mailed to 23,000 family physicians in Canada by the College of Family Physicians of Canada	<u>In Hand – An Ethical Decision-Making Framework</u> (psychosocial professionals) – complete and being distributed in French and English
<u>Fact Quiz on Elder Abuse</u> – this tool has been completed in French a pre-test post-test format based on the literature and the <i>Fact Quiz on Aging</i> template to measure learning among seniors and professionals after experiencing an education program. Negotiations underway to consider as part of this tool kit.	<u>Brief Abuse Screen for the Elderly (BASE)</u> – just piloted, about to print English and French versions. Triaging in a health agency if there is abuse and how urgently intervention needs to take place.	<u>Elder Abuse Assessment and Intervention Reference Guide</u> (Police Tool 1 for patrol and cadets) Being distributed in English. About to be piloted in French.
	<u>Caregiver Abuse Screen (CASE)</u> –screen to assess caregiver burnout and hopefully to prevent abuse situations. Being distributed in English and French	<u>Theft by Power of Attorney Investigation Reference Guide</u> (Police Tool 2) – guidance for police on how to investigate when an older adult is mentally capable, and mentally incapable
	<u>Indicators or Abuse – IOA</u> (psychosocial professionals) – is abuse present? Being distributed in English and French	<u>Elder Abuse Risk Assessment - Police Tool 3</u> - safety planning risk assessment tool for use with older adults where the abuser is not a partner, by police and other responders). Negotiations are underway to begin piloting

	<p><u>Resources for Older Women – BC, GTA (English and French) Newfoundland/Labrador – developed for older women by older women some of whom became homeless as a result of leaving abusive situations. Z.card and pocket card format in three jurisdictions so far</u></p>	<p><u>Financial Exploitation Screener and Checklist</u> – have connected with researchers from Chicago who have developed a screening tool and more detailed checklist....exploring how to bring use of it when it hasn't been validated here, to Canada.</p>
		<p><u>Being Least Intrusive: An Orientation to Practice</u> – for non-aboriginal responders to use to examine their own practice whilst intervening in abuse situations, to maximize cultural safety</p>

Underlined items are those currently under development. Non-underlined items are tools completed thus far.

²⁵⁴ Marie Beaulieu, Charmaine Spencer, et al., **An Environmental Scan of Abuse and Neglect of Older Adults in Canada: What's Working and Why**. September 2003, p. 28.

²⁵⁵ Prof. Charmaine Spencer is a gerontologist at Simon Fraser University. One of Canada's foremost experts on elder abuse she presented to the Parliamentary Committee at the Victoria B.C. roundtable November 9, 2010. The quote was taken from Hayley Mick, "Give them Shelters" Globe and Mail, July 29, 2008. <http://www.theglobeandmail.com/life/article700702.ece>

²⁵⁶ Kerby Rotary House provides temporary shelter to men and women over age 55 who are in crisis. Older adults who have been impacted by abuse or homelessness will find a welcome in this home-like setting.

Kerby Rotary House originally opened in 1999 as a safe, secure place for older adults who are leaving abusive situations. The shelter continues to assist individuals affected by physical, emotional, financial or sexual abuse. In addition, staff provides crisis intervention, support, advocacy and referral.

In 2009, in partnership with Abri Seniors Housing, six transitional beds were opened to provide safe housing for older adults in unstable housing situations or facing homelessness. Transitional housing is provided with a goal of achieving stable, independent living in the community.

http://www.kerbycentre.com/shelter_abused_seniors.php

Kerby Rotary House Shelter

24-hour crisis line (403) 705-3250

E-mail: shelter@kerbycentre.com

²⁵⁷ Marie Beaulieu, Charmaine Spencer, et al., **An Environmental Scan of Abuse and Neglect of Older Adults in Canada: What's Working and Why**. September 2003, p. 31.

“The lack of emergency shelters available for older persons who have experienced abuse was also mentioned as a factor that contributed to elder abuse. The Ottawa-Carleton CCAC told the Commission that existing emergency shelters are often full and tend to address the needs of younger women and children. Such facilities are not appropriate for older persons and options for people suffering abuse by caregivers are limited. Other organizations told the Commission that barriers to accessing shelters include a general lack of knowledge on the part of older persons regarding how to access emergency shelters. Furthermore, language and cultural barriers exist that further limit the accessibility of these facilities. ESAC suggested that temporary shelters should be established to aid older persons and those with disabilities in their transition from an abusive situation to a safe environment. The Ottawa-Carleton CCAC suggested that shelters should

exist for both men and women, should be walker and wheelchair accessible and staffed with people who are able to address the complex needs of older persons.”

Ontario Human Rights Commission, **Time for Action: Advancing Human Rights for Older Ontarians**. June 2001, p. 70. http://www.ohrc.on.ca/en/resources/discussion_consultation/TimeForActionsENGL/pdf

²⁵⁸ Ontario Human Rights Commission, **Time for Action: Advancing Human Rights for Older Ontarians**. June 2001, pp. 44, 48.

²⁵⁹ Susan Eng – Vice President Advocacy, Canadian Association of Retired Persons (CARP) “Elder Abuse Update” March 11, 2011 http://www.carp.ca/advocacy/adv-article-display.cfm?documentid=5653&adv_section=3

²⁶⁰ Craig Babstock, “Jail sought for elder neglect” Times Transcript, Friday March 20, 2009. <http://timetranscript.canadaeast.com/news/article/609459>

²⁶¹ Adam Huras, “Woman who neglected dying mom gets day parole” Telegraph Journal Friday April 23, 2010 <http://telegraphjournal.canadaeast.com/rss/article/1026788>

²⁶² Canadian Snowbird Association News Fall 2001, Issue 40 <http://www.snowbirds.org/issues/general/136/issue-40.html#anchor725>

²⁶³ Submission of Dr. Marjan Abbasi, Covenant Health Edmonton Alberta to the Parliamentary Committee on Palliative and Compassionate Care, Edmonton Roundtable October 23, 2010.

²⁶⁴ From the presentation of Agnes Soulard, Lambton Elderly Outreach, to the Parliamentary Committee on Palliative and Compassionate Care, Sarnia Ontario Roundtable September 3, 2010.

²⁶⁵ Constable Jared Buhler is from the Domestic Crimes section of the Edmonton Police Service. He presented before the Parliamentary Committee at the Edmonton Round Table, October 23, 2010.

²⁶⁶ Randolph Thomas is a Police Investigator and Law Enforcement Instructor at the Criminal Justice Academy of South Carolina. The quote is from comments he made to an Elder Justice Round Table at the U.S. Department of Justice October 18, 2000 <http://www.nij.gov/nij/topics/crime/elder-abuse/roundtable/education.htm>

²⁶⁷ *ibid.* From a short paper presented by Randolph W. Thomas to the U.S. Department of Justice Elder Justice Round table October 18, 2000. <http://www.nij.gov/nij/topics/crime/elder-abuse/roundtable/short-papers.htm>

²⁶⁸ Dr. Carmel Dyer is a geriatrician and Associate professor of medicine at Baylor Medical College. She is co-director of the Texas Elder Abuse and Mistreatment Institute. She is quoted as speaking at a 2008 National Institute of Justice, Elder Abuse Workshop, August 11, 2008. Her talk was entitled “Factors that impact the determination by Medical Examiners of Elder mistreatment as a cause of death in older persons.” <http://www.nij.gov/nij/topics/crime/elder-abuse/workshop-2008/day3-1.htm>

²⁶⁹ From Manon Thompson’s Ontario Network for the Prevention of Elder Abuse submission to the Parliamentary Committee on Palliative and Compassionate Care October 12, 2010.

²⁷⁰ Federal/Provincial/Territorial Elder Abuse Working Forum, November 8, 2007, Vancouver B.C. p.7.

²⁷¹ *ibid.* p.9.

²⁷² Testimony from the Edmonton Roundtable October, 23, 2010.

²⁷³ Arlene Groh R.N., Community Care Access Centre of Waterloo Region, **Restorative Justice Approach to Elder Abuse Project**, Kitchener Waterloo. “Restorative Justice: A Healing Approach to Elder Abuse.” <http://www.mcmaster.ca/mjtm/5-1b.htm>

The material in this report on restorative justice is extremely indebted to Arlene Groh, and follows her exposition closely.

See also the articles:

“Restorative Justice: A Healing Approach to Elder Abuse.” Another version of the above article archived by Simon Fraser university. <http://www.sfu.ca/cfrj/fulltext/groh.pdf>

“A Healing Approach to Elder Abuse and Mistreatment: The Restorative Justice Approaches to Elder Abuse Project” May 2003.

<http://www.healingapproaches.com/images/AHealingApproachElderAbuseMistreatment.pdf>

“Restorative Justice in Canada: A Consultation Paper.” Department of Justice, May 2000

<http://www.justice.gc.ca/eng/pi/pcvi-cpcv/cons.html>

Arlene, Gaudreault, “The Limits of Restorative Justice”

http://www.victimsworld.ca/pub/pdfs/restorative_justice.pdf

Jeff Latimer et al. “The Effectiveness of Restorative Justice Practices: A Meta- Analysis.” Dept. of Justice 2001.

http://www.justice.gc.ca/eng/pi/rs/rep-rap/2001/rp01_1-dr01_1/rp01_1.pdf

Pierre Allard, “**A Little Manual of Restorative Justice**”, Public Safety Canada, March 2008

<http://www.publicsafety.gc.ca/res/cor/rep/ fl/2008-03-lit-ma-res-eng.pdf>

²⁷⁴ *ibid.* p.3.

²⁷⁵ *ibid.* p.4.

²⁷⁶ *ibid.* p.4.

²⁷⁷ *ibid.* p. 4. It should be noted that while legal positivist and contractual legal approaches place a sharp distinction between violation of people and relationships and violation of law, a more traditional natural law/personalist approach would not have done so. By their nature persons are ordered to relationship, and law is ordered to the common good.

²⁷⁸ *ibid.* p.5.

²⁷⁹ *ibid.* p.7.

²⁸⁰ *ibid.* p.8

²⁸¹ Manon Thompson represented the **Ontario Network for the Prevention of Elder Abuse** before the Ottawa Elder Abuse hearing of the Parliamentary Committee October 25, 2010.

²⁸² Cst. Jared Buhler—Edmonton Police Service, Edmonton Roundtable Parliamentary Committee, October 23, 2010.

²⁸³ When Laura Watts presented to the Parliamentary Committee at the National Elder Law Conference in Toronto, October 28, 2010, she was still National Director of the Canadian Centre for Elder Law and a staff lawyer at the B.C. Law Institute. She has since become the CEO of Social and Enterprise Development Innovations (SEDI) and is responsible for the operations of the Canadian Centre for Financial Literacy.

²⁸⁴ The quotation is from the Submission of the **Office of the Public Guardian and Trustee of British Columbia** September 20, 2010. p. 3. Jay Chalke the public guardian of B.C. presented to the Parliamentary Committee in Ottawa, October 25, 2010.

²⁸⁵ Douglas Melville Ombudsman for Banking services and Investments – Toronto Ontario, presented to the Parliamentary Committee in Toronto at the National Elder Law Conference October 28, 2010.

²⁸⁶ Elder abuse leads to a range of serious health effects.

“Abused elderly people are at high risk of death. In a large 13-year longitudinal study, the survival rate was 9% for abuse victims compared with 40% for non-abused controls. Multivariate analysis to determine the independent effect of abuse indicated that risk of mortality for abused patients over a 3-year period after abuse was 3 times higher than that for controls over a similar period.” Merck Manual Online edition, Elder Abuse article: Last full review/revision September 2009 by Barbara J. Berkman, DSW, PhD; Daniel B. Kaplan, MSW

<http://www.merckmanuals.com/professional/sec23/ch344/ch344i.html>

Xin Qi Dong, Melissa Simon et.al. “Elder Self-neglect and Abuse and Mortality Risk in a Community Dwelling Population” **JAMA**, August 5, 2009 – Vol. 302, No.5. <http://jama.ama-assn.org/content/302/5/517.full.pdf>

Mark Lachs, Christianna Williams, et.al. “The Mortality of Elder Mistreatment” **JAMA**, August 5, 1998 – Vol. 280, No.5. <http://jama.ama-assn.org/content/280/5/428.full.pdf>

²⁸⁷ Penny Bain, Charmaine Spencer, “Abuse of Older Adults: Signs and Effects” **Fact Sheet #4 World elder abuse awareness day**, http://www.winnipeg.ca/police/TakeAction/elderabusefacts/FactSheet_4.pdf

For the physical and psychological health effects of abuse see:

Charmaine Spencer, “Health and Abuse: Does Abuse and Neglect Affect Older Adults’ Health?”

<http://www.cnpea.ca/health%20and%20abuse.htm>

Deborah Doherty, **Health Effects of Family Violence**, National Clearinghouse on Family Violence, 2003.

http://www.phac-aspc.gc.ca/ncfv-cnivf/pdfs/fv-healtheffects_e.pdf

Deborah Doherty and Dorothy Berglund, **Psychological Abuse: A Discussion Paper**. National Clearinghouse on Family Violence, Public Health Agency of Canada, 2008. http://www.phac-aspc.gc.ca/ncfv-cnivf/pdfs/fv-psych-abus_e.pdf

Janice L. Ristock, **The Impact of Violence on Mental Health: A Guide to the Literature**. Mental Health Division Health Canada, February, 1995. <http://dsp-psd.pwgsc.gc.ca/Collection/H39-292-3-1995E.pdf>

²⁸⁸ Constable Jared Buhler presented before the Parliamentary Committee Edmonton Round table October 23, 2010.

²⁸⁹ This information was quoted from the written submission of the **Office of the Public Guardian and Trustee of British Columbia**, as dated, September 20, 2010. p. 5. Jay Chalke the public guardian of B.C. presented orally to the Parliamentary Committee in Ottawa, October 25, 2010.

“PIPEDA, provides relief under section 7(3) for the disclosure of client information to the police in the event you suspect criminal activity. This disclosure is voluntary. There is no criminal penalty for not disclosing, however ... by not disclosing, you may be setting yourself at risk for civil action down the road should your client’s estate be plundered by the appointed attorney. Use your common sense; employ due diligence before you dismiss your involvement.” Sergeant Brian Trainor -- Saskatoon Police Service (retired)

<http://www.fraudsguard.ca/documents/Power%20of%20Attorney%20Abuse.pdf>

²⁹⁰ *ibid.* p.5.

²⁹¹ **Federal/Provincial/Territorial Forum on Financial Abuse of Seniors.** , June 2008, Ottawa Ontario. P.15.

http://www.seniorsbc.ca/documents/pdf/fpt_financial_abuse_forum_2008_EN.pdf

²⁹² Task Force on Financial Literacy, **Report of Recommendations on Financial Literacy, Canadians and their Money: Building a brighter financial future.** Dec., 2010. pp. 65-66.

<http://www.financialliteracyinCanada.com/canadians-and-their-money.html>

²⁹³ Sergeant Brian Trainor, before he retired from the Saskatoon Police Service, spent five years with the commercial crime unit investigating crimes against seniors. In retirement he continues to be active combating elder abuse, through his writing and speaking engagements.

<http://www.fraudsguard.ca/documents/Power%20of%20Attorney%20Abuse.pdf>

²⁹⁴ **Federal/Provincial/Territorial Forum on Financial Abuse of Seniors.** , June 2008, Ottawa Ontario. pp.3,19.
http://www.seniorsbc.ca/documents/pdf/fpt_financial_abuse_forum_2008_EN.pdf

²⁹⁵ Amanda Brown, Adult abuse and neglect response resource, Vancouver Coastal Health, Submission to the Parliamentary Committee, November 10, 2010, p.2.

²⁹⁶ From the written submission of the Ontario Network for the Prevention of Elder Abuse, October 12, 2010. p. 11.

²⁹⁷ From testimony given to the Parliamentary Committee Elder Abuse hearing, October 28, 2010 at the Annual Canadian Conference on Elder Law, Toronto Ontario.

²⁹⁸ Elliot PausJenssen is the Vice-president of the Saskatoon Council on Aging and a board member of the Canadian Network for the Prevention of Elder Abuse. Peggy MacLeod is Chair of the Older Adult Abuse Task Force of the Saskatoon Council on Aging. They presented to the Parliamentary Committee at the Saskatoon Round table November 9, 2010.

²⁹⁹ Peel Elder Abuse Prevention Network (PEAPN): testimony to the Parliamentary Committee, Brampton, Roundtable, October. 13, 2010.

³⁰⁰ Elder Justice Round Table, U.S. Department of Justice , October 18, 2000 -- Short Paper – Dr. Ann W. Burgess et. al. “Pilot study of 20 Sexually Abused Nursing Home Residents Demographic Characteristics of Victims.”
<http://www.nij.gov/topics/crime/elder-abuse/roundtable/short-papers.htm>

³⁰¹ Elder Justice Round Table, U.S. Department of Justice , October 18, 2000 -- Short Paper – Dr. Karl Pillemer, Department of Human Development – Cornell University. “Critical Research Needs in the Study of Elder Abuse.”
<http://www.nij.gov/topics/crime/elder-abuse/roundtable/short-papers.htm>
“There has been almost no effort to seriously evaluate intervention programs for elder abuse. Experimental demonstration projects are very rare and have not involved randomized, control group design. We know very little about the relative effectiveness of various programs to prevent and treat elder abuse. Rigorous evaluation research is needed. Elder abuse programs, which have proliferated around the country, should be evaluated. For example, what are the effects for victims and their families of protective services programs? To what extent does mandatory reporting assist in the identification of elder abuse victims? Further, demonstration projects are needed in which different treatment modalities or prevention strategies are scientifically evaluated.” ibid. Dr. Karl Pillemer

³⁰² *Peel Elder Abuse Prevention Network*, written submission to the Parliamentary Committee on Palliative and Compassionate Care, October, 28, 2010. **PEAPN** presented to the Committee at the Brampton Round table October 13, 2010.

³⁰³ Edmonton Round Table October 23, 2010.

³⁰⁴ From the Submission of Dr. Marjan Abbasi, head of the department of Geriatrics Misericordia Hospital, Covenant Health, Edmonton Alberta, to the Parliamentary Committee, Edmonton Roundtable, October 23, 2010.

³⁰⁵ From the submission of the **Older Adult Abuse Task Force** of the **Saskatoon Council on Aging**: as presented to the Parliamentary Committee at the Saskatoon Round table November 9, 2010.

³⁰⁶ Edmonton Roundtable on Palliative and Compassionate Care October 23, 2010.

³⁰⁷ Anne Sclater, MSc, M.D., FRCPC – Presented at the 6th Annual Update, Internal Medicine for the Primary Care Physician, Edmonton, AB, April, 2000.

³⁰⁸ Quotation is from a presentation made in Edmonton Alberta in 2007.
http://www.docstoc.com/docs/32824886/Microsoft-PowerPoint---_690_Judith-Wahl-Keynote-Elder-abuse

Judith Wahl presented before the Parliamentary Committee at the Roundtable held at the 5th Annual Canadian Conference on Elder Law, October 28, 2010, Toronto, ON.

³⁰⁹ Rob Wipond, “Who has the right to control your life?” *Focus*. January 2009, p.28.
<http://www.seniorsatrisk.org/pdf/FocusMagazineJanuary2009.pdf>

³¹⁰ Ibid.

³¹¹ The *Elder Advocates of Alberta Society* presented to the Parliamentary Committee in our Ottawa hearing, October 25, 2010. Their webpage contains substantial documentation of cases of institutional and other forms of elder abuse, and can be viewed at: <http://elderadvocates.ca/> While the committee cannot make determinations on the complexities of these individual cases, they do point to a need for monitoring and oversight within personal protective legislation. While personal protective legislation is very important, we must protect people from possible abuse intentional or unintentional, by the very system designed to protect vulnerable persons.

³¹² Ruth Maria Adria, *Elder Advocates of Alberta Society*, Submission to the Parliamentary Committee on Palliative and Compassionate Care, Ottawa ON, Oct. 25, 2010. Section 6, p. 8.

³¹³ Inga Thompson, Prevention of Senior Abuse Network Simcoe County ON, Brief to the Committee, October, 16, 2010.

³¹⁴ Rob Wipond, “Who has the right to control your life?” *Focus*. January 2009, p.29.
<http://www.seniorsatrisk.org/pdf/FocusMagazineJanuary2009.pdf>

³¹⁵ Elder Advocates of Alberta Society, “**Adult Guardianship and Trusteeship Act: Instrument of Protection or instrument of abuse?**” This pamphlet was attached to the written submission to the Parliamentary Committee, October 25, 2010.