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Influencing Change

A Living Lessons® Resource

A Patient and Caregiver Advocacy Guide

The GlaxoSmithKline Foundation

Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs

Acknowledgements

National Advisory Committee

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Tara Addis, Hospice Association of Ontario
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Bobbi Greenberg, ALS Society of Canada
Catherine Hofstetter, Patient Advocate

Project Co-Ordination

Ryan McCarthy, Canadian Hospice Palliative Care Association
Greg Adams, Canadian Hospice Palliative Care Association

Introduction

Welcome to *Influencing Change: A Patient and Caregiver Advocacy Guide – A Living Lessons® Resource.* This guide has been designed to provide patients and their caregivers with practical tools to help them advocate for better end-of-life care programs and services.

This guide provides you with information and tools to help you become a health-care champion for yourself and/or your loved one. It is designed to assist you in finding services and programs. As well, it will help you work with groups such as health-care professionals, government and media to raise awareness of issues related to end-of-life care.

The toolkit is divided into four sections:

1. **What is Advocacy** – Highlights what advocacy is and provides you with tips on how to take an active role in managing your loved one's care.

2. **Canada's Health Care System** – Provides you with an overview of how the health care system works and tips for navigating the system.

3. **Engaging the Political Level** – Provides you with an overview of how public policy is made as well as how you can get involved and make your case.

4. **Communicating Your Message** – Tips on how to engage the media so that your story can be told.

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What is Advocacy?

In general, advocacy can be defined as the effort to influence change through various forms of persuasive communication. This change could be in personal attitude or behaviour, political and public debate, public policy or legal issues.

Advocacy is about becoming knowledgeable and working with others to raise awareness of an issue or injustice and to effect change. We all act as an advocate at some time. Think of a time where you have worked with friends or colleagues to come up with a solution to a problem and then implemented that solution. That is advocacy.

As a patient or caregiver, advocacy is about the need for:

- **Access to Knowledge** – about your condition and care management (medical and non-medical)
- **Access to Resources** – finding the community services, programs and resources available to help you in your situation
- **Support** – asking for help or working with others to make change – you do not need to do this alone.

Being an advocate is being a champion – a champion for yourself or for someone you love. Each patient needs and deserves a champion, someone who will advocate on their behalf, who takes the opportunity to learn more and helps their loved one make informed decisions.

Becoming a Champion – The Patients' and Caregivers' Rights and Responsibilities

Being a champion for you and your loved one is a rewarding experience. Part of being a champion is accepting personal responsibility for the care of yourself and/or your loved one. It is an important way in which to feel that you are managing end-of-life care in the best way possible. Personal responsibility is:

- Recognizing that you have the ability to learn and accept
- Using what you learn to make choices and ask questions
- Knowing that you are responsible for the choices that you make

Health-care professionals are your partners in care. Being as active as you can in how your care is managed is very important. Here are some tips:

Handling Your Care Management

1. Make sure that you collect as much information as you can about:
    - a) Your symptoms such as nausea, fatigue, weight loss/gain
    - b) Your medications
    - c) Your medical tests
    - d) What has worked/not worked with your treatments
2. Ask specific questions when you do not understand something that your health-care professional tells you.
3. Learn as much as you can about your condition.
4. Follow the treatment plans that are outlined by your health-care professional. Some examples of this are taking medicines at certain times, attending follow-up medical appointments or following a specific nutrition plan.
5. Understand the choices that are available to you by gathering as much information as possible. Do not be afraid to ask questions.
6. Inform health-care professionals of your wishes. If you have Advance Care Planning, let your health-care provider know. Advance Care Planning is a process by which you and your health-care professional develop and establish a valid expression of your wishes regarding future health care at end of life. More information is available later in this guide.
7. Follow through on what you are asked to do. You are the most important part of managing your care. Follow instructions carefully, ask lots of questions to make sure you understand and make choices that are best for you and your loved ones.

More importantly, as a patient you have rights as well as responsibilities.

Your Rights

As an individual dealing with an end-of-life care situation, you have the right to:

1. A timely and accurate diagnosis that you are living with a life-limiting illness.
2. Information about your specific illness as well as your end-of-life care needs.
3. Access to hospice, palliative and end-of-life care specialists.
4. Access to adequate pain and symptom management medications and therapies.
5. Access to research that may influence your end-of-life care.
6. To be fully engaged in your care management.
7. Representation in your care management.
8. Engage your loved one to work with you on Advance Care Planning.

Your Responsibilties

1. Learn as much as you can about your condition and end of life.
2. Do everything you can to maintain your quality of life at end of life.
3. Actively participate in decisions about your care – this means you and your loved ones.
4. Follow the care management plan that you and your health-care professional decide upon. Review and revise your care management plan as you and your caregiver see fit.

For more on the rights of caregivers, patients, and family members, please visit the Living Lessons Website at www.living-lessons.org/cando/rights.asp.

Gaining Confidence

Taking responsibility for your care or a loved one's care can be a rewarding experience.
Here are some tips to help you along the way:

Set small goals
It is very satisfying to set a goal and achieve it. You can do this by focusing on small tasks, one by one. For

example, one task might be starting a journal where you keep information about how you are feeling, what medications you are taking and what you achieved that day. Another task might be doing 20 minutes of light exercise as recommended by your health-care professional. Keep a running list of your achievements and see how fast they add up!

Acknowledge your success

Successes come in all shapes and sizes. Congratulate yourself for your wins and remember that even failures can be successes when you learn from them!

Know what you know

Health-care professionals bring a wealth of expertise to their roles, but you are also an expert in your own health. There are many sources of information to learn about your condition and what may work best for you. Tell your health professional how you are feeling. Learn as much as you can about your illness, and do not let anyone dismiss what you know. No one knows how you feel better than you!

Visualize

Have a goal in mind. Is there a part of your care that you are unhappy with and would like to see changed? As a caregiver, are you often left out of discussions that should involve you? Visualize the conversation that you would like to have with your health-care professional and think about the results that would make you happy.

Making a Plan

How can you figure out where to start? Start by making a plan.

1. Define your goals

What do you want the result of your efforts to be? Are you trying to have your medication changed? Is there a program or service you feel you should have access to? As a caregiver, do you need assistance? Do you have specific questions that you need answered? Set a realistic goal and make a plan to achieve it.

2. Know who you need to talk to

Once you know what you want to achieve, figure out who you need to talk to. If you want to change your medication, you may want to talk to your doctor, but you can also talk to your nurse to get them to be a champion for you as well. You may need to talk to hospital or government administrators, to determine what programs and services are available and if you are eligible. Enlist others for help in identifying who needs to be involved and who you could talk to.

3. What you need them to hear
Health-care professionals or administrators are there to help, so it is important to be clear about the results you want. Figure out exactly what you need them to hear and how they can help you. Be as specific as possible.

4. How will you communicate?
Choose a way to communicate that works for you. Are you comfortable making a request or asking questions in person? Perhaps you would rather write a letter and request a response. There are many ways to communicate. Find the way that works best for you. Make sure to follow up with your health-care provider.

5. Setting timelines
When you are making your plan, set deadlines that you can achieve. It is important to identify when you wish to accomplish something.

Remember to recognize your successes!

Who can Help

You are not in this alone. Your loved ones are on this journey with you and are there to support you in whatever way they can. There are a number of people who may be able to help you throughout this journey including:

- **Family**
- **Friends**
- **Other families who have been through similar circumstances**
- **Doctors**
- **Nurses**
- **Home Support Workers**
- **Pharmacists**
- **Dietitians**
- **Spiritual Care Professionals (Rabbi, Pastor, Chaplain, Priest, etc.)**
- **Naturopathic Doctors**
- **Occupational Therapists**
- **Counsellors**
- **Homecare services**
- **Volunteers**
- **Hospice palliative care professionals and organizations**
- **Organizations that work with persons with specific diseases (ALS Society, Canadian Cancer Society, Heart and Stroke Foundation are some examples)**
- **Local and provincial government representatives who may be able to connect you to various programs**

Assessing Information: Is It Credible?

Learning about your illness and how you can best manage it will help you in managing your care. There are several sources you can use to learn more about your disease or condition, end-of-life care and programs and services that you may be able to access.

There are numerous sources for health information including:

- Your local library
- Local, provincial, and federal government offices
- District Health Authorities, Local Integrated Health Networks, Community Health Boards, Centres des services de santé et de services sociaux
- Non-profit organizations such as Canadian Hospice Palliative Care Association, Heart and Stroke Foundation of Canada, The Arthritis Society, ALS Society of Canada and Canadian Cancer Society, etc. are groups which often have provincial branches with local programs and services.
- Medical or university libraries
- Nurses
- Doctors
- Pharmacists
- Counsellors
- Internet

The Internet can provide a wealth of information, but do be careful as anyone is free to post information at anytime. People generally do not mean harm, but information regarding your care should come from your health-care team or other reliable sources to ensure they are safe. Here are some tips that you can use to evaluate the information that you are reviewing online:

Understand who runs the Website

Check if the Website is managed by a branch of government, a private company, a non-profit organization, a hospital, a community health board or an individual. Professional organizations and companies post credible information that has been evaluated. You can often find this information by looking for a section on the Website called "About us."

How is information made available?

Check how a Website posts its materials. Is there a committee of professionals who review the information? Websites that post credible medical information should have a process that is highlighted on their site.

Be aware

If something sounds too good to be true, it probably is. Use caution when a Website offers you a "cure," a "breakthrough" or something else that does not seem likely. Also look at how a site is financially supported – advertisements should be clearly marked.

Is the information new or old?

There is a lot of great information on the Internet, everything from the latest research on diseases to tips for coping with the loss of a loved one. When you are looking at information, look for the date that it was published. Scientific information, such as research regarding a particular illness, can become outdated quickly. Information on more general topics such as grief and coping with loss is often relevant for much longer periods of time.

What do they want from me?

Many Websites will track how you use the site, so they know what type of information people are looking for. If a site asks you to "subscribe" for more information, find out what kind of information they collect and how it will be used. They should have a privacy policy that clearly states how your information may be used.

Connecting with Others

It often helps to connect with others who have been through similar circumstances. Building a network of people who can support you during a difficult time can be a positive experience. These networks can also work together to affect changes in programs and services, so that patients and their families do not need to do things alone.

You might want to look for support groups in your area. You can search the Internet or contact organizations that deal with specific diseases or conditions to see if they have support groups or any kind of supportive care program. Ask your doctor, nurse or social worker if they know of any programs or services in your area that could be of assistance.

The Internet has also become a tool for people to develop their own support networks. A number of people write online journals about their experiences ("blogs") where people can connect with them and share experiences. Discussion boards, where people can post messages to ask questions regarding their experience and get answers from others who are experiencing the same thing, are a tool to connect with others. Finally, there are chat rooms where you can talk with people in real time. These are just some of the ways that people are connecting and building networks of support.

Remember the Internet is a wonderful tool to get connected, but make sure you discuss your health-care options with your health-care provider.

Website Resources

The following Websites can provide you with more information:

For tips on searching the Internet:

How to Search the Internet Effectively – www.media-awareness.ca/english/resources/special_initiatives/wa_resources/wa_teachers/tipsheets/search_internet_effectively.cfm

For information on hospice palliative care:

The Canadian Hospice Palliative Care Association – www.hospicepalliativecare.ca
The Canadian Hospice Palliative Care Association (CHPCA) is the national association which provides leadership in hospice palliative care in Canada.

You will find contact information for the provincial hospice palliative care associations, fact sheets about end-of-life care in Canada as well as an order form for "A Guide for Caregivers," a resource with practical tips for caregivers. This guide is part of a national program called Living Lessons® designed to provide support resources for those dealing with end-of-life care; such resources are available at www.living-lessons.org

The Canadian Virtual Hospice – www.virtualhospice.ca
The Canadian Virtual Hospice is an interactive network for people dealing with life-threatening illness and loss.

The following Websites can provide you with more disease-specific information. Many of their provincial affiliates can be reached through these sites.

Alzheimer's Society of Canada – www.alzheimers.ca
ALS Society of Canada – www.als.ca
Arthritis Society of Canada – www.arthritis.ca
Canadian AIDS Society – www.cdnaids.ca
Canadian Breast Cancer Network – www.cbcn.ca
Canadian Breast Cancer Foundation – www.cbcf.org
Canadian Cancer Society – www.cancer.ca
Canadian Diabetes Association – www.diabetes.ca
Canadian Liver Foundation – www.liver.ca
Canadian Mental Health Association – www.cmha.ca
Heart and Stroke Foundation of Canada – www.heartandstroke.ca
Kidney Foundation of Canada – www.kidney.ca
Lymphoma Foundation Canada – www.lymphoma.ca
Lung Association of Canada – www.lung.ca

Canada's Health Care System

Although the health care system is complex and challenging at times, there are simple things you can do to navigate your way through the system. Get to know how things work in your province or territory.

How the System is Set Up

The health care system is a number of insurance plans that provide coverage to Canadians. It is publicly funded and administered, meaning that each system is managed by each province or territory within guidelines and principles set out by the federal government in the Canada Health Act.

The provinces and territories are responsible for the administration of health-care delivery. Many provinces and territories have established structures within their borders to deliver health-care services that are based on what their communities need. These are often referred to as district health authorities (DHAs), local integrated health networks (LIHNs), or centres de santé et de services sociaux (CLSCs) depending on the province or territory. Their purpose is to allow a community focus in the delivery of care.

As there are no government-directed standards, availability of programs and services may vary from area to area. This means that some programs and services may not be available in your community. It is important for you to contact your DHA, LIHN or CLSC to find the specific programs and services available to you.

If a service or program is not available in your area and you think it should be, you can advocate for this service. You will be making a difference for you and for other families who may experience the same challenges. This guide is a great starting place for more information on:

- Meeting with your elected official
- Working with other patients to raise awareness in your community
- Speaking with media to highlight challenges

You and the Health Care System

The way health care is delivered can be explained in three different levels:

1. Primary Health Care – This is the first time that you make contact with the health care system. Whether you visit your family doctor, talk to a pharmacist, or visit the emergency room – you are accessing this level of care. Primary health care is designed to treat acute (e.g. pneumonia) or chronic illnesses (e.g. diabetes), prevent illness or injury and understand what factors can make a person ill.

Primary health care can also be delivered in many settings. There are four settings for end-of-life care: hospital, long-term care, home or residential hospice. The services that are available in each of the settings vary greatly between each province and territory. For more specific information about hospice palliative care services in your community, please contact your local hospice palliative care organization. Contact information for these associations is located at the end of this section.

Trends in primary care

As the health care system has evolved, there has been a significant shift in the setting which care is provided. It was not uncommon twenty years ago to enter a hospital and either not leave or be placed in a long-term care facility. As health care has progressed, governments have realized the importance of patients being treated at home, as well as the significant economic savings of home care in addition to improving quality of care.

Patients are also leaving the hospital much sooner with intense medical needs. Caregivers are faced with providing a high level of care such as changing pain pumps, administering medications and assisting loved ones with tasks such as bathing and dressing. This is all in addition to coping with the illness and impending death of their loved one. Sometimes patients do not feel comfortable with their family providing that level of care.

Families also often find themselves in uncomfortable situations when asked to provide high levels of care for a loved one. There are a number of legal, moral and ethical challenges that face family and informal caregivers, including worrying about giving the wrong medications, managing their own daily living while providing a significant amount of care and coping with the impending loss of their loved one. For more information, please visit the Canadian Hospice Palliative Care Association's Website (www.chpca.net/informal_caregivers/VOICE_PROJECT-DISCUSSION_DOCUMENT-August2004-2.pdf) to read more about the legal, moral and ethical challenges of family and informal caregivers at end of life.

What you can expect
Patients and their loved ones have the right to tell their health-care provider if they are unhappy or not comfortable in this situation. Do not suffer in silence – if you do not want to provide care, or are not at ease with the care you are receiving, please let your physician, nurse, or personal support worker know.

2. Secondary Care – Secondary care providers are specialists that focus on particular diseases (such as diabetes or cancer) or specialize in specific organs or functions of the body (such as kidneys, or ear, nose and throat). Secondary care also involves areas such as diagnostic testing (X-rays) or rehabilitation (respiratory therapy). Usually, your primary care provider refers you to such services.

3. Tertiary Care – The third level of services are those health-care professionals who have highly specialized skills. Hospice palliative care physicians and nurses are an example of tertiary care.

How to Find Your Way Around the System

Health professionals in Canada are under a great deal of pressure to keep current on the latest information regarding medical conditions, including end-of-life care. Knowing what is available to you will help you in being a partner in your and your loved one's care.

Resources to help you navigate the system

Patient Navigators/Case Managers – Some provincial agencies have "patient navigators" or a patient navigator program. They also have case managers who will help you find what programs and services you need in all settings of care. These programs work with families to refer them to services they need at the right time, suggesting programs and services that may be difficult to find and assisting them throughout their entire illness. Organizations and health-care institutions that work with patients that have a life-threatening illness sometimes offer these programs. Ask your health-care provider if they are available in your area.

Palliative Care Coordinators – Some DHAs, CLSCs, and LIHNs have palliative care coordinators that can help you access services throughout your illness.

Canadian Directory of Hospice Palliative Care Services – The Canadian Hospice Palliative Care Association maintains a national directory of programs and services. This on-line directory provides information on hospice palliative care services across Canada. You can visit the directory at www.chpca.net/canadian_directory_of_services.htm

Make sure to:

- Contact your provincial hospice palliative care association to find out what services are available in your community.
- Contact organizations that specialize in a particular disease that will also be able to provide you with information.
- Visit Websites that provide a wealth of information – get connected to Websites for your local DHA, LIHN, or CLSC.

Working with your Health-Care Provider/Team

Today people are more informed than ever and are taking a more active role in managing their care with their health-care professional. Traditionally, a doctor would make a diagnosis and advise the patient on next steps. Now patients are active partners in their own care.

The team that provides care is interdisciplinary and could include:

- **You and your loved one**
- **Your family physician**
- **Nurse/Nurse Practitioner**
- **Specialists (oncologist, neurologist, cardiologist)**
- **Home support worker**
- **Dietitian**
- **Pharmacist**
- **Palliative care physicians or nurses**
- **Volunteers**
- **Physiotherapist or occupational therapist**
- **Social Worker**
- **Counsellor**
- **Naturopathic Doctor**
- **Spiritual Care professional**
- **Religious leader (Rabbi/pastor)**
- **Surgeons**

The most important member of this team is *you*. You can best describe what level of pain you are experiencing, describe how your symptoms (such as fatigue) are affecting you and describe how certain medications or treatments are working. You and/or your caregiver can help make the best decisions for you based on your needs.

How you can advocate for your own care

1. Prepare for your doctor visit. Make a list of questions that you need addressed. If your doctor cannot answer a question, then ask your doctor to refer you to someone who can.

2. Keep a journal. Make a list of:
    - a) the medications you are taking
    - b) medications that you tried and did/didn't work for you
    - c) any treatments you are receiving
    - d) any changes you have noticed in your symptoms (pain, fatigue, weight loss/gain);
    - e) your entire test results to date (you can ask for copies)

3. Make sure you get contact information for everyone that you see along the way so you can contact him/her with any questions that you may have.

4. You and your caregiver need to be involved in all decisions that affect you. You are the captain of the team and you have the right to make the choices that are best for you. As a caregiver, if you are not comfortable with administering certain treatments in the home, tell your doctor. If you know about different medications that are available, ask your doctor which is the best and why he/she is recommending that particular medication.

5. Learn as much about your illness as you can. There are a lot of credible sources of information. Talk to your local librarian, use the Internet and contact local organizations that specialize in your illness or in end-of-life care. There are a number of ways to access this information. Let your doctor know that you are making an effort to manage your care.

6. Set goals for your care and tell your health-care provider what these goals are. You can set goals such as staying in your home as long as possible, managing your fatigue, or dealing with nausea. They can help you achieve these goals by developing a plan.

7. Try and understand the challenges your health-care provider faces. If you are frustrated with the system, chances are your provider is too. Try and anticipate questions that they are going to ask you or what your responses might be. Remember, you have the ability and the right to ask questions – it is your care!

8. Speak to your family physician regarding Advance Care Planning, a process by which you and your health-care professional develop and establish a valid expression of your wishes regarding future health care at end of life.

There are three components to Advance Care Planning:

1. **Advance Directives** – Your oral and written instructions about your future medical care in the event you become unable to communicate.

2. **Health-care Power of Attorney** – A document in which you appoint someone to make decisions about your medical care if you can't make those decisions yourself.

3. **Living Will** – A written form of advance directive in which your wishes regarding the administration of medical treatment are described, should you become unable to communicate at the end of life.

Case Management

Case management is having someone who works with patients and their caregivers to identify, monitor and evaluate clients' needs on an ongoing basis. They help assess what type of programs and services you may need as well as determine what programs and services you are eligible for. They then coordinate these activities and check with the patients and caregivers to make sure that it is going well. They are a central point for referral to various programs and services that may be available to you.

For example, a case manager may assess a patient and determine the best settings of care, what support is needed to ensure the patient receives adequate care and also provides referrals to the programs and services needed. Along the way, the case manager works closely with patients and caregivers to ensure that patients and their caregivers are getting the required information, programs and services.

Talk to your health-care professional to see if case management is available in your area. If not, you may want to work with other families and patients to see how case management can be part of your care plan.

For more information…

Provincial Hospice Palliative Care Associations:

Alberta – www.chpca.net/ahpca/index.htm
British Columbia – www.hospicebc.org
Manitoba – www.manitobahospice.mb.ca
Quebec – www.reseaupalliatif.org
Hospice Association of Ontario – www.hospice.on.ca
Ontario Palliative Care Association – www.ontariopalliativecare.org
Nova Scotia – www.nshpca.ca
Newfoundland and Labrador – www.nlpca.info
Prince Edward Island – www.hospicepei.ca
Saskatchewan – www.saskpalliativecare.ca
New Brunswick – www.chpca.net/provincial_associations/new_brunswick.htm

Federal Health Departments:

Health Canada – www.hc-sc.gc.ca
Public Health Agency of Canada – www.phac-aspc.gc.ca
Primary Health Care Awareness Strategy – www.primaryhealthcare.ca
Ten Year Plan to Strengthen Health Care – www.hc-sc.gc.ca/hcs-sss/delivery-prestation/ fptcollab/ 2004-fmm-rpm/index_e.html

Provincial/Territorial Health Departments:

Alberta – www.health.gov.ab.ca
British Columbia – www.gov.bc.ca/themes/healthy_living.html
Manitoba – www.gov.mb.ca/health
Northwest Territories – www.hlthss.gov.nt.ca
Nunavut – www.gov.nu.ca/hsssite/hssmain.shtml
Quebec – www.msss.gouv.qc.ca/en
Ontario – www.health.gov.on.ca
Nova Scotia – www.gov.ns.ca/heal
New Brunswick – www.gnb.ca/0051/index-e.asp
Newfoundland and Labrador – www.gov.nl.ca/health
Prince Edward Island – www.gov.pe.ca/hss
Saskatchewan – www.health.gov.sk.ca
Yukon – www.hss.gov.yk.ca

Provincial listing of District or Regional Health Authorities, Local Integrated Health Networks, and other provincial government health structures:

Alberta – www.health.gov.ab.ca/regions/RHA.html
British Columbia – www.hlth.gov.bc.ca/socsec/index.html
Manitoba – www.gov.mb.ca/health/rha/contact.html
Northwest Territories – www.hlthss.gov.nt.ca/content/About_HSS/hss_authorities.asp
Nunavut – www.gov.nu.ca/Nunavut/English/departments/HSS
Quebec – www.msss.gouv.qc.ca/en
Ontario – www.lhins.on.ca
Nova Scotia – www.gov.ns.ca/health/dha_map.htm
New Brunswick – www.gnb.ca/0051/index-e.asp
Newfoundland and Labrador – www.nlchi.nf.ca/links.asp
Prince Edward Island – www.gov.pe.ca/hss/index.php3
Saskatchewan – www.health.gov.sk.ca/ph_rha_map.html
Yukon – www.hss.gov.yk.ca

Engaging the Political Level

How Policy is Made

When a government takes office, they establish priorities of what they want to accomplish. Policy helps guide the actions of government and meet their objectives. Programs that are delivered, such as home care at end of life, are based on policy.

Policy-Making Process

1. **Someone identifies that a change is needed** – Citizens like you, health-care professionals, government, media, organizations that work with people living with certain diseases and conditions are all people that can identify that change is needed.

2. **Figure out who needs to be involved** – If you are trying to make sure that people have access to hospice palliative care, you may need to talk to the provincial government or a district health authority. This is a good opportunity to talk to other families who have similar experiences, talk with community groups and chat with health professionals who might be able to support your cause.

3. **Getting your message to the right people** – There are a lot of policy issues that the government is trying to resolve. Who better to convince them of its importance than someone who is living or has lived through the experience. It is important that when you are working with the government, you make it easy to understand why they need to address this particular issue. Get as much information as you can and try to find others who are trying to work towards this particular issue to work with you. Every voice counts, and the more voices, the better!

4. **Getting a policy or program developed** – Once a policy is being considered, a number of things might happen. The government will look at research to figure out how big the problem is; come up with some solutions/options that might work and get input from a number of different people. A program might be developed if a policy is in place, or the current policy may need to be changed.

5. **Keep involved** – When you have successes, remember that it is important to keep involved. Policy and the programs that are implemented need to be evaluated and monitored to ensure a continued momentum.

One difference that must be noted is the difference between legislation and regulation. Legislation takes a significant investment of time as it involves changing laws which could take years to achieve. Regulations are developed based on legislation and are often done by senior levels of government. This means regulations can be changed within a shorter timeframe. Remember, it takes patience to make change at a political level.

1. Engaging Your Elected Official

Whether you are working with elected officials at the federal level (MP) or a provincial level (MLA, MNA or MPP), you have an excellent opportunity to ensure that your voice is heard. Meeting with your elected official is a great way to have your concerns recognized. Here's a helpful guide.

Raise awareness of the issue

Write a Letter – Sending a letter is the first step in bringing your issue to the official's attention. Your letter should:

a) **Be brief and concise** – Given the number of letters they receive, it is best to keep it brief.

b) **Tell them who you are** – Let them know you are a constituent with an issue that is relevant for your family and the other families in your community.

c) **Focus on no more than three key points** – Tell them what you want to see changed and why it is important to change it. Tell them how your end-of-life experience could be better and highlight three key areas that you think could be addressed.

d) **Personalize the letter** – Tell your story and why it is important that changes are made. Let them know what impact your end-of-life care experience has had for you and your loved ones.

e) **Have "an ask"** – Close your letter by asking for some type of action. For example, you could ask your elected official for a meeting to discuss your concerns.

An effective letter should:

- Present the issue
- Present possible solutions
- Provide the reader with a call-to-action. Tell them what you would like them to do.

2. Meeting with Politicians

Remember, your elected official works for you. Your issue is just as important as everything else they are trying to address. Your job is to help them understand why end-of-life care is an important issue!

Tips for an effective meeting with your elected official

Decide who will go – It is helpful to have between two and four people attend the meeting. You could bring loved ones, someone from your community with a similar experience or someone from an organization that addresses end-of-life care or focuses on a particular disease. Whoever goes to the meeting should be able to make a connection by using personal stories.

Call to arrange a meeting – Call the official's constituency office to ask for a meeting. Be sure to call the day before your meeting to confirm the time as schedules change quickly.

Build relationships – Be polite and courteous with elected officials and their staff. Their staff often manages the agenda as well as schedules and can be a great asset to you.

Be Prepared – You will have a short time with your elected official and you want to be sure to get your points across.

- Decide on two or three key points that you want to discuss and stay on topic. The meeting can go off track very fast and your time will be up before you have a chance to talk about your issue.
- Try and know as much as you can. The elected official will try and present different opinions. Think of what they might say and come up with an answer that will keep to your point. Try to find out if your elected official has said anything publicly about your issue before you meet with him/her.
- Decide who will speak to what points during the meeting and stick to the plan as much as possible to ensure all your points are heard.
- Listen as well as talk. Your elected official might be trying to empathize or gain more insight into what you are trying to tell him/her.
- Be assertive, not aggressive. Be clear and concise.
- Thank the official for taking the time. Send a letter to him/her after the meeting highlighting a few points of your discussion.
- Leave information behind – You will have a lot of useful information to present at the meeting. Give brochures or a document that outlines your issue, the solutions and a call-to-action. This way when the elected official responds to your issue, they have all of the facts.

For more information

Contact your Federal Member of Parliament:

www2.parl.gc.ca/Parlinfo/Compilations/HouseOFCommons/MemberByPostalCode.aspx?Menu=HOC

Find your provincial representative:

Alberta – www.assembly.ab.ca/net/index.aspx?p=mla_home
British Columbia – www.legis.gov.bc.ca/mla/3-1-1.htm
Manitoba – www.electionsmanitoba.ca/mlasearch/mlasearch_link.htm
Northwest Territories – www.gov.nt.ca/research/mla/index.html
Nunavut – www.assembly.nu.ca/english/members/index.html
Quebec – www.electionsquebec.qc.ca/en/find_electoral_division.asp
Ontario – www.electionsontario.on.ca
Nova Scotia – www.electionsnovascotia.ns.ca/edf/edf.aspx
New Brunswick – app.infoaa.7700.gnb.ca/gnb/pub/ListMLA1.asp
Newfoundland and Labrador – www.hoa.gov.nl.ca/hoa/members
Prince Edward Island – www.assembly.pe.ca/index.php?number=1012298&lang=E
Saskatchewan – www.legassembly.sk.ca/members
Yukon – www.gov.yk.ca/services/abc/members_la.html

Communicating Your Message

Persuasive Communication

Whether you are meeting with a politician, talking to a health-care professional about managing your care, or working with a media person to get your story told, being able to use persuasive communication to get your message across is a helpful skill. Persuasive communication is used to change, modify or reinforce responses from the person you are communicating with.

Here are some tips:

Focus on the other person

What exactly is it that you want the other person to do for you? If you know what it is that you want and communicate it well, then the other person is more apt to be persuaded. Try and think of what it is that the person that you are trying to influence is going to want to know and any arguments he/she may make.

Show them what you know

You and your caregiver have a wealth of knowledge and are the best people to describe how you are feeling and what may not be working for you. When you are trying to persuade someone, use and trust that knowledge.

Be confident

You know what is best for you and your loved one and what your end-of-life care experience has been like. Be passionate and confident when you are trying to persuade someone to change his/her mind. No matter whom you are trying to persuade, confidence and passion about what you are talking about will help deliver your message.

Make it easy to understand

There are a lot of facts that you can present to make your case, but you want to be sure what you say is retained by the other party. Give them something to think about and to peak their curiosity. Use clear examples that they can relate to and that demonstrate the impact of the problem on people. Make it personal so they can apply it to specific situations in their lives.

Developing Key Messages

- Keep it short. The average radio or television sound bite is 10 seconds long. The average print quote is one to three lines. Use everyday language and avoid jargon.
- Ensure your thoughts are honest and compelling, e.g.: "Let me put it this way. This issue will have a tremendous impact for all families."
- Make your sentence a complete thought, so it stands on its own.
- Be passionate and energetic, e.g.: "Our population is aging. We have a responsibility to help people live as comfortably as possible with life-threatening illnesses."
- Be colourful or metaphorical. "We have to bring death and dying out into the open."

Working with the Media

What do reporters want?

Reporters want a story their audience can identify with – that people can see themselves being a part of. When you are approaching a reporter with a story that you think they should cover, try to outline:

- The personal aspect of the story: what kind of impact your experience has had on you and your family.
- Demonstrate how this story would be meaningful to the audience.
- Provide them with facts to support your position.

Writing a press release

You can write a press release to try and garner media support for your issue. Here is how you can write an effective release.

Choose a headline that will get attention. It needs to summarize the article, but be interesting to stand out.

1. The opening paragraph should summarize what follows and should provide a quick overview of who, what, where, when, why and how. It needs to tell the reader why this is important and why they should keep reading.

2. The body of the press release should outline the personal story and the facts to present your issue. The first paragraph should contain the most important information and quotes – this will help editors if they need to cut down the press release for their article.

3. The final paragraph should present any conclusions highlighting the importance of telling this story.

An example is provided in Appendix B.

Getting Your Message Heard

So now that you have your key messages, it's time to get them out. The media are a great tool to help tell your story. There are several mediums that you can target including:

- Print (newspapers, magazines and community newspapers)
- Radio
- Television (local, provincial, and national)

Print Media

Op-Ed

One of the easiest ways to get your name in the paper is to write an op-ed piece. An op-ed piece is simply your opinion of a particular issue and can be written at any time. The trick to writing an op-ed piece is to include facts and personal experiences to sway the reader's opinion. Here are a few tips to help you:

- Focus on one issue.
- Express your opinion and then use facts and personal experience to back it up.
- Be personal and conversational in tone which will engage your reader.
- Provide insight and demonstrate why people need to think differently.
- Be clear and concise.
- Clearly state your position and what you want to see happen at the end.
- Limit your op-ed piece to 600-800 words.

An example is provided in Appendix C.

Letter to the Editor

Letters to the Editor are usually in response to something that you have read in a newspaper or magazine that you do not agree with and/or think was presented in a misleading way. These letters are often much shorter than an op-ed piece (100-200 words). When writing the letter, do not restate what was already said, start by telling why you disagree.

An example is provided in Appendix D.

Working with Reporters

Building relationships with reporters will help you to meet your goal of getting the message out. When communicating with a reporter, remember they are often juggling two or three deadlines and want to get facts that are quick and easy. You know why the issue is important, so who better to present the facts in a convincing manner!

Radio

There are an increasing number of radio talk programs that often provide an opportunity for in-depth discussion on an issue. Interviews might happen individually or sometimes as part of a panel. Here's how to have a successful radio interview:

- You need to paint the picture for radio listeners, because there is no visual picture. It is an opportunity for you to provide detail and connect with the listener to demonstrate how important your point is.
- Try to answer each question in 15-20 seconds.
- Sound confident – you have a lot of information and personal experience to offer; listeners should hear your confidence.
- Make it personal – radio is a personal medium; stories and anecdotes connect with listeners.

Television

Television is very emotional and uses visuals. Don't be nervous if a camera is around…follow these suggestions and you won't even notice it's there:

- When being interviewed, do not look at the camera. Focus on the interviewer just like you are having a conversation with someone.
- Try and speak with as few "umm's" as possible. Try to rehearse what questions you think they will ask so you are prepared.
- Television news stories are short pieces that need to tell a story in a very compressed amount of time. Stick to your key messages and try and think of some quotes that will play back in 5 or 10 second segments.
- Body language is important. Do not fold your arms or put your hands in your pockets. This does not come across well on camera. Use your hands to gesture occasionally (shows you are passionate about the issue), but generally keep them at your side. If you are uncomfortable with this, try holding a notebook or a file folder.
- If you are seated in a chair that moves, don't swivel.
- Wear solid, bright colors that are "TV-friendly."

For More Information

Tips for Working with Media

Canadian Diabetes Association Media Guide – www.diabetes.ca/files/election_kit_2006/Module%206%20-%20News%20Release%20or%20Media%20Event%202005-06.doc

Preparing for a Media Interview – www.fullcirc.com/rlc/mediainterviewprep.htm

Appendix A *– Canada Health Act*

The principles of the Canada Health Act:

Public Administration – The health-care insurance plan of each province and territory must be carried out on a non-profit basis by a public authority that is responsible to the provincial/territorial government. For example, a district health authority (DHA) or local integrated health network (LIHN) is a public authority and they report directly to provincial or territorial governments on their accomplishments and challenges.

Comprehensiveness – All medically necessary health services must be insured including hospitals, doctors, and dental surgeons.

Universality – Every person in the province/territory is entitled to the same level of health care.

Portability – Health insurance moves with you. Whether you move from one province or territory to another or leave the country for a brief period of time, you are insured.

Accessibility – Every person should have access regardless of their ability to pay whether they are healthy or not and regardless of their age.

Appendix B *– Sample Press Release*

This sample press release was developed by the Hospice Association of Ontario to raise awareness of hospice services. You can use this sample as a base to write a press release that highlights what challenges you have encountered. Used with permission.

FOR IMMEDIATE RELEASE
Recognizing End-of-Life Care
Canadians Wish to Remain at Home during the Last Stages of Life
Hospice Awareness Week 2004 – October 10 - 17

First paragraph highlights the problem.

Toronto, October 10, 2004 – According to a national poll conducted by Ipsos Reid and released September 2004, more than 90 percent of Canadians want to die at home, yet 75% still die in hospitals. Only 15% of Canadians receive quality end-of-life care. And only 6% of people who care for family members facing end of life believe they could care for their loved one at home without integrated practical and emotional support provided by hospices.

The body of the release should highlight relevant facts and include quotes that will peak the reporter's interest.

These numbers, as well as Canada's aging demographics and increasing incidence of cancer and other diseases, provide a stark picture of the growing need for the care and compassion provided by hospices such as Bayview Community Hospice in Toronto or Hospice Northwest in Thunder Bay.

October 10th to the 17th marks Hospice Awareness Week across the province, and it has never been more important to recognize the gift of time, care and humanity that hospices provide in more than 450 communities throughout Ontario.

"In 10 years," said Janet Napper, Executive Director of the Hospice Association of Ontario, "our membership has experienced a growth rate of 1000%. Across Ontario our member hospices have seen an explosion in need for compassionate end-of-life care services, our members now represent 13,300 volunteers who dedicate 630,000 hours of service each year in communities across Ontario. Helping more and more people live fully until the end of life is our goal," says Ms Napper.

Helping people means providing ongoing emotional, psychological and spiritual support to people who are dying. For family members, it means being able to have someone relieve them of their care-giving role, to provide respite support. It also means providing emotional and bereavement support, on average, to five family members.

This year marks the 15th Anniversary of the Hospice Association of Ontario and never before have we seen the kind of momentum that is building towards a societal movement for quality of life during the last stages of life. Adequate funding of community services is vital if we are to provide the type of home based compassionate care Canadians seek when living with a life-threatening illness such as cancer, ALS or AIDS.

The final paragraph should include a "call to action." It should tell the reader what you are wanting the end result to be.

"As a society we often fear death more than we recognize the richness of life at end of life," says Hospice Association of Ontario Chairman, Bruce Peer. "All citizens have the right to die with dignity, free of pain, surrounded by their loved ones in a setting of their choice. Hospice palliative care provides the practical, emotional, spiritual and bereavement care necessary to ensure quality of life through the final stages of life. Hospice Week 2004 marks a celebration of life, recognition of the many gifts caring for one another holds," noted Mr. Peer.
-30-

Contact:
Put your contact information here

Appendix C *– Sample Op-ed Piece*

This Op-ed piece is written by Dr. Barbara Wylie, Chief Executive Officer of the Canadian Cancer Society. It presents the challenges, gives statistics to back up these challenges, provides potential solutions and then has a call to action. Used with permission.

By BARBARA WHYLIE
Globe and Mail Update
June 8, 2004

During the 37 days of this federal election campaign, almost 7,000 Canadians will die of cancer. Probably they will be strangers to you. Maybe, though, one of them will be someone you know a friend, a parent or a spouse.

Cancer wounds everyone in our society. It is the leading cause of premature death in Canada. In 2000, it eliminated an unimaginable 950,000 years of potential life and it's about to do much worse.

We are on the brink of a cancer epidemic. Between 1990 and 2010, the number of new cancer cases diagnosed in Canada each year will more than double. Why the increase? First, cancer is poised to strike the large baby-boom generation because as Canadians age, their risk of getting cancer increases. Second, the Canadian population is growing. The more people there are, the more cases of cancer will be diagnosed.

We must act now to prevent a national disgrace. Our new Parliament should heed the advice of the World Health Organization. In 2002, the WHO recommended that nations develop cancer control programs to reduce the number of new cancer cases and improve quality of life for people with cancer. This has not yet been done in Canada.

Just a few weeks ago, the WHO also endorsed a global strategy on diet, physical activity and health. This strategy stresses the need to prevent non-communicable diseases, including cancer, through diet and physical activity. The WHO strategy underlines the importance of cancer prevention and reminds us how much we need a Canadian strategy to control cancer - one that includes prevention.

Cancer-control strategies can save many thousands of lives. In the mid-1980s, targets for cancer control were set by the European Union's program known as Europe Against Cancer. Two members, Finland and Austria, reached their targets, reducing cancer by 15 per cent. Other countries such as the United Kingdom, Italy and Luxembourg achieved very significant reductions.

Canada is one of the few nations in the developed world that has failed to implement a strategy for cancer control. We are now paying for that failure with our very lives. Canadians are more likely to get some types of cancer than citizens of comparable nations such as the United Kingdom, Australia, Japan, Sweden or Singapore, and they are more likely to die of it.

Elements of cancer care in Canada are world-class, but the Canadian approach to cancer control is inconsistent, flawed and driven by political expediency rather than medical realities. Cancer prevention in Canada is pathetically underfunded and fragmented. Cancer patients experience uneven levels and quality of service. Cancer care is crippled by a growing lack of health-care providers and inconsistent support of research.

All this must change and soon. Every year, 68,000 Canadians die of cancer.

The groundwork for a national plan to fight cancer has already been laid. The Canadian Cancer Society and the National Cancer Institute of Canada have come together to advocate a comprehensive strategy. But agencies and individuals can only do so much. Health Canada, the Canadian Association of Provincial Cancer Agencies and more than 700 experts and cancer survivors have shared in this process. But, if a national strategy is to become a reality, at some point very soon, the federal government must provide leadership and funding.

Appendix D *– Sample Letter to the Editor*

Dear Editor,

Currently in Canada, only 5 to 15% of Canadians have access to quality hospice palliative care. The number of Canadians that are expected to die will increase by 33% by the year 2020. Our health care system resources are stretched. Even within the province I live in, the services and programs vary greatly depending on which jurisdiction the patient and their loved ones reside.

Access to quality hospice palliative end-of-life care is essential for every patient and their loved ones. Hospice palliative care aims to relieve the suffering at end of life. Even though Canadians should be able to access these specialized programs and services in acute care, long-term care, community and home settings, this is often not the case.

My experience has been…
(This is your opportunity to highlight your situation, present options for solutions and a call to action to move your challenge forward).

Everyone experiences death and most of us do not realize what challenges there are at end of life until we are living that situation. Every Canadian has the right to die with dignity, surrounded by their loved ones, free of pain, in a setting of their choice. We have a lot of work to do to make that happen and I for one am more than willing to ensure that other families will benefit from the experience of losing my loved ones.

Appendix E *– Sample Letters to Elected Officials*

John Doe
555 Main Street
Anywhere, Province H0H 0H0

Home Phone: (555) 5555

June 17, 2002

Honourable Jane Doe
Minister of Health
Government of Province

Dear Honourable Minister,

I have reached a point of desperation, and I need your assistance. Please help me.

I wrote to you on January 1, 2004 describing my plight in seeking approval for my medication. Although I applied at the end of November 2003, my application has been stalled in the system several times. Although my medical professional has supported the use of medication x, the provincial government still insists that I use medication y.

All this information was supplied to the appropriate person and yet this issue has yet to be resolved. My current supply of medication x is running low and I have had to resort to using the medication that is prescribed to another patient. It could take weeks or months for this drug to become effective again if I have to stop treatment.

Ms. Minister, I feel better now than I have in the almost 10 years since my diagnosis. I own and operate a small contracting business here in Anywhere, thus contributing to the financial prosperity of our province. Knowing what will happen if I have to go off medication x again, I will not be able to continue running my business. Don't let that happen. I need to receive an approval on my application for coverage and I need it within days to prevent a lapse in doses.

I know that my problem is not unique and that others are in the same situation. I would like to meet with you to discuss some solutions that would help people in this situation. I will contact your office in the next 14 days to request a time for a meeting. I look forward to working with you towards a positive outcome.

Respectfully yours,

Patient x

— Adapted from the Canadian Arthritis Bill of Rights.

1-877-203-INFO (4636)
www.living-lessons.org

Living Lessons® is an ongoing project of the Canadian Hospice Palliative Care Association (CHPCA) and hospice palliative care organizations across Canada, and is part of The GlaxoSmithKline Foundation's commitment to promoting quality of life during the end stage of life in Canada. The Living Lessons® campaign is focused on initiating public dialogue and promoting understanding, support and better access to quality care in the last stages of life.

Influencing Change:
A Patient and Caregiver Advocacy Guide

Additional copies can be obtained from the Canadian Hospice Palliative Care Association national office.