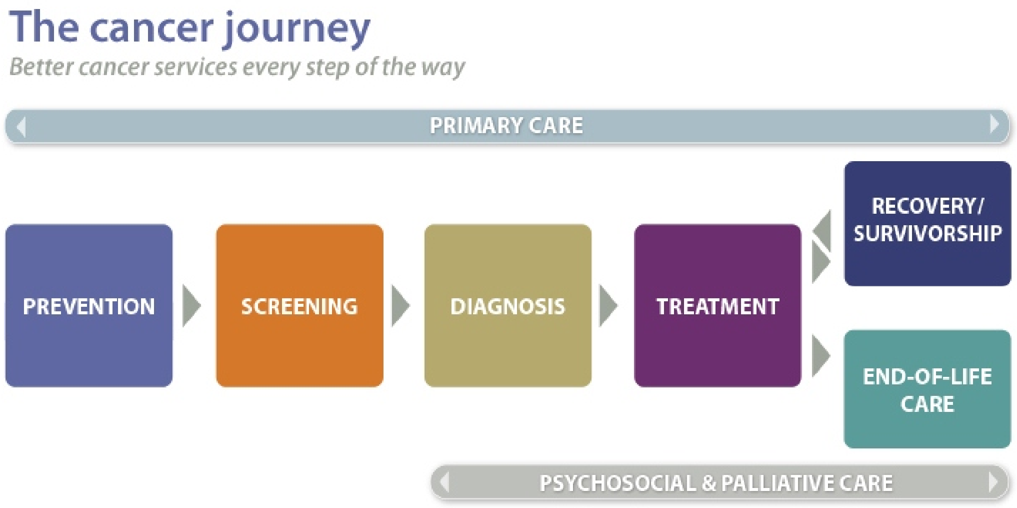
Cancer Care Ontario

Psychosocial & Palliative Care Pathway

Disease Pathway Management Secretariat
Version 2013.01



The cancer journey

Better cancer services every step of the way

PRIMARY CARE

PREVENTION
SCREENING
DIAGNOSIS
TREATMENT
RECOVERY/ SURVIVORSHIP
END-OF-LIFE CARE

PSYCHOSOCIAL & PALLIATIVE CARE

Disclaimer

The pathway is intended to be used for informational purposes only. The pathway is not intended to constitute or be a substitute for medical advice and should not be relied upon in any such regard. Further, all pathways are subject to clinical judgment and actual practice patterns may not follow the proposed steps set out in the pathway. In the situation where the reader is not a healthcare provider, the reader should always consult a healthcare provider if he/she has any questions regarding the information set out in the pathway. The information in the pathway does not create a physician-patient relationship between Cancer Care Ontario (CCO) and the reader.

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Pathway Disclaimer

This pathway is a resource that provides an overview of the psychosocial and palliative care that an individual in the Ontario cancer system may receive.

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Introduction

This Pathway describes the standard of care and support that all cancer patients and their families should receive, regardless of their cancer type and stage and at critical time points in the treatment phase of their cancer journey including:

- Confirmation of cancer diagnosis
- Start of treatment
- Regular intervals during treatment
- Post-treatment
- Transition to survivorship
- Progression to advanced disease and/or incurable disease
- Transitions or re-appraisal (e.g., in a family crisis, during survivorship, when approaching death, bereavement)

This pathway is designed to be a standalone document but also complements the references to Psychosocial Oncology, Palliative and End-of-Life Care in the disease site specific pathways. This ensures the integration of Psychosocial, Palliative and End-of-Life Care into all relevant disease site specific pathways.

Goals of Care Discussions

Discussion regarding both illness understanding, goals of care and expectations must occur and be regularly revisited along the illness trajectory given their iterative nature. Effective communication is critical amongst all health care teams as well as between health care teams and patients and families to ensure consistent messaging and planning throughout the illness trajectory.

Relevant Definitions

(**NOTE**: Definitions and Model of Care under revision. Definitions subject to change upon completion.)

Psychosocial Oncology focuses on a whole-person approach to cancer care, addressing the social, psychological, emotional, spiritual and functional aspects of the patient journey through a interdisciplinary team and service providers from various care settings. Psychosocial oncology programs/services may include professionals and specialists such as **social workers, psychologists, psychiatrists, advanced practice nurses, clinical counselors, marriage and family therapists, registered dietitians, rehabilitation specialists, spiritual care providers and speech and language specialists** (Canadian Association of Psychosocial Oncology, Standards of Psychosocial Oncology Health Services for Persons with Cancer and their Families, 2010). Cancer places a heavy emotional toll on patients and their families; psychosocial oncology is an essential service to improve the quality of life for people affected by cancer. Primary care providers, such as general practitioners, family physicians and nurse practitioners, should be involved in identifying and addressing psychosocial needs of patients throughout their illness trajectories.
Refer to **EBS # 19- 3**

Palliative Care is an approach that improves the quality of life of patients and their families facing the problems 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 (World Health Organization).
Palliative care is not limited to the end-of-life (i.e., last days or weeks). Studies show significant benefits, including improved quality of life, reduced psychological distress, fewer costs and longer survival when palliative care is initiated much earlier in the illness trajectory (Temel et al NEJM 2010). To improve earlier identification of patients who could benefit from a palliative care approach (even alongside treatments to control the disease), the "Surprise question" has been successfully used ("Will you be surprised if this patient died in the next 12 months?", Lynn J 2005) However, palliative care should ideally be considered even earlier. Palliative care is provided at a **primary level (referred to as Palliative Care Approach) by primary care providers, oncologists** and at a specialized level, by specialist-level palliative care professionals for patients with more complex needs (Quill TE, Abernethy AP. NEJM 2013).

End- of-Life Care End-of-Life (EOL) Care refers to the Palliative Care delivered to individuals and patients in the last months of life (defined in this pathways as the last 3 months of life).

Pathway Legend

▭ **Managing Physician(s) and Care Team**
⬚ **Possible Action or Result**
◇ **Referral to**

Effective, honest and sensitive communication is critical between health care teams and patients and families to ensure consistent and realistic messaging throughout illness trajectory.

IDENTIFY

Identify patients who could benefit from a palliative care approach early in the illness trajectory. At the very least use the following **screening question:**

"Would you be surprised if this patient were to die in the next 6 -12 months?"

If answer is **NO**

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Initiate Palliative Care Approach alongside treatments to control the disease if these are still appropriate. Start by screening for symptoms and functional status as outlined in "SCREEN" and continue along the pathway. Consider a referral to specialized palliative care services if the needs are complex*.

If answer is **YES**

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Screen for and manage symptoms and functional status as outlined in "SCREEN"

*If patient is nearing the last weeks of life proceed to End of Life Care Pathway (page 6 of 7).

SCREEN

Screen patient regularly for distress and other needs using validated screening tools.

This includes distress and needs in the following domains:
Physical, psychological, emotional, spiritual, social, nutritional, informational, practical, loss
Be aware of situations in which patients are unable to self-report. (e.g., delirium, cognitive impairment)

Edmonton Symptom Assessment System (ESAS)
- Refer to **ESAS**
- Emotional and physical domains
- All patients as regularly as possible

The ESAS assesses emotional and physical domains. Use other methods to assess social & spiritual domains.

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Palliative Performance Scale (PPS) or Eastern Cooperative Oncology Group Performance Status (ECOG) or the patient self-report version of the ECOG (referred to as Patient-ECOG or Patient Reported Functional Status (PRFS))
- Refer to **PPS**
- If PPS ≤ 50 or ECOG/Patient ECOG (PRFS) = 4 initiate discussions of End of Life Care. Proceed to End of Life Care Pathway (page 6 of 7).

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Additional validated screening and diagnosis tools may be used based on specific needs (e.g., tools for delirium, depression, anxiety, social needs, sexuality needs, spiritual needs).
- Canadian Problem Checklist
- FICA for spiritual and religious needs
- McGill Quality of Life
- Confusion Assessment Method (Delirium)
- Distress Thermometer
- PGSGA (nutritional needs)

Symptoms

🟩 **Mild Symptoms** (ESAS 1-3)

🟨 **Moderate Symptoms** (ESAS 4-6)

🟥 **Severe Symptoms** (ESAS 7-10)

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Functional Status

PPS ≤ 70% or ECOG/Patient-ECOG/PRFS = 3:
Reconfirm or initiate goals of care conversations

PPS ≤ 50% or ECOG/Patient-ECOG/PRFS = 4:
Reconfirm or initiate end-of-life care conversations

ASSESS

Explore symptoms and needs across ALL domains in more detail through history and examination.
Type and timeliness of assessment will depend on the severity, interference with life, urgency and complexity of the symptoms or needs identified.
Consider investigations to elucidate cause(s) of symptoms.

Symptom Management Guides-to-Practice provide guidance for assessment of the following symptoms:**

Pain	**Depression**
Dyspnea	**Appetite**
Nausea & Vomiting	**Fatigue**
Delirium	**Oral Care**
Anxiety	**Bowel Care**

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Interprofessional Care Plans
Refer to **Collaborative Care Plans**

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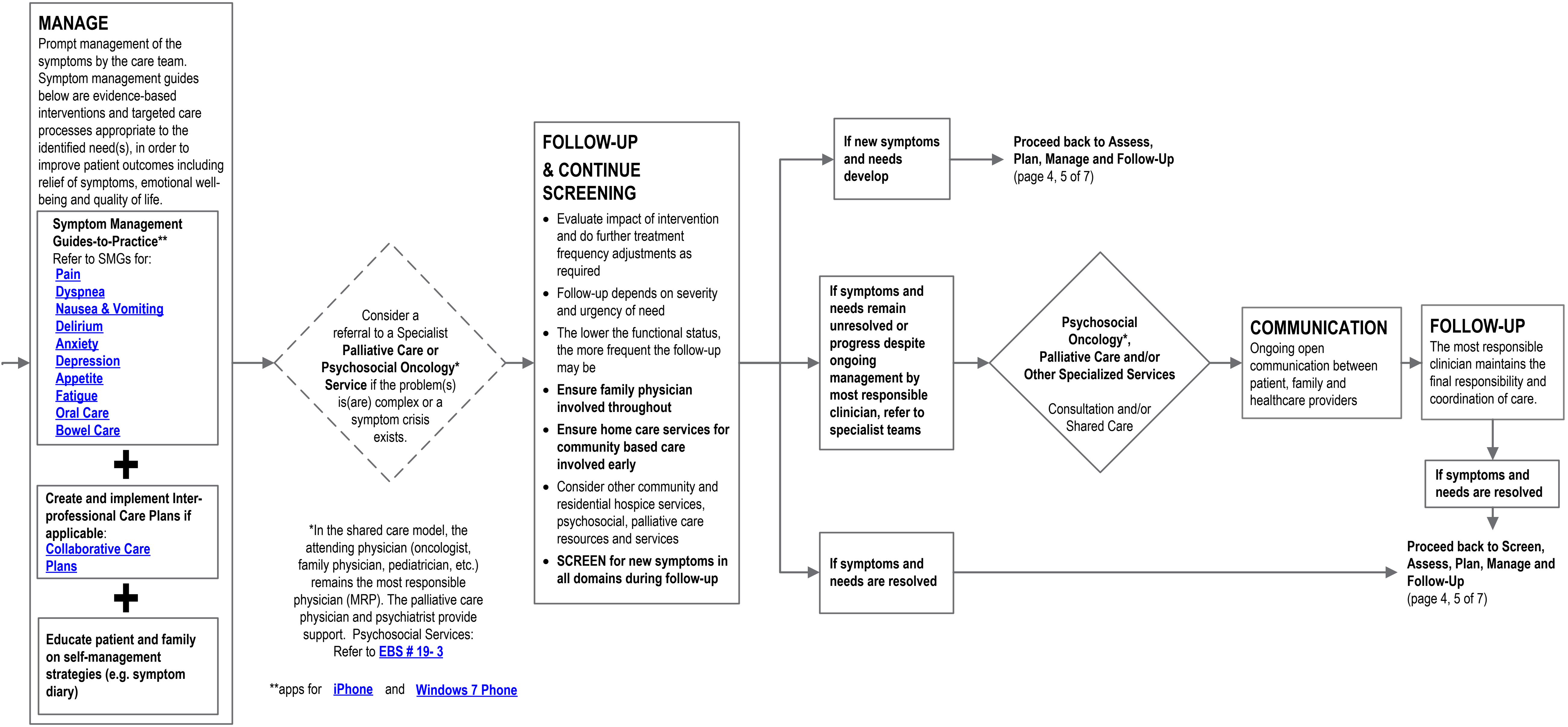
Proceed to prompt Management and Follow-up on page 5 of 7.

Manage and Follow-Up Across Illness Trajectory

Effective, honest and sensitive communication is critical between health care teams and patients and families to ensure consistent and realistic messaging throughout illness trajectory.



MANAGE

Prompt management of the symptoms by the care team. Symptom management guides below are evidence-based interventions and targeted care processes appropriate to the identified need(s), in order to improve patient outcomes including relief of symptoms, emotional well-being and quality of life.

Symptom Management Guides-to-Practice**

Refer to SMGs for:
- Pain
- Dyspnea
- Nausea & Vomiting
- Delirium
- Anxiety
- Depression
- Appetite
- Fatigue
- Oral Care
- Bowel Care

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Create and implement Inter-professional Care Plans if applicable:
Collaborative Care Plans

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Educate patient and family on self-management strategies (e.g. symptom diary)

Consider a referral to a Specialist **Palliative Care or Psychosocial Oncology* Service** if the problem(s) is(are) complex or a symptom crisis exists.

*In the shared care model, the attending physician (oncologist, family physician, pediatrician, etc.) remains the most responsible physician (MRP). The palliative care physician and psychiatrist provide support. Psychosocial Services: Refer to EBS # 19- 3

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FOLLOW-UP & CONTINUE SCREENING

- Evaluate impact of intervention and do further treatment frequency adjustments as required
- Follow-up depends on severity and urgency of need
- The lower the functional status, the more frequent the follow-up may be
- **Ensure family physician involved throughout**
- **Ensure home care services for community based care involved early**
- Consider other community and residential hospice services, psychosocial, palliative care resources and services
- **SCREEN for new symptoms in all domains during follow-up**

If new symptoms and needs develop → **Proceed back to Assess, Plan, Manage and Follow-Up** (page 4, 5 of 7)

If symptoms and needs remain unresolved or progress despite ongoing management by most responsible clinician, refer to specialist teams → **Psychosocial Oncology*, Palliative Care and/or Other Specialized Services** Consultation and/or Shared Care → **COMMUNICATION** Ongoing open communication between patient, family and healthcare providers → **FOLLOW-UP** The most responsible clinician maintains the final responsibility and coordination of care. → **If symptoms and needs are resolved**

If symptoms and needs are resolved → **Proceed back to Screen, Assess, Plan, Manage and Follow-Up** (page 4, 5 of 7)

Effective, honest and sensitive communication is critical between health care teams and patients and families to ensure consistent and realistic messaging throughout illness trajectory.

Pathway Target Population:

Individuals with cancer approaching the last 3 months of life and their families.

While this section of the pathway is focused on the care delivered at the end of life, the palliative care approach begins much earlier on in the illness trajectory.
Refer to "Screen, Assess & Plan" Pathway on page 4.

Triggers that suggest patients are nearing the last few months and weeks life

- **ECOG/Patient-ECOG/PRFS = 4**
  OR
- **PPS ≤ 50**
- **Declining performance status/functional ability**
- **Gold Standards Framework indicators of high mortality risk**

Screen, Assess, Plan, Manage and Follow-Up (pages 4, 5)

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End of Life Care planning and implementation
Collaboration and consultation between specialist-level care teams and primary care teams

End of Life Care

☐ **Discuss and document goals of care with patient and family**

- Assess and address patient and family's information needs and understanding of the disease, address gaps between reality and expectation, foster realistic hope and provide opportunity to explore prognosis and life expectancy, and preparedness for death
- Introduce patient and family to resources in community (e.g., day hospice programs)

☐ **Revisit advance care planning and discuss treatment withdrawal or withholding** (e.g., advance directives, surrogate/substitute decision maker, code status, feeding tubes etc.)

- Review regularly, particularly when there is a change in clinical status
- Refer to **EBS # 19- 1**

☐ **Screen for specific end of life psychosocial issues**

- Specific examples of psychological needs include: anticipatory grief, past trauma or losses, preparing children (young children, adolescents, young adults), guardianship of children, death anxiety
- Consider referral to available resources and/or specialized services

☐ **Identify patients who could benefit from specialized palliative care services (consultation or transfer)**

- Discuss referral with patients and family

☐ **Proactively develop and implement a plan for expected death**

- Explore place-of-death preferences and assess whether this is realistic
- Explore the potential settings of dying and the resources required (e.g., home, residential hospice, palliative care unit, long term care or nursing home)
- Anticipate/Plan for pain & symptom management medications and consider an emergency home kit for unexpected pain & symptom management
- Preparation and support for family to manage
- Discuss emergency plans with patient and family (who to call if emergency in the home or long-term-care or retirement home)
- Refer to **Collaborative Care Plans**

☐ **Home care planning**

- Connect with CCAC early (not just for last 2-4 weeks)
- Ensure resources and elements in place
- Consider an emergency home kit with access to pain, dyspnea and delirium mediation
- Identify family members at risk for abnormal/complicated grieving and connect them proactively with bereavement resources

Effective, honest and sensitive communication is critical between health care teams and patients and families to ensure consistent and realistic messaging throughout illness trajectory.

Patient Death

At the time of death:

- ☐ Pronouncement of death
- ☐ Completion of death certificate
- ☐ Allow family members to spend time with loved one upon death, in such a way that respects individual rituals, cultural diversity and meaning of life and death
- ☐ Implement the pre-determined plan for expected death
- ☐ Arrange time with the family for a follow-up call or visit
- ☐ Provide age-specific bereavement services and resources
- ☐ Inform family of grief and bereavement resources/services
- ☐ Initiate grief care for family members at risk for complicated grief
- ☐ Encourage the bereaved to make an appointment with an appropriate health care provider as required

Bereavement Support and Follow-Up

- ☐ Offer psychoeducation and/or counseling to the bereaved
- ☐ Screen for complicated and abnormal grief (family members, including children)
- ☐ Consider referral of bereaved family member(s) and children to appropriate local resources, spiritual advisor, grief counselor, hospice and other volunteer programs depending on severity of grief

Provide opportunities for debriefing of care team, including volunteers