The Fundamentals of Hospice Palliative Care

Program Guide

A Resource Guide for Health Care Providers
Acknowledgements

The Palliative Pain & Symptom Management Consultation Program of Southwestern Ontario, St. Joseph’s Health Care London acknowledge the contributions of our colleagues in Hospice Palliative Care who have developed, refined and promoted hospice palliative care education programs throughout Southwestern Ontario. Because of their ongoing commitment, health care providers throughout Southwestern Ontario have a broader knowledge of Hospice Palliative Care and provide better end-of-life care.

The Palliative Pain and Symptom Management Consultation Program (PPSMCP) of Southwestern Ontario, St. Joseph’s Health Care London provides multi-disciplinary hospice palliative care education and consultation services to health care providers across the continuum of care. This Program is funded by the Ontario Ministry of Health and Long-term Care through the Local Health Integration Networks (LHINs). The primary purpose of the PPSMCP is to build the capacity of service providers to provide quality hospice palliative care.

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Please reference as follows:

How to Use This Program Guide

This Program Guide provides a written resource to the learners who actively participate in the Fundamentals of Hospice Palliative Care Program (Core and Enhanced Streams).

This Program Guide has been developed as part of a blended learning strategy that includes:

- Independent content review and reflection (Program Guide and supplementary material)
- e-Learning Modules
- Peer-to-Peer Exchange
- A Reflective Activity
- Case-Based Learning Sessions
- Coaching

The Fundamentals of Hospice Palliative Care Program (Core)

The core Fundamentals program is intended for those working in the health system who have an interest in developing his or her capacity related to hospice palliative care. Roles can include:

- Volunteers
- Personal Support Workers
- Recreational therapists
- Housekeeping
- Dietitians
- Social Workers
- Developmental Service Managers
- Students (e.g. health science, PSW, RN, Gerontology)
- Case coordinators
- Directors of Care
- Health Administration
- Occupational Therapists
- Speech Language Professionals
- Physical Therapists
- Nurse Practitioners
- Registered Nurses
- Registered Practical Nurses
- Pharmacists
- Physician / Family Health Team staff
- Specialty care services (e.g. renal, obstetrics, ICU, Acute Care)
- Mental health case managers
- Emergency Medical Services
- Spiritual care providers

Following the completion of this course, the learner will:

1. Demonstrate sensitivity, understanding and respect for the individuality of the person, family and team/caregivers
2. Identify and understand issues associated with illness and bereavement (domains of issues)
3. Effectively communicate with the person, family and team
4. Recognize and report changes in any of the domains of issues associated with illness and bereavement
5. Provide hospice palliative supportive care strategies
6. Actively learn and develop personally and contribute as part of a team and organization
7. Demonstrate sensitivity to the impact of personal attitudes, behaviours and values on the illness experience of the person, family and team/caregivers

The Fundamentals of Hospice Palliative Care Program (Enhanced)

The Enhanced stream of the Fundamentals Program is intended for Registered Nurses, Registered Practical Nurses and Nurse Practitioners with an interest in developing his or her capacity related to hospice palliative care in a clinical setting.

In order to participate in the Enhanced stream of the Fundamentals program, the learner must additionally:

1. Be a Nurse Practitioner (NP), Registered Nurse (RN) or Registered Practical Nurse (RPN)
2. Have successfully completed the “Core” stream of the Fundamentals program
This Program Guide was produced by Gestalt Collective for The Palliative Pain & Symptom Management Consultation Program of Southwestern Ontario, St. Joseph’s Health Care London.

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# Table of Contents

Introduction .............................................................................................................. 4

Chapter 1: Introduction to Dying and Death ................................................................. 11

Chapter 2: Introduction to Hospice Palliative Care ...................................................... 20

Chapter 3: Disease Management Domain ................................................................. 38

Chapter 4: Physical Domain ...................................................................................... 63

Chapter 5: Psychological Domain ............................................................................. 85

Chapter 6: Spiritual Domain ..................................................................................... 100

Chapter 7: Social Domain ......................................................................................... 113

Chapter 8: Practical Domain ..................................................................................... 127

Chapter 9: End-of-Life Care and Death Management Domain .................................. 137

Chapter 10: Loss and Grief Domain ......................................................................... 154

Chapter 11: Occupational Wellness ......................................................................... 176

Chapter 12: Assessment Review (Fundamental Enhanced) ....................................... 188

Chapter 13: Pharmacological Review (Fundamental Enhanced) .............................. 201

Glossary .................................................................................................................... 214

Tools ......................................................................................................................... 219

Peer-to-Peer Exchange ............................................................................................ 236

Reflective Activity .................................................................................................... 238

Fundamentals Cases ............................................................................................... 240

Fundamentals Enhanced Coaching ......................................................................... 244
Chapter 1

Introduction to Dying and Death
Understanding Dying

In hospice palliative care, health care providers support persons with a life-limiting illness and their family members on a journey towards death. It is therefore critical that health care providers have knowledge and comfort with dying and death in order to create a space in which healing of mind and spirit is possible.

Death is the inevitable outcome of being born and is a journey common to all living things. Humans, by virtue of their ability to think and reason, are aware at both a conscious and unconscious level of their eventual demise. The thought of death usually arouses a variety of anxieties and fears.

Death Anxiety

Firestone and Catlett define death anxiety as “a complex phenomenon that represents the blend of many different thought processes and emotions: the dread of death, the horror of physical and mental deterioration, the essential feeling of aloneness, the ultimate experience of separation anxiety, sadness about the eventual loss of self, and extremes of anger and despair about a situation over which we have no control”.1

Emotional Responses to Death Awareness:2

In the face of death, fear often arises about one or more of the following:

- **Fear about the cessation of all consciousness at the moment of death:** This may lead to angst related to aging, deterioration in health, thought of being on one's deathbed and the omnipresent prospect of death throughout life.
- **Fear about the dying process:** This often leads to the avoidance of thinking about the process of dying and of association with the sick and dying. When confronted with deterioration in others we are confronted with our own mortality.
- **Fear about being on one's deathbed:** This fear confronts us with the immediacy of the inevitable, along with the fear of physical suffering, frustration at lack of mobility, and embarrassment at the possibility of losing control of physical functioning and being totally dependent on others.
- **Fear of death:** Fear of death itself can present as a fear of the unknown or fear of the seemingly randomness and impersonal manner in which death strikes. It has been articulated using terms such as dread, angst, anxiety and terror and is related to the uncertainty regarding the time and place of our own disappearance from life; of never again seeing, hearing, tasting, smelling, feeling the sensation of pain or pleasure.
- **Fear about the final separation from loved ones:** This fear is rooted in feelings of aloneness, isolation, and disconnection. Each separation and farewell becomes a reminder of the ultimate separation at death.
- **Anger about deprivation:** This refers to the fury of being deprived of those that one has come to love and cherish. Associated with this comes a sense of feeling cheated and robbed.
- **Shame:** This feeling can result from a sense of one’s body being deficient.
- **Guilt:** This can be related to bringing children into a world where they will face suffering and loss, and can lead to parents to be over protective of their children. In addition, people can experience death guilt or survivor guilt (i.e. self-condemnation for having lived when others have died such as with survivors of the holocaust), or existential guilt and regret from not having lived life to the fullest.
- **Sense of absurdity and meaninglessness of life:** This refers to persistent feelings of despair and hopelessness, potentially increasing suicide risk.
- **Sadness:** Sadness arises when one contemplates the death of oneself or of loved ones. Anticipatory grief and mourning often lends new meaning to life and enhances the ability to deal with distress.
- **Anguish:** This refers to deep worry and concern about the economic and psychological welfare of those one is leaving behind.

Neurotic emotional responses to the prospect of dying can lead to maladaptive behaviours that interfere with the ability to cope with life. Maladaptive behaviours include: obsessive compulsive disorder, hysteria, sadism, masochism, agoraphobia, panic disorder, as well as certain perversions and fetishes.

Historical Perspectives on Death

There are a number of ways in which dying and death can be understood. Sociologist Tony Walter speaks of death in terms of 3 ideal types: traditional, modern and neo-modern.3 Chart 1.1 has been adapted from Walter and indicates these changes over time. Western society's death culture is made up of these varied and conflicting elements. It must also be noted that different members of the same family may have contradicting ideas about death and how it should be approached.
In the early 19th century, hospitals offered little chance of curative care, therefore death often occurred in the home. In the 1930’s men were conscripted to war and women began taking on more work outside the home, thus decreasing opportunity and access to home care. The overwhelming sense of responsibility for veteran care influenced a rapid increase in the number of hospitals, resulting in more hospital-based care. Additionally, advances in medicine led towards a shift of focus from the person’s subjective experience to observation and technological management in a hospital setting.\(^5\)

In the Medicare era (1940–1969) federal initiatives were introduced which supported publicly funded hospital care. ‘Expert’ care in hospitals extended to care of the dying, however the comfort-focused care required by these individuals seemed to conflict with the growing medical model. During this era, the acknowledgement of death was replaced by hope to avoid death, thus making in-home comfort care less desirable.

After 1970 the increased number of hospital beds, surgical advances and women continuing to work outside the home reduced the possibility for family caregiving in the home. Palliative care was formally introduced in 1975 with two units opening in hospital settings.\(^6\) Criticisms were raised about cure-oriented in-hospital care and people began to feel that futile treatments may prolong the dying process.

In the decades since, there has been a growth in the number of locally funded hospices and a growing interest in natural death outside of the hospital setting. A greater incidence of DNR status for those dying in hospital and advances in palliative care guidelines, advanced directive laws and stronger support for palliative care has emerged.

There has been a major shift in the way that end-of-life care is provided today. The reality is that the Province of Ontario is facing escalating health care costs, and as a society, we are being challenged to set priorities. With new treatments and technology, people with life-limiting illnesses can be kept alive for many years. Management of chronic illness along with end-of-life care is a major concern for the health care system. There is also a growing realization that quality of life, as defined by the person with the illness, is as important a goal as prolonging life for its own sake. Health care professionals are being challenged to rethink their attitudes towards death and to more actively engage persons and families in setting goals of care and treatment decisions.

Families are being required to participate to a greater degree in the care of their loved ones who are chronically ill and dying. Following years of advocacy, this has lead to the development of Compassionate Care Benefits, which are now a part of the Employment Insurance System in Canada.

The current vision of the Ministry of Health and Long Term Care in Ontario is one in which the majority of deaths will occur in the home with a combination of professional and family caregivers providing support for the dying person. Professional services are aimed at being proactive in identifying and addressing issues and preparing for crises so that visits to emergency departments and hospitalization can be avoided.

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**Chart 1.1: Historical Comparative Analysis\(^\text{5}\)**

<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>Bodily context</td>
<td>Death quick and frequent</td>
<td>Death hidden, institutionalized</td>
<td>Death prolonged, after long period of chronic illness</td>
</tr>
<tr>
<td>Social context</td>
<td>Community</td>
<td>Publicly managed/ privately felt</td>
<td>Private and public intertwined</td>
</tr>
<tr>
<td>Authority</td>
<td>Religion</td>
<td>Medicine</td>
<td>Self</td>
</tr>
<tr>
<td>Social death</td>
<td>Follows physical death</td>
<td>Precedes physical death</td>
<td>At physical death</td>
</tr>
<tr>
<td>Values</td>
<td>Respect for the deceased, for transition and for social mores</td>
<td>Dignity, privacy, independence, a fighting spirit</td>
<td>Personal growth, sharing autonomy, informed choice</td>
</tr>
</tbody>
</table>

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Factors that Impact Attitudes Towards Death

Hadad explains that our family and peers, religion and culture, language, literature and the arts, and the media influence our attitudes toward death. What parents say and do informs a child’s view of life and of the world. If dying and death is hidden, children tend to form their own potentially frightening ideas of death. If stoicism and avoidance are the behaviours that the family promotes, children learn that emotions should not be displayed. As children grow, peer groups begin to have greater influence. In addition, interactions with other families may expose the child to other ways of behaving in the presence of dying and death. Open discussion of the topic along with acknowledgement of the feelings and reactions when confronted with a situation involving dying and death can help a child to recognize that there are many ways of coping with death and there is no right or wrong way.

Religious backgrounds impact the formation of attitudes toward death. For some, death may be the end of life on the physical plane and may carry with it the fear of final judgment. For others, death may be viewed as the end of suffering and the chance for a peaceful rest in a better place where all loved ones will join together in time. Death may also be a time of rest before entering into a new body and beginning life’s journey again. Religious beliefs may also affect other end-of-life issues such as blood transfusions, artificial feeding and hydration, abortion, assisted suicide and euthanasia.

In addition to religion, culture has an impact on how one views dying and death and has a significant effect on conversations, choices, and the decision making process. In some cultures, the dying person is not to be told that he or she is dying.

Language around death can indicate certain beliefs and attitudes towards death. Euphemisms which are vague such as “lost” or “passed on” can distance the bereaved from the reality. Phrases such as “kicked the bucket” may devalue and make light of death.

Literature and the arts offer many diverse ways of considering the themes of dying, death and bereavement. Music, opera, and novels, both fiction and nonfiction, offer us many thought provoking opportunities to contemplate our own attitudes around death and dying.

The media has a great impact on attitudes towards death. We are constantly being informed of death with news reports on war, assassinations, murder, accidents and catastrophic events. Over time, such exposure may lead us to become desensitized to death.

The portrayal of death in other types of media can lend an understanding of attitudes towards death. Often in movies, graphic scenes produce horror, while death on TV is frequently sanitized and unrealistically quick, for instance, exciting resuscitations insinuate that death can be avoided if we can just get to a hospital. In video games portrayal of death is often very graphic and the characters simply come back to life in the click of a key.

Other factors affect the way we approach death. Our social network, our financial situation, our gender and our age will all have an effect on the experience of death. The extent to which family members and friends are available will affect the ability to die at home. Our financial status will determine the availability of interventions that lead to enhanced comfort e.g. complementary therapies such as massage therapy. The economic state of the family may also affect one’s choices with regard to trials and alternative treatments. Women tend to outlive men and therefore women are more frequently widowed. Thus women frequently lack a primary caregiver in the home when they experience deterioration in their health as they age and approach death.

Ageism also factors into how we die. Ageism, also called age discrimination is stereotyping of and discrimination against individuals or groups because of their age. It includes a set of beliefs, attitudes, norms, and values used to justify a way of looking at older people as weak, frail and disabled. Prejudices toward the elderly may affect their access to care and how vigorously they are treated throughout the illness trajectory. Ageism may affect the autonomy of elders when caregivers go to family members for decisions instead of getting consent for treatments from a capable elder.

Ageism in health care could also be used to describe prejudice and discrimination against adolescents and children, including ignoring their ideas because they are too young, or assuming that they should behave in certain ways because of their age. Ageism affects the young in terms of mistaken caregiver beliefs that pain is not a serious consideration when dealing with infants, or that children do not have the right to be involved in life and death decision making. It seems that the younger the person the greater the attempt to prolong life despite suffering. Masera and Spinetta as part of a working group who developed the 6th edition of guidelines for assistance to terminally ill children with cancer advocate that health care providers avoid a ‘ruthless obstinacy’ approach and know when to move from cure-oriented therapy to palliative care.

There are many factors that may influence attitudes towards dying and death and an understanding of how different members within the family and within the team view death
will enable the caregiver to interact with more sensitivity and compassion.

**Self-Care**

As care providers and partners we bring our knowledge and skill to the bedside but we also bring our experiences, history and beliefs. Taking care of our own physical, emotional and spiritual well-being contributes to our being able to replenish ourselves from the struggles we witness. Therefore, we must balance caring for others with caring for ourselves.

Self-care can include eating well, exercising, taking time to do cherished activities, meditating, socializing or any other activity which helps us restore and refresh. Not attending to self-care can lead to a sense of burnout, compassion fatigue and a decreased ability to effectively function in your role.

**Self-Awareness**

As hospice palliative care providers involved in the care of the sick and dying, we are called upon to look death in the face, not as an enemy, but as a natural and inevitable part of life. We are called to embrace life in the face of death. The extent to which palliative care team members have confronted their own death anxieties may affect both their ability to understand the issues that the dying face as well as their ability to establish therapeutic relationships.

Self-awareness is an opportunity to reflect on our thoughts, feelings and motivations and is an essential component of working in a therapeutic relationship. Sharing feelings about death and dying with friends and colleagues and attempting to find meaning in our own existence can lead to death awareness. It allows us to be conscious of triggers for emotions and behaviours and is an opportunity for personal growth and discovery. This awareness can help us work with others to explore their wishes, values and beliefs. To be effective in our work we must be in touch with our own beliefs, issues and biases. Self-reflection helps sharpen this focus and equips us to more thoughtfully approach our fellow human beings.

**References**

1. Firestone R, Catlett J. Beyond Death Anxiety. New York; Springer Publishing Company, LLC: 2009; p.g.16
Chapter 1: Introduction to Dying and Death
Chapter 2

Introduction to Hospice Palliative Care
The dying process is an inevitable part of the human experience. Feared by many and understood by few, the journey toward death can be challenging. If the needs of a person who is dying are met however, the journey can be a profound experience. Even in the midst of such an overwhelming situation, a person may find meaning and completeness to his or her life.¹

The Fundamentals of Hospice Palliative Care program focuses on developing comfort and familiarity around dying and death. Health care providers will become familiar with the issues encountered by persons living with life-threatening illness based on the Domains of Issues (i.e. Disease Management, Physical, Psychological, Spiritual, Social, Practical, End of Life Care/Death Management and Loss and Grief).

This chapter introduces learners to The Model to Guide Hospice Palliative Care, which was published in 2002 after over 10 years of consensus building among experts in hospice palliative care across Canada. The Model to Guide Hospice Palliative Care provides direction to government, health care professionals, caregivers and volunteers as they attempt to develop services and standards to improve care throughout the illness trajectory.²

In addition, other key strategies and reports have also shaped the way that care is being provided at end of life. Ontario’s End-of-Life Care Strategy (2005) enabled provincial and regional networks, as well as local service provider committees to address systemic and care delivery issues by building and maintaining a system that supports health care providers to be proactive in identifying and addressing issues. Building on this strategy, the Ministry of Health and Long Term Care initiated a provincial hospice palliative care review in 2011 which resulted in Advancing High Quality, High Values Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action.³ Hospice palliative care was examined from four perspectives: integration and shared care; accountability and governance; education, mentorship and specialized support; and care pathing across the continuum of chronic disease management. The Declaration details many shared priorities and action commitments made by the participating organizations and ultimately will guide policy development at the Ministry, inform best practice and be a call to action for change.

A paradigm shift is underway and hospitals are no longer considered the most appropriate place to die. Deaths in hospitals will however continue as this may be the preferred site of death for some individuals, and there are cases in which the person's symptoms cannot be managed in the home setting or there are not sufficient caregivers available to provide the necessary care.

Persons living with a life-threatening illness will, over the course of the illness, need to access services in various settings. Improvements are being made on an ongoing basis to the collaboration and communication processes among various disciplines within and across settings. The goal of these improvements is to facilitate change in the person’s experience, from one that may be inadequate or fragmented, to an experience that is proactive in identifying issues and truly meets the needs of the person and family.

**UNDERSTANDING HOSPICE PALLIATIVE CARE**

Let’s look at the history of the modern specialty known as hospice palliative care. As it began in the 1970’s, modern hospice and palliative care provided a promising alternative to a cure-oriented and impersonal approach of the biomedical model. Hospice palliative care has ancient roots in the compassionate vision of those who were moved by the suffering and despair of dying people long before the advent of the modern health care system.

Dame Cicely Saunders, who trained first as a nurse then as a social worker and finally as a physician, was referred to at the time of her death in July 2005, as the founder of the modern hospice movement. She founded St. Christopher’s Hospice in the United Kingdom in the mid 1960’s to care for the dying. Balfour Mount, a Canadian physician, coined the term palliative care in 1975 because it was a term deemed acceptable in both English and French. The first hospital based Palliative Care Units in Canada opened the same year in Montreal at the Royal Victoria Hospital and in Winnipeg at St. Boniface Hospital. Both hospice and palliative care movements have flourished in Canada since. Palliative care programs developed primarily within health care institutions while hospice care developed within the community primarily as volunteer programs.

To recognize both the convergence of hospice and palliative care into one movement and common norms of practice, the term “hospice palliative care” was adopted. While hospice palliative care is the nationally accepted term to describe care aimed at relieving suffering and improving quality of life, individual organizations may continue to use hospice, palliative care or another similarly acceptable term to describe their organization and the services they are providing.

Every hospice palliative care organization will have one of the following principal activities as its mandate:⁴

- Direct care of persons and families
- Education
- Research
- Advocacy
Key Elements of Hospice Palliative Care

- Aims to relieve suffering and improve the quality of living and dying
- Strives to help the person and his or her family to address issues, expectations, needs, hopes and fears; prepare for and manage self-determined life closure and the dying process; cope with loss and grief during illness and bereavement
- Aims to treat all active issues, prevent new issues from occurring and promote opportunities for meaningful experiences, personal and spiritual growth, and self-actualization
- Is appropriate for any person and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care
- May complement and enhance disease-modifying therapy or it may become the total focus of care
- Is most effectively delivered by an interdisciplinary team of health care providers who are both knowledgeable and skilled in all aspects of the caring process related to their discipline of practice.

Chart 2.1: Guiding Principles of Palliative Care

<table>
<thead>
<tr>
<th>Person and Family Focused</th>
<th>The person and family are always treated as a unit in a manner that is sensitive to the individual values and beliefs of the person and his or her family.</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Quality</td>
<td>Activities are guided by ethical principles: autonomy, beneficence, non-maleficence, justice, truth-telling and confidentiality, as well as nationally accepted standards of practice and norms of practice, standards of professional conduct for each discipline, policies and procedures based on best practice, data collection and documentation guidelines that are based on validated measurement tools.</td>
</tr>
<tr>
<td>Safe and Effective</td>
<td>Palliative care is conducted in a manner that is collaborative, ensures confidentiality, privacy, safety, continuity and accountability, is without coercion, discrimination, harassment or prejudice, aims to minimize unnecessary duplication and repetition and complies with laws, regulations and policies in effect within the jurisdiction, host and hospice palliative care organizations.</td>
</tr>
<tr>
<td>Accessible</td>
<td>Each person and his or her family have equal access to hospice palliative care services wherever they live (at home, or within a reasonable distance from their home) in a timely manner.</td>
</tr>
<tr>
<td>Adequately Resourced</td>
<td>The financial, human, information, physical and community resources are sufficient to sustain the organization's activities, and it's strategic and business plans.</td>
</tr>
<tr>
<td>Collaborative</td>
<td>Each community's needs for hospice palliative care are assessed and addressed through the collaborative efforts of available organizations and services in partnership.</td>
</tr>
<tr>
<td>Knowledge-based</td>
<td>Ongoing education of the person, his or her family or caregivers, staff and stakeholders is integral to the provision and advancement of quality hospice palliative care.</td>
</tr>
<tr>
<td>Advocacy-based</td>
<td>Regular interaction with legislators, regulators, policy makers, health care funders, other hospice palliative care providers, professional societies and associations, and the public is essential to increase awareness about hospice and palliative care, and develop their activities and the resources that support them. All advocacy is based on A Model to Guide Hospice Palliative Care.</td>
</tr>
<tr>
<td>Research-based</td>
<td>The development, dissemination, and integration of new knowledge are critical to the advancement of quality hospice palliative care. Where possible, all activities are based on the best available evidence.</td>
</tr>
</tbody>
</table>
Role of Hospice Palliative Care during Illness

Figure 2.2 below, adapted from *A Model to Guide Hospice Palliative Care* depicts the journey that a person takes; from the point that a life-threatening illness becomes a concern, through diagnostic procedures, to confirmation of the diagnosis, to attempts to cure the disease, treat the symptoms and prolong life.

**Figure 2.2: Therapy to modify disease**

At some point, the person with the illness dies and others are left to grieve the loss. Along the journey, the needs of the person and family are best met by a combination of interventions aimed at treating the disease, managing the symptoms and providing support for the whole person, body, mind and spirit.

At the beginning of the journey, interventions aimed at cure may be most important, as well as needs for information and support. However, as the person approaches end of life, quality of life and the need for comfort and care may take precedence.

The above diagram speaks to the balance that can be achieved throughout the journey. It is not necessary to forgo comfort if one wants to have life-prolonging therapies. Nor do all efforts to prolong life stop when the person is receiving palliative care. Hospice palliative care interventions should not be introduced days or hours before death but early in the journey. Since the family is the unit of care, support is extended into the bereavement period.

**Foundational Concepts**

Hospice palliative care is based on three foundational concepts:

- Effective communication
- Effective group function
- The ability to positively facilitate change

**Foundational Concept 1: Effective Communication**

Effective communication is critical to the process of providing palliative care. Below is a list of potential sources of communication difficulty in hospice palliative care.

**Social Denial of Death**

- Lack of experience in the family
- High expectations of health and life
- Materialism: the penalty of death by being parted from material possessions
Knowledge, Fears and Personal Beliefs of Members of the Health Care Team

- Changing role of religion: not everyone shares the same idea about God or afterlife
- The person’s fears of dying
- Sympathetic pain: others absorb the feeling of discomfort and distress of those facing death
- Fear of being blamed: often there is a notion that someone must be to blame when bad news is delivered or a person deteriorates
- Many lack knowledge and skill in communicating with the dying
- Fear of eliciting a reaction: many have not been taught how to cope with reactions from persons and families
- Fear of saying “I don’t know”
- Fear of expressing emotions: we are trained to hide and suppress emotions but when a person is facing death, however a professional who expresses no emotions is likely to be perceived as cold and insensitive
- Ambiguity of “I’m sorry”: the phrase has two distinct meanings; a form of sympathy or a form of apology when accepting responsibility for an action. Rather than simply saying “I’m sorry” we should be more specific and say why we are sorry e.g. “I’m sorry that happened to you”
- Our own fears of illness and death: this can lead to avoidance or blocking of communication with the dying person.
- The medical hierarchy: a breakdown in communication between team members can make it difficult to respond to a person’s desire for information. Effective communication is aided by using common terms, standard protocols and tools (See Chapter 12 for Definitions of Commonly Used Terms), sensitive sharing of important information and education of all team members

The CLASS Protocol presents communication strategies that support the exchange of information in a way that centres on the person’s feelings and emotions and that enables the conversation itself to be a therapeutic action. The components of the CLASS protocol are listed below.

**Context (or setting):**

**Spatial Arrangements:**

- Ensure privacy
- Move physical objects out of the line between you and the person
- Ask that television, radio be turned off
- Sit down
- Maintain a distance (body buffer zone) of 2 to 3 feet
- Ensure you are at or below the eye level of the person
- When others are present, sit next to the person
- Have tissues nearby

**Body Language:**

- Move and talk in an unhurried manner
- Sit comfortably with both feet on the floor, shoulders relaxed, and hands on the knees (neutral position)

**Eye Contact:**

- Maintain eye contact if the person is talking
- Break eye contact if the person gets angry or begins to cry

**Touching the Person**

- Can be of benefit as a show of support
- Be sensitive to the person’s reaction; if the person is uncomfortable stop the contact
- Touching the hand or forearm is usually non-threatening
- Can be misinterpreted so requires self awareness

**Commencing the Interview**

- Introduce yourself and explain what you do
- If shaking hands, shake the dying person’s hand before others present at the interview.

**Listening Skills:**

**Open Questions:**

- Use questions that require more than a one word answer
- Open ended questions frequently start with “How”, “What”, “When”
- Avoid questions that start with “Why”, as it may trigger defensiveness

**Silence:**

- Wait for the person to stop talking before you start talking
- Recognize the power of silence: A person may be experiencing emotions that are too intense to express in words
- The person may be thinking or feeling something important and a pause might enable them to formulate words to express what they are feeling
- A helpful way to break the silence is to say “What were you thinking about just then?”

**Evident Hearing:**

- Nodding, smiling, using responses such as yes, Mmm, or “tell me more” demonstrate that you are listening.
- Employ one or two of key words from the person’s last sentence in your response.
- Reiterate to confirm that you have heard what was said
Clarifying:

- When you have not understood what the person means, use phrases such as “I'm not sure what you meant when you said...” or “When you say ...do you mean that ...?”

Handling Time and Interruptions:

- Hold all calls and turn off your pager if possible
- If an interruption is necessary, express your regret and explain that you will resume the interview shortly
- For time constraints, explain that you regretfully have to leave but that you will resume the conversation at a future time (provide a time)

Acknowledgement (and exploration) of Emotions

An empathic response consists of 3 steps:

- Identifying the emotion that the person is experiencing
- Identifying the origin and root cause of the emotion
- Responding in a way that expresses that you have made the connection between 1 and 2
- If the person is expressing strong emotion, you must acknowledge the emotion or all further attempts at communication will fail

**Strategy for Management**

- Determine what you believe to be the ideal plan
- The plan must be something that the person will agree with and follow
- Determine the person’s expectations of treatment, condition and outcome and summarize and clarify that understanding with the person
- Propose a strategy based on the ideal plan and what the person wants
- Constantly assess the person’s response to the proposed plan, acknowledge emotions negotiate until you arrive at a plan that the person will buy into and will follow

**Summary**

This provides closure to an interview. Emphasize that this will be a continuing relationship. To do this, cover the following three points:

- Reiterate the main points covered in the encounter
- Invite the person to ask questions
- Make an arrangement for the next interaction.

Both verbal and written communication is very important among team members. In order to avoid team conflicts that will impinge on the person’s well-being and quality of life, chart 2.3 outlines some communication strategies that support effective person to person interaction, family/provider interaction and overall group function.

---

**Chart 2.3: Communication Strategies to Support Effective Group Function**

<table>
<thead>
<tr>
<th>Common language</th>
<th>Care providers must share a common language and understanding of the definitions of the terms they use during the process of providing care. Caregivers must ensure that the person and family share that same understanding.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standard approach to information sharing</td>
<td>Using a standard approach to communicate, listen and respond ensures that information is shared appropriately and promotes understanding. Sharing information with team members is appropriate if it will increase understanding and assist care giving, however it is respectful to inform the client about the need for information.</td>
</tr>
<tr>
<td>Data collection</td>
<td>The collection of data that documents the person’s and family’s issues makes it easy to ensure that the appropriate team member engages in a therapeutic encounter that promotes desired outcomes thereby ensuring satisfaction. Document or relay information as per your agency’s policy. Caregivers can assist the person and family by utilizing a combination of appropriate therapeutic interventions aimed at restoring the capacity to live as close to normal as possible.</td>
</tr>
</tbody>
</table>
Foundational Concept 2: Effective Group Function

Every Hospice Palliative Care Team is comprised of various groups/disciplines:

- The person and family are core members of the team. These individuals enter the team with well-established group leadership and dynamics. The group dynamics within a family, which may or may not have been effective in the past, may change dramatically during the illness.
- The primary and secondary hospice palliative care team consists of members of various disciplines involved in meeting the complex needs of the person and family. To be most effective this team requires leadership and consistent membership. See Palliative Care Team Member Roles, in the Tool section at the end of this guide, for team member roles and responsibilities.
- Group functioning depends to a great extent on an understanding of and respect for the various individuals who are responsible for supporting the person and family. Although there is a hierarchy in Health Care, palliative care seeks to overcome those attitudes and respect all members of the team as equal partners. Stein has identified the feelings, behaviours and team tasks associated with each stage of team development. She has added an additional stage, termination, which in the case of the palliative care team would happen at the time of death. Although some of the same team members may become part of a new team forming around a new person and family, the composition of the team is ever changing.

The Model to Guide Hospice Palliative Care refers to Tuckman's stages of team development (i.e. forming, storming, norming and performing) as a framework for understanding a palliative care team. In the provision of hospice palliative care, some members of the team (e.g. nurses, support workers, therapists) may remain stable while other members of the team (e.g. physicians) will change with each new case. Stein notes that stages are a helpful framework for recognizing a team's behavioral patterns and they are most useful as a basis for team conversation, rather than boxing the team into a specific category. A team can maximize its productivity and facilitate a change in the illness experience by understanding the functioning of the group. Team development is not always a linear process, just as human development is not always either (think of the five-year old child who reverts to thumb-sucking when a new sibling is born). Having a way to identify and understand causes for changes in the team behaviours can help the team maximize its process and productivity.

Stein has identified the feelings, behaviours and team tasks associated with each stage of team development. She has added an additional stage, termination, which in the case of the palliative care team would happen at the time of death. Although some of the same team members may become part of a new team forming around a new person and family, the composition of the team is ever changing.

See Tuckman's Stages Of Team Development, in the Tool section at the end of this guide, for more information about Tuckman's stages of team development.

Trust and respect among health providers is at the heart of interdisciplinary teamwork. Each discipline has its own set of knowledge and skills based on education, training and experience. A collegial environment that supports all team members and listens respectfully to each person's observations, concerns and opinions enhances decision making, creativity and innovation. A commitment to teamwork and collaboration allows health professionals to learn from each other and gain an understanding of the competencies of their peers.

While working on a high-performing team may be a truly pleasurable and a growth experience, it is not the end of team development. There is still a need for the team to focus on both process and product, setting new goals as appropriate. Changes such as members coming or going or within the external environment can lead a team to cycle back to an earlier stage. If these changes- and their resulting behaviors are recognized and addressed directly, teams may be able to successfully remain in the Performing Stage indefinitely.

Examples of groups that support the work of caregiver teams within the district, region and province include:

A local committee with membership from various stakeholder organizations (e.g. hospitals, CCAC, Long Term Care Homes, Palliative Pain and Symptom Management Program)
develops and supports the delivery of hospice palliative care services across settings.

The End-of-Life Care Regional Network functions within each Local Health Integration Network (LHIN) to promote the system level coordination and integration necessary for seamless care delivery for the person and family.

Provincial groups such as the Provincial End-of-Life Care Network, Hospice Palliative Care Ontario, the End-Of-Life Care Coalition and other provincial bodies advocate on behalf of their members for broad system designs that will improve care delivery at the bedside and ultimately facilitate change in the illness experience for the person and family.

Foundational Concept 3: The Ability to Facilitate Change

This third foundational concept calls upon all care providers to become effective change agents in order to enable the person and family to live and die with the best quality of life. When symptoms of illness develop and particularly when a person is diagnosed with a life-threatening illness, there is a potential for a dramatic change in the way life is experienced. Such changes can be perceived as a threat to a person’s capacity for meaningful and valuable experiences, however the choices that each person makes will ultimately affect how the illness is experienced. Change agents are individuals with knowledge, skills and tools; they are able to identify issues, gain an understanding of the effects of those issues, determine goals and identify possible solutions. Effectiveness as a change agent is a combination of competence and confidence. Palliative care practitioners who desire to be effective change agents require education and training, practice opportunities, feedback and reflection and a support system. In addition to this, superb communication skills are essential. As change agents, the health care team members use their knowledge and skills to address all the identified issues. This may involve using logical arguments, facts, and success stories to overcome obstacles for the person and family (e.g. fear of pain medications). The more expertise the team member is perceived to have, the more chance there is to be successful in changing attitudes and behaviours. Each team’s effectiveness is based on the commitment to reflection and on-going evaluation of the team’s accomplishments in terms of meeting the goals of the person and family. It is important however to remember that the person him or herself is ultimately responsible for the decisions that will contribute to how the illness is experienced.

Palliative care providers are responsible for maintaining practice standards and continuing to build competence in their role. As knowledge changes with new research, attitudes change with new learning, skills and behaviours change in response to new attitudes and information. Each member of the caregiver team is required to be open and adaptable as every person on the palliative care team has the role of a change agent. At the bedside, the expertise of knowledgeable and skilled caregivers can be applied to identifying and responding to the multiple issues associated with the illness. At the system level, identifying issues and gaps and working collaboratively with all stakeholders leads to enhanced service delivery.

Scope of Practice

Working within a palliative care team is a rewarding experience. It is an opportunity to add your own unique skill set to the mix of high-functioning team. To deliberately and effectively participate as a team member, it is important to be able to understand and articulate one’s own scope of practice. Scope of practice is defined as the procedures, actions and processes that one is allowed to do within the context of their role. It can draw on education and training, as well as organizational and regulatory bodies and policies. Throughout the course, consider how each concept relates to your own scope of practice, as well as what you can contribute within your role on the team. See Palliative Care Team Member Roles, in the Tool section at the end of this guide, for a list of palliative care team member roles.

Types of Care

Despite the fact that a person may want to die at home, he or she may at times have needs that can best be met within different settings. An understanding of the various settings where care can be provided enables health care providers to advocate on behalf of the person and family. It is important for caregivers to have knowledge of the available alternatives in the event that needs cannot be met within the home environment. Not every community will have access to every type of care.
<table>
<thead>
<tr>
<th>Types of Care</th>
<th>Settings of Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Acute care: for issues that require time-limited attention</td>
<td>• Acute care hospitals: including emergency rooms, intensive care units as well as on medical, surgical, obstetrics, pediatric, geriatric, and rehabilitation units</td>
</tr>
<tr>
<td></td>
<td>• Offices or clinics</td>
</tr>
<tr>
<td>2. Chronic care: for issues that require continuous support and/or skilled nursing care</td>
<td>• Individual homes: including single family dwellings, apartments, retirement homes, boarding houses, group homes, correctional facilities, on the street</td>
</tr>
<tr>
<td></td>
<td>• Complex continuing care</td>
</tr>
<tr>
<td></td>
<td>• Palliative care units in hospitals or long term care homes</td>
</tr>
<tr>
<td></td>
<td>• Free standing residential hospices</td>
</tr>
<tr>
<td></td>
<td>• Long term care homes</td>
</tr>
<tr>
<td>3. Respite care: when caregivers become fatigued and require a break or a vacation</td>
<td>• Day programs</td>
</tr>
<tr>
<td></td>
<td>• Individual homes</td>
</tr>
<tr>
<td>4. End-of-life care: issues and the need for care can rise considerably in the last days</td>
<td>• All settings</td>
</tr>
<tr>
<td>5. Bereavement care: for those who survive the person's death</td>
<td>• All settings</td>
</tr>
</tbody>
</table>
Diagram 2.5: Potential Journey of a Person with Progressive Life-Limiting Illness through Various Settings of Care

1. Person with life threatening illness
2. Physician Office
3. Hospital
4. Disease Specific Clinic
5. Hospital for treatment of disease
6. Physician Office
7. Hospital for acute symptom management
8. Home with increased services
9. Respite, long-term care home, residential hospice
10. Death
Service Delivery Models

Each dying person and family will have unique issues and needs. Primary health care providers have always cared for the dying as part of their role and in many instances are capable of meeting the needs of the person and family. There are, however, situations when more specialized knowledge and skill would be of benefit to the person and family.

Diagram 2.6

Diagram 2.6, adapted from A Model to Guide Hospice Palliative Care acknowledges the role of primary caregivers as well as secondary and tertiary level experts.

Hospice palliative care is a recognized specialty within health care. It is difficult for the generalist practitioner to remain current in every field. Therefore, as the secondary level consultants keep abreast of and share new research findings and best practice guidelines, they may also provide mentorship and coaching to the primary care provider. Additionally, awareness of community resources will help primary providers advocate on behalf of persons regarding specific needs.

Ideally, a system supports timely access to secondary and tertiary experts who are available to support primary providers in their care of persons living with life-threatening illness. Secondary Level Consultants offer consultation that may include:

- One-time consultation with no follow-up by experts
- Ongoing consultation and support with overall responsibility held by primary providers
- Consultation coupled with an overall responsibility (where primary providers maintain a supporting role)
- Consultation followed by assumption of care with no primary providers involved in care.

Effective pain and symptom management is vital. Awareness of community resources will help primary providers advocate on behalf of persons regarding specific needs.

The Model to Guide Hospice Palliative Care based on National Principles and Norms of Practice has two very important concepts underpinning many education programs developed in Canada. Those concepts are the Domains of Issues and the Process of Providing Care. Those two concepts together are the basis for the Square of Care.
Domains of Issues

Living with a life-threatening illness impacts a person and his or her family in all aspects of their lives. The issues are complex and multiple and can be categorized under the following headings or domains. Whenever an issue is identified in any domain, it needs to be addressed.

Diagram 2.7

**Disease Management**
- Primary diagnosis, prognosis, evidence
- Secondary diagnosis (e.g. dementia, substance use)
- Co-morbidities (e.g. delirium, seizures)
- Adverse events (e.g. side effects)
- Allergies

**Physical**
- Pain and other symptoms
- Level of consciousness, cognition
- Function, safety, aids (motor, senses, physiologic, sexual)
- Fluids, nutrition
- Wounds
- Habits
- Allergies

**Psychological**
- Personality, strengths, behaviour, motivation
- Depression, anxiety
- Emotions
- Fears
- Control, dignity, independence
- Conflict, guilt, stress, coping responses
- Self-image

**Loss and Grief**
- Loss
- Grief (e.g. acute, chronic, anticipatory)
- Bereavement planning
- Mourning

**Person and Family**
- Demographics
- Culture
- Personal values, beliefs, practices and strengths
- Developmental stage, education, literacy
- Disabilities

**Social**
- Cultural values, beliefs, practices
- Relationships, roles with family/friends, community
- Isolation, abandonment, reconciliation
- Safe environment
- Privacy, intimacy
- Routines, recreation, vacation
- Legal issues
- Family/caregiver protection
- Guardianship, custody issues

**End-of-Life Care/Death Management**
- Life closure
- Gift giving
- Legacy creation
- Preparation for expected death
- Anticipation and management of physiological
- Changes in the last hours
- Rites, rituals
- Pronouncement, certification
- Perideath care of family, handling of body
- Funerals, services

**Practical**
- Activities of daily living (e.g. personal care, household activities)
- Dependents, pets
- Telephone access, transportation

**Spiritual**
- Meaning, value
- Existential, transcendental
- Values, beliefs, practices, affiliations
- Spiritual advisors, rites, rituals
- Symbols, icons
**Square of Care**

In the 21st century, people are living with illness much longer than ever before. Today, they must deal with many complex questions: How can they get relief from their symptoms? How can they carry on with life as they have known it? How will the illness affect their roles and relationships? How can they restore or maintain their capacity for meaningful and valuable experiences that give quality to their lives? What can be done to positively change the illness experience?

The Square of Care provides a process that can guides caregivers in establishing therapeutic relationships and ensuring that all issues are identified and addressed to the satisfaction of all concerned. Just as a builder's square ensures that a structure is built on a solid foundation, this square of care assists us in ensuring that of our care giving. The Fundamentals of Hospice Palliative Care focuses primarily on the domains of issues noted on the vertical axis of the diagram as well as the foundational concepts of effective communication, effective group function and the ability to facilitate change. The process of providing care noted along the horizontal axis is featured in the Comprehensive Advanced Palliative Care Education (CAPCE) course for nurses.

**Chart 2.8**

<table>
<thead>
<tr>
<th>Common Issues</th>
<th>Assessment</th>
<th>Information-Sharing</th>
<th>Decision-Making</th>
<th>Care Planning</th>
<th>Care Delivery</th>
<th>Confirmation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease Management</td>
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<td>Physical</td>
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<td>Psychological</td>
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<td>Social</td>
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<td>Spiritual</td>
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<tr>
<td>Practical</td>
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<tr>
<td>End of life/Death</td>
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<tr>
<td>Management</td>
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<tr>
<td>Loss, Grief</td>
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</tbody>
</table>
Chapter 2: Introduction to Hospice Palliative Care

References


3 Advancing High Quality, High Value Palliative Care in Ontario: Declaration of Partnership and Commitment to Action. Ontario: Ministry of Health and Long Term Care; 2011 December. 72 p.


5 Ferris F D, Balfour H M, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P. A model to guide hospice palliative care; Based on national principles and norms of practice. Ottawa: Canadian Hospice Palliative Care Association; 2002.


7 Ferris F D, Balfour H M, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P. A model to guide hospice palliative care

8 Ferris F D, Balfour H M, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P. A model to guide hospice palliative care


23 Ferris F D, Balfour H M, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P. A model to guide hospice palliative care: Based on national principles and norms of practice. Ottawa: Canadian Hospice Palliative Care Association; 2002

Chapter 3

Disease Management Domain
UNDERSTANDING THE FUNDAMENTALS

An understanding of the disease process and its treatment will help the caregiver to be effective in facilitating a more positive experience for both the person and family. Although cancer is a disease commonly associated with hospice palliative care, there are many other diseases that merit a similar approach to care, such as ALS (amyotrophic lateral sclerosis, or Lou Gehrig’s disease), liver disease, heart disease, COPD (chronic obstructive pulmonary disease), renal failure, AIDS (Acquired Immune Deficiency Syndrome), and Alzheimer Disease.

Navigating the Journey

The course of most progressive life-limiting diseases is unpredictable. Throughout the illness journey, including the end stage, palliative care is closely tailored to each of the domains of issues. In many illnesses, treatments aimed at prolonging life are often aggressively administered up to the point of death. The pediatric palliative care guidelines refer to this as ruthless obstinacy. Discussing the burdens and benefits of treatment interventions throughout the illness trajectory, and ensuring that individuals are aware that they can choose to withhold or withdraw life-prolonging treatments at any time is part of good palliative care. Defining clear goals of care assists in ensuring that the person’s wishes are honoured.

The roadmap below (diagram 3.1) depicts when and how one’s path of life can suddenly change to an illness journey with an uncertain future. Entering this uncertain path can cause anxiety as we are confronted with our mortality. The roadmap can also help care providers recognize the path a person is travelling, and how they might best support that person at different points in his or her journey. The roadmap also demonstrates the need for professionals in all fields of medicine to either have knowledge and skill in hospice palliative care, or to know how those skills can be accessed.

Diagram 3.1: Navigating Life’s Journey: A Roadmap to Support Decision-Making

The road map represents the various routes and the decision-making points from the onset of symptoms to the person's ultimate death. Decisions are made regarding testing and treatment options. The health care provider is present along the illness path to be an advocate, to give information, encouragement, and support as well as good bedside care.

In the prenatal period, families can be confronted with death through miscarriage, therapeutic abortion, or knowledge of a serious congenital anomaly in utero. Death can occur at birth or in the neonatal period from any number of complications. Through technologies such as ultrasound, disease can be detected and the fetus can be diverted from the normal path with an anticipated future onto the illness path even before birth. In order to support families through this crisis, there is a need for obstetrical and neonatal staff to be grounded in the art and science of hospice palliative care.

In infancy and childhood, symptoms can develop that put the child on the illness path. The child will go through testing and hopefully a diagnosis. Treatment can lead to either a cure or, in the case of a progressive illness, may keep the child on an illness path that impacts the rest of his or her life. If the disease is a progressive life-limiting one, there may be a remission or the child may undergo ongoing treatment to manage the disease process. Pediatric staff with knowledge and skill in hospice palliative care can be of great support to families undergoing crisis. There is an emerging specialty within hospice palliative care related to provision of Pediatric Palliative Care.

In adolescence, acute illness, injury or chronic life-limiting conditions can put the teen on the illness journey. Sudden death is a possibility at any age but in this age group, suicide in particular is of great concern. The grief related to sudden death often requires the ongoing support of skilled bereavement counselors, as well as emergency department staff who are skilled in hospice palliative care, as they are usually the first to attend to a distraught family.

At some point in the trajectory of a progressive life-limiting illness the person comes to the circular road. Professionals must recognize that the person is getting closer to death, and support critical decision-making related to goals of care. These goals will determine which road to take: the lifesaving, life prolonging or comfort road. Critical care staff and those in many specialties such as geriatrics, oncology, cardiology, nephrology, respirology, endocrinology and neurology need an awareness of palliative care in order to assist people in their decision making in these situations.

Death seldom comes without struggle and it is always difficult for us to look death in the eye. We want to deny that death will come to us or to those we love. Field and Casel are optimistic that people individually and together can take action to face death constructively and reduce suffering at the end of life.3

Palliative Performance Scale

Another way of looking at an illness trajectory is in terms of stages. The Palliative Performance System was researched in the cancer population but has application in other illnesses in terms of measuring functional status.

The Palliative Performance Scale (PPS) is an 11-point scale designed to measure persons’ performance status in 10% decrements from 100% (healthy) to 0% (death) based on five observable parameters: ambulation, ability to do activities, self-care, food/fluid intake, and consciousness level.

**Stages based on PPS scores:**

- Stable Stage when the PPS scores range from 100%-70%
- Transitional Stage when the PPS scores range from 60%-40%
- End-of-Life Stage when the PPS scores range from 30%-0%

The PPS is a reliable and valid tool that can help caregivers identify and track care needs as they change with disease progression. The PPS provides a framework for measuring progressive decline over the course of the illness; it also provides a “best guess” projection of length of survival and serves as a communication tool for the team. The PPS can also serve as a workload measurement tool (e.g. A person who scores between 0-40% usually requires increased hands-on care and family members need more support compared to those persons with higher PPS scores).

See **Palliative Performance Scale (PPSv2) Version 2 And Instructions For Use**, in the Tool section at the end of this guide, for the Palliative Performance Scale (PPSv2) Version 2 and instructions on the use of PPS.

**Who Should Complete the PPS**

Any regulated health care provider can complete the PPS. It is anticipated that in most cases, a registered nurse or a registered practical nurse will complete the PPS. All team members are responsible for observing the person carefully and identifying and reporting any changes in ambulation, activity and evidence of disease, self-care, intake and consciousness that would indicate a change in the PPS score.

**Where to Document the PPS**

The PPS score is transcribed into the health care record, on
the flow sheet or in the progress notes as per organizational policy.

An understanding of the specific disease process and commonly experienced symptoms will promote early identification of issues. Only when issues are identified can proper interventions be initiated and evaluated. Being mindful of what stage of the illness trajectory the person is in and being sensitive to the lived experience of the person and family will promote appropriate disease and symptom management throughout the illness trajectory. Identification of the final or terminal phase of the illness creates an opportunity for health care providers to prepare the person and family for the inevitable death.

How to Use the PPS

PPS scores are determined by reading horizontally at each level to find a ‘best fit’ for the individual that is then assigned as the PPS% score.

Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that individual. In this way, ‘leftward’ columns (columns to the left of any specific column) are ‘stronger’ determinants and generally take precedence over others.

Example 1: The person who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious with good intake would be scored at PPS 50%.

Example 2: An individual who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although this person may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The person may have normal intake and full conscious level.

Example 3: However, if the person in example 2 was paraplegic and bed bound but still able to do some self-care such as feed self, then the PPS would be higher at 40% or 50% since he or she is not ‘total care’.

PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a ‘best fit’ decision. Choosing a ‘half-fit’ value of PPS 45%, for example, is not correct. The combination of clinical judgment and ‘leftward precedence’ is used to determine whether 40% or 50% is the more accurate score for that person.

Palliative Illnesses

The following chart (chart 3.2) includes information related to common progressive life-limiting illnesses along with common symptoms and suggested disease management interventions. Symptoms may occur prior to diagnosis as well as throughout the illness trajectory.

| Chart 3.2 |
|---|---|---|
| **Acquired Immune Deficiency Syndrome (AIDS)** | The human immunodeficiency virus is a retrovirus that causes acquired immune deficiency syndrome. Before the advent of antiretroviral treatment, AIDS resulted in death within a few years. Now with treatment, it is a chronic progressive illness that is still incurable. Symptom recognition and management are important for quality of life and palliative care should accompany disease management throughout the trajectory. Regardless of how the disease was acquired, as life expectancy is extended, infected individuals are developing more malignancies and organ failure related to the toxicity of the antiretroviral treatment itself. It is important that the person’s goals of care be reviewed throughout the illness to ensure that treatment to prolong life is in keeping with these goals. End stage events with this disease can happen quickly, therefore it is not unusual for the person with HIV/AIDS to be admitted, intubated, and dead within hours or days. |

<table>
<thead>
<tr>
<th>Trajectory</th>
<th>Interventions</th>
<th>Commonly Experienced Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
• Gradual decline over months or years
  • Stages: Early, Progressive, Advanced, Terminal
• Medications to manage disease
  • Antibiotics for opportunistic infections
  • Chemo and radiation for related cancers
  • Supportive Care
• Fatigue, fever, pain (especially in hands and feet), nausea, diarrhea, sadness/depression, sleep problems, skin problems, cough, headaches, anorexia (lack of or loss of appetite for food), weight loss, dyspnea
• Side effects of antiretrovirals include loss of facial fat, muscle wasting, anorexia, myalgias (muscle pain), nausea and eventually unresponsiveness and sepsis

### Alzheimer Disease
Alzheimer is the most common form of dementia. It is a chronic, progressive and incurable neurodegenerative disease that results in much loss and significant suffering for both the person and family. As with other forms of dementia, impairments in memory, judgment, language, behaviours and function occur over time. Prevalence increases with age and the population of persons with dementia is expected to increase 10 fold over the next 40 years. Failure to recognize neurodegenerative illnesses as progressive and incurable may result in inadequate symptom management and end-of-life care. Prognosis guidelines focus on functional indicators such as the Functional Assessment Staging Scale. A combination of functional and nutritional impairment is associated with shorter survival times. Acute illnesses and hospitalizations are associated with poorer prognosis. A study of demented patients with a diagnosis of hip fracture or pneumonia found that half the patients died within 6 months.5

<table>
<thead>
<tr>
<th>Trajectory</th>
<th>Interventions</th>
<th>Commonly Experienced Symptoms</th>
</tr>
</thead>
</table>
| • Usually a slow steady decline. Advance care planning is helpful in setting goals and planning for disease progression | • Medications to slow progression (efficacy in late stages is questionable)  
• Symptom management and supportive care | • Early: confusion, forgetfulness, depression, anxiety, insomnia  
• Later: visual and aural hallucinations, paranoia, agitation and restlessness are seen in up to 80% of cases  
• Other behaviours that may be exhibited include physical and verbal aggression and sexually inappropriate actions  
• Impairment in abilities related to ADLs and IADLs, pacing and wandering are all progressive over time  
• RULE OUT DELIRIUM whenever there is an acute change in behaviour |
Heart Disease: Congestive Heart Failure (CHF)
Heart failure is increasingly viewed as a chronic disease that can be managed. It is a fluctuating life-limiting illness and there may not be a discrete point at which it is deemed terminal. Both physicians and persons with heart disease are not inclined to consider the possibility of treatment failure. With each exacerbation, prognosis is unpredictable. The terminal phase is not clearly defined and sudden death is frequent. Because of the high symptom burden, palliative care has much to offer to this group of persons. Pneumonia is common in persons who are debilitated by heart failure and treatment depends on the person’s goals of care. Frank conversations about likely symptoms and prognosis need to be carried out at multiple points along the trajectory.

If the person has an Automated Implantable Cardiac Defibrillator (AICD), a discussion about deactivation needs to happen when dying is evident. Studies have shown a low percentage of person’s with CHF having a DNR as opposed to illnesses such as cancer and dementia, which is probably indicative of a lack of discussion about goals of care and prognosis.6

<table>
<thead>
<tr>
<th>Trajectory</th>
<th>Interventions</th>
<th>Commonly Experienced Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Multiple stages during which a combination of disease managing therapies and symptom directed therapies are appropriate</td>
<td>• ACE inhibitors &lt;br&gt; • Beta Blockers &lt;br&gt; • Diuretics &lt;br&gt; • Digoxin &lt;br&gt; • The above medications have symptomatic benefits and so should be maintained &lt;br&gt; • There is no evidence to support oxygen as a life prolonging treatment &lt;br&gt; • Opioids or sedatives for symptoms &lt;br&gt; • Supportive care</td>
<td>• Dyspnea related to angina &lt;br&gt; • Dyspnea may be due to a comorbid condition such as COPD, asthma, &lt;br&gt; • Fatigue may be exacerbated by sleep apnea &lt;br&gt; • Pain other than angina is generally related to other conditions such as arthritis &lt;br&gt; • Depression</td>
</tr>
</tbody>
</table>

Amyotrophic Lateral Sclerosis (ALS)
ALS is one form of neurodegenerative disease; others include Multiple Sclerosis, Parkinson Disease, Muscular Dystrophy. ALS can manifest in different ways depending on the groupings of neurons involved. Motor neurons in the upper spine control the arms and hands while neurons in the lower spine control the legs and feet. Motor neurons in the brainstem control speech, chewing and swallowing. Symptoms are vague at first, however the person and family need support throughout the trajectory from the time of testing to the end of life. Symptom management is critical to enhance quality of life. The health care providers need to be alert to subtle changes and attempt to be one step ahead in order to avoid crises from arising.7

<table>
<thead>
<tr>
<th>Trajectory</th>
<th>Interventions</th>
<th>Commonly Experienced Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Average survival from diagnosis is 3 years</td>
<td>• With permission refer to ALS Society &lt;br&gt; • Arrange home care services early &lt;br&gt; • Frequent assessments &lt;br&gt; • Medications to manage the symptoms &lt;br&gt; • Supportive care</td>
<td>• Symptoms that result from muscle weakness include: muscle cramps, spasticity, dysarthria (difficulty with speech), dysphagia (difficulty swallowing), drooling, dyspnea, pain, choking, anxiety, depression &lt;br&gt; • Indirect symptoms include pain, constipation, nausea, sleep disturbance and depression &lt;br&gt; • Some persons with ALS may develop frontotemporal dementia that results in changes in personality, social withdrawal, finding words, difficulty as well as problems with organization &lt;br&gt; • A syndrome of pathological laughter or tears can occur</td>
</tr>
</tbody>
</table>
Renal Disease

Persons with renal failure who are on dialysis have a significantly shortened life expectancy, high symptom burden (on average 9 symptoms) and multiple co-morbid conditions. Diabetes, cardiac disease, and anemia often are forerunners of renal failure. Almost all individuals with end stage renal disease who stop renal dialysis die within a month, yet very few are referred for palliative care. There is a growing trend to have nephrologists and their staff acquire education and skill in palliative care so they may address symptoms, advance care planning and goal setting. It is important to note that as the age at which dialysis is begun has become older, older persons on dialysis withdraw treatment more often than younger persons.\(^8\)

<table>
<thead>
<tr>
<th>Trajectory</th>
<th>Interventions</th>
<th>Commonly Experienced Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 year survival rate on dialysis is 33%</td>
<td>Dialysis</td>
<td>Early: muscular pains, edema (swelling caused by fluid), weakness and fatigue</td>
</tr>
<tr>
<td>When dialysis is withdrawn death from uremia usually occurs within 8 to 12 days although persons have lived for up to a month</td>
<td>Peritoneal dialysis</td>
<td>Later, following initiation of dialysis: chest pain, bone or joint pain, difficulty becoming sexually aroused, trouble falling asleep, muscle cramps, itching, fatigue</td>
</tr>
<tr>
<td>Death is usually gentle with increasing somnolence as death approaches</td>
<td>Hemodialysis</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Kidney transplant</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Symptom management and supportive care</td>
<td></td>
</tr>
</tbody>
</table>

Chronic Obstructive Pulmonary Disease (COPD)

COPD is one of many progressive respiratory illnesses. Others include Pulmonary Fibrosis, Cystic Fibrosis, and Occupational Lung Diseases etc. COPD is the 4th leading cause of death in the world. It is a progressive life-limiting illness. Primary disease management includes combinations of short and long acting bronchodilators, corticosteroids, oxygen, pulmonary rehabilitation and preventative measures such as vaccinations for flu and pneumonia. Treatments are aimed at improving pulmonary function tests, exercise capacity, function and symptoms. The summary of studies from the Association of Palliative Medicine Science Committee regarding persons with COPD advises that there is equivocal evidence for the use of long term oxygen at rest for palliation of dyspnea. Oxygen may be of benefit for decreasing breathlessness associated with exercise. The effect of oxygen on quality of life during ambulation cannot be predicted by patient characteristics. It must be based on a trial. Opiates and benzodiazepines are very helpful in the management of dyspnea and the accompanying anxiety. Analysis of numerous trials involving nebulized opioids suggests that it has no role in the relief of dyspnea.\(^9\)

<table>
<thead>
<tr>
<th>Trajectory</th>
<th>Interventions</th>
<th>Commonly Experienced Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>COPD involves inevitable decline and increasingly frequent hospital admissions to treat exacerbations, often with extensive periods of ventilator support</td>
<td>Prevention of infection</td>
<td>Dyspnea</td>
</tr>
<tr>
<td></td>
<td>Chest physiotherapy</td>
<td>Anxiety</td>
</tr>
<tr>
<td></td>
<td>Medications to manage symptoms</td>
<td>Depression</td>
</tr>
<tr>
<td></td>
<td>Surgery: lung transplant</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Ventilators</td>
<td>Confusion</td>
</tr>
<tr>
<td></td>
<td>Supportive care</td>
<td>Cough</td>
</tr>
</tbody>
</table>

Liver Disease: Cirrhosis and Fibrosis

Cirrhosis is a progressive liver disease, and damage sustained to the liver is irreversible. In chronic liver disease, there is gradual destruction of liver tissue over time. However, with proper nutrition, avoidance of certain toxins (e.g. alcohol), vitamin supplementation, and management of cirrhosis complications, further liver damage can often be delayed or stopped. In severe cases of cirrhosis, liver transplantation may be considered. Cirrhosis is the 7th leading cause of death in the U.S. Because of chronic liver damage, functioning tissue is replaced by scar tissue and blood flow through the liver is diminished. Nutrients, hormones, drugs and poisons are then not effectively processed and other functions are inhibited. The most common cause of cirrhosis is alcohol abuse. A few of the other causes include hepatitis and other viruses, use of certain drugs, chemical exposure, bile duct obstruction, and autoimmune diseases. Fibrosis is the growth of scar tissue due to infection, inflammation, injury, or even healing. Fibrosis in the liver can inhibit the organ’s proper functioning and usually results in cirrhosis.\(^10\)
Chapter 3: Disease Management Domain

### Trajectory
- Usually slow and tedious process

### Interventions
- Management of:
  - Electrolytes
  - Bleeds
  - Infections
  - Ascites (abdominal fluid)
  - Encephalopathy
- Supportive care
- Liver transplant

### Commonly Experienced Symptoms
- Depend on severity of disease
- Abnormal nerve function
- Ascites (abdominal fluid) itching
- Coughing up or vomiting blood
- Jaundice
- Kidney failure
- Muscle loss, weakness
- Liver encephalopathy (confusion)
- Fatigue, lack of stamina,
- Decreased appetite
- Abdominal bloating

### Cancer
Cancer is a genetic disease in which the regulation, characteristics and function of normal cells is abnormal. Genetic mutations allow malignant cells to gain advantage over normal cells and grow uncontrollably. The development of cancer involves many steps that can take place over many years. Although some cancers are inherited, most are due to a series of somatic mutations. Environmental and personal factors can affect the development of cancer. Environmental factors include chemicals, smoking, excessive alcohol intake, radiation (ionizing e.g. x-rays and ultraviolet e.g. sun), chronic irritation, viral agents and dietary influences. Personal factors include immune system function, advancing age, and failure of the body's surveillance system that detects the presence of foreign invaders and destroys them. Some individuals have a genetic predisposition that influences the carcinogenetic process. Race is a genetically determined characteristic that plays a role in cancer incidence. Cancer incidence and survival can be related to socioeconomic factors as well. Many types of cancer cells have the ability to spread or metastasize. Some parts of the body are more apt to develop metastases than others. It is quite common for cancer to spread in the liver, lungs, and bones, but rare for cancer to spread in skin. Each type of cancer has its own pattern for spread. Cancer can spread via the blood stream, the lymphatic system or by local invasion. Metastasis can happen accidentally when a biopsy is done or during surgery when a malignant cell may actually drip from a needle or instrument. This spread is rare and is caused by implantation or inoculation.

Cancers that metastasize remain the same cancer i.e. cancer of the breast that spreads to the lung remains cancer of the breast; it is not lung cancer.

### Breast Cancer
Breast Cancer can include: the nipple, areola, ducts, lobules, adipose tissue, pectoralis minor and major muscles and associated lymph nodes. It is the most common cancer in women in industrialized countries and the incidence increases with age.

### Metastasizes to
- Bone
- Lung
- Liver
- Brain
- Trajectory: depends on staging at the time of diagnosis

### Treatments
- Surgery
- Radiation
- Chemotherapy
- Hormone therapy

### Commonly Experienced Symptoms
- Depend on locations of cancer metastases
- Lymphedema (excess fluid causes swelling)
- Pain
- Fatigue
- Shortness of breath
- Loss of appetite
- Headaches
Central Nervous System Malignancies are cancers of the brain or spinal cord. Primary brain tumours originate from neuronal or non-neuronal tissue in the brain or spinal cord.

Many tumours of the CNS are metastatic arising from primary tumours of the lung, breast, colon, skin (melanomas) and kidney.\(^\text{13}\)

<table>
<thead>
<tr>
<th>Trajectory</th>
<th>Interventions</th>
<th>Commonly Experienced Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Variable, depends on tumour type</td>
<td>• Based on tumour type but includes:</td>
<td>• Increased intercranial pressure leading to headache, nausea, vomiting, altered level of consciousness and seizures</td>
</tr>
<tr>
<td></td>
<td>• Surgery</td>
<td>• Depending on tumour location there may be weakness, sensory changes, personality changes and endocrine abnormalities</td>
</tr>
<tr>
<td></td>
<td>• Radiation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Chemotherapy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Steroids</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Anticonvulsants</td>
<td></td>
</tr>
</tbody>
</table>

Gastrointestinal malignancies include anal cancer, biliary cancer, gallbladder cancer, colon and rectal cancer, esophageal cancer, gastric cancer, liver cancer, pancreatic cancer.\(^\text{14}\)

<table>
<thead>
<tr>
<th>Trajectory</th>
<th>Interventions</th>
<th>Commonly Experienced Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Variable depends on tumour location and staging at diagnosis</td>
<td>• Surgery</td>
<td>The following symptoms are possible and depend on site:</td>
</tr>
<tr>
<td>• Pancreatic cancer generally has a poor prognosis, while anal cancer, if caught early, is curable</td>
<td>• Radiation</td>
<td>» Weight loss</td>
</tr>
<tr>
<td></td>
<td>• Chemotherapy</td>
<td>» Anorexia (lack or loss of appetite for food)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>» Nausea</td>
</tr>
<tr>
<td></td>
<td></td>
<td>» Vomiting</td>
</tr>
<tr>
<td></td>
<td></td>
<td>» Pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>» Dysphagia (difficulty swallowing)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>» Jaundice</td>
</tr>
<tr>
<td></td>
<td></td>
<td>» Itching</td>
</tr>
</tbody>
</table>

Genitourinary Cancers include cancers of the bladder, penis, prostate, kidney, and testicles.\(^\text{15}\)
<table>
<thead>
<tr>
<th>Metastatic sites</th>
<th>Interventions</th>
<th>Commonly Experienced Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bladder</td>
<td>• Surgery</td>
<td>Bladder</td>
</tr>
<tr>
<td></td>
<td>• Radiation</td>
<td>• Frequency</td>
</tr>
<tr>
<td></td>
<td>• Chemotherapy</td>
<td>• Urgency</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Dysuria (painful urination)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Altered stream</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Bone pain, flank and pelvic</td>
</tr>
<tr>
<td>Prostate</td>
<td>• Surgery</td>
<td>Penile</td>
</tr>
<tr>
<td></td>
<td>• Radiation</td>
<td>• Small papules to fungating lesions</td>
</tr>
<tr>
<td></td>
<td>• Chemotherapy</td>
<td>• Frequency, hesitancy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• decreased stream, nocturia</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• (excessive urination during the night)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Bone pain, usually ribs, back and hips related to bone metastases</td>
</tr>
<tr>
<td>Kidney</td>
<td></td>
<td>Kidney</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Flank pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Hematuria (blood in the urine)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Weight loss</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Fatigue</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Anemia (red blood cell deficiency)</td>
</tr>
<tr>
<td>Testicular</td>
<td>• Surgery</td>
<td>Testicular</td>
</tr>
<tr>
<td></td>
<td>• Radiation</td>
<td>• Swelling, nodules, pain, hardness, feeling of heaviness</td>
</tr>
<tr>
<td></td>
<td>• Chemotherapy</td>
<td>• Advanced: back or abdominal pain, weight loss, gynecomastia (benign enlargement or breast tissue in males), supraclavicular lymphadenopathy (swollen lymph nodes), superior vena cava syndrome, urinary obstruction, dyspnea, hemoptyisis, bone pain, headaches, seizures</td>
</tr>
</tbody>
</table>
**Gynecological Cancers** includes cancer of the cervix, endometrial tissue, ovaries, vagina, and vulva.\(^6\)

<table>
<thead>
<tr>
<th>Metastatic sites</th>
<th>Interventions</th>
<th>Commonly Experienced Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cervical</strong></td>
<td>• Surgery</td>
<td>Cervical (is a sexually transmitted disease associated with chronic infection by oncogenic types of HPV)</td>
</tr>
<tr>
<td>• To vaginal mucosa, myometrium, peracervical lymphatics, to common lymph nodes</td>
<td>• Chemotherapy</td>
<td>Early symptoms</td>
</tr>
<tr>
<td></td>
<td>• Radiation</td>
<td>• Vaginal discharge</td>
</tr>
<tr>
<td></td>
<td>• Hormonal Therapy</td>
<td>• Painless postcoital spotting</td>
</tr>
<tr>
<td><strong>Ovarian</strong></td>
<td></td>
<td>Late symptoms</td>
</tr>
<tr>
<td>• Other abdominal organs</td>
<td>• Dysuria, hematuria (blood in the urine), rectal bleeding, pain in flank or legs, persistent lower extremity edema (swelling caused by fluid), massive hemorrhage, uremia</td>
<td></td>
</tr>
<tr>
<td><strong>Vaginal</strong></td>
<td></td>
<td>Endometrial</td>
</tr>
<tr>
<td>• Most vaginal neoplasms are metastases from other primary sites such as the cervix, vulva and endometrium</td>
<td>• Abnormal vaginal discharge</td>
<td>• Vague abdominal discomfort</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Dyspepsia (indigestion or upset stomach)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Mild digestive disturbances</td>
</tr>
<tr>
<td><strong>Vulvar</strong></td>
<td></td>
<td>Vaginal</td>
</tr>
<tr>
<td>• Local spread</td>
<td>• Bloody vaginal discharge</td>
<td>• Postcoital spotting</td>
</tr>
<tr>
<td></td>
<td>• Postcoital spotting</td>
<td>• Irregular or post menopausal bleeding</td>
</tr>
<tr>
<td></td>
<td>• Dysuria</td>
<td>• Dysuria</td>
</tr>
<tr>
<td></td>
<td>• Pelvic pain is a late symptom</td>
<td>• Pelvic pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Vulvar</td>
</tr>
<tr>
<td></td>
<td>• Pruritis (itch)</td>
<td>• Pruritis</td>
</tr>
<tr>
<td></td>
<td>• Local pain</td>
<td>• Local pain</td>
</tr>
<tr>
<td></td>
<td>• Bleeding</td>
<td>• Bleeding</td>
</tr>
<tr>
<td></td>
<td>• Drainage</td>
<td>• Drainage</td>
</tr>
</tbody>
</table>
Head and Neck Cancers include cancer of the larynx, oral cavity, pharynx, salivary glands, thyroid and parathyroid.\textsuperscript{17}

<table>
<thead>
<tr>
<th>Metastatic sites</th>
<th>Interventions</th>
<th>Commonly Experienced Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laryngeal</td>
<td>• Surgery</td>
<td>Laryngeal</td>
</tr>
<tr>
<td></td>
<td>• Radiation</td>
<td>• Sore throat, painful swallowing, referred ear pain, weight loss, change in voice quality, hoarseness, difficulty swallowing, dyspnea, stridor (high pitched wheezing sound), throat irritation, hemoptysis</td>
</tr>
<tr>
<td></td>
<td>• Chemotherapy</td>
<td></td>
</tr>
<tr>
<td>Oral Cavity</td>
<td></td>
<td>Oral cavity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Leukoplakia (white or grey patches in the mouth), ulcers, lump of thickening, feeling of fullness in the throat, dysphagia (difficulty swallowing), jaw swelling, unilateral otalgia (ear pain) without hearing loss, pain, bleeding</td>
</tr>
<tr>
<td>Thyroid Cancer</td>
<td></td>
<td>Pharangeal</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Neck mass, nasal obstruction, change in voice quality, sore throat, difficulty swallowing, sense of foreign body in the throat, ear pain, dysphagia (difficulty swallowing), weight loss</td>
</tr>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Salivary Glands</td>
<td></td>
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<tr>
<td></td>
<td>• Painless swelling, numbness or weakness in the face, persistent facial pain</td>
<td></td>
</tr>
<tr>
<td>Thyroid and parathyroid tumors:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Fatigue, weight loss, forgetfulness, renal stones</td>
<td></td>
</tr>
</tbody>
</table>
**Leukemias** are malignant neoplasms characterized by abnormal proliferation and development of leukocytes, which infiltrate bone marrow, peripheral blood and other organs, resulting in altered normal cell differentiation. Leukemias (lymphocytic or myelogenous) can be acute or chronic.¹⁸

<table>
<thead>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Chemotherapy</td>
<td>Presenting symptoms are related to bone marrow failure with resulting anaemia, neutropenia (abnormally low number of white blood cells), thrombocytopenia (abnormally low amount of platelets) or organ filtration with leukemic cells in the spleen, liver and gums</td>
</tr>
<tr>
<td></td>
<td>Interferon therapy</td>
<td>Malaise (general feeling of discomfort)</td>
</tr>
<tr>
<td></td>
<td>Radiation therapy</td>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
<td>Stem cell transplantation</td>
<td>Bone pain especially sternum</td>
</tr>
<tr>
<td></td>
<td>Surgery to remove enlarged spleen</td>
<td>Sweats</td>
</tr>
<tr>
<td></td>
<td>Bone marrow transplant</td>
<td>Bleeding, bruising</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pallor (pale, absence of colour), petechiae (small purple-red spot on skin), ecchymosis (bruise), lymphadenopathy (swollen lymphnodes), sphenomegaly, hepatomegaly (enlarged liver), mediastinal mass (growth in the chest, separate from the lungs), abdominal adenopathy (swelling of the lymph nodes in the abdomen)</td>
</tr>
</tbody>
</table>

**Multiple Myeloma** is a cancer of the plasma cell.¹⁹

<table>
<thead>
<tr>
<th>Metastatic sites</th>
<th>Interventions</th>
<th>Commonly Experienced Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bisphosphonates</td>
<td>No symptoms in the early stages</td>
</tr>
<tr>
<td></td>
<td>Supportive care</td>
<td>Pain as a result of osteoporosis and fractures of the lower back and ribs. Other osteoporotic sites are pelvis and skull</td>
</tr>
<tr>
<td></td>
<td>Pain management</td>
<td>Fatigue from anemia</td>
</tr>
<tr>
<td></td>
<td>Radiation therapy</td>
<td>Recurrent infections particularly pneumonia</td>
</tr>
<tr>
<td></td>
<td>Surgery for problematic lytic bone lesions</td>
<td>Hypercalcemia (elevated calcium level)</td>
</tr>
<tr>
<td></td>
<td>Chemotherapy</td>
<td>Renal damage and potential kidney failure</td>
</tr>
<tr>
<td></td>
<td>Stem cell transplantation</td>
<td></td>
</tr>
</tbody>
</table>

---

¹⁸: Leukemia (lymphocytic or myelogenous) can be acute or chronic.

¹⁹: Multiple myeloma is a cancer of the plasma cell.
Chapter 3: Disease Management Domain

**Lung Cancer** is the cancer in any area of the lungs or bronchus. It has two main types: small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC). Tobacco is the primary risk factor.

<table>
<thead>
<tr>
<th>Metastatic sites</th>
<th>Interventions</th>
<th>Commonly Experienced Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NSCLC</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Adenocarcinoma</td>
<td>• If localized, surgery is the treatment of choice</td>
<td>• Persistent cough</td>
</tr>
<tr>
<td>• Squamous carcinoma</td>
<td>• Radiation therapy</td>
<td>• Shortness of breath</td>
</tr>
<tr>
<td>• Large cell carcinoma</td>
<td>• Chemotherapy</td>
<td>• Blood tinged sputum</td>
</tr>
<tr>
<td>• Spreads locally and can occlude the bronchial lumens, grow into the pleura and chest wall. It also spreads via the lymphatic system and the blood stream. It finally spreads to bone, liver, adrenal glands and the brain</td>
<td></td>
<td>• Chest pain</td>
</tr>
<tr>
<td><strong>SCLC</strong></td>
<td>• Surgery – rare</td>
<td>• Hoarseness</td>
</tr>
<tr>
<td>• Few are cured</td>
<td>• Radiation</td>
<td>• Recurrent bronchitis or pneumonia</td>
</tr>
<tr>
<td></td>
<td>• Chemotherapy</td>
<td>• Pain from bone mets</td>
</tr>
<tr>
<td></td>
<td>• Prophylactic brain</td>
<td>• Fatigue</td>
</tr>
<tr>
<td></td>
<td>• Radiation is controversial</td>
<td>• Anorexia and weight loss</td>
</tr>
<tr>
<td></td>
<td>• Palliative radiation is done for symptom management</td>
<td>• CNS changes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Hypercalcemia (elevated calcium level)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Same as above</td>
</tr>
</tbody>
</table>

**Sarcomas** are primary cancers of many different types. Sarcomas arise from tissue called mesenchymal tissue which is the precursor to fibrous tissue, muscle, bone and fat.

Chondrosarcoma and Ewing’s sarcoma are primary bone cancers and are often curable with treatment.

Kaposi’s Sarcoma is a cancer of the lymphatic endothelium and forms vascular channels that fill with blood cells giving it a bruise-like appearance. It is generally not considered to be a true sarcoma which is a tumour arising from connective tissue.

Osteosarcoma is another primary bone cancer. It can be cured but can metastasize to the lung. Soft tissue sarcomas occur in the supporting tissues and soft tissues of the body (e.g. muscle, fat, blood vessels, lymph vessels, nerves and ligaments, tissues around joints, fibrous tissues). There are 50 or more subtypes of soft tissue sarcomas.

<table>
<thead>
<tr>
<th>Metastatic sites</th>
<th>Interventions</th>
<th>Commonly Experienced Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Can spread throughout the body, although certain sarcomas have more or less of a tendency to spread than others</td>
<td>• Surgery</td>
<td>• Symptoms vary depending on the part of the body involved</td>
</tr>
<tr>
<td>• Spread through the blood, often to the lung, liver, and brain</td>
<td>• Radiation</td>
<td>• Lumps</td>
</tr>
<tr>
<td></td>
<td>• Chemotherapy</td>
<td>• Pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Fever</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Weight loss</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Fatigue</td>
</tr>
</tbody>
</table>

**Skin Cancer**: There are three main types of cells in the outer layer of skin: squamous cells, basal cells and melanocytes. Skin cancers are malignant lesions that occur in these cells.

Melanomas are related to the cells that make the pigment melanin. Skin cancers are generally associated with ultra violet light exposure.
### Fundamentals Education Program Guide

<table>
<thead>
<tr>
<th>Interventions</th>
<th>Commonly Experienced Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Basal and squamous cell cancers are less aggressive than malignant melanomas</td>
<td>• Change in size, shape, colour or diameter of an existing skin lesion</td>
</tr>
<tr>
<td>• Surgical excision with wide margin</td>
<td>• Appearance of a new lesion</td>
</tr>
<tr>
<td>• Regional lymph node dissection</td>
<td>• Generally on sun exposed areas but can occur anywhere</td>
</tr>
<tr>
<td>• Chemotherapy</td>
<td></td>
</tr>
</tbody>
</table>

**Basal and squamous cell cancers**
- Surgical excision with wide margin
- Regional lymph node dissection
- Chemotherapy

**Commonly Experienced Symptoms**
- Change in size, shape, colour or diameter of an existing skin lesion
- Appearance of a new lesion
- Generally on sun exposed areas but can occur anywhere

Melanoma: signs are promoted as ABCD
- Asymmetry—one half of the mole does not match the other half
- Irregular border
- Colour such as blue, black or variation in the same mole
- Diameter greater than 6mm

<table>
<thead>
<tr>
<th>Lymphomas</th>
<th><strong>are cancers of the B or T lymphocytes or natural killer cells that originate in the lymphatic system. There are two major categories, Hodgkin Lymphoma and non-Hodgkin Lymphomas.</strong></th>
</tr>
</thead>
</table>

**Trajectory**

<table>
<thead>
<tr>
<th>Interventions</th>
<th>Commonly Experienced Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Hodgkin Lymphoma is considered a curable disease</td>
<td>• Unexplained weight loss</td>
</tr>
<tr>
<td>• Chemotherapy</td>
<td>• Unexplained fevers for more than 3 days</td>
</tr>
<tr>
<td>• Immunotherapy</td>
<td>• Drenching night sweats</td>
</tr>
<tr>
<td>• Radioimmunotherapy</td>
<td>• Pruritis (itch)</td>
</tr>
<tr>
<td>• Radiation therapy</td>
<td>• Pain in involved areas after alcohol consumption</td>
</tr>
<tr>
<td></td>
<td>• Painless adenopathy (cervical or supraclavicular)</td>
</tr>
<tr>
<td></td>
<td>• Splenomegaly (enlarged spleen)</td>
</tr>
<tr>
<td></td>
<td>• Painless adenopathy (neck, armpit, groin or abdomen)</td>
</tr>
<tr>
<td></td>
<td>• Fatigue</td>
</tr>
</tbody>
</table>

**Non Hodgkin Lymphomas**

- Painless adenopathy (neck, armpit, groin or abdomen)
- Fatigue

MALT lymphoma affects the stomach lining and can cause nausea, vomiting and abdominal pain

Cutaneous T-cell lymphoma affects the skin and cause raised patches, redness and itching
Dying Trajectories

Hallenbeck wrote that people both desire and fear certainty in life. They want to know what is going to happen, yet they are fearful when it is not perceived as good. A person who is informed that treatment is failing will often ask “How long do I have?” Perhaps having a time frame provides some sense of control for the dying person. For most serious and chronic disease processes, the quicker the decline, the sooner the death.

Reflecting on possible trajectories and applying that knowledge to each particular case can help health care providers to identify that a person is in the process of dying. Information on prognosis promotes informed person centered decision making and allows people to plan their remaining time, create advance directives, and avoid potentially burdensome interventions that may not be aligned with their wishes, values, beliefs, and preferences. Maida and Chidwick identify the following benefits of providing information about prognosis: 24

- Allows the person and his/her SDM(s) to be informed and make informed decisions reflective of wishes, values, beliefs, and preferences
- May be helpful in the creation of advance directives
- May assist in the development of time-sensitive goals and objectives (match to time expectancy)
- Promotion of autonomous decision-making
- May facilitate timely transition to a “palliative care” that may enhance achieving higher levels of comfort, dignity, and quality of life
- May promote earlier planning of future care needs
- Can facilitate a person to “get affairs in order”
- Can reduce levels of late-stage “futile” intervention
- Individuals and families may be less likely to harbour “false hope” and this may reduce development of complicated grief
- May help minimize potential harm that may result in potential “harm” to persons that may result from the adoption of aggressive, unproven, or futile treatments

There are several ways of describing the dying process. Duration refers to the time involved between the onset of dying and the arrival of death. Shape refers to the course or the dying process (i.e. how predictable the process and timing will be).

The following examples of dying trajectories related to cancer have been described:

1. The gradual slant trajectory is characterized by a long slow decline, sometimes lasting for years.

2. The steep downward slant trajectory is represented by a rapid decline toward death in which the chronic phase of the illness is either short or non-existent.

3. The peaks and valleys trajectory involves alternating periods of remission and relapse. Relapses tend to become more frequent as the illness progresses.

4. The descending plateaus trajectory involves decline followed by re-stabilization. Each period of re-stabilization involves adjusting to a different level of functioning. The length of time the person remains in the stable phase tends to become shorter as the illness progresses.
The following chart (chart 3.3) depicts another method used to describe dying trajectories and implications.

**Chart 3.3**

<table>
<thead>
<tr>
<th>Trajectory</th>
<th>Description</th>
<th>Implications</th>
</tr>
</thead>
</table>
| Sudden Death                                   | Nothing can be done for the person found suddenly and unpredictably dead. Care of survivors is of paramount concern.                                                                                     | • Lack of preparation  
• No chance to say goodbye  
• Often no will, funeral plans  
• Bereavement needs are intense                                                                                                                                                                                                                                             |
| Cancer Death                                    | If recognized, this trajectory offers the potential for getting one’s house in order.                                                                                                                                                                                | • Those with metastatic disease remain functional until about 5 to 6 months before death and then slowly decline until two to three months before death  
• Decline accelerates rapidly and symptom needs escalate  
• Individuals with advanced cancer who take to their beds without a correctable cause will usually die in a matter of weeks to months                                                                                                                                               |
| Sine-Waving is a trajectory that involves oscillating or swinging back and forth from chronic ill health to acute crisis | This is the dying trajectory of congestive heart failure, chronic obstructive pulmonary disorder and many infirmities of advanced age. It involves periodic crises followed by stabilization. Any particular crisis could lead to death. If you would not be surprised if the person were to die in the next two years, the person has a serious life-limiting illness. Discussion and planning relative to end-of-life care is indicated. | • Health status is low for 6 to 24 months prior to death  
• Acute exacerbations occur intermittently and tend to increase over time  
• Frequent hospital admissions  
• Frequently not identified as dying  
• Live miserably on a roller coaster of decline and transient improvement                                                                                                                                                                                                                           |
| Death following Aggressive Life-Sustaining Treatment in Acute Care | This dying trajectory is common to many illnesses including chronic illnesses with sine-waving or those with acute catastrophic events such as stroke, overwhelming sepsis or adverse outcomes of surgery. Many will die as aggressive treatment continues. | • Enmeshed in high tech medicine  
• Probability of imminent death may not be recognized by individuals, families or staff.  
• Person doesn’t die, the person “codes”  
• Emotional impact of death is great  
• Second thoughts and guilt arise                                                                                                                                                                                                                                                                                   |
| Predicted Death                                 | Death will occur in the not too distant future, regardless of specific care decisions. When decision is made to withdraw life saving interventions, parties generally desire a quick death. The person who is on a ventilator and declared brain dead is an example of this trajectory. | • Shift or transition in the focus of care; decisions are related to withdrawal of treatment and the desired setting for the death to occur  
• Special communication skills are needed  
• Person and family may experience a sense of abandonment due to withdrawal of treatment  
• If death takes longer than expected, families who wish for the quick death may suffer intense guilt                                                                                                                                                                           |
OBSERVING THE INDIVIDUAL’S EXPERIENCE

Pain and other distressing symptoms can present in a number of ways. A variety of tools can assist with observing the presence and extent of symptoms.

The Edmonton Symptom Assessment System

One of the best ways to get an overall sense of how the person is experiencing his or her illness is to measure the burden of various physical, psychosocial, and spiritual symptoms. In order to facilitate a positive change in the experience of the illness, everything about the person’s situation needs to be taken into consideration. Since there can be significant differences in the perception of needs (e.g., between formal and informal caregiver, or caregivers and the person and family), the use of a validated tool to measure the burden of symptoms is helpful. The revised Edmonton Symptom Assessment System (ESAS-r) is a tool designed to assist in the assessment of a variety of symptoms and has been researched and validated with the cancer population.25 ESAS-r is brief and easily administered and all identified symptoms are relevant to other chronic illnesses, therefore it can be easily applied to other diseases as well.

Early identification and reporting of symptoms may lead to improved management and better quality of life. The ESAS-r tool enables the person to identify the degree of distress/burden related to each particular symptom and helps us as caregivers to understand the impact of the disease on the person’s quality of life. Caregivers can more readily engage in conversations related to goals of care when there is an understanding of the illness experience from the perspective of the person and family.

The ESAS-r was designed to allow the person or his or her family caregiver to self-administer the tool. It is the person’s opinion of the severity of the symptoms that is the gold standard for symptom assessment.

The tool is designed to assist in the assessment of pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath. One “other problem” line is available for the person to use as needed. Since bowel function is a frequent symptom of those suffering with chronic illness, permission was sought to add bowel function to the list of symptoms and the tool with bowel function included is found in this resource guide. The severity at the time of the assessment of each symptom is rated from 0 – 10 on a numerical scale; with 0 meaning that the symptom is absent and 10 that it is the worst possible severity.

The ESAS-r provides a clinical profile of symptom severity over time. Documentation of scores provides a context within which symptoms can begin to be understood. It is not a complete symptom assessment in itself. For good symptom management to be attained, the ESAS-r must be used as just one part of a holistic clinical assessment.

See Edmonton Symptom Assessment System (ESAS-r), in the Tool section at the end of this guide, for a copy of the ESAS-r and instructions for use or visit: http://www.cancer-care.on.ca/toolbox/symptools/

When to do the ESAS-r

- In palliative home care, complete and graph the ESAS-r during each telephone or personal contact.
- If symptoms are in good control, and there are no predominant psychosocial issues, then the ESAS-r can be completed weekly for people in the home.
- In hospice and tertiary palliative care units, the ESAS-r should be completed daily.
- In other settings, palliative care consults will use the tool on initial assessments and follow up visits.

Who should do the ESAS-r

Optimally, the person will provide ratings of symptom severity. If the person cannot provide ratings of severity but can provide input, then the ESAS-r is completed with help of a caregiver (family, friend, health professional involved in care). If the person cannot participate in the assessment at all or refuses to do so then the caregiver can complete the ESAS-r. Caregivers are encouraged to rate objectively. Examples of objective indicators include: grimacing and guarding for pain, increased time spent resting for tiredness, decreased level of alertness for drowsiness, retching or vomiting for nausea, quantity of food intake for appetite, increased respirations or effort causing distress for shortness of breath, tearfulness, flat affect, withdrawal for depression, agitation, flushing, restlessness for anxiety and how the person appears overall for well-being. If it is not possible to rate a symptom, the caregiver may indicate “U” for “unable to assess”.

It is important to indicate who completed the tool on the bottom of the ESAS-r.

How to Use the ESAS-r

The Regional Palliative Care Program of Edmonton, Alberta (2010) recommends the following when completing the ESAS-r:

1. In palliative home care, complete and graph the ESAS-r during each telephone or personal contact.
2. If symptoms are in good control, and there are no predominant psychosocial issues, then the ESAS-r can be completed weekly for people in the home.
3. In hospice and tertiary palliative care units, the ESAS-r should be completed daily.
4. In other settings, palliative care consultants will use the tool on initial assessments and follow up visits.

Who should do the ESAS-r

Optimally, the person will provide ratings of symptom severity. If the person cannot provide ratings of severity but can provide input, then the ESAS-r is completed with help of a caregiver (family, friend, health professional involved in care). If the person cannot participate in the assessment at all or refuses to do so then the caregiver can complete the ESAS-r. Caregivers are encouraged to rate objectively. Examples of objective indicators include: grimacing and guarding for pain, increased time spent resting for tiredness, decreased level of alertness for drowsiness, retching or vomiting for nausea, quantity of food intake for appetite, increased respirations or effort causing distress for shortness of breath, tearfulness, flat affect, withdrawal for depression, agitation, flushing, restlessness for anxiety and how the person appears overall for well-being. If it is not possible to rate a symptom, the caregiver may indicate “U” for “unable to assess”.

It is important to indicate who completed the tool on the bottom of the ESAS-r.

How to Use the ESAS-r

The Regional Palliative Care Program of Edmonton, Alberta (2010) recommends the following when completing the ESAS-r:
It is recommended that the person complete the ESAS-r with guidance from a health care professional especially on the first occasion.

The person should be instructed to rate the severity of each symptom on a 0 to 10 scale, where 0 represents absence of the symptom and 10 represents the worst possible severity. The number should be circled on the scale.

The person should be instructed to rate each symptom according to how he or she feels now. The health care professional may choose to ask additional questions about the severity of symptoms at other time points e.g. symptom severity at best and at worst over the past 24 hours.

Definitions have been added to items that have been found to be more problematic for people to understand or rate. You can review these with the person:

- Tiredness: lack of energy
- Drowsiness: feeling sleepy
- Depression: feeling sad
- Anxiety: feeling nervous
- Well-being: how you feel overall
- With the previous version of the ESAS, people often reversed the scale for appetite i.e. they considered “0” as “no appetite” and “10” as “best appetite”. The scale has now been re-labeled as “lack of appetite”. Coaching people on the correct direction of the scale is recommended
- The body diagram on the reverse side of the ESAS-r can be used to indicate sites of pain
- The circled numbers can be transcribed onto the ESAS-r graph

**INTERACTING WITH THE PERSON AND FORMAL/INFORMAL CAREGIVERS**

Communication with the person from the outset is important to build trust. If early symptoms of disease are dismissed and the person eventually is diagnosed with a serious disease, feelings of anger and frustration may affect the relationships with team members throughout the illness. If testing is prolonged, the person needs to be supported and encouraged to believe that an answer will come. The way in which the diagnosis is conveyed to the person will also have an impact on how the person experiences the health care system. Awareness of the CLASS protocol in all interactions is helpful in developing communication skills.

**REMEMBER CLASS:** Context, Listening, Acknowledgement of emotion, Strategy for management, Summary

The health care provider needs to be mindful that his or her physical, emotional, or psychological exhaustion can affect the ability to communicate care, empathy and compassion. Therapeutic conversations with the person and family may involve seriousness of the illness, the likely path the illness will take, goals, expectations, values and beliefs, and treatment options including the benefits and burdens of various options. Therapeutic conversations with the person and family may be challenging for some of the following reasons:

- Fear of upsetting a person by talking about his or her illness and dying
- Fear of extinguishing hope
- Fear of providing more information than expected/desired
- Fear of not having the right answers
- Lack of knowledge and skills around effective communication

**Health Care Team Sharing**

To improve care, the following information is helpful to share with team members:

- The disease process and treatment goals (cure, prolonging life or palliation)
- Any particular concerns or wishes
- The Palliative Performance Scale score
- The understanding of the goals of treatment by both person and family
- The person's level of satisfaction related to the plan of treatment
- ESAS scores

**Person, Family and Friend Sharing**

Often when the diagnosis of a life-threatening illness comes, friends and family will encourage positive thinking and discourage any reflection about death. They may give advice about any number of treatments that could result in cure and will promote the adoption of a “fighting spirit”. It is not easy for the person with the illness, or his or her family and friends, to face the inevitable. Being realistic about the situation can be equated with giving up on the part of the person or lack of compassion and concern on the part of the caregiver.

**PROVIDING SUPPORTIVE CARE STRATEGIES**

The routes outlined in the “roadmap” for Navigating the Journey and the stages defined in the PPS (stable, transitional, and end of life), represent the progressive nature of life-threatening illnesses. Each person and family will have specific issues that need to be addressed along the illness trajectory.

A person waiting for test results may benefit from emotional support. The period of uncertainty while awaiting a diagnosis can be worse than receiving the diagnosis. Ambiguity
generates anxiety. Determining the person’s need for information and how he or she wishes to have news communicated gives the person a measure of control. When a diagnosis cannot be confirmed, acknowledging the ongoing search for answers can be supportive. Ensuring that the person has access to as much information as desired and is allowed to voice concerns is important. Symptom management, regardless of the fact that there is no diagnosis, is necessary to ensure the best possible quality of life.

Once a diagnosis has been given, the person needs to be made aware of all the treatment options in order to determine which ones meet his or her goals. Appropriate information sharing related to the disease, treatment options and side effects is necessary for an informed consent. Awareness of community resources, including support groups, empowers the person and family to access services that might be of benefit to them along the journey. It is often difficult for the person to attempt to cope with the demands of life while simultaneously attempting to comply with treatment and symptom management regimes and resulting side effects. Appropriate and early referrals to various team members will enhance comfort and support an enhanced quality of life for the person.

The person and family may be searching and hoping for a cure and receive a variety of suggestions regarding alternative and/or complementary therapies. Because alternative treatments may have adverse interactions with prescribed treatments it is important for the caregiver to encourage the individual to inform his or her physician of all current therapies. Complementary therapies such as imagery, meditation, music and art can be very beneficial but care is required when using these therapies as powerful emotions can be released.

When it has been determined that there are no further curative options available for the person with a life-threatening illness, monitoring of PPS scores should be initiated. Cancer Care Ontario has developed three generic care plans that identify appropriate interventions for each stage. The care plans are based on the domains of issues and the process of providing care from the model, addressing the three stages that correspond to the Palliative Performance System Scores.

- The Stable Stage Collaborative Care Plan is applicable for those with a PPS score between 100% and 70%.
- The Transitional Stage Collaborative Care Plan is applicable for those with a PPS score between 60% and 40%.
- The End of Life Collaborative Care Plan is applicable for those with a PPS score between 30% and 0%.

The care plans can be found on the Cancer Care Ontario website; http://www.cancercare.on.ca/toolbox/pallcaretools/

The transition from PPS 20% to 10% is very different than other transitions; the families must make a critical shift from “doing” for the person to “being” with the person. Time spent with the person now shifts from predominantly task-oriented activity to a quieter pace of sitting and providing companionship.

WORKING AS A TEAM

Identifying and managing issues throughout the illness journey requires a team of caregivers who communicate consistently through the use of a common language and tools. An integrated care plan with input from all disciplines ensures that everyone is on the same page. The issues the person confronts and the symptoms identified and measured by the ESAS-r change throughout the illness journey. The person’s issues and distressing symptoms must be managed and his or her wishes and goals need to be identified and incorporated into the care plan. The health care providers should consider the following:

- Know who the team members are at the different stages of the journey and how to get in contact with them
- Ensure that everyone is aware of the care plan whenever changes are made
- Communicate regularly to team members using standardized reporting format
- Implement comfort measures within each discipline’s scope of practice and document the effectiveness of the measures
- Understand the PPS and communicate the score to the team
- Understand the ESAS-r and communicate the scores to the team
- Be aware of the challenge of working with many team members and the blending of roles
- Develop with the person a plan of care that addresses goals for comfort and function and respects his/her rights
- Share a common knowledge base, tools and language for care planning and person and family education
- Respect each team member’s contribution and role

Remember: The goal of care is to provide a combination of appropriate therapeutic interventions, agreed upon by the person, aimed at disease management, relieving suffering, and improving quality of life so as to facilitate a positive change of the experience of illness for the person and family.
References


24 Maida V and Chidwick P. Prognosis: Important information when obtaining informed consent. J Palliative Care Med. 1(1); 200. 1-4


Chapter 4

Physical Domain
UNDERSTANDING THE FUNDAMENTALS

Depending on the disease process, a person can experience a variety of physical symptoms such as pain, vomiting, shortness of breath, constipation, and fatigue. Often, as the illness progresses, the person experiences not only one but several issues and physical symptoms on a daily basis, the combination of which greatly impacts the person’s quality of life.

Consider the person living with advanced bone cancer, experiencing severe back pain increasing in intensity with every movement, unable to sleep or eat due to nausea, constipated from medications, fatigued, depressed, feeling isolated and concerned about being a burden to his or her family. That’s an example of a person experiencing distressing issues in several domains. Profound suffering can be the result of a single distressing issue or a combination of symptoms and circumstances.

The term Total Pain, coined by Dame Cicely Saunders the founder of the modern hospice movement, refers to complex and multiple issues in all the domains of issues associated with the illness and bereavement. Pain does not occur in isolation; it affects all those who are in contact with the person. Balfour Mount speaks of the noble task of caring for the seriously ill person and his or her family with “tough clinical science and compassion”. Management of total pain calls for integrated care plans that reach for perfection in terms of managing physical symptoms and psychosocial and spiritual suffering. Skilled health care providers need to remember that quality of life is not dependent on the management of physical issues alone. Good pain and symptom management and an environment that promotes comfort can enable healing at a deep personal level.

Total Pain

Diagram 4.1 on the following page demonstrates that deep suffering or total pain is the culmination of issues that impact the person who is living with life-limiting illness. Examples of issues from each domain that create the suffering follow.

This chapter addresses the common symptoms of physical pain, dyspnea and constipation. There are numerous other physical symptoms that impact the well-being of those with progressive illness but these three will be dealt with in more detail.

Pain

Fink and Gates note that “pain is a common companion of birth, growth, death and illness; it is intertwined intimately with the very nature of human existence”. Few things are of more concern to the person and family at end of life than the control of pain. However, people should not have to wait until end of life to have their pain addressed. Formal and informal caregivers must understand pain and advocate for pain relief whenever it is identified.

A variety of definitions exist for pain:

- McCaffery and Pasero define pain as being whatever the experiencing person says it is, existing whenever the experiencing person says it does
- RNAO states that pain is subjective (occurring where and when the person indicates it does), multidimensional and a highly variable experience for everyone regardless of age or special needs
- Thai and Fainsinger define pain as a biopsychosocial event
- The International Association for the Study of Pain defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”

Types of Pain

There are two categories of pain – acute and chronic (charts 4.2 and 4.3). Acute pain is associated with tissue damage, inflammation, a disease process that is relatively short, or a surgical procedure. Acute pain warns the person that something is wrong. Chronic pain on the other hand is persistent, worsening, and endures for an extended period of time, resulting in decreased function and well-being.

Chronic pain is further divided into malignant pain and non-malignant pain. Regardless of the type of pain, all pain should be addressed with the same rapid and comprehensive management approach. Remember: “Pain is whatever the person says and occurs whenever the person says it does”.

The face of acute pain and the face of chronic pain are reproduced from Cancer Pain: A Monograph on the Management of Cancer. The characteristics and responses to acute and chronic or persistent pain are derived from Jovey.

The American Geriatric Society has classified chronic or persistent pain into subcategories in order to assist the care provider to determine the best management strategy based on the subtype. These include:

- Nociceptive pain resulting from stimulation of peripheral pain receptors
  - Visceral: pain associated with organs such as lungs, liver, heart, etc.
Chapter 4: Physical Domain

Diagram 4.1: Total Pain

**Disease Management Issues**
- Concern about advancing illness
- Concern about adverse effects from medications/treatments
- Concern about existing conditions and allergies

**Physical Issues**
- Unmanaged pain
- Unmanaged symptoms; nausea, shortness of breath, constipation, etc.
- Sleep disturbances
- Increasing fatigue, diminishing appetite, diminishing strength and mobility

**Psychological Issues**
- Emotions associated with increasing losses; loss of role, loss of dignity, loss of control/independence/autonomy
- Compromised self-image
- Increasing anxiety related to anticipated decline in health status and the dying process
- Concern about unpredictable flood of emotions; anger, sadness, fear

**Spiritual Issues**
- Struggle to find meaning and purpose in life
- Increasing feelings of hopelessness
- Questioning and re-evaluating religious beliefs
- Feelings of guilt and regret

**Social Issues**
- Diminishing role within the family, workplace and community
- Changing family relationships, compromised intimacy
- Diminishing social routines/relationships
- Concern about becoming a burden
- Feelings of isolation and abandonment
- Concerns about finances, housing, property and wills

**Practical Issues**
- Diminishing ability to perform ADLs and IADLs such as driving, shopping, and communicating by telephone, email, etc.
- Concern about increasing caregiver burden
- Concern about pets and home maintenance

**End-of-Life Care and Death Management**
- Fear of the unknown
- Fear of increasing pain and symptoms and that distress will not be managed
- Fear of the dying process
- Fear of abandonment
- Fear of indignity to the body after death

**Loss and Grief Issues**
- “Struggle to let go”
- Grief related to loss of sense of self as a person, loss of roles, diminishing prestige and ultimately the separation of body and spirit at the time of death
- Grief related to loss of relationships, particularly those most cherished
- Grief related to the inability to participate in future events such as the graduation or wedding of a child
- Grief related to loss of income, home, possessions, and treasures
Fundamentals Education Program Guide

Pain can be categorized using other terms as well, including:

- **Anticipatory Pain**: Having experienced pain in a certain situation, the person expects to have pain in a similar circumstance. This has the effect of causing fear and anxiety.
- **Baseline Pain**: A constant pain state for at least half of the day.
- **Breakthrough Pain**: A transitory increase in pain over and above baseline pain. This causes increased psychological distress and significant decreases in function.

### Components of the Pain Experience

Many components may drive the person’s response to pain and his or her willingness to accept certain care strategies. Understanding these components will help in the provision of more individualized pain management strategies. There will always be unique expressions of pain. Information in the following chart (chart 4.4) was gathered from Al-Atiyyat and McCaffery and Pasero.

### Chart 4.2

**Acute Pain**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Recent onset</td>
<td>• May be anxiety depending on the intensity, predictability and meaning of the pain</td>
</tr>
<tr>
<td>• Transient in nature</td>
<td>• May be overt pain behaviours (e.g. grimacing, splinting)</td>
</tr>
<tr>
<td>• Lasts for a limited time (several minutes to several days, usually under 30 days)</td>
<td>• Sympathetic nervous system signs e.g. increased pulse and respiration rates, sweating, raised BP</td>
</tr>
<tr>
<td>• Usually caused by tissue damage</td>
<td></td>
</tr>
<tr>
<td>• Associated with some degree of inflammation</td>
<td></td>
</tr>
</tbody>
</table>

### Chart 4.3

**Chronic or Persistent Pain**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Persists beyond the usual course of an injury or disease resolution; usually beyond 3 to 6 months</td>
<td>• Emotional, depressive symptoms e.g. isolation, anxiety, guilt, fatigue, sadness</td>
</tr>
<tr>
<td>• Pattern of recurrence over months or years</td>
<td>• Objective physiological signs are often absent</td>
</tr>
<tr>
<td>• Associated with a chronic pathological condition</td>
<td></td>
</tr>
</tbody>
</table>

» Somatic: superficial somatic pain (skin) and deep somatic pain (bone, muscle, ligaments, joints)

Neuropathic pain resulting from peripheral or central nervous system stimulation

Mixed or unspecified pain

Pain due to psychological disorders

- Incident Pain: A type of breakthrough pain that results from movement or action (e.g. turning in bed, sitting to standing, painful dressing changes)
- Remembered Pain: Usually never forgotten and triggered by certain events or times of day
### Chart 4.4

<table>
<thead>
<tr>
<th>Component</th>
<th>Description</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cultural Background</td>
<td>Individuals will react to pain in the manner they have learned as acceptable within their group</td>
<td>If the family values “stoicism” the person will be silent, whereas if the family values pathos, there may be behavioural indications e.g. crying, moaning etc.</td>
</tr>
<tr>
<td>Gender</td>
<td>A society’s attitudes can influence the way a male should respond and react to pain versus how a female should respond and react to pain</td>
<td>A woman may be allowed to cry whereas men are expected not to</td>
</tr>
<tr>
<td>Age</td>
<td>With increasing age, tolerance to cutaneous pain increases and tolerance to deep pain decreases</td>
<td>Reporting of pain by the elderly may differ from that of younger persons as they may be more stoic about pain.</td>
</tr>
<tr>
<td>Meaning of pain</td>
<td>Pain is determined by what the pain means to the person</td>
<td>A person may perceive increased pain to be related to worsening disease</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some people may interpret pain as a punishment for past sins</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some people do not see pain as evil or negative but part of life</td>
</tr>
<tr>
<td>Life experiences</td>
<td>An individual’s previous experiences with pain will influence how he or she responds to pain</td>
<td>Repeated experiences with pain usually teach the person how severe pain can become and how difficult it is to get relief. Such persons may have higher levels of anxiety and lower pain threshold</td>
</tr>
</tbody>
</table>

### Pain Threshold

Pain Threshold is defined as that point at which the individual feels an increasing intensity of stimuli as painful. Everyone does not perceive the same intensity of pain from the same stimuli. A person’s pain threshold can be raised or lowered based on several factors.

### Chart 4.5

<table>
<thead>
<tr>
<th>Factors that Raise Pain Threshold</th>
<th>Factors that Lower Pain Threshold</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Relief of symptoms</td>
<td>• Discomfort</td>
</tr>
<tr>
<td>• Sleep</td>
<td>• Insomnia</td>
</tr>
<tr>
<td>• Rest</td>
<td>• Fatigue</td>
</tr>
<tr>
<td>• Sympathy and understanding</td>
<td>• Anxiety</td>
</tr>
<tr>
<td>• Companionship</td>
<td>• Fear</td>
</tr>
<tr>
<td>• Diversional activity</td>
<td>• Sadness</td>
</tr>
<tr>
<td>• Elevation of mood</td>
<td>• Depression</td>
</tr>
<tr>
<td>• Anti-depressants</td>
<td>• Boredom</td>
</tr>
<tr>
<td>• Anxiolytics</td>
<td>• Introversion</td>
</tr>
<tr>
<td>• Analgesics</td>
<td>• Social isolation</td>
</tr>
</tbody>
</table>
There are many different causes and effects of pain; the following chart highlights some of the most common ones.

**Chart 4.6**

<table>
<thead>
<tr>
<th>Causes of Pain</th>
<th>Effects of Pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arthritis: low back pain, painful peripheral joints, especially hips, shoulders, knees</td>
<td>Physical</td>
</tr>
<tr>
<td>Musculoskeletal: compression fractures of the spine, old hip and other fractures, contractures</td>
<td>• Decreased functional capability</td>
</tr>
<tr>
<td>Diabetes: peripheral neuropathy</td>
<td>• Poor appetite, interrupted sleep</td>
</tr>
<tr>
<td>Cancer: bone infiltration, nerve compression, raised intra-cranial pressure, therapy related to the disease, soft tissue damage</td>
<td>• Diminished strength/endurance</td>
</tr>
<tr>
<td>Cardio-vascular: angina, claudication, CVA</td>
<td>• Increased constipation</td>
</tr>
<tr>
<td>Muscle spasm</td>
<td>• Reduced activities of daily living</td>
</tr>
<tr>
<td>Constipation: rectal pressure, urinary incontinence, confusion, abdominal cramps, and diarrhea</td>
<td>Psychological</td>
</tr>
<tr>
<td>Oral Pain: poorly fitting dentures, decayed teeth, gum disease, candidiasis</td>
<td>• Diminished leisure, enjoyment</td>
</tr>
<tr>
<td>Soft Tissue: bruises, skin tears</td>
<td>• Increased fear, anxiety, anger</td>
</tr>
<tr>
<td>Visceral damage: ulcerative colitis, tumour</td>
<td>• Depression</td>
</tr>
<tr>
<td>Ulceration: decubitus ulcers</td>
<td>• Loss of control</td>
</tr>
<tr>
<td>Lymphedema: swelling of limbs due to congestive heart disease, cancer</td>
<td>• Resistance to care</td>
</tr>
<tr>
<td>Herpetic neuralgia: related to “shingles”</td>
<td>• Self abuse</td>
</tr>
<tr>
<td></td>
<td>• Distressful and difficult behaviour</td>
</tr>
<tr>
<td></td>
<td>Social</td>
</tr>
<tr>
<td></td>
<td>• Diminished social relationship</td>
</tr>
<tr>
<td></td>
<td>• Increased sexual function</td>
</tr>
<tr>
<td></td>
<td>• Increased caregiver burden</td>
</tr>
<tr>
<td></td>
<td>• Distraught families</td>
</tr>
<tr>
<td></td>
<td>• Isolation and decreased quality of life</td>
</tr>
<tr>
<td></td>
<td>Spiritual</td>
</tr>
<tr>
<td></td>
<td>• Increased suffering; “why is this happening to me?”</td>
</tr>
<tr>
<td></td>
<td>• Re-evaluation of religious beliefs</td>
</tr>
<tr>
<td></td>
<td>• Demoralization</td>
</tr>
</tbody>
</table>
Barriers to Optimal Pain Assessment and Management

Some common barriers to effective pain assessment and management have been identified by Fink and Gates under the three headings that follow in chart 4.7:

<table>
<thead>
<tr>
<th>Person / Family / Societal Barriers</th>
<th>Health Care Professional Barriers</th>
<th>System Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The subjective and personal nature of the pain experience</td>
<td>• Prejudice and bias; not believing the person; paternalistic attitudes</td>
<td>• A system that fails to hold staff accountable for pain assessment and management</td>
</tr>
<tr>
<td>• Lack of awareness on the part of person and family regarding pain assessment</td>
<td>• Lack of identification of pain, pain assessment, and relief as a priority in care</td>
<td>• Lack of tools for pain assessment and management in the setting</td>
</tr>
<tr>
<td>• Lack of communication with health care professionals about pain</td>
<td>• Inadequate knowledge about how to perform a pain assessment</td>
<td>• Lack of institutional policies for performance and documentation of pain assessment</td>
</tr>
<tr>
<td>• Reluctance to report pain</td>
<td>• Perceived lack of time for pain assessments</td>
<td>• Misinterpretation of stringent laws inhibits the appropriate use of opioids</td>
</tr>
<tr>
<td>» Not wanting to bother staff</td>
<td>• Failure to use validated tools</td>
<td>• Confusion between the legitimate and illegitimate use of opioids</td>
</tr>
<tr>
<td>» Fear of not being believed</td>
<td>• Inability of clinician to empathize or establish rapport</td>
<td>• Focus on cure rather than care</td>
</tr>
<tr>
<td>» Stoicism</td>
<td>• Concern about addiction</td>
<td>• Lack of co-ordination as people move through the system</td>
</tr>
<tr>
<td>» Attitudes: i.e. What’s the use; nothing works</td>
<td>• Confusion related to addiction, tolerance and physical dependence</td>
<td>• Red tape involved to obtain analgesics not normally covered by government plan</td>
</tr>
<tr>
<td>» Concern that curative therapy might be curtailed if pain and symptom management become a focus</td>
<td>• Poor understanding of opioid side effects</td>
<td>• Cultural attitudes and beliefs</td>
</tr>
<tr>
<td>» Lack of common language to describe pain</td>
<td>• Low expectation for successful pain management</td>
<td>• Confusion around ethical and moral principles</td>
</tr>
<tr>
<td>• Unfounded beliefs, misconceptions, and myths about pain and its treatment</td>
<td>• Inability of clinician to empathize or establish rapport</td>
<td>• Fear of being accused of practicing euthanasia, hastening death</td>
</tr>
<tr>
<td>» Pain is inevitable</td>
<td>• Concern about addiction</td>
<td>• Confusion around ethical and moral principles</td>
</tr>
<tr>
<td>» If pain is worse, the disease is spreading</td>
<td>• Confusion related to addiction, tolerance and physical dependence</td>
<td>• Fear of being accused of practicing euthanasia, hastening death</td>
</tr>
<tr>
<td>» Should wait to take medication until it is really needed</td>
<td>• Poor understanding of opioid side effects</td>
<td>• Confusion around ethical and moral principles</td>
</tr>
<tr>
<td>» Too much medication now means there will nothing for later</td>
<td>• Low expectation for successful pain management</td>
<td>• Focus on cure rather than care</td>
</tr>
<tr>
<td>» Family think I am too 'spacey” so better cut back</td>
<td>• Inability of clinician to empathize or establish rapport</td>
<td>• Lack of co-ordination as people move through the system</td>
</tr>
<tr>
<td>» If it’s morphine, I must be close to the end</td>
<td>• Concern about addiction</td>
<td>• Red tape involved to obtain analgesics not normally covered by government plan</td>
</tr>
<tr>
<td>» Taking medication will lead to addiction</td>
<td>• Confusion related to addiction, tolerance and physical dependence</td>
<td>• Cultural attitudes and beliefs</td>
</tr>
<tr>
<td>» If the medication is taken before it really hurts, I’ll get too much</td>
<td>• Poor understanding of opioid side effects</td>
<td>• Confusion around ethical and moral principles</td>
</tr>
<tr>
<td>» Best to hang in, just tough it out</td>
<td>• Low expectation for successful pain management</td>
<td>• Fear of being accused of practicing euthanasia, hastening death</td>
</tr>
<tr>
<td>» I’d rather not be constipated</td>
<td>• Inability of clinician to empathize or establish rapport</td>
<td>• Confusion around ethical and moral principles</td>
</tr>
<tr>
<td>» Don’t want to bother the staff, they are busy with other people</td>
<td>• Concern about addiction</td>
<td>• Focus on cure rather than care</td>
</tr>
<tr>
<td>» Too much pain medication will hasten death</td>
<td>• Confusion related to addiction, tolerance and physical dependence</td>
<td>• Lack of co-ordination as people move through the system</td>
</tr>
<tr>
<td>» Good patients don’t complain</td>
<td>• Poor understanding of opioid side effects</td>
<td>• Red tape involved to obtain analgesics not normally covered by government plan</td>
</tr>
</tbody>
</table>
Common Myths About Pain and Opioids

Of the barriers to effective pain management previously listed, the two most persistent are myths about pain and myths about opioids.

**MYTH:** Pain is a normal part of aging.
**FACT:** Pain is a result of disease process or injury. Pain is not synonymous with aging.

**MYTH:** Pain is only felt while one is awake.
**FACT:** Pain can be experienced while sleeping, hence the need for around-the-clock dosing.

**MYTH:** Pain can only be controlled with strong opioids.
**FACT:** While opioids are frequently used to control pain, non-opioid medications and non-drug therapies can also be helpful.

**MYTH:** Opioids make you feel high.
**FACT:** Pain management may make the person feel better but getting a high is uncommon.

**MYTH:** Opioids cause respiratory depression which can lead to death.
**FACT:** When opioids are utilized for pain management and are properly titrated, respiratory depression is virtually non-existent.

**MYTH:** Opioids cause addiction.
**FACT:** Addiction is very uncommon when opioids are utilized properly for pain management.

**MYTH:** Persons on opioids develop tolerance and over time the medications won’t work anymore.
**FACT:** Tolerance is a factor with long-term use of opioids but is not necessarily the reason for upward titration. There is no ceiling dose.

**Myth:** “Shots” are stronger than pills
**Fact:** Oral route is effective and preferred.

1. **Addiction**
   Addiction is a primary, chronic neurobiological disease, with genetic, psychosocial, and environmental factors, influencing its development and manifestations. It is characterized by behaviours that include one or more of the following (4Cs):
   » Impaired Control over drug use: May be reflected in requests for early prescription refills, double doctoring, using street sources.
   » Compulsive use: May be reflected in non-compliance with non-opioid components of the plan, inability to acknowledge psychosocial contributors to pain, or the perception that nothing but opioids will relieve the pain.
   » Continued use despite harm or consequences: Consequences associated with use of opioids may include persistent over sedation or euphoria, deteriorating level of function despite pain relief, increased distress such as anxiety, sleep disturbance or depression.
   » Craving: Manifested as an intense desire to use a substance for its psychoactive effect rather than for the analgesic effect or to stave off physiological withdrawal symptoms.

2. **Pseudo-Addiction**
   Pseudo-Addiction occurs when those with severe, unrelied pain may become intensely focused on finding relief for pain. It is a behavioural process that mimics psychological dependence; this behaviour is related to poor pain management; the person has a “pain relief” seeking behaviour versus a “drug seeking” behaviour.

3. **Tolerance**
   Tolerance is a state of adaptation in which exposure to a drug induces changes that result in a diminution of one or more of the drug’s effects over time. Tolerance to most of the unwanted opioid side effects (e.g. nausea, sedation, respiratory depression) occurs rapidly. Tolerance to the analgesic effects is indicated by the need for increasing or more frequent doses of the medication to maintain the analgesic effect. Tolerance occurs in an area of the brain separate from the brain pathways related to addiction.

4. **Physical Dependence**
   Physical dependence is a state of adaptation that often includes tolerance and is manifested by a drug class-specific withdrawal syndrome that can be produced by abrupt cessation, rapid dose reduction, decreasing blood level of the drug and / or administration of an antagonist. Physical dependence is an expected physiological response and may develop in 7-10 days. It occurs in an area of the brain thought to be unrelated to addiction.
Dyspnea

Dyspnea is a frequently encountered symptom in progressive life-limiting illness and it may be just as or more distressing than pain for the person and his or her family.

The American Thoracic Society defines dyspnea as “the term used to characterize a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity”. Dyspnea or shortness of breath requires as aggressive assessment and management as pain. Remember that opioids are indicated for dyspnea as well as for pain.

The experience derives from interactions among multiple physiological, psychological, social and environmental factors, and may induce secondary physiological and behavioral responses.

More simply stated, dyspnea is an uncomfortable awareness of breathing and is associated with:

- functional and social limitations
- suffering
- psychological distress
- impaired quality of life.

Dyspnea is often present for long periods of time in the illness trajectory of many progressive diseases. Dudgeon notes that dyspnea is reported to be an issue for 50% of cancer outpatients with the incidence rising to 70% in the terminal phase of the disease. Shortness of breath is a distressing symptom for approximately 90% of those with lung cancer. Persons with end stage COPD (95%) report extreme breathlessness. Over half the individuals with CHF have found dyspnea to be a major concern in the last year of life. Persons with ALS, dementia and stroke also report dyspnea. The presence of dyspnea accounts for 25 to 53% cases in which palliative sedation is required for uncontrolled symptoms. Those with dyspnea are more likely to die in hospital than at home partly due to the increased distress for caregivers and staff. Unfortunately, doctors and nurses do not always provide proper assistance and leave the person and family to cope with this debilitating symptom in isolation. Like pain, dyspnea is a subjective symptom and it is what the person says it is. When asking about shortness of breath it is important to ask about the person’s experience at rest, while walking, climbing stairs or eating. The team must take reports of dyspnea seriously and make every effort to alleviate this symptom.

Constipation

Constipation is another symptom that causes untold distress for many persons with debilitating illness or using medications such as opioids to relieve pain or dyspnea. Constipation is common, affecting 70 to 100% of cancer patients, and yet undertreated by both physicians and nurses. Constipation causes physical, social and psychological distress and affects quality of life. Proactive anticipation and management of constipation will prevent the difficulties encountered in relieving the problem. Nurses need to monitor bowel function on an ongoing basis throughout the illness trajectory. All health care providers need to take complaints of constipation seriously and address the problem immediately beginning with a proper assessment. The Victoria Bowel Performance Scale and Bowel Management Guidelines can be downloaded from the following website: http://www.victoriahospice.org/health-professionals/clinical-tools

Other Physical Symptoms

Some physical symptoms other than pain, dyspnea and constipation are listed below. This list is not exhaustive and the person can experience any number of symptoms.

- Anorexia/loss of appetite
- Bleeding
- Cough
- Confusion
- Diarrhea
- Dysphagia (difficulty swallowing)
- Seizures
- Weakness
- Hiccoughing
- Sweating
- Nausea/vomiting
- Pruritis (itching)
- Insomnia
- Wounds
- Urinary frequency and/or Incontinence
- Urinary retention

Reflecting on the person’s situation (pain or other symptoms) with the question “Why does this person have this symptom now?” initiates the gathering of data as part of the assessment required to determine an effective management plan.
**OBSERVING THE INDIVIDUAL’S EXPERIENCE**

Identifying the person's physical symptoms is critical to facilitate a change in the illness experience for the person and family. In order to address symptoms, the caregiver must understand the individual’s experience. This understanding that is gained through knowledge of the disease process, careful observation and active listening. A systematic approach to exploring each symptom will help ensure a comprehensive assessment has been completed. The information can then be used to guide discussions about treatment options for each symptom. A commonly used approach uses the letters OPQRSTU as a guide. Further information can be found in **OPQRSTUV Symptom Assessment Acronym**, in the Tool section at the end of this guide, at the end of this guide.

**Observing Pain**

McCaffery & Pasero suggest the following order of importance related to pain intensity:21

- **Person’s self-report** using a pain rating scale e.g. the ESAS-r tool is the best indicator
- **Pathologic conditions or procedures** that usually cause pain should alert professionals to observe for signs of pain
- **Behaviours** (e.g., facial expressions, body movements, crying) are frequently seen in those with cognitive impairment and those who cannot verbally express pain
- **Reports of pain** from family or others close to the person can assist professionals in understanding how pain will be expressed or why it will not be expressed
- **Physiologic measures** such as B/P or pulse are the least sensitive indicators of pain

The following indicators of pain are particularly important in identifying pain in a non-verbal person (e.g. cognitively impaired adults, infants and young children). There are a number of assessment tools that can be utilized in this population.

1. **A change in facial expression.**
   - A pained facial expression most often reflects the presence of physical pain (from usually relaxed to continuously troubled with wrinkled forehead, frowning, wide open or ‘scrunched’ eyes with distressed look)
2. **A change in behaviour**
   - Behaviours that indicate distress may reflect physical, intellectual, emotional, environmental, spiritual, or psychosocial pain.22 A caregiver may observe any of the following behaviour changes:
     - from being quiet, still to moaning, rocking
     - from being friendly, outgoing to being combative, resisting care

When family/staff/volunteers report a suspicion of pain further investigation should take place. Any change in the person’s condition should warrant an inquiry about pain. Pain as the 5th vital sign is a concept that is being advocated in many settings. Whenever temperature, BP, pulse and respirations are taken, the person should be asked to rate pain as well. When a condition that is normally associated with pain is diagnosed, providers need to monitor for pain. When provided with information that the person is stoic and will not acknowledge pain the caregivers need to use different terminology to illicit information e.g. discomfort, soreness, uncomfortable.

When it has been determined that pain is an issue for the person, it is important that a pain assessment be completed to collect as much information as possible concerning the pain. A thorough assessment and a pain diagnosis are the key to an effective management plan. Pain assessment and monitoring forms have been developed to facilitate consistency in reporting. The RNAO Best Practice Guidelines for the Assessment and Management of Pain23 provides samples of tools used for pain assessment. Further information is available at www.rnao.org.

As part of the initial pain assessment, as well as the ongoing monitoring of pain, it is important to attempt to quantify the pain a person is experiencing. The most commonly used scales that have proven to be effective in measuring pain are:24

1. The Visual Analogue Scale (VAS)
2. The Numeric Rating Scale (NRS)
3. Verbal Descriptor Scale (VDS)
4. Faces Scale (Wong-Baker)
5. The Faces Pain Scale Revised (FPS-R)
6. Pain Thermometer
See **Pain Intensity Scales**, in the Tool section at the end of this guide for a comparison of the various pain intensity scales. Learners can also search online for visuals and more information on each.

The ESAS-r that is advocated for use throughout Ontario by Cancer Care Ontario uses a numeric rating scale for a number of commonly experienced symptoms related to chronic progressive illnesses. The tool is one of the best ways to get an overall sense of how the person is experiencing his or her illness by measuring the burden of various symptoms that together have a significant effect on the person’s overall sense of well-being. The severity ratings on the ESAS alerts the care-provider to engage in a more fulsome assessment and exploration of the symptom severity as indicated by the person. In order to facilitate a positive change in the experience of the illness, everything about the person’s situation needs to be taken into consideration.

**Observing Dyspnea**

As with pain, the person’s self-report is the most accurate indicator of the level of distress. Observations of the following should be made when dyspnea is an issue.

- Skin tone and colour
- Use of accessory muscles
- Pursed lips
- Ability to speak
- Positioning e.g. seated leaning forward
- Agitation and restlessness
- Mood, ability to concentrate and solve problems
- Level of distress related to walking, going shopping, making a bed
- Respiratory rate

Remember that an abnormally fast or slow rate of respiration is not necessarily indicative of a subjective experience of shortness of breath.

There are a number of tools that can be used to measure dyspnea; the Visual Analog Scale, the Oxygen Cost Diagram, the Modified Borg Scale, Reading Numbers Aloud Test and the ESAS-r.

**Observing Constipation**

Besides observing the frequency, amount and consistency of stool, other symptoms associated with constipation should be noted such as: abdominal distension or bloating, change in amount of gas passed rectally, oozing of liquid stool, rectal fullness or pressure, rectal pain with bowel movements, and degree of strain required to pass stool. There are a number of tools available for assessment and management of constipation e.g. The Constipation Assessment Scale and the Victoria Hospice Bowel Performance Scale.

**INTERACTING WITH THE PERSON AND CAREGIVERS**

Each person’s symptom experience is unique. The person’s past experiences with pain and other symptoms, progression of illness, cognition, culture, and many other factors affect the ability and willingness to communicate the experience.

Failure to believe the person’s report of pain and/or other physical symptoms may result in potentially harmful effects such as neglecting the detection of a complication or to provide adequate treatment. Using a tool as a guide can help the novice clinician to gain all of the important information but usually a few questions such as “tell me about your pain/symptom?” or, “describe how your pain/symptom is affecting your life?” will bring forth a great deal of information that can be documented on the tool without having to ask too many questions. Through active listening and clarification, the clinician can usually gain most of the answers needed. The report of the person’s word descriptors related to pain or other symptoms is crucial. Such descriptions are particularly important in diagnosing the type of pain and implementing the appropriate interventions. Any barriers, misunderstandings or myths must be uncovered if compliance with the plan of treatment is to be expected. In addition, identification and communication of the goals of the person and family with regard to pain and symptom management is paramount. If goals are not being met with the current treatment plan, health care providers have a duty to advocate for consultations with secondary or tertiary level experts in the field. Health care providers are legally and ethically obligated to advocate for persons within the health care system to ensure that the most effective pain relieving strategies are utilized in promoting the person’s comfort and the relief.

**PROVIDING SUPPORTIVE CARE STRATEGIES**

Much of hospice palliative care revolves around management of pain and other symptoms. There is nothing more important to the experience of the illness than the management of symptoms resulting from a disease or its treatment. The traditional health care system utilizes medications and other treatments such as chemotherapy, radiation, Trans Electrical Nerve Stimulation, heat, cold, and acupuncture to manage physical pain. Individuals can choose other modalities as well. Most are on a fee for service basis.

**Complementary Therapies**

In recent years there has been a growing interest in Comple-
Complementary Therapies. In this program, the term Complementary Therapies is used rather than Alternative Therapies. The distinction is important:

1. Alternative Therapy
   • Choice between one or another therapy; one is chosen to the exclusion of others.

2. Complementary Therapy
   • That which completes or supplies a deficiency
   • Adds the psychosocial and spiritual component to a holistic care approach
   • Many of these therapies open the person's spirit to experiences that transcend the pain of the present experience and provide insight, comfort, peace, and meaning

Complementary Therapies include:

• Acupressure
• Acupuncture
• Affirmations
• Alexander Method
• Aromatherapy
• Art Therapy
• Ayurvedic Medicine
• Bach Flower Remedies
• Bioenergetics
• Biofeedback
• Body Toning
• Bowen Therapy
• Chakra Balancing
• Craniosacral Therapy
• Colonhydrotherapy
• Expressive Arts Therapies
• Dream Interpretation
• Feldenkrais
• Facial Therapy
• Herbalist
• Healing Touch
• Hypnosis
• Homeopathy
• Visualization
• Imagery
• Kinesiology
• Iris Analysis
• Light Touch Therapy
• Labyrinth
• Meditation
• Massage Therapy
• Moxibustion (Cupping)
• Mitzvah Technique
• Music Therapy
• Naturopathy
• Nutrition
• Neuro-Linguistic Programming
• Osteopathy
• Pilates
• Polarity Therapy
• Prayer
• Reiki
• Reflexology
• Rolfing
• Shiatsu
• Spiritual Healing
• Tai Chi
• Therapeutic Touch
• Traditional/ Shamanic Healing
• Trager Approach
• Yoga

Supportive Strategies for Pain

• Believe the person
• Conduct a thorough assessment
• Implement the treatment plan consented to by the person
• Pharmacological: non-opioid analgesics, opioids, adjuvant medications such as corticosteroids, tricyclic antidepressants, anticonvulsants, bisphosphonates, muscle relaxants, anaesthetic agents
• Non pharmacological: distraction, radiation therapy, relaxation therapy, physical and occupational therapy, TENS, acupuncture, heat, cold, other complementary therapies
• Monitor effectiveness of interventions
• Consult with experts if goals are not met within a predetermined time period (e.g. 48 hrs).

Supportive Strategies for Dyspnea

• Conduct a thorough assessment
• Implement the treatment plan consented to by the person
• Administer opioids, bronchodilators, anxiolytics, oxygen as directed
• Be calm and reassuring
• Position: sitting up and leaning forward supporting arms on a table
• Educate person and family; teach pursed lip or diaphragmatic breathing, relaxation techniques
• Use a fan to move the air or sit the person by an open window
• Acupuncture may be helpful
• Complementary therapies

Supportive Strategies for Constipation

• Be alert to medications that increase the risk of constipation
• Be proactive in initiating laxative therapy when opioids are initiated
• Remember that tolerance can develop, a specific laxative may become less effective over time
• When medication doses that cause constipation are titrated upward, increase anti constipation therapy
• Position so that gravity can assist with bowel movements
• Place feet on a stool when on commode or toilet
• Encourage exercise within tolerance
• Increase fluid intake if able
• Utilize dietary interventions as appropriate
• Provide privacy for defecation

## Chart 4.8: Supportive Strategies for Other Physical Symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Description</th>
<th>Helpful Hints</th>
</tr>
</thead>
</table>
| Anorexia/loss of appetite | • Very common
   • May be due to depression, unrelieved pain, mouth discomfort, difficulty swallowing, nausea, constipation, effects of chemotherapy/radiation, changes in taste, decreased saliva production | • Small servings of favourite foods, attractively presented
   • Dry sherry or champagne as a stimulant
   • Two-handled cup or use of bendable straws
   • Supplements i.e. Ensure, Carnation Breakfast, milk shakes
   • Assist the very weak person
   • Check for yeast infection in the mouth
   Towards end of life:
   • Family may feel they are failing to nurture and care if they don't “encourage” the ill person to eat and drink. Explanations of the normal dying process must be given
   • Allowing the ill person to have what he or she wants when he or she wants it is the ideal
   • Frequent and thorough mouth care is necessary and required at least q1-4h |
| Anorexia is a normal occurrence at the end of life |                                                                                   |                                                                                   |
| Diarrhea                 | • Relatively uncommon but usually due to “overflow” around a fecal impaction, viral/bacterial infection, radiation therapy, medications
   • (i.e. antibiotics), tumours of the colon or rectum | • Ensure that there is no fecal impaction
   • Dietary measures i.e. banana, yogurt, may help
   • Discreetly assist the person to maintain personal hygiene to avoid embarrassment as well as skin breakdown. Use barrier creams as necessary
   • Administer medications and treatments as ordered |
| Urinary frequency and/or incontinence | • Commonly experienced by individuals with advanced malignancy
   • Due to bladder infections, diabetes, elevated calcium levels, pelvic tumours, radiation therapy | • Avoid embarrassing the person
   • Assist to bathroom every 3 – 4 hours
   • Use bedside commode, urinal, catheter when necessary
   • Protect mattress with pads
   • Encourage adequate fluid intake if appropriate
   • Use incontinence products discreetly |
| Urinary Retention         | • May be caused by tumours obstructing the bladder, drugs (e.g. anti-depressants) | • May require catheter |
| Cough                    | • May be caused by environmental irritants (smoke, dust), dry air, lung infections/tumours
   • Tiring | • Sit up, prop with pillows
   • Try warm drink e.g. lemon and honey
   • Use medication as ordered |
<table>
<thead>
<tr>
<th>Symptom</th>
<th>Description</th>
<th>Helpful Hints</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hiccough</td>
<td>• Caused by spasm of the diaphragm or abdominal distension&lt;br&gt;• Distressing and exhausting</td>
<td>• Elevate head of bed&lt;br&gt;• Re-breath into paper bag&lt;br&gt;• Use medication as necessary</td>
</tr>
<tr>
<td>Nausea/Vomiting</td>
<td>• May be related to gastrointestinal or neurologic causes&lt;br&gt;• (i.e. vagal stimulation), medications (anti-inflammatory, antibiotics, iron, opioids), emotions, increased intra-cranial pressure&lt;br&gt;• Often related to constipation</td>
<td>• Determine the cause and initiate treatment&lt;br&gt;• Offer small amounts of favourite food or beverage&lt;br&gt;• Ice chips, cold beverages&lt;br&gt;• Calm environment&lt;br&gt;• Eliminate offending odours&lt;br&gt;• Medicate as necessary</td>
</tr>
<tr>
<td>Weakness</td>
<td>• Due to disease process, inadequate/poor nutrition, dehydration, fever, pain, chemotherapy, radiation therapy, electrolyte imbalances&lt;br&gt;• Part of the dying process</td>
<td>• Treat cause if possible&lt;br&gt;• Decrease non-essential activities&lt;br&gt;• Arrange for help&lt;br&gt;• Set nap times&lt;br&gt;• Encourage and support but avoid nagging</td>
</tr>
<tr>
<td>Sweating</td>
<td>• Can be part of disease process side effect of medication</td>
<td>• Determine cause and treat appropriately&lt;br&gt;• Check for fever&lt;br&gt;• Change bedding and sleepwear as necessary&lt;br&gt;• Tepid sponge/fan if fever&lt;br&gt;• Medicate as necessary</td>
</tr>
<tr>
<td>Insomnia</td>
<td>• Usually due to unrelieved physical and/or psychological symptoms&lt;br&gt;• May also be caused by prolonged bed rest or decreased diversion during late night</td>
<td>• Relaxing activities in evening&lt;br&gt;• Decrease caffeine consumption&lt;br&gt;• Physical&lt;br&gt;• Warm bath, warm drink, back rub&lt;br&gt;• Hot water bottle (on feet), change position&lt;br&gt;• Quiet room, soft music, shaded light&lt;br&gt;• Psychological&lt;br&gt;• Reassure&lt;br&gt;• Be within sight, if that helps&lt;br&gt;• Talk about past or family's future&lt;br&gt;• Read, watch TV, music</td>
</tr>
<tr>
<td>Mouth Pain</td>
<td>• May be due to local radiation therapy, chemotherapy, mouth breathing, infections (thrush), medications (e.g. antidepressants), loose-fitting dentures, poor dental hygiene</td>
<td>• Keep mouth clean and moist&lt;br&gt;• 1 teaspoon baking soda in ¼ cup water is a good cleaning solution or mouthwash&lt;br&gt;• Keep lips moist&lt;br&gt;• Ice chips, favourite drink, sips of water, artificial saliva&lt;br&gt;• Hard sugarless candies&lt;br&gt;• Glycerine or balm for lips&lt;br&gt;• Moist room air (humidifier in winter)&lt;br&gt;• Treat fungal infections&lt;br&gt;• Treat painful sores with analgesics</td>
</tr>
<tr>
<td>Symptom</td>
<td>Description</td>
<td>Helpful Hints</td>
</tr>
<tr>
<td>---------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Dysphagia     | • Difficulty swallowing may be related to mouth care problems, mechanical obstruction of the esophagus, tumours in the throat/chest area                                                                                 | • Determine cause and treat appropriately  
• Soft foods  
• Avoid fluids if choking  
• Thicken fluids if recommended  
• Treat mouth sores | |
| Dehydration   | • Related to decreased fluid intake  
• Common occurrence in dying process                                                                                                                                                                              | • Support and educate the family  
• Have favourite fluids available if person wants. It’s important not to insist that they must drink!  
• Give frequent mouth care                                                                                                                 |
| Pruritus (Itch) | • Persistent itchiness may be due to excessively dry skin, jaundice, environmental and/or drug reactions                                                                                                     | • Soothing baths/lotions  
• May require medication or surgical intervention                                                                                               |
| Confusion     | • A complex symptom related to medication administration (e.g. tranquilizers, hypnotics, antidepressants), infections, cerebral tumours, decreased oxygen supply, cardiovascular disease, altered or unfamiliar environment | • Re-assure, point out familiar surroundings  
• Talk about family or other favourite topics  
• Maintain safety through close observation  
• Have someone familiar stay with the person  
• Consider changes in medication regime  
• May require diagnostic testing  
• Keep small light on in room at night                                                                                                           |
| Skin Problems | • Due to deteriorating condition  
• Inactivity may lead to pressure sores                                                                                                                                                                        | • Avoid massage over bony prominences  
• A mattress with low interface pressure, such as high-density foam, is recommended  
• For more detail and hints for skin problems refer to the RNAO Best Practice Guidelines at www.rnao.org | |
| Bleeding      | • Due to tumour infiltration of blood vessels, varices, tumour erosion, wound erosion, hemorrhage  
• Before evidence of bleeding, the client may become restless, confused, may yawn or pluck at bedclothes  
• May observe bleeding at dressing site  
• Blood appears like coffee grounds or grape colour when vomiting  
• Bowel movements appear black/tar-like                                                                                                         | • Educate family if there is a risk  
• Call professional  
• Reassure client and family  
• Keep client warm, elevate feet  
• Have dark or red towels on hand to absorb blood – less frightening to the person and family |
Here is a sample of tools with disease specific strategies to support care:

- **Oncology:** Cancer Care Ontario Collaborative Care Plans. Interdisciplinary guides to practice designed to place the person at the focal group of care and to promote continuity and coordination of care. CCPs define the activities, interventions and expected outcomes for people who need palliative services based on their functional performance as defined by the Palliative Performance Scale (PPS). https://www.cancercare.on.ca/toolbox/pallcaretools/

- **Nephrology:** The RNAO has a Best Practice Guideline (BPG) called Decision Support for Adults Living with Chronic Kidney Disease. In this guideline there are some suggestions regarding holding conversations with people re: resuscitation status, advance directives and choosing not to initiate or to withdraw dialysis treatment http://www.rnao.org/Page.asp?PageID=1115&BL_WebsiteID=1

- **Other RNAO BPGs:** RNAO produces additional best practice guidelines such as the following for end-of-life care. Though palliative care spans the entire disease trajectory, this resource may be helpful. http://rnao.ca/bpg/guidelines/endoflife-care-during-last-days-and-hours

### Intractable Suffering

When the person’s symptoms do not respond to traditional treatment strategies, they are considered to be intractable or refractory. If comfort is the primary goal of the person’s care, consideration may be given to the use of palliative sedation. The Pallium Palliative Pocketbook (2011) defines palliative sedation as deliberate sedation aimed at relieving intractable symptoms in the person who is close to death. The goal of this sedation is NOT to deliberately cause death. When used appropriately, it is an ethically justifiable option. The sedation may be temporary or may continue until the person’s death. It is highly recommended that a palliative care team be consulted prior to initiation of palliative sedation since palliative care practitioners may be aware of other treatment options.

### WORKING AS A TEAM

Seeing a person suffer with pain or other symptoms is common in hospice palliative care and can be distressing for staff, family members and friends. All members of the care team, including family and friends can observe, monitor and report pain and other symptoms. Professionals on the team have a duty to assess, share information, assist in the decision making process related to treatments, planning, and delivering care. Confirmation that the plan is acceptable to the person and that the goals are being met as well as being an advocate for the best possible symptom management is the duty of everyone on the team.

McCaffery & Pasero offer tips for establishing a collaborative approach to pain management. These tips, which have been adapted to relate to other symptoms as well, include:

1. Establish common goals
   - Agree on comfort/function goals for pain and/or symptom management
   - Agree that the person has the right to determine which treatments will be included in the plan
   - Develop an integrated plan of care with consideration given to every team member’s input.

2. Use common language and tools
   - ESAS-r
   - PPS

3. Develop a common knowledge base
   - Educate members of the health care team
   - Educate the person and family
   - Use validated assessment tools and treatment protocols.

4. Engage in routine communication
   - Respect the input of all members of the team
   - Monitor outcomes (ESAS flow sheet)
   - Maintain routine contact (e.g. daily progress report, fax, notes)
   - Use standardized report format

The whole team must work together to determine the cause of each symptom. Appropriate assessment tools should be utilized and every person on the team is responsible for...
reporting observations. When the symptom is related to the disease process, treat the underlying disease as appropriate.

When planning for pain management, consider the following points:

- Don’t delay treating the pain
- Use multiple methods, such as modifying the pathological process, elevating the pain threshold, interrupting the pain pathway, modify lifestyle
- Use the WHO ladder (chart 4.9)
- Give medication orally whenever possible
- Chronic pain present more than 12 hours in 24 requires a constant level of analgesia so administer medications around the clock (ATC)
- Give breakthrough doses as necessary (BTD)
- Consider adjuvant therapies/treatments
- When giving analgesics to the elderly, start low and go slow
- Treat opioid side effects (constipation, nausea) aggressively
- Inform person to expect to feel somewhat sedated for a few days when opioids are begun or the dose is increased and instruct family to notify the team if the person is difficult to rouse

References


Chapter 5: Psychological Domain
UNDERSTANDING THE FUNDAMENTALS

Psychology is the study of the mind and mental processes in relation to behaviour. Hospice palliative care examines how the mind deals with the threat of death, the process of dying, death itself, and how mental processes in such circumstances affect the behaviour of the person and family. Brescia notes that psychiatric issues and symptoms are not as widely recognized as physical symptoms. Depression, anxiety and psychological distress often cause great suffering and decreased quality of life for both the person and family.

Living with a life-threatening illness is tough, demanding, and intense for loved ones as well as for the person. When provided with practical, emotional, and spiritual support through all the stages of illness, the person and family often experience privileged moments of special communication, growth, and even joy.

Emotional distress is a normal response to the diagnosis of a life-threatening illness; it can appear any time during the illness trajectory. The response may be characterized by shock, anxiety, disbelief, depression, sleep disturbances, or inability to perform activities of daily living.

Sources of distress for the person and family may include:

- Unmanaged symptoms
- Limited support
- Feelings of being a burden
- Physical limitations imposed by the illness
- Lack of control
- Lack of information
- Insensitivity by care providers
- Health care system issues
- Practical issues such as financial concerns; care of children
- Conflict in relationships

Utilization of the Edmonton Symptom Assessment System (ESAS-r) tool will help identify the severity of a number of components of a person’s subjective psychological status such as depression, anxiety, and well-being. Synonyms for words that may be difficult for some persons to understand when scoring these particular symptoms in the ESAS-r tool include the following:

- Anxiety: nervousness or restlessness
- Depression: feeling blue or sad
- Well-being: overall comfort, both physical and otherwise, truthfully answering the question, “How are you?”

Anxiety

Brescia describes anxiety as a normal human response to a threat. An anxious person experiences feelings of uneasiness, uncertainty, and helplessness.

Risk Factors for Anxiety

- Fear of uncontrolled symptoms
- Altered physiologic states such as hypoxia (lack of oxygen), delirium, bleeding
- Certain medications such as steroids, antihypertensives
- Pre-existing anxiety disorder
- Some hormone secreting tumours (e.g. ACTH-secreting lung tumours) are associated with anxiety

Assessment tools for anxiety include the Hamilton Anxiety Scale and the Beck Anxiety Scale.

Depression

Depression is a psychiatric illness characterized by the presence of depressed mood or loss of enjoyment, interest, or pleasure for at least two weeks. The presence of five specific criteria must be noted. Four or fewer symptoms indicate a minor depression.

1. Appetite disturbance with weight gain or loss of at least 5% in 1 month
2. Sleep disturbance
3. Motor agitation or retardation
4. Fatigue or loss of energy
5. Excessive guilt or feelings of worthlessness
6. Indecisiveness and trouble concentrating
7. Recurrent thoughts of death

Pasacreta, Minarick and Nield-Anderson state that depression is often under recognized and under treated. Depression has the potential to decrease immune response, decrease survival time, and impair quality of life. The assessment of depression in any setting relies on the awareness of risk factors associated with depression and the ability to elicit from the person key signs, symptoms, and the history of illness. The ESAS-r is an excellent screening tool for depression; however when ESAS-r identifies a possible depression, it is critical that another tool be utilized to accurately assess the depression. There are a number of assessment tools to measure depression (e.g. Hamilton Depression Rating Scale, Beck Depression Inventory, Geriatric Depression Scale, and Confusion Assessment Measure (CAM)).
Risk Factors for Depression

- Genetic makeup
- Psychosocial stresses
- Physical disability
- Acute Pain
- Serious medical illness
- Personal or family history of depression
- Lack of social support
- Alcoholism and/or substance abuse
- Personal history of sexual or family abuse
- Certain medications
- Poorly controlled pain
- Common in pancreatic cancer and may precede other symptoms of the disease by several months

Dementia, Delirium and Depression

In palliative and end-of-life care, those with dementia will require special attention and screening since both depression and delirium can co-exist with dementia. It is often difficult for care providers to distinguish between dementia, delirium and depression. Dementia is defined as a gradual and progressive decline in mental processing ability that affects short-term memory, communication, language, judgment, reasoning and abstract thinking. Dementia eventually affects long-term memory, the ability to perform familiar tasks, and may also be changes in mood and behaviour. Delirium on the other hand is a medical emergency characterized by an acute and fluctuating onset of confusion, disturbances in attention, disorganized thinking and/or decline in level of consciousness. Delirium needs to be distinguished from a pre-existing dementia. Both delirium and dementia can be present at the same time. Delirium can be either hypoactive (unrousable, very sleepy with slowing of speech, movement and thinking), hyperactive (agitated, pacing, restless, hyperactive behaviour along with visual, auditory, tactile, gustatory or olfactory hallucinations) or mixed (combination of both manifestations). Delirium is caused by the direct physiological consequences of a general medical condition and requires prompt recognition, assessment and treatment.

The following chart (chart 5.1) from the Toronto Region Best Practice in LTC Initiative 2007 compares Dementia, Delirium and Depression.

<table>
<thead>
<tr>
<th></th>
<th>Delirium</th>
<th>Depression</th>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Definition</strong></td>
<td>Medical emergency which is characterized by an acute and fluctuating onset of confusion, disturbances in attention, disorganized thinking and/or decline in level of consciousness. Delirium cannot be accounted for by a preexisting dementia; however, can co-exist with dementia.</td>
<td>Depression is a term used when a cluster of depressive symptoms (as identified on the SIG E CAPS (see below) depression criteria) is present on most days, for most of the time, for at least 2 weeks and when the symptoms are of such intensity that they are out of the ordinary for that individual. Depression is a biologically based illness that affects a person’s thoughts, feelings, behaviour, and even physical health.</td>
<td>Dementia is a gradual and progressive decline in mental processing ability that affects short-term memory, communication, language, judgment, reasoning, and abstract thinking. Dementia eventually affects long-term memory and the ability to perform familiar tasks. Sometimes there are changes in mood and behaviour.</td>
</tr>
<tr>
<td><strong>Onset</strong></td>
<td>Sudden onset: hours to days</td>
<td>Recent unexplained changes in mood that persist for at least 2 weeks</td>
<td>Gradual deterioration over months to years</td>
</tr>
</tbody>
</table>

Chart 5.1
<table>
<thead>
<tr>
<th></th>
<th>Delirium</th>
<th>Depression</th>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Course</strong></td>
<td>• Often reversible with treatment</td>
<td>• Usually reversible with treatment</td>
<td>• Slow, chronic progression, and irreversible</td>
</tr>
<tr>
<td></td>
<td>• Often fluctuates over 24 hour period and often worse at night</td>
<td>• Often worse in the morning</td>
<td></td>
</tr>
<tr>
<td><strong>Thinking</strong></td>
<td>• Fluctuations in alertness, cognition, perceptions, thinking</td>
<td>• Reduced memory, concentration and thinking, low self-esteem</td>
<td>• Cognitive decline with problems in memory plus one or more of the following: aphasia, apraxia, agnosia, and/or executive functioning</td>
</tr>
<tr>
<td><strong>Psychotic Feature</strong></td>
<td>• Misperceptions and illusions</td>
<td>• Delusions of poverty, guilt, somatic symptoms</td>
<td>• Signs may include delusions of theft/ persecution and/or hallucinations depending on type of dementia</td>
</tr>
<tr>
<td><strong>Sleep</strong></td>
<td>• Disturbed but with no set pattern (differs night to night)</td>
<td>• Disturbed</td>
<td>• May be disturbed with an individual pattern occurring most nights</td>
</tr>
<tr>
<td><strong>Mood</strong></td>
<td>• Fluctuations in emotions: outbursts, anger, crying, fearful</td>
<td>• Depressed mood</td>
<td>• Depressed mood especially in early dementia</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Diminished interest or pleasure</td>
<td>• Prevalence of depression may increase in dementia; however, apathy is a more common symptom and may be confused with depression.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Changes in appetite (over or under eating)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Possible suicidal ideation/ plan; hopelessness</td>
<td></td>
</tr>
<tr>
<td><strong>Psycho-Motor Activities</strong></td>
<td>• Hyperactive delirium: agitation, restlessness, hallucinations</td>
<td>• Hyperactive: agitated depression</td>
<td>• Wandering/ exit seeking or</td>
</tr>
<tr>
<td></td>
<td>• Hypoactive delirium: unarousable, very sleepy</td>
<td>• Hypoactive: withdrawn, decreased motivation/ interest</td>
<td>• Agitated or</td>
</tr>
<tr>
<td></td>
<td>• Mixed delirium: combination of hyperactive and hypoactive manifestations</td>
<td></td>
<td>• Withdrawn (may be related to coexisting depression)</td>
</tr>
</tbody>
</table>
### Chapter 5: Psychological Domain

<table>
<thead>
<tr>
<th>Delirium</th>
<th>Depression</th>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Screening Tools</strong></td>
<td><strong>Screening Tools</strong></td>
<td><strong>Screening Tools</strong></td>
</tr>
<tr>
<td>• Confusion Assessment Method (CAM) – An algorithm used to screen for delirium: Screen for delirium is positive if the person has features 1 &amp; 2 plus either 3 or 4 as listed below</td>
<td>• Geriatric Depression Scale (GDS)</td>
<td>• Mini Mental Status Exam (Folstein) measures cognitive functioning</td>
</tr>
<tr>
<td></td>
<td>• Interpretation of the 15 Question GDS Screen:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• &lt; 4 = Indicates absence of significant depression</td>
<td>• Interpretation of Score:</td>
</tr>
<tr>
<td></td>
<td>• 5-7 = Indicates borderline depression</td>
<td>• 25-30 = normal</td>
</tr>
<tr>
<td></td>
<td>• 7 = Indicates probable depression</td>
<td>• 20-24 = mild</td>
</tr>
<tr>
<td></td>
<td>• Inattention AND EITHER</td>
<td>• 10-20 = moderate</td>
</tr>
<tr>
<td></td>
<td>• Disorganized thinking OR</td>
<td>• &lt; 10 = severe cognitive impairment</td>
</tr>
<tr>
<td></td>
<td>• Altered level of consciousness</td>
<td>• Clock Drawing Test (CDT)</td>
</tr>
<tr>
<td></td>
<td>• Assess for causes:</td>
<td>• Mini-Cog Dementia Screen</td>
</tr>
<tr>
<td></td>
<td>• I WATCH DEATH [Infections, Withdrawal, Acute metabolic, Toxins, drugs, CNS pathology, Hypoxia, Deficiencies, Endocrine, Acute vascular, Trauma, Heavy metals]</td>
<td>• Interpretation of Score:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 0 to 2 = high likelihood of cognitive impairment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 3 to 5 = low likelihood of cognitive impairment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• If behavioural issues, consider using Cohen-Mansfield Agitation Inventory (CMAI)</td>
</tr>
<tr>
<td><strong>Laboratory Tests</strong></td>
<td><strong>Laboratory Tests</strong></td>
<td><strong>Laboratory Tests</strong></td>
</tr>
<tr>
<td>• Hgb, WBC, Na, K, Ca, O2 sats, Blood gases, Urea, Creatinine, Liver function tests, Chest X-ray, Urinalysis and Culture, alcohol / drug/toxicology screen</td>
<td>• TSH, B12, folate, Ca, Albumin, FBS, Ferritin, Iron, Hgb, K, ESR</td>
<td>• CBC, TSH, Blood glucose, Electrolytes, including Ca</td>
</tr>
<tr>
<td></td>
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</tr>
<tr>
<td>Delirium</td>
<td>Depression</td>
<td>Dementia</td>
</tr>
<tr>
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</tr>
<tr>
<td><strong>DSM-IV Criteria</strong></td>
<td>Five (or more) of the following symptoms have been present during the same two-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure</td>
<td>The development of multiple cognitive deficits manifested by both memory impairment (impaired ability to learn new information or to recall previously learned information) one (or more) of the following cognitive disturbances:</td>
</tr>
<tr>
<td>• Disturbance of consciousness (i.e., reduced clarity of awareness of the environment) with reduced ability to focus, sustain or shift attention</td>
<td>• Depressed mood most of the day, nearly every day marked diminished interest or pleasure in normal activities significant weight loss or gain</td>
<td>• Aphasia (language disturbance)</td>
</tr>
<tr>
<td>• A change in cognition (such as memory deficit, disorientation, language disturbance) or the development of a perceptual disturbance that is not better accounted for by a preexisting, established or evolving dementia</td>
<td>• Insomnia or hypersomnia nearly every day</td>
<td>• Apraxia (impaired ability to carry out motor activities despite intact Motor function)</td>
</tr>
<tr>
<td>• The disturbance develops over a short period of time (usually hours to days) and tends to fluctuate during the course of the day</td>
<td>• Psychomotor agitation or retardation nearly every day</td>
<td>• Agnosia (failure to recognize or identify objects despite intact sensory function)</td>
</tr>
<tr>
<td>• There is evidence from the history, physical examination or laboratory findings that the disturbance is caused by the direct physiological consequences of a general medical condition</td>
<td>• Fatigue or loss of energy nearly every day</td>
<td>• Disturbance in executive functioning (e.g., planning, organizing, sequencing, abstracting)</td>
</tr>
<tr>
<td></td>
<td>• Feelings of worthlessness or excessive guilt</td>
<td>• The cognitive deficits in the above criteria (Criteria A1 and A2) each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning</td>
</tr>
<tr>
<td><strong>Next Steps</strong></td>
<td><strong>Refer to:</strong></td>
<td><strong>Refer to:</strong></td>
</tr>
<tr>
<td>Notify:</td>
<td>• Attending Physician and if suicidal risk consider transfer to Emergency Department</td>
<td>• Attending Physician</td>
</tr>
<tr>
<td>• Attending Physician ASAP (consider delirium as a medical emergency and may require transfer to an Emergency Department)</td>
<td>• Geriatric Mental Health Outreach Team</td>
<td>• Geriatric Mental Health Outreach Team</td>
</tr>
<tr>
<td></td>
<td>• Geriatric Mental Health Outreach Team</td>
<td>• Psychogeriatric Resource Consultant (PRC)</td>
</tr>
<tr>
<td>Involve:</td>
<td>• Psychogeriatric Resource Consultant (PRC)</td>
<td></td>
</tr>
<tr>
<td>• Internal team members including Psychogeriatric Resource Person (PRP) [PIECES trained staff]</td>
<td></td>
<td>• Internal team members including Psychogeriatric Resource Person (PRP) [PIECES trained staff]</td>
</tr>
<tr>
<td>• Family members</td>
<td></td>
<td>• Family members</td>
</tr>
<tr>
<td><strong>Note</strong></td>
<td>For issues of violence or abuse, follow LTCH protocols.</td>
<td></td>
</tr>
</tbody>
</table>

For issues of violence or abuse, follow LTCH protocols.
Suicide

Brescia believes that a clear relationship exists between depression and suicide. A sense of hopelessness is a strong risk factor and the possibility that a person with cancer will end his or her life is twice that of the general population. There is no evidence to suggest that raising the issue of suicide encourages a person to act in a self-destructive manner. Lynn, Lynch, Schuster, Wilkinson and Simon note that depression is under recognized in older adults and is often mistaken for early dementia or considered a normal part of aging. Suicide rates increase with age and depression is the key risk factor. Screening for depression is important in hospice palliative care and the ESAS-r is an easy tool to use for this purpose. The well-being symptom on the ESAS-r tool may speak to hopelessness - a risk factor for suicide in persons with cancer. Most tools used to assess depression have questions related to suicidal ideation.

Depression and anxiety may also affect other members of the family. Since the unit of care is the family, hospice palliative care providers must also monitor the mental state of the family caregivers. The caregiver’s physical, emotional, and psychological exhaustion may also affect his or her ability to communicate with empathy and compassion. It is thus very important to determine how well the caregiver is coping.

OBSERVING THE INDIVIDUAL’S EXPERIENCE

The responsibility of caregivers is to identify and report the signs and symptoms that may indicate psychological distress.

Anxiety

The common signs and symptoms of anxiety are:

- Fear, including unrealistic fears (phobias)
- Inability to perform normal activities of daily living
- Nervousness
- Hypervigilance, excessive worry
- Restlessness, agitation
- Frequent crying spells
- Headache
- Gastrointestinal upsets
- Shortness of breath
- Palpitations
- Insomnia, trouble falling or staying asleep
- Irritability, muscle tension
- Obsessions (persistent painful ideas)
- Compulsions (repetitive ritualistic acts)
- Anorexia or over eating
- Self medicating

Delirium

Common signs of delirium are:

- Sudden onset of confusion
- Fluctuates over 24 hour period and is often worse at night
- Misperceptions and illusions
- Disturbed sleep with no set pattern
- Fluctuations in emotions (outburst, anger, fear, crying)
- May be hypoactive, hyperactive or mixed

Depression

Common Signs and Symptoms of Depression are:

- Depressed mood; feeling sad or empty, tearful
- Decreased interest or pleasure in all or almost all activities
- Significant weight loss
- Insomnia or hypersomnia
- Psychomotor agitation or retardation
- Fatigue or loss of energy
- Feeling of worthlessness or excessive or inappropriate guilt
- Diminished ability to think or concentrate or indecisiveness
- Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation or suicide attempt

All too often when a person with a life-limiting illness admits to being depressed, family members and health care professionals dismiss it as a natural reaction to knowing that one’s life is ending. When feelings of grief and sadness do not subside, health professionals need to determine if there is a clinical depression. In addition to this one must determine the level of suicide risk.

Keys to determining suicide lethality include:

- Suicide plan determined
- Method chosen e.g. gun, knife, medication overdose, carbon monoxide etc.
- Intended outcome is death as opposed to rescue
- Availability of resources for treatment and support
- Ability to communicate affects the potential for success of therapy

Severely depressed individuals must be identified quickly to ensure a safe environment and appropriate treatment. A person with an immediate, lethal and precise suicide plan needs strict safety precautions and continuous or close supervision. The motivation for suicide can be reduced by managing pain and other symptoms, referral for treatment of depression, discussion of alternative interventions to improve quality of life, referral for psychosocial spiritual care, education about the dying process and accurate facts about the options for end-of-life care and decision-making.
INTERACTING WITH THE INDIVIDUAL AND FORMAL/INFORMAL CAREGIVERS

Attention to the principles of good communication when a person is diagnosed with a serious or life-threatening illness is paramount. The caregiver enhances communication by being fully ‘present’ to the person and/or family. He or she needs to be sensitive to the person, making attempts to pick an appropriate time and place for conversation while acknowledging that the discussion may produce discomfort. Brescia articulates that the person approaching death often feels separate from “those who are seen” and are therefore “often in a state of crisis” in which they feel “fragile, fearful, vulnerable, wounded, dependent, time bound and above all distressed”.13

Chochinov acknowledges that in our time pressured culture of modern health care the core values of kindness, humanity and respect are too often being overlooked.14 Dignity conserving care is a means by which to restore those values but it requires effort on the part of the health care provider. A person’s dignity is upheld relative to the ability of the health care provider to see the person as is or as he/she was, rather than just as the illness that has been diagnosed. When a person’s dignity is not being upheld, his or her sense of value and worth are more likely to be compromised. Chocinov uses an “A B C D” framework to help remind practitioners to not only care for people but to care about them.

Attitudes are based on perceptions that may or may not reflect the person’s reality. Often our perceptions are based on faulty assumptions (e.g. intoxication as the reason for confusion in a homeless confused person, poor quality of life in a severely disabled person, malingering in a person with chronic pain). Each health care practitioner needs to examine his or her attitudes and make a conscious effort to challenge and question attitudes in personal and team practice.

Attitude impacts one’s Behavior and interactions with others. Imagine what our interactions would look like if all of our actions were predicated on kindness and respect? It doesn’t take much time to perform small acts of kindness that are so meaningful to those in our care. Those with progressive life-limiting illness are particularly vulnerable and simply acting in a manner that gives the person your undivided attention speaks volumes to the person about his or her worth. Asking permission of the person to perform an examination or to initiate a treatment conveys respect and dignity.

Compassion speaks to feelings that are evoked by contact with the person and how those feelings shape our approach to care. Compassion develops over time and can be conveyed as a gentle look or a reassuring touch that expresses recognition of the human story that accompanies illness.

Dialogue is the most important component of the framework of a therapeutic relationship that instills dignity, and is dependent upon the previous building blocks of the person’s experience. Dialogue must acknowledge personhood and be intentional in portraying the recognition of the emotional impact of the illness. Getting to know the person and family, determining what is important to them and acknowledging that the effects of the illness are overwhelming at times will enhance self-worth and self-coherence.

Therapeutic Conversations

A therapeutic conversation takes place with conscious intention, involving skills and knowledge on the part of caregiver. The focus of communication is on the person, not on the caregiver.

A therapeutic conversation with the person and the family related to anxiety or depression may involve the following questions:

- How are your spirits?
- What do you see for yourself in the future?
- Do you feel helpless?
- Do you feel in control?
- Do you feel like a burden?
- Are you able to fall asleep?
- Do you waken early? Do you feel refreshed when you wake up?
- Do you look forward to eating? Do you find pleasure in eating foods that you have always liked?
- Are you able to concentrate?
- Do you feel irritable or restless?
- Do you think you would be better off dead?
- Do you feel hopeless?
- Do you have any thoughts of hurting yourself?


Engaging in therapeutic conversations with the person and family can reduce anxiety and isolation, enhance a person’s sense of dignity, clarify understanding, inform decision making, build a relationship of trust, improve pain and symptom management and prevent conflict.
PROVIDING SUPPORTIVE CARE STRATEGIES

Coping with personal stress in a positive manner is important for the professional caregiver and will better prepare him or her to help families and individuals cope with their own stress.

There are a variety of coping mechanisms that work for different people. Some people use smoking, eating, or drinking to bring a sense of immediate relief from tension; however, such strategies do not last long and the negative side effects can potentially add problems if repeated over a long period of time. Encourage strategies and therapies that promote well-being (e.g. exercise yoga, meditation, play, friends, journaling, art, music, drama, dance or movement therapy etc.). Health practitioners can themselves endeavor to become models of effective coping.

Usually no single strategy will be effective in managing all of life’s challenges. Pasacreta and colleagues15 suggest the following strategies to help to the person and family with the management of psychological distress:

1. Provide concrete, neutral information
   - Help the person to know what to expect; fear of the unknown may be a source of anxiety
   - Encourage the person to ask questions
   - Use simple terms; avoid medical jargon
   - Repeat information as needed

2. Prepare the person prior to a stressful event
   - Anticipation and rehearsal of a potentially traumatic or painful experience will assist the person to maintain control and tolerate the procedure
   - Educate (within caregiver scope of practice) regarding interventions

3. Increase opportunities for the person to maintain control
   - Focus on what the person can control
   - Encourage decision-making regarding appointments e.g. scheduling, timing

4. Encourage participation in care
   - Allow the family to contribute to the care; involvement may reduce helplessness and increase sense of control. Family involvement may assist the family in recognizing and adjusting to the deterioration of the person
   - Respect cultural differences in expectations of the delivery of care
   - Respect the interest of the caregiver in participating
   - Assist family to gain expertise in expertise therapies such as relaxation and massage
   - Make certain that family caregivers have access to the numbers to call in a crisis

5. Encourage the use of a stress diary – self-monitoring
   - Ask the person to record circumstances, thoughts and feelings that cause stress and anxiety such as treatment-related stress, illness-related stress or unrelated stressful anxiety; this process can provide assessment information and improve working together to help the person understand thoughts and feelings

6. Acknowledge fears
   - Listen to the person’s communication of feelings
   - Create mutual support and trust
   - Reduce isolation; avoiding the anxious person or his or her fears is likely to increase vulnerability and anxiety

7. Explore near-miss events
   - A near-miss event is an upsetting experience that may overwhelm a person’s ability to cope. For example, a person’s own near death experience, the cardiac arrest of a person in similar circumstances, or repeated, daily, painful wound care. It is important to investigate, acknowledge fear, and examine the person’s situation in order to understand the reason for the anxiety.

8. Physical symptom management
   - Explore strategies that will reduce stress and allow the person to rest
   - Investigate pain as it may signal a threat (meaning of the symptom, more treatment, more fear)
   - Make certain that pain is managed, especially before a painful or frightening procedure
   - Promote self-control for managing pain, shortness of breath and fatigue
   - Use pharmacological interventions as needed
   - Recruit the support of others; refer to appropriate discipline

9. Structure uncertainty
   - Acknowledge that this is a time of many unknowns
   - Concentrate on expected events such as meetings with caregivers, procedures, and updates.

10. Be aware of the impact of sensory deprivation
    - Be aware that signals in the environment may take on frightening meanings for the person, for example, loud noises, darkness, and marked, extended silence, may signal feelings such as abandonment or helplessness
    - Ensure that glasses and hearing aides are in place and in good working order
11. Encourage hope
- Recall joyous, meaningful events
- Create a legacy; scrapbooking, videos, letter writing
- Focus attention on others, such as the well-being of children or spouse
- Focus attention on the short-term future
- Revise goals; shifting hope from cure to comfort

People cope successfully with the majority of their stressors, making hundreds of adjustments each day to positively manage most situations. The examples that follow are additional coping strategies that may assist the person to manage stress during life-changing situations. The ability to partake in these activities will depend upon the person's health care status.

- Diversion (e.g. Spend time alone; see a movie; daydream; write; paint; create something; try scrapbooking; play an instrument; sing; listen to music; play a game; visit with friends)
- Family (e.g. take time to be together; build family traditions; express affection; accept the good with the bad; share feelings)
- Interpersonal (e.g. believe in self; trust others; state needs and wants; show feelings; share feelings; accept others' boundaries; drop some involvements; share problems with others; ask for support from others)
- Mental (e.g. look for the humour; set clear goals; hope for the best; plan for all the possibilities; take charge; make decisions that take into account values and meet goals; seek outside help in order to ensure choices are informed; tackle problems head-on; look for some good in a bad situation; focus on top priorities)
- Physical (e.g. listen to the body; recognize physical limitations; breathe deeply; try complementary therapies)
- Spiritual (e.g. find purpose and meaning in life; share beliefs with others; confess; ask forgiveness; pray for others; give thanks; let go of little problems; learn to live with the situation; set priorities; spend time and energy wisely)

**WORKING AS A TEAM**

Team members can contribute to supporting the person and family by sharing with each other their observations, interactions, and interventions. The person / family members will determine the team members with whom they will share their deepest thoughts and concerns. It may not be the person with the knowledge and skill to respond to the issue. Permission should be sought to share the information with the team. Referral to a professional team member for further assessment and management of psychological distress may be necessary.

An interdisciplinary team approach is essential for the optimal management of depression. Every team member has a role to observe, report, and share information regarding:

- Change in behaviour (e.g. restlessness, agitation, sleeplessness, change in appetite, withdrawal)
- Change in emotional state (e.g. anger, hostility, hopelessness, despair, fearfulness, profound sadness)
- Change in cognitive status (e.g. confusion, disorientation).

As previously mentioned, the ESAS-r tool can screen issues in the psychological domain but is not in itself an assessment tool. Referral to other experts is important when ESAS-r scores for depression, anxiety and well-being remain high in spite of interventions by the primary team.
References


Chapter 6

Spiritual Domain
Chapter 6: Spiritual Domain

UNDERSTANDING THE FUNDAMENTALS

Hospice Palliative Care upholds the tenant that personal growth along the illness journey is possible, and that such growth occurs in spite of or perhaps even because of suffering. Although a diagnosis of a life-threatening illness, accompanied by loss, separation, suffering, and loneliness can lead to spiritual distress, that same distress may be the springboard to growth in spirit.

Spirituality often becomes very important when approaching the end of one’s life. The diagnosis of a life-threatening illness can raise questions about beliefs and values, the meaning of suffering, mortality, life after death, and relationships. It is the spiritual part of us that seeks answers and longs for meaning and purpose in our lives.

A person’s spiritual nature challenges him or her to explore questions such as:

- Who am I?
- Is there a higher power?
- Do I have meaning?
- What happens after death?
- What is my role and purpose in this world?
- Why is this happening to me?

Death and dying have been reflected upon since the recording of written history. People die today with the same concerns, struggles and fears that millennia ago were recorded in various books of the dead. The books (Gnostic, Tibetan, Egyptian and Medieval Monastic) all reflect universal themes that transcend culture and spirituality. In the Celtic tradition, the wisdom related to the care of the dying was passed on verbally. Celts saw a parallel between the birth and the death processes and employed anamcara (a soul friend) or midwife who supported both processes.

In hospice palliative care, there is a growing interest in applying the wisdom of the ancestors to address the unique emotional and spiritual distress of those who are living with dying.

Groves and Klauser note that all books of the dead, regardless of culture, time and place indicate that spiritual pain is related to meaning, forgiveness, relatedness or hopelessness. Meaning Pain, or spiritual pain, is related to the question: Who am I? Often the same spiritual pain that creates a crisis of meaning can also lead to a path out of the crisis. Forgiveness pain is the most common spiritual pain. Healers of every spiritual tradition indicate that we are forgiven to the extent that we can release others. Often, the most challenging one to forgive at the end of life is oneself.

Relatedness pain refers to the suffering experienced by having to leave everything known behind. Relatedness does not refer only to personal relationships but also to relationships with possessions, roles and identities. Resisting the natural balance between darkness and light, and life and death, leads to spiritual pain. By leaning into the pain rather than resisting, growth and healing is possible. Many who have worked in hospice palliative care over the years have had spiritual teachers who say they would never exchange the experience of living with a progressive life-limiting illness with the life they had before the diagnosis.

Finally, hopelessness pain refers to the loss of all reason for living. Hope comes from the ability to imagine what could be life-giving. When such a desire is sustained by an expectation of fulfillment, hope results. For those living with progressive illness, there comes a recognition that the familiar life is no longer sustainable. Hopelessness may result or the person may shift priorities and give more attention to inner awareness.

Religion and spirituality are examples of how we attempt to make sense of the world and ourselves. There are many definitions of spirituality and religion. A Model to Guide Hospice Palliative Care defines spirituality as the way in which a person makes meaning and organizes his or her sense of self around a personal set of beliefs, values, and relationships, sometimes understood in terms of transcendence or inspiration. Involvement in a community of faith and practice may or may not be a part of an individual’s spirituality.

Religion is defined by Wright as the affiliation or membership in a particular faith community that shares a set of beliefs, rituals, morals, and sometimes a health code, centered on a defined higher power or transcendent power, most frequently referred to as God. An example of a health care code would be the withholding of blood transfusion in the Jehovah Witness faith.

Baird notes there is considerable discussion related to what constitutes good spiritual care and to date there are no universally agreed upon terms. The definitions used in an attempt to demystify spiritual care follow:

- Spirituality: our relationship with ourselves, others, nature and the transcendent
- Religion: an organization that has a set of rites, rules, practices, values, and beliefs that prescribe how individuals should live their lives and respond to God
- Spiritual care: allowing our humanity to touch another’s humanity by providing presence, deep listening and compassion
- Compassion: the ability to be empathically present to another while he or she is suffering and is trying to find meaning
- Existential: relating to human existence and experience
A person who is deeply spiritual may not subscribe to a particular religion. Conversely, simply acknowledging affiliation with a particular religion does not necessarily mean that the person is spiritually inclined. Some individuals may deny being spiritual and reject organized religion but virtually everyone has some sort of understanding of how the universe functions.

Finding meaning, forgiveness, relatedness and hope in illness is a unique journey for each person.

**OBSERVING THE INDIVIDUAL'S EXPERIENCE**

It is important for every caregiver to be mindful to identifying issues in the spiritual domain. A friend, a volunteer, a personal support worker or someone cleaning the room may be the one to whom the person bares his or her soul. The choice of whether to recognize and nourish spirituality is a personal choice, not the choice of health care providers or family.

A rising score in well-being on the ESAS-r may point to spiritual distress. Other indicators of spiritual distress may include:

**A sense of abandonment**
- “My friends don’t visit anymore.”
- “My wife won’t let me talk about dying!”
- “Why isn’t God answering my prayers?”

**Anger**
- “God shouldn’t allow this to happen!”
- “I hate myself for not having stopped smoking!”

**Remorse**
- “I wish I had spent more time with my kids!”
- “I wish I had gone to church more often.”
- “I’m scared.”
- “I’m afraid to go to sleep.”

**Difficulty accepting love**
- “I don’t deserve this special treatment.”

**Discouragement**
- “Why do I have to suffer like this?”
- “What’s the use?”

**Hopelessness**
- “I wish it would all end!”
- “Why don’t you just give me something to end it all?”

**Withdrawal and isolation**
- “Leave me alone!”
- “Leave the blinds closed!”

**Doubt**
- “I wonder if there really is a God?”

There are a number of spiritual assessment tools that can be used if the caregiver suspects spiritual pain is an issue. This very simple tool akin to the ESAS tool can be used to screen for spiritual issues. It is adapted from Groves and Klauser and involves having the person score the following:

**Spiritual Pain Scale**

<table>
<thead>
<tr>
<th>Completely Peaceful</th>
<th>General Well-being</th>
<th>Extreme Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
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<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Meaning Pain Scale**

<table>
<thead>
<tr>
<th>Life is filled with meaning and purpose</th>
<th>I feel generally motivated</th>
<th>Life has become meaningless</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>6</td>
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<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Forgiveness Pain Scale

<table>
<thead>
<tr>
<th>I feel a deep sense of reconciliation toward myself and others</th>
<th>There are no outstanding issues that are calling for forgiveness in my life</th>
<th>I feel a strong sense of unforgiveness toward myself and / or others</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4</td>
<td>5 6 7</td>
<td>8 9 10</td>
</tr>
</tbody>
</table>

Relatedness Pain Scale

<table>
<thead>
<tr>
<th>I feel a strong sense of connection with the person and things that matter most to me</th>
<th>The most important areas in my life seem balanced</th>
<th>I feel seriously alienated from someone or something that is important to me</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4</td>
<td>5 6 7</td>
<td>8 9 10</td>
</tr>
</tbody>
</table>

Hope Pain Scale

<table>
<thead>
<tr>
<th>I feel hope filled and optimistic</th>
<th>I generally trust what the future holds for me</th>
<th>I am experiencing deep depression and hopelessness</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4</td>
<td>5 6 7</td>
<td>8 9 10</td>
</tr>
</tbody>
</table>

Other tools and accompanying examples of specific questions from Taylor12 include:

**HOPE**

**Sources of Hope**
What or who is it that gives you hope?

**Organized religion**
Are you a member of a religious or spiritual community?

**Personal experience or practice**
What beliefs are most helpful or meaningful?

**Effects on medical care**
How do your beliefs affect the kind of medical care you would like to receive?

**FICA**

**Faith**
What is your faith?

**Importance/influence**
What importance does your faith have in your life?

**Community**
Are you part of a religious community?

**Address**
How would you like me to address these issues in providing care?

**SPIRIT**

**Spiritual belief system**
Do you have a formal religious affiliation?

**Personal spirituality**
In what ways is your spirituality important to you?

**Integration**
Do you belong to a religious or spiritual community?

**Ritualized practices and restrictions**
What practices are important to you?

**Implications for medical care**
Do you have beliefs that will affect medical care?

**Terminal events planning**
Are there aspects of care at end of life that we should incorporate in your care plan.
Regardless of the assessment tool used, spiritual needs at the end of life need to be explored regularly. The process must be determined by members of the interdisciplinary team and documented so that unnecessary repetition is avoided. Re-evaluation is needed to ascertain the extent to which counselling and support is meeting the needs of the person and/or family.13

**INTERACTING WITH THE INDIVIDUAL AND FORMAL/INFORMAL CAREGIVERS**

Serious illness forces a person to ponder and perhaps even reappraise the meaning in life and the meaning of life. Meaning is tied to relationships, connectedness, and spirituality. While the process of finding meaning involves an inward journey, it also relies on the storytelling of the journey.14

In order to appreciate the uniqueness and complexity of a person's journey, asking open-ended questions can help the person to tell the story. Open-ended questions that inquire about the person's feelings or experience are generally welcomed.15 Examples include:

- What are some things that are scaring you right now?
- What makes life worth living?
- What are some of the things that you have not yet done?
- What do you hope for?
- What are you most afraid of?
- What are you most proud of in your life?
- Do you have regrets? If so, what are they?

Every time a caregiver listens to another person's experience or life story, he or she is involved in spiritual care giving. “Listen for more than words; listen for symbols; listen for where the person places energy; listen for emotion in addition to cognition.”16

The person may discover answers and find meaning in life by asking questions and telling his or her story. It is not up to the caregiver to provide answers; he or she can share only thoughts and ideas. Only the person will be able to discover the answers to his or her questions and the meaning of his or her life.

Silence is necessary when listening to a person's spiritual and sacred story. Sometimes when an emotion is experienced, it takes time to find the words to express it; the person needs to take time to collect his or her thoughts. Frequently silence is necessary for new insight to break through. Silence allows the listener to closely observe behaviours that can convey a message. A caregiver's silence can communicate support, acceptance, and understanding. Silence is a valuable and powerful therapeutic technique that can encourage a person to talk, indicate unconditional acceptance and show respect. Gaining comfort with silence is a skill that can be learned.

Although observations, interactions or assessments of physiologic issues are readily documented, similar information regarding issues in the spiritual domain is less frequently documented. Merely documenting a religious affiliation and whether the person wishes to have a referral to the spiritual care provider does not adequately indicate a person's spiritual status and need.17 Spiritual observations and care should be documented for the following reasons:

- To facilitate understanding and awareness of the person’s issues
- To emphasize the importance of the holistic approach in hospice palliative care and to meet accreditation standards for holistic care
- To encourage ongoing therapeutic conversation with the person and facilitate continuity of care by enhancing communication among the hospice palliative care team members

In a multi-faith, multi-cultural society like Canada, health care providers must acknowledge their ignorance of the tenants of many of the world religions. Just as the different Christian denominations have different beliefs and practices, so do other religious traditions. Even within a particular tradition there will be those who are more orthodox than others. Although having a cursory understanding of the world's major religious traditions provides team members with a framework for inquiry, remaining open to the variation of religious experience and expression is essential.18 Cultural and religious sensitivity demands that we never assume, but rather ask the person or family to provide information about how particular beliefs and practices should be included in the care plan.

### Hope

The focus of hope shifts throughout the disease experience. Upon diagnosis a person and family may hope for a cure, during treatment a person and family might hope for a pain free day or to live life to the fullest in the time left, and at end of life a person and their family may instead hope for a peaceful death. In supporting the person and their family on their illness journey, we can continue to hope for the best but prepare for the worst, enabling for shifts in hope. In this context hope is very different from optimism (i.e. the desire for a happy outcome), and is more akin to trust.

How we communicate can impact hope. Communication about the death or dying process is often done poorly and opportunities are missed to address concerns and fears. We
are obligated to be honest with person and families and to share the facts. We also must understand the person and what they know and expect. When hope for a cure is gone, we can assist in redirecting hope to move towards wishes and goals that are realistic and achievable. Knowing what to prepare for, having control over what happens and having access to information and supports can enable a sense of hope.

People living and dying from a life threatening illness have indicated the importance of symbols of hope and the positive thoughts that contribute to the experience of hope. In addition, receiving factually honest information, symptom control, leaving a legacy, achieving short term goals, being able to ‘turn your mind off’, and having supportive family and friend are also very important at end of life. Many dying people hope that their family will be able to cope and carry on afterward. Spirituality, that sense of something stronger or bigger, has been shown to contribute to a caregiver’s sense of hope and ability to cope.

Dame Cecily Saunders writes “You matter because you are you, you matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but to live until you die” This is an important aspect of our role as care providers in hospice palliative care.

PROVIDING SUPPORTIVE CARE STRATEGIES

The goal of care is to encourage spiritual wholeness and a sense of well-being, connectedness, and peace. Exploring and acknowledging one’s own deeply held beliefs and values and engaging in personal spiritual questing enables the caregiver to more fully appreciate the centrality of spirituality and/or religion in the lives of many persons and families as they approach death. Consider the following ways to provide spiritual support. If any of these supports are outside the expectations of your role, consider how other specialized roles can be pulled in.

When providing spiritual support:

- Respect the beliefs of the individual and the family
- Respond to the individual's spiritual needs according to his or her religious background and belief system. Remember that there are individual sectarian beliefs and practices within each of the major religious traditions
- Share personal beliefs sensitively only if requested
- Do not proselytize or try to convert the person to your beliefs
- Provide whatever the person asks for in terms of spiritual support or contact the spiritual care provider of person’s choice
- With permission, engage the person's faith community in providing care
- Observe the person’s environment for clues about his or her spiritual/religious inclination.
- Are there religious pictures, sacred writings or objects on the wall or at the bedside?

Groves and colleagues offer a variety of traditional healing tools and therapies to support persons who are dying. Most of these strategies have a precedent in the ancient books of the dead and have been tested in contemporary clinical practice.

- Art therapy (e.g. the Sacred Circle or Mandala, doodling, art journals, clay creations, sand painting, death masks) The arts whether music, drama, dance, poetry, drawing or photography may help a person to gain new insight as well as to give expression to ideas.
- Breath work: Begins with a relaxation exercise and then mingles the breath. The anam cara or soul friend synchronizes his or her breathing with the person's breathing.
- Dream work is often successful in bringing forth hidden anxieties. Dreams can be recalled, shared, recorded, or drawn. The feelings created in the dream are explored as well as the content. In most cases it is more important to be a dream companion than a dream therapist.
- Guided visualizations (can include healing and assistance from ancestors).
- Intercessory prayer: As long as intentions are pure, you cannot harm another person with prayer. Everyone has the capacity to be a conduit of loving kindness. Prayer connects one to God but can also connect one to others. Knowing that one is being prayed for by those near and far can be deeply nurturing.
- Journaling: e.g. waking journaling, random journaling, prayer journaling, life geographying (a form of life review based on mapping out life events that occurred within specific time periods), portraits of the soul (adding a picture or doodle to the writing).
- Life review can involve looking at disappointments as well as times of joy and playfulness. Further reflection on themes may help the person to discover commonalities such as high expectations leading to disappointment. Making a hurt listing; those that the person disappointed and those who disappointed the person can help the person move from disappointment to...
Being present on a consistent basis throughout the process of dying is primary spiritual care. The caregiver has an opportunity to provide this by simply being present; all that is required is to be present for suffering, fear, despair, and all the physical, emotional, social, and spiritual trials of dying. Being fully present involves letting go of one's own fears and needs in order to be with the other. It is necessary to respect the wish of the dying if they ask to be alone; however presence, when wanted, may in fact be the greatest gift the caregiver can give to those who are living with life threatening illness.

WORKING AS A TEAM

Some team members are less comfortable than others in providing spiritual care, as they may experience feelings of embarrassment, insecurity, or their own doubts and struggles related to spirituality. Personal philosophy or world view can colour assessment techniques and interpretation. Self-awareness on the part of all team members involved in hospice palliative care is necessary if team members are to be able to deal with other's struggles.

All individuals involved with the person need to share with other team members any disclosures indicative of spiritual pain. Referrals can be made to spiritual care providers or the team members can address the needs of the person. Teams must support one another, and may be able to assist the team member who has been chosen by the person to be the anam cara or soul friend.

The practice of mercy – of watching through the night – is central to hospice palliative care. The caregiver team has the great privilege of participating in the “watching through the night”. Team members contribute to this process by sharing with each other their particular observations, interactions, interventions and outcomes.

There are a number of interventions that require team collaboration, coordination and cooperation.

- Organizing clergy/chaplain visits, worship services or other rituals when physical or other limitations are a barrier to attendance at a place of worship requires team collaboration
- Empowering the dying person to contribute to the wellbeing of others requires team ingenuity
- Members of the team offer the person examples of activities that other dying persons have engaged in to benefit others e.g. creating or affirming memories through scrapbooks, audio or video tapes, planning a funeral service or celebration of life, creating a legacy, sharing wisdom, giving away treasured possessions, praying for others, encouraging a parent of young children to contribute to their care, or making a point of reconciling with others
- Fostering and enabling participation in prayer, ritual, and sacred reading activities requires planning on the part of various team members
- Healing music can be provided by a few choir members coming to the home, or by providing favourite selections via an audio system at the bedside. Various team members can collaborate in making such interventions a reality.

By being present and witnessing to what is sacred for the person and family, team members indicate that grappling with spiritual issues is normal and valuable as they journey with a progressive illness.
References


20 Saunders C. Care of the dying: The problem of euthanasia. Nursing Times. 72(26); 1976 1003-1005


Chapter 7

Social Domain
UNDERSTANDING THE FUNDAMENTALS

There are many issues that fall under the social domain, however this section will concentrate primarily on family roles and relationships, as well as the legal issues related to the illness journey.

The psychosocial context is a key component of the experience of facing a life-threatening illness, as “It is within the psychosocial context, not the disease, that people truly live their lives”. This process may be overwhelming for both the person and his or her family.

In order to assist them with the complex issues involved, caregivers need to recognize the individuality of the person and the uniqueness of the family system. Each family has usual roles and responsibilities (formal and informal), with unique coping mechanisms and patterns of interaction. Remember, the definition of “family” is determined by the person with the illness. The family may include spouse, children, partner, blood relatives, neighbours, friends, and/or pets.

Family Roles and Relationships

In hospice palliative care, the person and the family are the “unit of care”. The person and his or her family can be viewed as a system that functions according to many internal and external influences. Facing a life-threatening illness is not just a medical event, it is also a human experience for the person and family members as they work through the many losses that are experienced along the illness trajectory. The family members will experience changes in their roles and relationships throughout the illness; some may need to add caregiving and/or additional household duties to their usual roles. The impact of a family member dying and the effect of his or her death can have significant implications on family systems. All family members can experience feelings of abandonment, anger, and frustration and need to face their own losses. Each member of the family may be at a different point in the process of coping and they may not always be able to support one another. Gaining an understanding of the family unit is an important step to providing support.

The RNAO Best Practice Guideline, Supporting and Strengthening Families through Expected and Unexpected Life Events advises us to remember that each family is unique and that assessment is a continually evolving process of data collection as family needs change. How a family may deal with progressive illness, dying and death often depends on the family’s characteristics, prior experiences, developmental level, and personal resources.

It is important to note the differences between adult and pediatric hospice palliative care. Pediatric hospice palliative care is an active holistic approach to care, which mirrors the National Model’s definition of Hospice Palliative Care but also recognizes the unique aspects for families faced with their child’s illness and death. Children have different abilities and developmental needs and issues; they communicate differently than adults and their stage of development directly impacts their understanding of the disease, death and dying. Children react to and experience medications and treatments differently and require individualized attention; advocacy for children is most often from family members.

When a child has a life-threatening illness, the family is profoundly impacted. Some of the life threatening illnesses that affect children are rare and may have a familial component (i.e. they can affect more than one child in that family). Some childhood diseases involve years of caregiving. Parents bear a huge responsibility for their child’s care and decision making while they themselves are highly stressed, and grieving. They may also be experiencing financial losses, and loss of time/ability to parent their other children. Grief associated with children’s deaths has long term impacts for the entire family. To read more about pediatric palliative care, refer to the Canadian Hospice and Palliative Care Association’s (CHPCA) Pediatric Norms of Practice.

Cultural Beliefs, Values, and Practices

Culture refers to learned patterns of behaviours, beliefs and values shared by individuals in a particular social group. Culture provides us with a sense of identity and belonging and gives us a framework with which to understand our experiences. Canada is a multicultural country and as such, health care providers must remember that differences in beliefs, values and traditional health care practices between the health team and the person and family have the potential to cause serious harm. The Canadian healthcare system subscribes to a western value system that holds autonomy (the right to make personal choices) and truth telling as sacred tenants.

In health care, specifically hospice palliative care, a person’s culture may have effects on:

- Perception of health, illness
- Meaning and role of suffering
- View of hospitals, health care providers, healers
- Rituals and customs
- Expressions of loss, grief (e.g. the words “death” and “dying” may not be accepted)
- Boundaries regarding privacy, age, gender, and relationships
• Effectiveness and values of therapies
• Time-keeping beliefs
• Family and social relationships (roles, hierarchies)
• Decision-making, consent to treatment (e.g. some families have decisions made by one person, others may use a more collaborative approach)
• Independence/self-care vs. interdependence
• Communication norms (eye contact, asking questions, who speaks)

Caregivers must avoid grouping or stereotyping people from a particular race, ethnicity, or professional designation, as it is possible for members of the same ethnic group or profession to have very different values and beliefs. It is important to ask rather than assume. It is important to note however that although individuals with different cultural backgrounds may have different perceptions about healthcare, we are bound by specific laws that impact how we provide care.

Treatment

Treatment is defined as anything that is done for a therapeutic, preventative, palliative, diagnostic, cosmetic, or other health-related purpose. This includes a course of treatment or a plan of treatment. All treatments require informed consent.

Informed Consent

Consent to treatment is informed if, before giving it, the person received information about:

1. The nature of the treatment
2. The expected benefits of the treatment
3. The material risks of the treatment
4. The material side effects of the treatment
5. Alternative courses of action
6. The likely consequences of not having the treatment

If the person requests additional information, they must receive a response in order for it to be considered ‘informed consent’.

Consent to treatment is always given by the capable person. In order for consent to be valid, it must relate to the treatment; it must be informed; it must be given voluntarily and not be obtained through misrepresentation or fraud. If an individual has decided that they do not want to know all of the details, we are not able to obtain informed consent; if we do not provide all of the necessary information we may be causing harm. In a situation such as this (for cultural or other reasons the person does not want to know), a health care professional must provide all the information necessary to make an informed decision to another appropriate person who would make the decision related to treatment. The health professional then must go to the person from whom consent was required and explain that the conversation resulted in a decision to have, withhold or withdraw a specific treatment, and that person would then be asked to confirm his or her consent to the plan.

Capacity

According to the Health Care Consent Act, a person has capacity to consent if that person is capable of:

• Understanding the information that is relevant to making a decision about the treatment
• Appreciating the reasonably foreseeable consequences of a decision or a lack of decision

A person who is capable of providing consent is also capable of withdrawing consent to the treatment. A person may be capable of consenting to some treatments and not others depending on the complexity of the decision. It is also possible for a person to lose or regain capacity.

Substitute Decision-Maker (SDM)

Prior to any treatment being initiated, consent is required. If the person is capable, then he or she makes the decision. If the person is deemed mentally-incapable, then the health care provider refers to the substitute decision-maker(s).

The substitute decision-maker is determined according to the ranked priority list called the Hierarchy of Substitute Decision Makers:

1. The guardian of the person if the guardian has authority to give or refuse consent
2. The Attorney for Personal Care if the Power of Attorney (the document) confers authority to give or refuse consent
3. A representative of the consent and capacity board
4. The incapable person’s spouse or partner
5. A child or parent or children’s aid society. All children have equal ranking. If children disagree with one another about a decision, the Consent and Capacity Board representative will make the decision in their stead.
6. A parent of a child with right of access
7. A brother or sister
8. Any other relative
9. Public guardian and trustee

Meaning of Spouse: Two persons are spouses if:

• They are married to each other; or
• They are living in a conjugal relationship outside of marriage and,
have cohabited for at least one year
» are together the parents of a child, or
» have together entered into a cohabitation agreement
under the Family Law Act

Two persons are not spouses if they are living separate and apart as a result of a breakdown of their relationship.

**Meaning of Partner:** A partner refers to two persons who have lived together for a least a year and have a close personal relationship that is of primary importance in both persons’ lives.

**Meaning of Relative:** Two persons are relatives if they are related by blood, marriage or adoption. The SDM(s) may give or refuse consent only if he or she is:

- Capable with respect to the treatment
- Is at least 16 years old or is the incapable person’s parent
- Is not prohibited by court order or separation agreement from access or giving or refusing consent
- Is available (a person is available if it is possible, within a time that is reasonable for the circumstances to communicate with the person and obtain consent or refusal)
- Is willing to assume the responsibility

**Principles for Giving or Refusing Consent**

If the SDM(s) knows of a wish applicable to the circumstances that the incapable person expressed while capable and after reaching the age of 16, the SDM(s) shall give or refuse consent based on the known wishes. If the SDM(s) does not know of a wish applicable to the circumstance or it is impossible to comply with the wish, the SDM(s) shall act in the person’s best interest.

**Best Interests**

In deciding what the incapable person’s best interests are, the SDM(s) shall take into consideration:

- The person’s values and beliefs
- Whether the treatment is likely to:
  » Improve the person’s condition or well-being
  » Prevent the person’s condition from deteriorating
  » Reduce the extent or rate at which deterioration is likely
- Whether the condition is likely to improve remain the same or deteriorate without the treatment
- Whether the benefit of the treatment outweighs the risk of harm

Whether a less restrictive or less intrusive treatment would be just a beneficial as the one proposed The SDM(s) is entitled to receive the same information required for an informed consent as would be given to the capable person.

**Confidentiality**

On November 1, 2004, the Personal Health Information Protection Act (PHIPA) came into action. The purpose of PHIPA is to provide consistent and comprehensive rules governing the collection, use, retention, disclosure and disposal of personal health information in the custody and control of health information custodians. The Privacy Act “extends the present law in Canada that protects the privacy of an individual and provides the individual with a right of access to personal information about themselves”.

Confidentiality refers to the person’s right to expect that events and discussions between him/her and health care providers will not be shared with anyone else unless permission to do so has been given. Sometimes sensitive information that a care provider has acquired may be important to the other members of the care team in order to help them better understand or care for the person. Information shared to facilitate future care is usually thought of as within the boundaries of confidentiality. It is important to let the person know why the information needs to be shared and to ask the person for permission to share it. Maintaining confidentiality can be challenging for a specific care provider on the team when personal information disclosed may benefit the provision of care by some but not necessarily all members.

In smaller communities, confidentiality can be very challenging. For instance, when a health care provider is asked about a person’s situation by a neighbour, friend or even a family member of the ill person, the care provider must politely inform the individual about their responsibility to maintain confidentiality. In acknowledging the rules of confidentiality, the care provider is demonstrating that he or she is a professional and can be trusted. Various professional colleges have ethical principles and standards around privacy and confidentiality and other members of the team such as PSWs and volunteers are required to sign agreements related to confidentiality as part of their employment or association with a hospice or other organization.

**Legal Documents**

The following documents are frequently referred to in the process of providing hospice palliative care and are specifically related to Ontario legislation. There are variances in legislation between different provinces, states and countries.

**A Power of Attorney for Personal Care (POAPC)** is a document in which a person names an Attorney for
Personal Care. The substitute decision-maker named in the document takes on the responsibilities of the substitute decision-maker only when the person becomes incapable of providing consent. Personal care includes health care, nutrition, shelter, clothing, hygiene, and safety. Wishes about future health and personal care can be documented on the form. The POAPC document must be signed and dated and witnessed by two people. Forms are available free of charge from the office of the Public Guardian and Trustee. A Power of Attorney for Personal Care document is the only way to name a specific SDM(s). If a Power of Attorney for Personal Care does not exist, then the health care provider will consult the hierarchy of Substitute Decision-Makers to determine who is the highest ranked person willing and available to be the SDM(s).

An Advance Care Directive or Living Will is commonly thought of as a document in which wishes about future care are expressed. This document can help the SDM(s) make decisions based on the person’s wishes when that person cannot make decisions for himself or herself. Wishes need not be documented but can be provided verbally, recorded or through any means of communication. The most recent wishes prevail over earlier ones in Ontario. It is important that those who will have to make decisions in the event of incapacity be apprised of the person’s wishes, goals, and beliefs.

Living wills and advance directives or expression of wishes do NOT speak to the health care team but are wishes/information given to the substitute decision-maker(s). The danger in providing the health care provider with written wishes such as advance directives, a living will or other levels of care documents is that the information may be used by the physician in determining what treatment options to offer (without getting consent), or by the nurse in determining whether or not to report symptoms to the physician. This is not a legitimate use of such documents. The health care provider who knows of the wishes or goals and values of the person can assist in the decision making process by sensitively referring to the wishes when a decision has to be made either by a capable person or the SDM(s) about treatment for a current condition. Note that though the terms “living will” or “advance care directive or plan” are common, they are not terms reflected in law in Ontario. These are terms from other jurisdictions or countries, Ontario law uses the term wishes.

Each new issue that arises along the illness trajectory requires discussion and consent to a plan of treatment related to the current health care situation. A capable person or the SDM(s) in cases of incapacity can consent to a plan of treatment for end-of-life care in which specific treatments are withheld or withdrawn. This is only appropriate if the particular disease process will lead to the need for the treatment being discussed. An example of this might be a person with ALS has indicated a wish never to have a feeding tube inserted. He or she may be provided with all the information necessary in order to make an informed decision because the disease trajectory for ALS includes loss of the ability to swallow. He or she may consent to a plan of treatment to withhold the feeding tube. However when the actual time comes when a feeding tube is indicated, the person should again be given the option to confirm the plan or change his or her mind. However, if the person is incapable, the former plan of treatment would need to be upheld by the team unless the SDM(s) could provide evidence that the person had changed his or her mind and had withdrawn consent.

A Continuing Power of Attorney for Property is a legal document in which a capable person authorizes an individual or individuals to make financial decisions on his or her behalf. The Attorney for Property can make decisions related to finances, home, and possessions. The POAP (document) comes into effect when signed unless otherwise stated and gives authority for the person named to continue to act even when the person becomes incapable. The document must name one or more persons, be signed and dated by the capable person, and be signed by two witnesses who saw the person sign the document.

**Advance Care Planning (ACP)**

ACP is a process of planning for a time when a person no longer has the mental capacity to make decisions about aspects of his or her care or treatment. ACP may involve expressing wishes about end-of-life care versus care during an extended period of time of incapacity and should involve the discussion of diagnosis, prognosis, expected course of illness, possible treatment alternatives and risks/benefits of each treatment, all of which should be placed in the context of the person’s goals, expectations, fears, values, and beliefs.

Steps involved in Advance Care Planning may include:

1. Consideration of your values, goals, beliefs
2. Consultation with people you trust who can give you guidance e.g. your doctor, your lawyer, your faith leader
3. Consideration of whom you could trust to make the decisions you would want them to make if you were capable
4. Communication of your goals, values and wishes about future care with your family and friends as well as your health care providers
5. Appointing a substitute decision-makers in a Power of Attorney for Personal Care if you want to name a specific person or persons to make decisions if you become incapable.
6. Ensuring that your SDM(s) and family are aware of your goals, wishes, and values

Another legal issue that sometimes arises in the care of those with progressive life-limiting illness are the issues of physician assisted suicide and euthanasia. These are both considered criminal offences in Canada.

Physician assisted suicide is described by Dr. Nuala Kenny10 as an act which involves a physician providing the means for a person to end life either by prescribing a lethal dose of medication or furnishing information to enable the person to perform the act that causes death. Euthanasia can be categorized as voluntary, involuntary or non-voluntary.

- Voluntary euthanasia is requested by the person
- Involuntary euthanasia is performed despite the objection of the person
- Non-voluntary euthanasia occurs when the person’s decision has not been sought e.g. when those to be euthanized lack capacity

Dr. Kenny contends that it is the phenomenal advances in medical science and technology of the 20th century that have created this debate. The same technologies that can save life can prolong dying. Meier11 contends that debates about euthanasia date back to 400 B.C. with the Hippocratic Oath which states, “I will give no deadly medicine to anyone if asked, nor suggest any such counsel.” In recent times, public anxiety about end-of-life care, fear of loss of control once one is in the medical care system, and rising demands for self-determination have led to a resurgence of the debate. A number of Canadians, alarmed about suffering associated with dying, are beginning to consider euthanasia and assisted suicide as a means of ending suffering. Canadian law currently prohibits both physician assisted suicide and euthanasia, however the case for euthanasia and physician assisted suicide has been brought before the senate and the legislature in recent years. Though there are advocates for changing the law, the Canadian Hospice Palliative Care Association does not support these approaches. Hospice palliative care, with the focus on relieving suffering, has the goal of improving quality of life, so that a person does not view ending his or her life as the best or only option.

Hospice palliative care supporters restrict the definition of euthanasia to situations in which there is intent to end life. Managing pain and other symptoms with doses of medications that could have been considered to potentially hasten a person’s death is NOT considered euthanasia or assisted suicide. Medications are given for the sole purpose of managing the distress caused by symptoms. More recent studies have demonstrated that the use of “palliative sedation” to manage symptoms (e.g. opioid to manage intractable pain or shortness of breath) does not hasten death. This unintended effect of the medication is known as the principle of the ‘double effect’; however, as stated in the Pallium Palliative Pocket Guide, “the use of the principle of double effect is inappropriate when appropriate guidelines are followed and its continued use may serve to perpetuate the myth that palliative interventions shorten life”.12

Hospice palliative care never intentionally ends life but, in knowing that death will naturally occur, supports the following compassionate care interventions focused on providing comfort and maintaining dignity:

- Allowing refusal/withdrawal of treatment by a competent individual/substitute decision-maker(s)
- Allowing refusal/withdrawal of treatment through an advanced directive to a substitute decision-maker(s)
- Allowing the withholding or withdrawing of treatment deemed futile or of no benefit or if it is causing harm
- Allowing appropriate pain and symptom management (including palliative sedation when other methods of treatment fail) to be provided (applied using standard guidelines, appropriate doses and dose titration)

OBSERVING THE INDIVIDUAL’S EXPERIENCE

Observation of the person’s and family’s physical and emotional environment will help to inform the health care providers about such things as relationship issues, role difficulties, cultural beliefs and practices. It is important to be aware of:

- Items suggesting the importance of cultural practices
- Family photos, greeting cards from family, friends
- Whether they have regular or frequent visitors or no visitors
- Family members providing care – are they comfortable/reluctant/avoiding?
- Interactions: are they comfortable or tense?
- Are relationships strained or warm?
- Are caregivers exhausted or managing?
- What do family gatherings look like?
- Interactions between parents and children
- Is the atmosphere chaotic, strained or peaceful?

One of the important observations team members can note of (without judgment) is the coping strategies of various members of the family. Coping strategies are neither right nor wrong. Remember, the way in which the person and other members of the family approach life and death is a choice. As skilled caregivers, we can be alert for opportunities that invite deeper investigation and more authentic communication.
Chapter 7: Social Domain

INTERACTING WITH THE INDIVIDUAL AND FORMAL/INFORMAL CAREGIVERS

Persons and family members living with chronic progressive illness will often voice concerns about the future and share information about emotional and family problems to other members of the interdisciplinary team rather than to the physician. They may not want to burden the doctor or nurse with concerns that they consider unrelated to the disease process itself. The roles of various members of the team are delineated by the person and family and they will act accordingly. Though all members of the team need to observe and report expressed concerns and symptoms, the volunteer or the PSW may be the one who first becomes aware of issues in the social domain. Is important to know when to refer to social work if this is needed. The social worker on the team is generally the team member with the greatest knowledge and skill to talk to the person about emotions, family problems, and psychosocial concerns.

Discussing Legal Issues

In terms of issues related to the legal aspects of care at the end of life, it is important for the topics of goals, values, beliefs, substitute decision making, expressions of wishes to be discussed early in the illness trajectory and as the illness progresses in order to avoid conflict between family members or between family and the health care team. The health care team will need to ascertain, who is the SDM(s) in the event that the person becomes incapable. During a crisis it is not the time to be discerning who takes on this role or what the goals and values of the person are.

Starks, Vig and Pearlman\(^\text{13}\) offer the following advice around advance care planning:

Who should initiate the conversation?

Any clinician can initiate the conversation. Different expertise and points of entry are brought to the case by physicians, case managers, nurses and social workers. The medical facts and available treatment options are best discussed by the physician who knows the person’s condition and the probable trajectories of the illness as well as the range of options and outcomes of various treatments. Nurses are often the ones who explore the psychosocial aspects and elicit information about values and goals. They can offer answers to questions, clarify misunderstandings, explain details of medical treatments and revisit any topics addressed in previous discussions. Social workers may introduce the topic of advance care planning and help the person complete legal documents. They are also adept at leading family conferences and have the skills to negotiate differences of opinion among family members and gain consensus about changing goals of care.

What communication strategies are best?

Good communication skills are vital to the process. Particularly necessary in this discussion are being able to listen without interruptions, being open to questions, being sensitive to when persons chose to engage or not to engage, using plain and honest language, ensuring that the person and family understand what is being said and appearing comfortable when talking about death and dying.

How should the topics be introduced?

Normalizing the topic and being comfortable with the subject puts the person at ease. It is important to explain why the topic is being introduced.

Possible Scripts

Routine Visit with no Recent Changes in Health Status:

You seem to be doing well right now and I have no reason to believe that things will change in the next while, but I do like to talk to all my patients about their preferences for care in case they get very sick. I think it is best to talk about these things when you are feeling well and before we need to react in a crisis. That gives both of us time to talk about what matters to you. I would like to give you the kind of care that you want in the future. Would it be okay to talk about this today?

Episode of Acute Illness or Hospitalization

It’s vital that we work together when you are so sick. It may be hard to think about these things right now but it is really important that I understand your goals. Would it be okay if we talk about this right now?

Follow-up Visit after Illness Exacerbation

You were pretty sick last time I saw you. Are you feeling better now? At times like this I like to talk about goals of care to make sure that I’m up to date with what you would want in case you have another episode like that and others have to make decisions for you. Would it be okay to talk about this now?

Specific Questions to elicit Preferences and Goals of Care

- Have you completed a Power of Attorney for Personal Care? If yes: Who have you named as your attorney for personal care? If no: Who would you like to make decisions for you if you are incapable? If the person stated is the SMD(s) according to the hierarchy then the person doesn’t need to formally appoint him or her in a legal document.
If the person does not wish to engage in discussions, it is reasonable to inform the person that when consent to treatments are required in the future, the information will be provided to the capable person or in cases of incapacity, to the SDM(s). If the SDM(s) does not know the person's wishes, he or she will be required to make the decisions based on the person's best interests at the time. It is also reasonable to point out to the person that knowledge of wishes is very helpful for the SDM(s) since he or she knows what decision the person would make in various situations. Having a clear understanding eases the burden of responsibility.

**SUPPORTIVE CARE STRATEGIES**

Establishing what the person and family knows and understands about the disease and its prognosis provides clues as to how each person is coping. When family members collude in withholding the truth from the person, it is generally out of love and because they cannot face the it. Approaching collusion from this perspective makes it possible to respect the family member's reasons and work positively with them. McGuire & Weiner\(^\text{14}\) suggest that the first step is to acknowledge the collusion. Ask: “Why do you think that... ought not to know that he is dying?” Check out if there are emotional costs as a result of the collusion. Ask: “Can I ask what effect this has been having on you personally?” If there is evidence of emotional strain or an effect on the relationship, ask if the person would like you to suggest how the situation could be handled. Indicate that you would like to have a chat with the person about his or her understanding of what is happening and ask if the family member would like to be present. Emphasize that you have no intention of telling the person and if necessary enter into a contract to that effect but also indicate that you will not lie if directly asked. Very often the person's perception is that of a deteriorating condition but he or she wants to protect the family by not talking about it. Breaking collusion is difficult, however it can lead to finishing business, strengthening relationships and a more positive grief experience for the family following the death.

Denial is used as a defense mechanism when the truth is too painful to bear and as such, it need not be challenged unless it is causing serious problems for the person or member(s) of the family. In challenging denial, be gentle but explore any awareness. Ask the person to relate what has happened since the illness was first discovered and explore how it felt at each key point as well as the perceptions of what was wrong. If any ambivalence is uncovered, acknowledge that it appears that part of the person prefers to believe the situation is not serious but another part considers that things are getting worse. Ask how the person would like you to relate to him or her. It is appropriate to challenge the incongruence between perceptions and experiences. If the person seems
discouraged, ask if there is ever a moment when he or she feels that the situation may not be as simple as they wish.

Assisting the person to shift from denial to reality can be very satisfying for the team member but it is important to determine whose needs are being met.

In terms of addressing legal issues, decision making capacity is an aspect of care in which all members of the team can participate. Those who spend considerable time with the person may be the first to observe signs of incapacity.

Language barriers also need to be identified and using family members to translate should be avoided. Ensure that translators are aware that they should accurately translate what has been said and not change the words in an attempt to soften the message.

Other supportive strategies include:

- Attempting to anticipate questions the family or person may ask and being emotionally prepared to discuss social issues / concerns
- Frequently asking the person and family to identify any concerns, unaddressed issues and priorities
- Bringing any questions or misunderstanding about the illness or its treatment to the team
- Making referrals to appropriate team members to address social issues
- If the person is in a facility e.g. hospital, long term care home, enhance the environment to support quality of life and be hospitable to family and friends

In the situation when the person is considered mentally incapable and there is no one available or willing to act on their behalf as listed on the ranked priority list of the hierarchy of substitute decision makers then the Office of the Public Guardian and Trustee (OPGT) may be contacted. The OPGT would be responsible for making health care or placement decisions on behalf of the incapable person. The OPGT is also in place to make decisions on personal care for an incapable person in order to protect them from risk or harm. They would be responsible for making decisions about health care, place of residence, nutrition, hygiene and clothing. In some circumstances health care providers may request involvement of the OPGT in cases of disagreement of care for an incapable person between substitute decision-maker(s).

**WORKING AS A TEAM**

Communicating the PPS among team members will help to inform the team of declining functional status which may indicate impending death. Generally, if PPS scores decline over months or weeks, the person has months or weeks to live. If the PPS changes over days, the person may have only days to live.

Each member of the team has an important part to play in:

- Alerting the team to problems that the person or family are not able or willing to share with professionals
- Advocating for quality of life by communicating all symptoms, side effects, observations and concerns with the rest of the health care team in a timely manner
- Educating the person and family in order to debunk myths and enable them make decisions based on research and best practice guidelines as well as personal values and goals

There are many decisions to make once a person is told he or she has a terminal illness. Often people feel overwhelmed and alone in making those decisions, wondering how to involve those they care about, fearful of asking for help from others or participating in the decision-making process. One way to pursue this decision-making process is to have a family meeting/conference. The person, a trusted family member or friend, or a health care professional will usually initiate a family conference. Any member of the team can be invited to participate in the meeting, including the social worker or spiritual advisor.

A family meeting or conference can be arranged:

- After the diagnosis is made
- Any time an issue causes significant challenges; the conference can be initiated by health care providers or by the person and/or family
- When an important intervention or change of treatment is considered
- When the person has had a significant deterioration that may suggest the appropriateness of a change in focus or direction of the medical management
References


UNDERSTANDING THE FUNDAMENTALS

Family Roles and Relationships

When a family member is facing a life-threatening illness, all members are affected and adjustments in the usual roles and responsibilities within the family result. As disease progresses the person is less and less able to continue his or her usual recreational activities or to participate in many formerly enjoyed family activities. The person will also be facing the loss of work roles, social roles and usual family roles. A mother may no longer be able to care for her children and instead observes as others take on this role. A husband may be frustrated and concerned as he sees his wife having to complete work in the home that was formerly his responsibility. This inability to fulfill usual roles and responsibilities may threaten a person’s sense of worth. Instead of feeling as if he or she is a contributing member to family life or society, the person may come to feel dependent on others or even to feel like a burden. However, it is possible for people who are facing such changes to actually experience personal growth, healing of estranged relationships, and to find new ways or roles to contribute to their family and community. Byock1 reminds us of Freud’s definition of mental health as the ability to love and work. When a person has relinquished expectations of being able to work, the capacity to love may be the predominant determinant of a person’s health. A person who feels loved and is able to love may express a sense of well-being despite the pains of illness, fears of the future and rigors of treatment.

Family members have always cared for ill family members but the expectations placed upon caregivers today is much more complicated than in the past.3 Family caregivers provide for the needs of most long term and medically complex family members for months and sometimes years. Most of these caregivers are themselves middle aged or older and most are women. Care giving consumes time and money, affects employment, and is associated with depression and thoughts of physician assisted suicide and euthanasia.3 Carol Levine4 is a family caregiver who has focused attention on the abandonment of the chronically ill and their overwhelmed caregivers. In her article, “The Loneliness of the Long-Term Care Giver” she indicates that caregivers want better communication with professionals, education and training, emotional support, and advocacy to obtain needed services for their ill family member and for themselves. They want help in negotiating the system, and they want respite tailored to their needs. She reminds us that family caregivers need support because the health care system cannot manage without them. Another compelling reason to provide adequate support is that caregivers are at risk for mental and physical health problems themselves. Exhausted caregivers often become the recipients of care.

There are some relatively recent developments in Ontario and in Canada which can be of practical and financial help to family caregivers involved in end-of-life care.

Caregiver Assistance

Two types of assistance have been developed to help family members who want to provide care and support to a family member who is gravely ill. One type supports a leave from work; the other type provides benefits for the caregiver.

Work Leave

An amendment made to the provincial Labour Code now allows a leave of up to eight weeks duration with job protection for the purpose of providing compassionate care to a family member.

Compassionate Care Benefit

In January 2004, the federal government put into place the Compassionate Care Benefit Program under the Employment Insurance Program. A family member can receive compassionate care benefits to provide care or support to the following family members:5

- Brothers or sisters and stepbrothers and stepsisters
- Grandparents and step grandparents
- Grandchildren and their spouse or common-law partner
- Son-in-law and daughter-in-law, either married or common-law
- Father-in-law and mother-in-law, either married or common-law
- Brother-in-law and sister-in-law, either married or common-law
- Uncle and aunt and their spouse or common-law partner
- Nephew and niece and their spouse or common-law partner
- Current or former foster parents
- Current or former foster children and their spouse or common-law partner
- Current or former wards
- Current or former guardians or tutors and their spouse or common-law partner

A medical certificate from a physician is needed to indicate that a person is gravely ill with a significant risk of death in the next six months (26 weeks). The six weeks of compassionate care benefits can be shared among members of a family. Each family member must apply for and be eligible for these benefits. Individual family members can claim the benefits at any time during the 26-week period, either at the same time or at different times (maximum 6 weeks in total). Compassionate care benefit ends when the six-weeks is paid off or if the gravely ill family member dies.

For further information visit: www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml
Inviting friends, acquaintances, neighbours lessen former colleagues and others to form a support team, helps to lessen the burden of care lessened for the primary caregiver. Practical tasks such meal preparation, shopping, and yard work can be delegated to members of the team. Activities that the person enjoys and periods of respite for the primary caregiver can also be organized by the care team. The team can be as formal or informal, as small or a large as the person and family wish. Frequently, the family will need support in implementing the concept. There are excellent resources at www.sharethecare.org.

Unfortunately, sick people often resist help and underestimate the extent to which friends and neighbours are willing to help. The person may fear losing control if others get involved and may be concerned about privacy. Family members themselves may also resist help and it may take time to come to the realization that support is needed. When heavy reliance is placed on one or two people, the risk of burnout is high. Primary caregivers need not feel guilty about being honest about their own needs and feelings. They may have to tell the ill person that if they are to continue helping him or her, they will need support.6

OBSERVING THE INDIVIDUAL’S EXPERIENCE

The better the dying person is able to redefine him or herself, the easier is it for spouses and others to provide support, to discuss the changes and to attend to unfinished business. For example, when a parent is able to redefine his/her role, children are better able to appreciate that death is a part of life.7 Family members who search for meaning frequently reevaluate their goals. Sacrificing today for the sake of a future goal may no longer make sense. They may want to make the best of each day and enjoy the time they have left. Those who don’t search for meaning or are unable to find meaning often focus on simply “getting through” or enduring.

Sexuality is a sensitive issue that needs to be addressed in hospice palliative care. “A person’s sexual identity can be both altered and compromised during the course of an incurable disease, deleteriously affecting both the identity and the role fulfillment of the affected persons.”8 The ability to give and receive physical love does not evaporate with the diagnosis of a progressive life-limiting illness. Matzo acknowledges the broad complexities of human sexuality and utilizes the Sexual Health Model that identifies ten broad components that are considered essential domains of healthy human sexuality. The components are:9

- Talking about sex
- Culture and sexual identity
- Sexual anatomy and functioning
- Sexual health care and safer sex
- Overcoming challenges to sexual health
- Body image
- Masturbation/fantasy
- Positive sexuality
- Intimacy and relationships
- Spirituality and values

The ability to talk comfortably and explicitly about sexuality, especially one’s own sexual values, preferences, attractions, history and behaviours is the cornerstone to sexual health. However, each individual/couple will determine their comfort level with discussions and to what extent physical expressions of love will remain a part of their life. Couples may need assistance from the team; by addressing the topic of sexuality early in the trajectory, sexual issues are legitimized and it will be easier for the couple to voice any concerns as the illness progresses.

Individuals and families rely on the health care team to recognize everyday practical issues that affect their lives. They need guidance and support in working out practical concerns throughout the journey. Sometimes practical issues are the straws that break the camel’s back. Lack of support and lack of confidence have been found to be determinants of hospital admissions. Families attribute this breakdown in family coping to lack of support from the health system, fragmentation of services and lack of preplanning.10 Good palliative care is an exercise in anticipation. Monitoring the coping of all members of the family is important in avoiding caregiver burnout.

INTERACTING WITH THE INDIVIDUAL AND FORMAL/INFORMAL CAREGIVERS

When interacting with the person and his or her family it is important for the caregiver to:

- Recognize that each person and family is unique; the person may have a history of troubled familial relationships, a loosely organized family, or a “tightly knit” family
- Avoid “taking sides” in a family situation, and remain non-judgmental
- Foster communication and understanding between the person and his or her family members
- Resist imposing personal standards and values, and respect cultural and religious differences of the person and his or her family
- Be sensitive to the economic difficulties of the person or his or her family
- Be aware that feelings of anger, grief or depression are unique to each person and manifest differently
• Establish boundaries early with the person and his or her family (i.e. what the health care caregiver is willing/not willing to do)
• Immediately report to a supervisor any suspected abuse of the person

As the health care provider engages in a therapeutic encounter with the person and family, it is helpful to understand how to build a comfortable therapeutic relationship. This is a process that begins with the first visit and continues throughout the contact. Some tips for this communication include:

• Sit at the same level as the person
• Say the person’s name (only use a first name if given permission)
• Offer the opportunity for privacy and uninterrupted time for unhurried discussion
• Acknowledge that several brief discussions may be better than a single lengthy one due to limited energy
• Observe and respect mood and behaviour
• Be guided by the person about how much contact is comfortable
• Explore background and interests, e.g. the person’s preferences in music
• Heaviness, sadness, anger, frustration may need to be acknowledged before any further issues are raised
• Address issues of sexuality by asking questions such as:
  » Some people who have a serious illness are frustrated by the lack of private time with their spouse/sexual partner. How is this experience for you?
• Set boundaries to help the person to feel safe and know what they can and cannot expect from the caregiver
• Respond to opportunities to talk about death
• Be respectful
• Be honest; use gentle art of truth telling

Introduce the concept of a Share the Care Team™ when the person is experiencing difficulties with activities of daily living (ADLs) e.g. ambulating, grooming, preparing meals etc. and instrumental activities of daily living (IADLs) e.g. driving, shopping. There may be reluctance to consider the idea of a care team as the person may not want to impose upon friends and neighbours. Over time, the person may come to realize that it takes a village to care for a gravely ill or dying person. It may be the family members who recognize the need for more assistance and take the initiative to develop a dedicated informal caregiver team.

SUPPORTIVE CARE STRATEGIES

General Guidelines for Caregiver Interventions

Davies and Steele outline four interventions for formal caregivers to support a person and family members:¹¹

1. **Maintain hope in the person with a terminal illness and family members**

   As families move through the illness, the nature of their hope can change on an ongoing basis. The hope for a cure may change to hope for remission, which may change to hope for comfort, which may change to hope for a peaceful death. Reassure families that everything will be done to ensure the person’s comfort. Talking about the past can help to reaffirm good times and the family connections that will continue. Referring to the future beyond the immediate suffering and emotional pain can also sustain hope (i.e. when adult children reassure the ill parent that they will care for the other parent, the person is hopeful that the surviving spouse will be all right). Helping to provide opportunities for the person and family members to carry out cultural practices and rituals may contribute to hope and comfort. Kubler Ross’s interviews with people who were dying in the 1960s, revealed that even those who were most realistic about their situations left the possibility open for a cure, for some new drug or last minute success in a research project.¹² Perhaps this hope accounts for the fact that many are willing to undergo significant financial burden and suffering to try an experimental or alternative treatment. That small spark of hope for cure or yet another remission may remain until the last days of life.

2. **Involve families in all aspects of care**

   With consent from the person, include family members in decision-making and encourage active participation in the physical care of their loved one. Include children in care during the terminal phase and in all activities following the death. The more children are involved in the care (e.g. physical care or decision-making) during the terminal phase, and in the activities following the death, the better able they are to cope with the bereavement process. At the same time, family members need to be respected and support when they indicate that they are not comfortable acting in these roles.

3. **Offer information**

   With the permission of the person, explain to the family what is happening and what they can expect. Doing so provides them with a sense of control. Initiate discussion of relevant issues, such as how the family is torn between caring for their loved one and their own activities.

4. **Communicate openly**

   Open communication with nurses and other health care workers is often the most important need of families. They need to be informed and have opportunities to ask ques-
tions which are answered in terms that they can understand.

Family, friends and even children can help the person and the primary caregiver in many ways. Specific suggestions that can be made to family members and friends include:

- Understand that you may be turned away from visiting for various reasons on any particular occasion. Seek out support and be open to offers of it if this happens when you had planned to visit.
- Visit but be aware of signs of fatigue and don’t overstay your welcome. Set your watch or ask for someone to return in 10-15 minutes.
- Offer to do small tasks for the person e.g. walk the dog, return books to the library, take the children to their lessons or on an enjoyable outing.
- Provide opportunities for recreation such as card games, reading aloud, listening to music, reading the newspaper.
- Keep a diary of activities, visits.
- Engage in reminiscence: aspects of history and culture can be transmitted and preserved.
- Remember that some individuals may be reluctant to reminisce because of painful memories.
- Respect the reticence.
- If the person is interested, talk about daily activities such as school activities, who you met at the store, what the neighbours are doing.
- Make sure the person is included in conversations.
- Make some meals/treats that the person would enjoy.
- Offer to drive to an appointment or scheduled event or pick up medications or supplies.
- Assist with personal care of the person, if comfortable and the person consents.
- Gather a list of persons who offer to help or are willing to be available. Utilize the list to make a schedule of activities so that everyone doesn’t visit the same day or bring treats the same day. Visit www.sharethecare.org for ideas about developing a team to support the person and primary caregiver. There are various tools that can be downloaded to assist with organization of a team.

Supporting Children: Specific Suggestions for Family Members

Children can be made to feel comfortable when visiting the person, regardless of the setting. They can be supported by:

- Listening to their worries and fear
- Communicating at their level of understanding
- Answering questions truthfully with gentleness
- Inviting children to help out in some way e.g. using their art work to decorate the room. Let children be a part of what is happening to the family (i.e. going to get things, letting them help with small tasks such as rubbing the person’s feet, hands, encouraging them to tell the person stories about what is happening in their life
- Letting them know that what is happening is not their fault
- Making sure they know that they will not be left alone
- Always keep lines of communication open
- Providing resources that are age appropriate

Other ways of providing practical support include:

- Provide education/resources regarding care giving, grief, sexuality.
- Be proactive in providing equipment e.g. walker, commode chair, continence products, hospital bed. Notify CCAC when function is declining so that equipment will be there when needed.
- Be specific about what is expected to happen as the disease progresses.

WORKING AS A TEAM

One of the frustrating aspects of health care for the person is the number of times that the same questions are posed. All caregivers need to have information about the person and family but every member of the team need not ask the same questions. Gathering data regarding the person and family is necessary to provide good palliative care and team members need to determine who will gather the data. There also needs to be a process developed whereby, with the person’s permission, all team members have access to information that has been collected.

Practical family information to be collected includes:

- Who will be the Substitute Decision-Maker(s) if the person becomes mentally incapable?
  - If so, does that person accept responsibility for communicating with other family members?
  - If not, who in the family will act as the designated communication person for others in the family? This arrangement saves much time for the team and empowers the family to communicate within itself. If there are persons who need direct communication (not within the family circle) these can be named and if the dying person agrees can receive direct communications from the health care team.
- What family members will be involved in care?
- Are there extended family members who need to be kept updated?
- How do family members communicate with one another?
- Who makes decisions in the family and how are they made?
- Are there cultural issues, religious/spiritual practices that would be helpful for caregivers to know?
• How is affection expressed in this family?
• Are there any areas of conflict?
• How is conflict resolved in the family?
• What are the family / household rules that the caregivers should be aware of?
• What are the family concerns?

In terms of other practical issues, the following information should be gathered:

• What help does the person need in regard to personal care?
• How comfortable is the person with receiving personal care from others? Who would the person find unacceptable in regard to provision of personal care e.g. child, member of the opposite sex?
• What activities or household duties does the person feel are causing a burden?
• Are there issues with child care, pet care?
• Is transportation an issue?
• Is the person ever left alone? If so, is there need for a system to access help in an emergency e.g. connect care
• Does the person know how to access team members?

The hospice palliative care team members play an important role in assisting the person and family throughout the illness journey. Doing so requires humanity, compassion and warmth in addition space to the usual medical, nursing, social, spiritual, and practical care skills. Over and over again, team members are called upon to counsel, educate, train, and support persons and families living with dying. The extent to which the team meets the needs of the person and family ultimately influences how families experience and remember one of life’s most profound transitions.13

References


6 Caposella C & Warnock S. Share the Care: How to organize a group to care for someone who is seriously ill. Fireside: New York. 2004


Chapter 9

End-of-Life Care and Death Management Domain
UNDERSTANDING THE FUNDAMENTALS

In western society, peaceful awareness of death is an example of an ideal that is broadly held by those working in hospice palliative care. Palliative care in the traditional model only referred to care at the end-of-life care, whereas in the current model, palliative care is to be provided throughout the illness trajectory of those with a progressive life-limiting illness. Peaceful awareness of death is difficult to achieve unless the team members are skilled in recognizing and communicating issues and engaging the principles of hospice palliative care throughout the care of the person and family. It is also difficult to properly address these needs in a short period of time (i.e. only at the end). In addition to this, when palliative care is applied too late in the illness trajectory, the person and family may well have lived for a long period of time with many unresolved issues.

Determining when the end-of-life phase in the trajectory of a progressive life-limiting illness begins can be challenging. Organizations however do need to determine when persons in their care should be categorized as being at ‘end of life’. A question frequently used for classifying individuals for statistical and clinical care purposes is “Would you be surprised if the person died within the next 6 months? “ If the health care practitioner would not be surprised, the person is classified as requiring palliative / end-of-life care. Though palliative care ought to begin whenever symptoms of a progressive life limiting illness affect quality of life and comfort, the support provided in the last 6 months of life is important in preparing for the kind of death that the person desires.

Barbus offers the following Bill of Rights for the dying person in chart 9.1:

Chart 9.1: The Dying Person’s Bill of Rights

I have the right to be treated as a living human being until I die.
I have the right to maintain a sense of hopefulness however changing its focus may be. I have the right to participate in decisions concerning my care.
I have the right to expect continuing medical and nursing attention even though “cure” goals must be changed to “comfort” goals.
I have the right not to die alone.
I have the right to be free from pain.
I have the right to have my questions answered honestly. I have the right not to be deceived.
I have the right to have help from and for my family in accepting my death. I have the right to die in peace and dignity.
I have the right to retain my individuality and not be judged for my decisions which may be contrary to beliefs of others.
I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.

Other Rights include:

- The right to express my feelings about my approaching death in my own unique way
- The right to die in peace and dignity
- The right to expect that the sanctity of the human body will be respected after death

As end of life approaches, decisions need to be made. The decisions can range from simple to extremely complex. Ethical principles are frequently taken into consideration in end-of-life decision making.
Chapter 9: End-of-Life Care and Death Management Domain

Ethical Principles include:

- Autonomy: the right of a capable person to determine what may be done to his or her body
- Beneficence: the duty of health care providers to do good
- Non-maleficence: the duty of health care providers to do no harm
- Justice: the fair treatment of individuals as well as equitable distribution of health care resources and dollars

When two or more ethical values apply to a situation but support diverging courses of action, an ethical conflict or dilemma exists. Many organizations employ ethicists to help team members when ethical conflicts arise.

Examples of end-of-life decisions that may need to be made include:

- Extent of family involvement in care giving and decision making
- Setting for care: home or in a facility
- Caregiver help wanted or needed
- Who will make decisions if/when incapacity is determined
- How will limited energy be expended
  - Engagement in meaning making, life review, making a will, funeral planning, forgiveness, legacy work etc.
  - The withholding or withdrawing of life prolonging interventions e.g. CPR, artificial nutrition, antibiotics
- The timing for withdrawal of life prolonging treatments e.g. cardiac devices, life prolonging medications, ventilation

Friends and/or hospice volunteers are particularly valuable members of the team when the dying person is interested in activities such as life review and legacy work. Volunteers can help the person with activities such as videotaping the person giving a history of the home and precious possessions, writing a life story, and creating memory boxes. These activities require some energy so waiting until the last days to introduce hospice volunteers may jeopardize the fulfillment of such goals.

Friends and volunteers can also be supportive of the family and help them to get away for a while or get some needed rest. Providing meals or running errands are other concrete ways that they can contribute to care. Since it is not easy for most people to accept help even when it is offered, team members should encourage family caregivers to give their friends an opportunity to help. Consideration can be given to forming a Share the Care team.

Modern technology with its ability to prolong life along with a philosophy that sees disease as an enemy that must be conquered, makes it difficult for physicians and other health care providers to recognize/acknowledge when a person is dying.\(^3\) For example, a particularly toxic chemotherapy regimen or a difficult dialysis treatment can result in symptoms that make the care provider wonder whether the person is actually dying rather than just experiencing the effects of the treatment. The diagnosis of dying is a combination of science and art. When health care professionals are unsure of what to do for dying persons they may simply continue with the treatment they know thereby avoiding the problem of diagnosing dying.\(^4\) Identifying that dying is actually happening allows for appropriate planning, enables informed decisions about end-of-life care and death management to be made, and facilitates appropriate use of resources and the avoidance of futile treatments.

Research using the PPS scores has determined that declining PPS scores are indicative of earlier death and stable PPS scores are consistent with longer survival. Data has demonstrated that with a PPS score of 10%, 50% of persons will die within 24 hours and 97% will die within 7 days. With a PPS score of 30%, 50% of persons will die within 14 days and 98% by 6 months. The Palliative Prognostic Index utilizes the PPS score along with reduced oral intake, presence of edema, dyspnea at rest, and presence of delirium as a tool for determining prognosis. The rate of change in the PPS score is of greater importance than the amount of change. A change in PPS from 50% to 30% is more significant if it happens over 2 days than if it changes over a 4-month period. Personality, the will to live, the extent of disease and the early response to treatment all affect the prognosis.\(^5\)

As illness progresses and it becomes apparent that death will almost certainly be the outcome in the not too distant future, the person may become more introspective and wish to withdraw from active engagement in the world. The social circle generally becomes smaller as energy is more and more depleted due to the disease process.

Just as there are developmental landmarks and tasks described for other points along life’s journey, there are developmental landmarks and tasks for end of life.

In order for individuals to have opportunity to meet the developmental landmarks described by Byock, someone needs to be courageous enough to name the fact that the disease process is one of a progressive nature that will end in death. Exploring these tasks with the person and family is an important role for health care providers. These developmental landmarks and tasks reflect the transition from worldly and social aspects of life to interpersonal aspects, then finally to introspective aspects.

Byock describes the developmental landmarks and tasks for the end of life in chart 9.2.\(^6\)
### Chart 9.2

<table>
<thead>
<tr>
<th>Landmarks</th>
<th>Tasks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sense of completion with worldly affairs</td>
<td>Transfer of financial, legal, and formal social responsibilities.</td>
</tr>
<tr>
<td>Sense of completion in relationships with community</td>
<td>Closure of multiple social relationships (employment, commerce, organizational, congregational). Components include: expressions of regret, expressions of forgiveness, acceptance of gratitude and appreciation. Leave taking; the saying of goodbye.</td>
</tr>
<tr>
<td>Sense of meaning about one’s individual life</td>
<td>Life review; the telling of “one’s stories”.</td>
</tr>
<tr>
<td></td>
<td>Transmission of knowledge and wisdom.</td>
</tr>
<tr>
<td>Experienced love of others</td>
<td>Acceptance of worthiness.</td>
</tr>
<tr>
<td>Sense of completion in relationships with family and friends</td>
<td>Reconciliation, fullness of communication and closure in each of one’s important relationships. Component tasks include: expressions of regret, expressions of forgiveness and acceptance, expressions of gratitude and appreciation, acceptance of gratitude and appreciation, expressions of affection. Leave-taking; the saying of goodbye.</td>
</tr>
<tr>
<td>Acceptance of the finality of life - of one’s existence as an individual</td>
<td>Acknowledgment of the totality of personal loss represented by one’s dying and experience of personal pain of existential loss.</td>
</tr>
<tr>
<td></td>
<td>Expression of the depth of personal tragedy that dying represents.</td>
</tr>
<tr>
<td></td>
<td>Emotional withdrawal from worldly affairs and emotional connection with an enduring construct. Acceptance of dependency.</td>
</tr>
<tr>
<td>Sense of a new self (personhood) beyond personal loss</td>
<td>Developing self-awareness in the present.</td>
</tr>
<tr>
<td>Sense of meaning about life in general</td>
<td>Achieving a sense of awe; recognition of a transcendent realm. Developing/achieving a sense of comfort with chaos.</td>
</tr>
<tr>
<td>Surrender to the transcendent, to the unknown - “letting go”</td>
<td>In pursuit of this landmark, the doer and “taskwork” are one. Here, little remains of the ego except the volition to surrender.</td>
</tr>
</tbody>
</table>

According to the Palliative Performance Scale, a score of 30 indicates that the person has entered the end-of-life stage of the illness. The person will have extensive disease and in terms of function, will be virtually bed bound, unable to engage in activities, and will require total care for all activities of daily living. The person may be fully conscious or may be drowsy with or without confusion. Intake of food and fluids will continue to decrease as the person approaches death. By this point in time it is hoped that most of the tasks outlined by Byock will have been completed and if it is
the person’s goal to have reached a peaceful awareness of death, that goal will have been accomplished.

Caregivers in hospice palliative care choose to walk closely with the person and family, journeying with them through this important stage of life. By the time the PPS score is 30%, hopefully, health care providers will have addressed issues in the physical, psychological, social, spiritual, and practical domains. They will be continuing to engage in managing issues and will be assisting with issues of loss and grief for the person as well as the family and in care planning for the end of life. Caregivers should be cognizant of what people usually want at the end of life. A frequently quoted study by Singer, Martin & Kelner suggests that the issues identified were:

1. Receiving adequate pain and symptom management
2. Avoiding inappropriate prolongation of dying
3. Achieving a sense of spiritual peace
4. Relieving burden
5. Strengthening relationships with loved ones

David Kuhl reminds us that only through hearing the stories of those who are experiencing a terminal illness will our understanding and knowledge of human suffering be enhanced. People who are dying are still living. In their quest to know themselves, others and God, they help us to appreciate the fullness of life and challenge us to define our purpose, values and goals.

During the final stage of the dying process two different dynamics are at work in the dying person. On the psychological/spiritual plane, a process of withdrawal and letting go of the material world is taking place. On the physical plane, the body begins its final process of shutting down which results in the systems ceasing to function. In an expected death, these changes generally occur in a progressively and invasive interventions are unnecessary. There are times when incidents that are more distressing, such as extreme dyspnea or a massive hemorrhage, are the final event in the dying process. If such catastrophic episodes are deemed possible based on the person’s disease, every effort must be made to prepare the person, the family and the caregivers for the situation.

Sometimes a person who is ready to die may just want it to be over. Conversely, sometimes it is the family who are exhausted from their vigil who long for the suffering to end. Expressions of a wish to die or requests for help to die must not be ignored. The person who expresses a wish for premature death should be made aware of the team member’s duty to report such conversation. Confidentiality needs to be maintained and not everyone on the team needs access to all information. Assessment and management of the underlying reasons for wishing to end life need to be undertaken by the appropriate health care professionals.

One of the reasons for wishing for a premature death is often related to the person’s sense of being a burden to the family. Simply telling the person that he or she is not a burden is not helpful when independence in activities of daily living is virtually lost. Encouraging family members to engage in honest communication is paramount if the best possible solution to the dilemma of dying is to be found. Expressing that yes, care giving is a burden but it is a burden of love, or that the caregiver is learning and growing because of the experience may be helpful. It is also helpful to acknowledge the support that the person has provided to the caregiver in the past, or that if circumstances were different, it could be the dying person caring for the caregiver.

Studies have demonstrated that there are significant risks to health and well-being for those assisting in end-of-life care. Redinbaugh, Baum, Tarbell & Arnold suggest that the family’s ability to accept the fact that the illness will lead to death may determine the amount of strain experienced. It also needs to be acknowledged that not all situations involving end-of-life care are based on a previous relationship of love and kindness.

The final report of the study of Family Caregiver Coping in End-of-Life Cancer Care determined that those most at risk for negative health outcomes are more likely to be younger females with a low income, who are employed or are taking a paid or unpaid leave from work and who are caring for a parent. The younger women caregivers demonstrated lower levels of resilience and optimism, had greater stress and reported less sense of coherence. These family caregivers also reported feeling less prepared for the care giving role and reported lower levels of family functioning. Those least at risk for negative health outcomes are more likely to be older retired females who are caring for their partner, had higher than average incomes and reported fewer financial worries. They had higher levels of resilience, optimism, sense of coherence and family functioning. These family caregivers also reported low levels of stress and felt more prepared for the care giving role.

OBSERVING THE INDIVIDUAL’S EXPERIENCE

Ferris, Danilychev & Siegel identify the following changes and clinical signs of impending death in chart 9.3.
<table>
<thead>
<tr>
<th>Common changes experienced during the dying process</th>
<th>Observable Signs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue, weakness</td>
<td>Decreasing function, inability to move about in bed, inability to lift the head off the pillow, loss of muscle tone</td>
</tr>
<tr>
<td>Cutaneous ischemia</td>
<td>Redness over bony prominences, cyanosis, skin breakdown, wounds</td>
</tr>
<tr>
<td>Pain</td>
<td>Verbal report if conscious, facial grimacing, tension in forehead, between eyebrows</td>
</tr>
<tr>
<td>Decreasing food intake and wasting</td>
<td>Anorexia or loss of appetite, poor intake, weight loss noticeable in temples (loss of muscle and fat)</td>
</tr>
<tr>
<td>Inability to close the eyes</td>
<td>Eyelids not closing, whites of eyes showing with or without pupils visible</td>
</tr>
<tr>
<td>Altered handling of fluids</td>
<td>Decreasing fluid intake, peripheral edema from hypoalbuminemia, dehydration, dry mucous membranes/conjunctiva of the eyes</td>
</tr>
<tr>
<td>Cardiac dysfunction</td>
<td>Faster or slower heartbeat than usual, higher or lower blood pressure than usual, peripheral cooling, peripheral and central cyanosis (bluing of the extremities), mottling of the skin, venous pooling along dependent skin surfaces</td>
</tr>
<tr>
<td>Renal failure</td>
<td>Dark concentrated urine, oliguria (urine output less than 400 ml in 24 hours), anuria (urine output less than 50 ml in 24 hours)</td>
</tr>
<tr>
<td>Decreasing level of consciousness</td>
<td>Increasing drowsiness, decreased awareness of surroundings, difficulty awakening, lack of response to verbal and tactile stimulation</td>
</tr>
<tr>
<td>Decreasing ability to communicate</td>
<td>Decreased concentration, decreased attention, difficulty finding words, use of monosyllabic words, short sentences, delayed or inappropriate responses, lack of verbal responses</td>
</tr>
<tr>
<td>Terminal delirium</td>
<td>Early signs of cognitive failure (e.g. confusion, day/night reversal), agitation, restlessness, hallucinations, purposeless repetitive movements, moaning, groaning</td>
</tr>
<tr>
<td>Respiratory dysfunction</td>
<td>Shortness of breath, changes in ventilator rate (first increasing then slowing), decreasing tidal volume (volume of gas inhaled and exhaled in one respiratory cycle), abnormal breathing patterns e.g. apnea (breath becomes shallow and there is a period of not breathing), cheyne stokes respirations (breathing becomes shallower and shallower, slower and slower until it stops for a period of time and is followed by progressively stronger and deeper respirations with the cycle being repeated), agonal breathing (infrequent, shallow, ineffective inspirations)</td>
</tr>
<tr>
<td>Loss of ability to swallow</td>
<td>Difficulty swallowing, coughing, choking, loss of gag reflex, build-up of oral secretions, gurgling, noisy breathing</td>
</tr>
</tbody>
</table>
Chapter 9: End-of-Life Care and Death Management Domain

Common changes experienced during the dying process | Observable Signs
--- | ---
Loss of sphincter control, urinary retention | Incontinence of urine, involuntary bowel movements, maceration of skin around perineum, perineal infections (e.g. candidiasis)
Other changes | Fever, sweating, bursts of energy just before death occurs (the “golden glow”), aspiration

As the dying person’s condition deteriorates, caregiver burden increases. Monitoring the family for signs of exhaustion is important. Signs of stress include:

- Inability to concentrate
- Changes in sleeping and eating patterns
- Irritability and/or anger
- Forgetfulness
- Increased use of alcohol or tobacco or other drugs
- Weight loss or excessive gain
- Activity that is scattered and frantic

INTERACTING WITH THE INDIVIDUAL AND FORMAL/INFORMAL CAREGIVERS

Every person’s life experience and illness journey is unique. Knowledge of the disease process as well as cultural and family norms will help the health care provider to sensitively guide the family at this time. The goals and values of the person and family must be respected and all efforts and interventions should reflect those goals and values. This does not prevent professionals from offering recommendations based on knowledge and experience. Caregivers can provide information but must always remember that each end-of-life journey belongs to the person and family.

Information regarding the dying process, provided in a compassionate and sensitive way assists the family members to support the person and one another. “People who know what to expect have a very different experience of dying and death than do those who are ignorant of the process.”

Preparing the person and family has the following effects:

- Reduces anxiety and fear
- Increases competence and confidence in providing care
- Increases the sense of value and gifting during the process
- Creates good memories of the experience
- Prepares them for impending losses
- Shifts roles, responsibilities and support systems
- Reduces dependence on health care providers

Ferris, Dainekycev & Siegel recommend conducting one or more family conferences to convey information, facilitate the development of an effective team, facilitate life closure, support decision making around issues such as CPR, artificial hydration, organ donation, help arrange for rites and rituals, and encourage planning for the funeral or memorial services.

It may be helpful to understand dying through the analogy of being born. Just as there is labour involved in being born, there is labour involved in dying (birthing into a different existence, whatever that may be for the person). The labour cannot be taken away and it will go on for as long as is required for consciousness or spirit to exit the body.

Planning Issues

As death becomes imminent, the plan of care should be reviewed and clarified. It is important to ensure that family caregivers have the equipment, and supplies, and the information, knowledge and skill to manage the various tasks required of them. Being sure that the family has a number to call for guidance and/or support, encouraging them to call at any time of day or night whatever the circumstance and providing a prompt response to such calls is paramount. Clearly reiterating the plan for expected death in the home can prevent panic and inappropriate summoning of emergency medical services. Transitions across health care settings at the end of life are particularly fraught with complications e.g. medical errors, unnecessary tests, lack of continuity. If the goal is to die at home, family members should be reminded that 911 should not be called unless a crisis arises prior to death that can only be managed in an acute care setting. Provide the family with 24/7 access to telephone contact and suggest that the family call the number before calling an ambulance. If an ambulance is called, families need to ensure that paramedics understand the goals of care and are given the DNR Confirmation form. The DNR status as outlined in a plan of treatment and confirmed in a DNRC form should accompany the person to the setting where care will be given. If transfer to hospital due to a crisis...
Feeding and Hydration Issues

One of the concerns frequently expressed by family members during the dying process is that the person will starve to death. Explaining that loss of appetite and of the ability to swallow is an expected part of the dying process can relieve caregiver guilt and frustration. Dying persons do not commonly experience hunger. The change in a dying person’s ability and desire to eat and drink can be particularly difficult for family and loved ones to accept.

As the body systems begin to shut down in the dying process, adding fluids into the person’s system can actually increase discomfort rather than relieve it. Additionally, forcing oral feeding or fluids can increase the person’s distress and can lead to painful choking and aspiration. With increased fluids there is more of a possibility of urinary incontinence leading to more frequent changes to maintain cleanliness and prevent skin breakdown. This additional activity contributes to increased discomfort and caregiver burden. Retained fluid can cause painful swelling throughout the body and can increase lung congestion making breathing more difficult. Tubes and other high tech equipment can be a barrier impeding physical and emotional closeness. There are times, however, when careful administration of artificial fluid may be necessary to control symptoms at end of life.

Tube feedings are not appropriate in the last stages of a person’s life. A number of studies have considered the effects of tube feeding at the end of life, specifically with persons in advanced stages of dementia. Tube feeding was not found to be effective in preventing malnutrition, pressure sores, or aspiration pneumonia. Tube feeding did not seem to provide comfort, improve functional status, or extend life. Potential complications related to gastrostomy tubes in the person with dementia include infection and pain at the site, tube leakage/blockage or migration, nausea, vomiting, diarrhea, gastroesophageal reflux, agitation and self-extubation. The presence of a gastrostomy feeding tube often results in the need to restrain the person as he or she may try to remove the tube. Some studies suggest that tube feeding may have an effect opposite to the desired and actually increase mortality, morbidity and reduce quality of life.14

Feeding and Hydration Issues

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There are many more ways to nurture than by providing food but because eating is so much a part of nurturing and celebration in most cultures, issues and family conflicts related to feeding frequently arise during the dying process.

Cultural and religious beliefs can impact decision-making around feeding and nutrition and can be a source of conflict between the family and the team. Sensitivity and education about burdens and benefits of treatments is important.

Communication Issues

Hearing is believed to be intact until death; families should be made aware of this so that inappropriate conversations do not take place at the bedside of the dying person. The family should be encouraged to engage in conversations during the times that the person is awake and alert. Speaking at the bedside about the physiological changes happening and that the person is dying is not necessarily inappropriate. It may be very helpful for the person to hear what is happening to his or her body. Reminiscing and celebrating the person’s life with joy and laughter as well as expressing grief and crying in the presence of the loved one are all appropriate activities at the bedside. Conflicts should be addressed away from the person and as much as possible an environment of tenderness and care should be maintained.

The person who is dying may begin to speak of people who have died. Be alert for symbolic language such as “I’m going on a trip” or “Help me pack my bags”. These may be opportunities to respond with words such as “I know you have to go and I’ll miss you”. There are many articles and books written about the symbolic language of the dying.

Providing Supportive Care Strategies

As the reality of the situation is recognized, hopes change; each moment is precious.

Supporting the person and family in looking back, reviewing life events and milestones can help the person to identify meaning. Education about the dying process for the person, family, and caregivers is very important. Many people have never watched someone die and fear the experience. Sharing information can alleviate some of the fear and distress. Preparation for an expected death includes preparing the family for the changes that accompany the dying process. With this information, family members may
be less likely to expect actions to be taken to address changes that are frightening to the inexperienced person but are normal.

Supportive strategies related to all the domains of issues continue to be relevant in the end-of-life stage. Utilizing the domains of issues as a framework at this end-of-life stage can prove helpful in ensuring that issues in all domains are addressed. The Cancer Care Ontario Collaborative Care Plans for each stage of the trajectory (including end of life) can be found at www.cancercare.on.ca/toolbox/pallcare-tools/. Strategies specific to managing the active dying process (last days and hours) include:

**Issues / Management Across the Domains of Care**

**Disease Issues/Management**
- Address deficits in understanding of disease, possible co-morbidities and prognosis
- Reassess relevance of disease management protocols (e.g. medications, treatments, clinic visits); testing (e.g. BP, glucose testing); goals of care (e.g. comfort or life prolonging interventions); and plan of treatment; in order to make appropriate adjustments
- Establish most responsible physician and ensure caregiver access to 24/7 telephone support
- Facilitate transfer of the plan of care if relocation occurs

**Physical Issues/Management**
- Pain and other symptoms
- Monitor symptoms (ESAS-r), reassess pain and symptom management medications and plan for change in route of administration in the event that the person is no longer able to swallow i.e. oral route to rectal, s/c, buccal or transdermal route. Avoid IM route.
- Educate the family caregivers about care provision at this stage.
- Continue to give around the clock medications for pain, dyspnea, nausea as ordered even when the person is comatose. Monitor for signs of drug toxicity (inability to rouse, myoclonus, etc) as organs begin to shut down. Medication dosage or frequency may need to be adjusted.
- Continue to treat constipation. When intake has been nil for 3 days, it is reasonable to reconsider the need for continuing the normal bowel management protocol.
- Inspect mouth daily for crusting, coating, redness, pocketing of food, sores, white patches and dryness. Report findings. Cleanse mouth with toothettes and favourite liquid q1-4 hours as necessary. Moisten oral mucosa q 15 – 30 minutes with artificial saliva. Use a water based lubricant (e.g. Muco or K-Y Jelly) to loosen crusting and Vaseline for dry cracked lips and nasal mucosa. Ensure Vaseline does not clog nasal prongs.
- Monitor for ability to close eyelids and for eye discomfort. Use warm compresses bid, artificial tears or saline drops q 15- 30 minutes or a lubricating gel q 3-4h. Eyelash reflex is a useful indicator of level of awareness during the dying process.
- Maintain good hygiene and minimize body odours. Moisturize the skin to minimize risk skin tears.
- Manage incontinence with incontinence products. Consider use of indwelling catheter or condom if incident pain is an issue. If diarrhea is an issue, a rectal tube may help to contain the liquid stool, prevent skin maceration and preserve dignity.
- Manage fever with rectal antipyretics or NSAIDs as well as topical cooling with tepid baths or fans.
- Maintain positioning for comfort; utilize special mattresses and overlays as appropriate.
- Use a careful log roll technique to minimize pain on movement. Use a lifter to avoid shearing and attempt to keep the head of the bed less than 30 degrees the majority of the time if possible.
- Reposition q 1-4 hours until last hours and then reposition (as opposed to turning) only as necessary for comfort and cleanliness. As death approaches, the need for turning lessens as the risk of skin breakdown becomes less important.17
- Use comfort measures e.g. massage, repositioning.
- Report observations related to pain or other symptoms to appropriate team members.

**Psychological Issues / Management**
- Soothing music may be helpful for both the family and person.
- Monitor coping of family caregivers

**Social Issues/Management**
- Maintain close contact with family members
- Encourage SDM(s) or next of kin to notify all members of family and friends of current condition.
- Determine any cultural preferences regarding handling of the body at the time of death.

**Spiritual Issues/Management**
- Notify spiritual companions of the impending death.
- Arrange for cultural and religious rituals as desired by person and family
- Provision of care that will meet the goals of the person and family requires that caregivers have knowledge about what would be helpful. Discussion about traditions and rituals that would be meaningful to the family can help team members to create the space, provide the permission and the privacy for special ceremonies to occur.
Practical Issues/Management

- Frequently clarify the goals of care, the futility of life prolonging therapies and the irreversibility of the dying process.
- Arrange for privacy and hospitality in a facility setting.
- Encourage intimacy including curling up in the bed with the person.

End-of-life Care Issues and Death Management

- Arrange for respite for family as required/requested.
- Encourage family and staff to say goodbye each time they leave the person.
- Encourage family to give permission to the person to let go and to reassure the person that the family will be okay.
- When the ability to swallow is gone, stop all oral fluids to prevent aspiration.
- Manage terminal secretions by starting antimuscarinic medications (e.g. scopolamine, atropine, glycopyrrolate) early and administering them routinely. Postural drainage in a Trendelenburg position (on back with feet above head) may allow gravity to bring secretions into the oropharynx where they can be removed with a sponge. Do not leave the person in this position for more than a few minutes. Educate the family that the person is not drowning or suffocating. The crackling and gurgling noises are caused by movement of air over pooled secretions that build up in the tracheobronchial tree. These noisy respirations are extremely upsetting for families and they need reassurance. The use of soothing background music can be helpful for those in attendance who are distressed by the sounds.
- Confirm pronouncement and certification plan. A Plan of Care for an expected death includes the following:18
  » Identification of the person and family’s cultural and religious beliefs and values about the death and treatment of the body after death
  » Identification of whether the family wants to see the body after death (if death occurs in a facility)
  » Identification of the most appropriate category of provider to contact when the person dies; (if death occurs in a facility)
  » Identification of the family member to contact when the person dies; (if death occurs in a facility)
  » Determination of which category of provider will pronounce the death
  » Identification of the physician responsible for determining the cause of death and signing the certificate
  » A time frame to carry out these activities
  » Documentation of the above information in a written plan of care.
- Confirm arrangements for care of the body after death including organ or body donation, funeral/cremation.

Loss and Grief Issues/Management

- Assess family members for risk of complicated grief.
- Provide information related to normal grief and bereavement support available through hospice or other agencies.

There are a number of situations that can occur at end of life that are more critical and require special consideration.

If seizures are a possibility due to the particular disease process, appropriate medications need to be on hand to manage the situation. Family caregivers need to be made aware of the possibility and be provided with written instructions for management.

If the dying person has an automatic implantable cardioverter defibrillator, following informed consent, arrangements should be made to deactivate the defibrillating pacemaker when the goal of care changes from prolonging life to comfort. If the decision is made to keep the device active, offer pain relief and a sedative when the device starts delivering shocks in the last days and hours.

If hemorrhage or exsanguination is a possibility, the person and family need to be made aware of the situation and be provided with instructions. Medication to reduce pain or sedate the person should be available and family taught how to administer it. Dark towels/blankets should be on hand if an external hemorrhage is a possibility. The towels or blankets are used to cover the person and absorb the bleeding.

Terminal delirium is an irreversible, acute confusion that occurs in the last hours or days of life. Up to 85% of patients will develop delirium in the last weeks of life.19 Failure to recognize and treat delirium may result in worsening agitation, myoclonus and seizures. If signs of active dying are not present, health care providers should look for reversible causes e.g. hypoxia, electrolyte imbalance, acidosis, infections, and toxin accumulation due to liver or renal failure, adverse effects of medications, disease related factors, and reduced cerebral perfusion. Always check for urinary retention and fecal impaction as these are easily corrected causes of reversible delirium.

D delirium towards end of life is one situation in which a trial of artificial hydration may be warranted. Delirium can be hypoactive or hyperactive. Both types involve confusion with the hyperactive type being more difficult for families to witness. Symptoms often come and go and the agitated state (purposeless movements, e.g. pulling blankets on and off, attempting to climb out of bed, sitting up and lying down, tossing and turning) may be interspersed with periods
of calm and lucidity. Terminal delirium is often associated with moaning and groaning which can be mistaken as pain. If delirium is mistaken as pain, the situation is often made worse as increases in opioids result in further accumulation of the opioid and its metabolites as the kidneys are shutting down in the dying process. Look for tension across the forehead, furrowing of the eyebrows or facial grimacing in an attempt to distinguish delirium from pain. If these signs are absent, the moaning and groaning is most likely from delirium. For delirium, antipsychotics (e.g. Haldol) are the medications of choice. Antipsychotics lower the seizure threshold so at times, both benzodiazepines and antipsychotics are required for an acutely disturbed person. For terminal restlessness, benzodiazepines may be used but there is a risk of paradoxical agitation.

Ferris and colleagues advise the following supportive strategies:\(^2\)

- attempt to reduce the day/night cycle reversal by using appropriate lighting during the day and maintaining darkness at night
- provide a quiet relaxed atmosphere
- minimize external stimulation
- preferably keep the person in a familiar environment with familiar people
- avoid using restraints

**Death Management**

At the moment of death, the vital systems within the body cease to function. It is, for many who work in this field, an experience of the sacred. Something of great significance has transpired and health care providers are privileged to be a witness. Some family members may be silent, some may cry or wail, others may engage in prayers common to their particular religion. There is no right or wrong way for family members to respond. Extreme grief reactions may require therapeutic interventions by other team members e.g. social worker, psychologist, chaplain, physician.

Clinical signs of death include:

- Absence of vital signs
- Fixed dilated pupils

Other signs include:

- Eyes may be open or closed
- Jaw will relax and the mouth may fall open
- There may be incontinence of urine and stool, leakage of other body fluids

The plan for expected death should be followed. A nurse (RN or RPN) can pronounce or declare that death has occurred when:

- Vital signs have ceased (pulseless at the apex and absent respirations) and the pupils are dilated and fixed
- The death of the person is anticipated by the person, the family and the health team
- The death has been planned for in a written plan\(^2\)

A physician must complete a death certificate. The details of the cause of death can be documented on the death certificate by the attending physician prior to the death but the Certificate of Death may not be signed until after death has been pronounced. Nurse Practitioners may certify expected deaths if they have been involved prior to the death. In certain situations, even though the death was expected, the coroner will need to be notified, i.e. every 10th death in a Long Term Care Home.

When the time seems right, begin caring for the person’s body with dignity and respect. Follow the wishes of the family, pay particular attention to cultural customs and the protocols of the agency/home. There is generally no need to rush. The general procedure is as follows:

- The family is invited to participate as fully as they wish in any of the post mortem rituals.
- If it is not a coroner’s case, tubes and masks can be gently removed. Dressings may be left intact on draining wounds. The removal of these things is a concrete act that makes real the fact that the person is truly dead. It can be shocking to the family so determining readiness to move forward with care of the body is important.
- The body can be washed and the environment tidied. Remember to practice universal precautions related to blood and body fluids. Wounds are covered with waterproof dressings. The dentures can be inserted if appropriate. The body is positioned lying on the back with the head slightly elevated on a pillow. Close the eyes and place a small rolled up towel under the chin if necessary to keep the jaw closed.\(^2\)
- Relatives are invited to spend as much time as they wish with the deceased. There is no need to rush and privacy should be provided as desired. Adequate chairs, access to a telephone (in a private area), refreshments are appreciated.
- If it is a death in the community, the funeral home is called when the family is ready.
- The family is empowered to assist with transfer of the body and to make meaningful funeral arrangements.
- Information on bereavement resources is provided.
WORKING AS A TEAM

The last days and hours can be an incredibly stressful time for family caregivers. Team members need to keep abreast of any changes in goals of care and communicate effectively with one another in order to avoid giving mixed messages. An important factor in experiencing job satisfaction depends on dealing well with the dying person and family.

The way the team members interact with the dying person will be observed and family members may engage in similar ways. Team members have opportunity to act as coaches and mentors to families and less experienced staff. Sometimes caregivers have talked to family members about the importance of expressing thanks, telling the person how much they are loved, or that the person might need permission to “let go”, and yet observe the family at bedside unable to initiate such a conversation. In such instances, a team member can quietly go to the bedside and tell the person about a conversation with family members who spoke of their memories and how much they love and will miss him or her. Similarly, touching the person before and after the death gives the family permission to do so as well. Remember, people live and die in families that have histories and cultures. Generally they approach death in the same way that they approach life but death is often a new experience that requires a coach.

Developing a team philosophy and actively engaging in team building are primary coping mechanisms that help reduce the stress of team members involved in caring for the dying. The need to work through team dynamics and decision-making are tasks crucial to maintaining the energy and spirit required in hospice palliative care work. Vachon and Muller identify that the best and most effective outcomes are achieved when professionals work together, learn together, engage in clinical audit of outcomes together and generate innovation to ensure progress in practice and service.23

In her book, Beyond all Pain: A Companion for the Suffering and Bereaved,24 Cicely Saunders, the founder of the modern hospice movement, compiled some of her favourite quotes. The following is one that speaks to the experience of many who work in hospice palliative care.

“I have seen death too often to believe in death. / It is not an ending, but a withdrawal. As one who finishes a long journey Stills the motor, turns off the lights, Steps from his car. / And walks up the path to the home that awaits him.” — An American Poet

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Chapter 9: End-of-Life Care and Death Management Domain

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Chapter 10

Loss and Grief Domain
UNDERSTANDING THE FUNDAMENTALS

Loss and Grief

Grief is an emotional response to the realized loss of a significant object, person or part of the self and is not first experienced with death. In hospice palliative care, both the person and family will experience grief over the multiple losses that occur all along the illness journey. At each decision point of the journey they will have losses to grieve. For example, with a diagnosis of a life-limiting illness, the person will grieve the loss of good health. Changes in body image from surgery or treatment may leave the person grieving the loss of body part or some other aspect of self. As function and independence diminish, the person may be unable to attend an important family function like a wedding or graduation; or family members may see their mother become a different person, unable to fulfill her usual family roles. It is the role of the caregiver to understand grief and support the person and family as they encounter loss on the illness journey.

When the person dies, the family members will make the transition from caregivers to bereaved persons. Death has brought the journey to an end for their loved one but the journey continues for the family. The person and family as the unit of care, takes on particular importance following the person’s death. The connection between the team and the family does not end for some members of the team, and these individuals need to be well informed about the grieving process in order to be helpful not only along the journey, but also during bereavement.

Bereavement

Bereavement is described as the state of having experienced the death of a significant other. For example, a woman whose husband has just died is said to be bereaved.

Mourning

Kagawa-Singer describes mourning as “the social customs and cultural practices that follow a death”. Mourning is an introspective process that helps a person deal with grief on a conscious and subconscious level. It is also an outward acknowledgment of the death. The rituals of mourning (e.g. funerals, wearing a black armband, burial rites) are an extension of one’s social and cultural background.

Factors that Influence Grieving

Some factors that influence a person’s grieving in relation to death are:

- Nature of the relationship with the person who died (e.g. mom, dad, child, sibling)
- Perceived nature of the relationship despite what society expects
- Ability or inability to use social support
- Unique characteristics of the bereaved person
- Unique characteristics of the person who died
- Nature of the death (expected, unexpected, violent, suicide)
- Religious beliefs
- Other stresses in the person’s life
- Previous experiences with death
- Health of the bereaved individual
- Coping skills of the bereaved

Types of Grief

Knowledge of the different types of grief can prepare caregivers to recognize healthy as well as more harmful types of grief and realize when further assessment and assistance may be indicated.

Anticipatory Grief

Anticipatory grief is experienced before the actual loss occurs. It can begin at the time of a terminal diagnosis. The feelings of helplessness, guilt, anger, denial, fear, confusion and rage can be as intense for the person and family then as the feelings are for the family after the death has occurred. Persons need to be reassured that anticipatory grief is a healthy response to an anticipated death. Grief work can be started when the impact of the impending death is first felt. By preparing for the death, the reality is gradually absorbed. Anticipatory grieving helps the person and family to prepare for the death, attend to unfinished business, participate in life review, resolve conflict, engage in legacy work, and to adapt to changes as they occur. The goal of anticipatory grief is to help the individual cope by discussing details of the crisis before it occurs.

Healthy, Uncomplicated Grief

Grief is the healthy response to any loss. It can include physical, emotional, spiritual, behavioural, and cognitive responses. The process of grief is based on the person’s perception of the loss. Niemeyer saw meaning reconstruction as the central process to grief and developed a set of propositions to capture adaptation to loss:
1. Death as an event can validate or invalidate the constructions that form the basis on which we live or it may stand as a novel experience for which we have no constructions.
2. Grief is a personal process, one that is unique, intimate and inextricable from our sense of who we are.
3. Grieving is something we do, not something done to us.
4. Grieving is the act of affirming or reconstructing a personal world of meaning that has been challenged by loss.
5. Feelings have functions and should be understood as signals of the state of our meaning-making efforts.
6. We construct and reconstruct our identities as survivors of loss in negotiation with others.

**Complicated Grief**

Complicated grief involves the presentation of certain grief-related symptoms at a time beyond that which is considered adaptive. Corless refers to intensive intrusive thoughts, pangs of severe emotion, distressing yearnings, feeling excessively alone and empty, excessively avoiding tasks reminiscent of the deceased, unusual sleep disturbances and maladaptive levels of loss of interest in personal activities.

Risk Factors include:

- **Personal**
  - Markedly angry, ambivalent or dependent relationship with the bereaved
  - History of multiple loss experiences
  - Mental health issues
  - Perceived lack of social support
- **Circumstantial**
  - Sudden, unexpected death, especially when violent, mutilating or random
  - Death following an excessively long illness
  - Loss of a child
  - Mourners perception of the loss as preventable
- **Historical**
  - Previous experience with complicated grief
  - Insecurity in childhood attachments
- **Personality**
  - Inability to tolerate extremes of emotional distress
  - Inability to tolerate dependency feelings
  - Self-concept, role and value of “being strong”
- **Social**
  - Socially unspeakable loss (e.g. suicide)
  - Socially neglected loss (e.g. death of an ex-spouse)
  - Absence of social support network

Egan and Arnold describe five types of complicated grief:

1. **Chronic grief** is normal grief that continues unchanged for an unusually long time and involves the bereaved person defining him or herself by the experience of the loss e.g. “I am George’s widow.”
2. **Delayed grief** is experienced when the survivor deliberately avoids feeling his or her grief by avoiding persons or circumstances that are reminders of the loss. The person might work long hours or become overly concerned with others’ problems. Resolution comes only after the person takes the time to grieve.
3. **Exaggerated grief** is evidenced by a person who is so devastated by loss that he or she seeks relief by engaging in self-destructive behaviours (e.g. unsafe sex, alcohol or drug abuse). Safety is a key concern in supporting such individuals as they may attempt suicide.
4. **Masked grief** may be considered when the survivor has an unconscious fear of further loss and distances him or herself from others and rejects attempts to help. Another portrayal of masked grief may involve the person becoming overly dependent on others to the point of straining relationships.
5. **Disenfranchised grief** is grief that cannot be openly acknowledged, publicly mourned, or socially supported. Doka noted that the concept of disenfranchised grief recognizes that societies have sets of norms that attempt to specify who, when, where, how long, and for whom people should grieve. Examples of those who might experience disenfranchised grief are mistresses or children conceived outside a legally recognized union, homosexual partners, colleagues, friends, ex-wife or ex-husband, step-children, families who suffer a miscarriage or still birth. Corless states that “Grieving in secret is a burden that makes the process more difficult to complete. Disenfranchised grief may also be a harbinger of unresolved grief.”
Chapter 10: Loss and Grief Domain

Unresolved Grief

Unresolved grief occurs when there is a failure to accomplish the necessary grief work. There are many causes including multiple losses, feelings of guilt, frail health, lack of support systems, self-identity attached to the person who has died, unfinished business, or lack of closure such as when a person is presumed dead but there is no body. Unresolved or complicated grief can lead to serious physical, emotional, and psychological issues that can affect the quality of life of the bereaved.

Common Myths About Grief

The following are 5 common myths about grief.

Myth #1: Grief and mourning are the same experience.

Most people tend to use the words grief and mourning interchangeably. However, there is an important distinction between them. We have learned that people move toward healing not by just grieving, but through mourning. Simply stated, grief is the internal thoughts and feelings we experience when someone we love dies. Mourning, on the other hand, is taking the internal experience of grief and expressing it outside of ourselves. In reality, many people in our culture grieve, but they do not mourn. Instead of being encouraged to express their grief outwardly, they are often greeted with messages such as “carry on,” “keep your chin up,” and “keep busy”. This forces them to grieve within themselves in isolation, instead of mourning outside of themselves in the presence of loving companions.

Myth #2: There is a predictable and orderly progression to the experience of grief.

Stage-like thinking about both dying and grief has been appealing to many people. Somehow the “stages of grief” have helped people make sense out of an experience that isn’t as orderly and predictable as we would like it to be. If only it were so simple! The concept of “stages” was popularized in 1969 with the publication of Elizabeth Kubler-Ross’ landmark text On Death and Dying. Kubler-Ross never intended for people to literally interpret her five “stages of dying.” However, many people have done just that, not only with the process of dying, but with the processes of bereavement, grief, and mourning as well. Often people around the grieving person believe that he or she should be in ‘stage 2’ or ‘stage 4’ by a certain period of time, however each person’s grief is uniquely his or her own. It is neither predictable nor orderly. Nor can its different dimensions be so easily categorized or marked on a timeline. We only get ourselves in trouble when we try to prescribe what the grief and mourning experiences of others should be.

Myth #3: It is best to move away from grief and mourning instead of toward it.

Many grievers do not give themselves permission or receive permission from others to mourn. We live in a society that often encourages people to prematurely move away from their grief instead of toward it. Many people view grief as something to be overcome rather than experienced. The result is that many of us either grieve in isolation or attempt to run away from our grief. People who continue to express their grief outwardly—mourn—are often viewed as weak, crazy or self-pitying. The common message is “shape up and get on with your life”. Suffering in silence, and ‘being strong’, are thought to be admirable behaviors, however such messages encourage the repression of thoughts and feelings important to the grieving process. Attempting to mask or move away from grief results in internal anxiety and confusion, as a person may begin to judge themselves, thinking their thoughts and feelings are abnormal. In order to heal, however, they must move toward their grief through continued mourning, not away from it through repression and denial.

Myth #4: Tears expressing grief are a sign of weakness.

Unfortunately, many people associate tears of grief with personal inadequacy and weakness. Crying on the part of the mourner often generates feelings of helplessness in friends, family, and caregivers. Out of a wish to protect mourners from pain, friends and family may try to stop the tears. Comments such as, “Tears won’t bring him back” and “He wouldn’t want you to cry” discourage the expression of tears. Yet crying is nature’s way of releasing internal tension in the body, allowing the mourner to communicate a need to be comforted. Crying often makes people feel better, emotionally and physically. Tears are not a sign of weakness. In fact, crying is an indication of the griever’s willingness to do the ‘work of mourning’.

Myth #5: The goal is to ‘get over’ your grief.

We have all heard people ask, “Are you over it yet?” However, we never ‘get over’ our grief but instead become reconciled to it. We do not resolve or recover from our grief. These terms suggest a total return to normalcy and yet, the person is forever changed by the experience of grief. For the mourner to assume that life will be exactly as it was prior to the death is unrealistic and potentially damaging. Those people who think the goal is to resolve grief become destructive to the healing process. Mourners do, however, learn to reconcile their grief. They learn to integrate the new reality of moving forward in life without the physical presence of the person who has died. With reconciliation comes a renewed sense of energy and confidence, an ability to
fully acknowledge the reality of the death, and the capacity to become re-involved with the activities of living. Acknowledging pain and grief are difficult-yet necessary-parts of life and living.

As the experience of reconciliation unfolds, the grieving person recognizes that life will be different without the presence of the person who died. At first this is realized in the mind, and later it is realized the heart. Reconciliation is a process, not an event. The sense of loss does not completely disappear yet softens, as the intense pangs of grief become less frequent. Hope for a continued life emerges as commitments to the future are made. The person who died will never be forgotten, yet life can and will move forward.

The Process of Grief

In the late 1960s, Dr. Kübler-Ross began publishing her research findings about the emotional stages people move through during their dying process. Her stages have also been applied to the reactions of bereaved individuals, and her model has come to serve as the foundation upon which many others have built their own theories. One common misconception is that everyone must move through all of the stages in a specific order. It is important to note that reactions can happen at different times all together, and in no particular order. Furthermore, sometimes people experience elements of the various stages more than once as they move through their grieving process. The stages Dr. Kubler-Ross proposed are as follows:12

- Denial – “It can’t be true”
- Anger – “Why me?”
- Bargaining – “Maybe I can bargain with God”
- Depression – Accompanies grief and mourning as death approaches.
- Acceptance – Acceptance of the inevitable by the person.

Worden13 describes Four Tasks of Mourning and outlines the tasks involved in grief work that may occur simultaneously or in various order. These tasks need to be completed by persons who are bereaved as they work through their grief, assimilate the loss, invest in new relationships, and go on to develop a new life without the person who has died. For some, this work will mean integrating their experience of loss into a larger acceptance of human mortality. Individuals who have worked through each of these four tasks will sometimes report increased energy and ability to enjoy their present lives without guilt and fear.

<table>
<thead>
<tr>
<th>Task</th>
<th>Description</th>
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</table>
| 1. Accept the reality of the loss | - Even when death was expected, there is still a feeling that it did not happen.  
- This task involves recognizing that the person is dead and will not return.  
- Death must be accepted on both an intellectual and emotional level.  
- Traditional rituals, such as funerals, help the bereaved to begin to accept the death as real. |
| 2. To work through the pain of grief | - The intensity of the pain and the way it is experienced and expressed is different for everyone.  
- It is impossible not to experience some amount of pain when someone very close dies.  
- Friends and family sometimes are uncomfortable with the survivor's pain and may try to interrupt this task.  
- The bereaved may try to avoid this task by masking the pain through the use of alcohol or drugs, by idealizing the deceased, by avoiding reminders of the deceased, by relocating or quickly getting into a new relationship.  
- No matter how successful the bereaved person is at avoiding the pain, it eventually will come back again, maybe in the form of depression or when a new loss is experienced. |
Chapter 10: Loss and Grief Domain

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<tr>
<th>Task</th>
<th>Description</th>
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</table>
| 3. Adjust to an environment in which the deceased is missing | • Adjusting to the new environment is dependent upon the nature of the relationship and what role the deceased played in the relationship.  
• During this task, grief work focuses on coming to terms with living alone, raising children alone, facing an empty house, managing home maintenance and finances, and caring completely for oneself.  
• It is important that regression to a state of helplessness, inadequacy or incapacity does not occur during this task.  
• It takes time and patience to figure out how to take over the roles of the deceased.  
• It is also during completion of this task that the bereaved tries to make sense of the loss and tries to regain some sense of control over his or her life. |
| 4. Emotionally relocate the deceased and move on with life | • For many, this task is the most challenging to complete.  
• During this task, the bereaved often finds the ability to invest emotionally in someone or something else.  
• The deceased is not forgotten, nor are the memories that were shared, but instead, the bereaved finds enjoyment in life again.  
• In this task, the bereaved do not give up their relationship with the deceased, but find an appropriate place for the deceased person in their emotional life - a place that enables them to go on living effectively in the world.  
• This task can be hindered by holding on to the past attachment rather than going on and forming new ones. Some people find loss so painful that they make a pact with themselves never to love again.  
• The deceased are never forgotten or replaced—but remain a part of the bereaved.  
• The bereaved is not the same person he or she was, and he or she never will be the same again.  
• With time and grieving, however, the pain will lessen, and the bereaved redefines him or herself. |

Corr and Doka built on the work of Worden and proposed the following tasks:

1. To share acknowledgement of the reality of death  
2. To share the process of working through the pain of grief  
3. To reorganize the family system  
4. To restructure the family’s relationship with the deceased and to reinvest in other relationships and life pursuits

Despite working through grief, it is normal for survivors to hold the deceased in loving memory forever.

**Meaning Making**

Finding meaning in loss and death is a difficult task and one that is unique to the individual. It is natural for those faced with a life-limiting diagnosis and their loved ones to ask ‘why’ and certain circumstances, such as long-term suffering, tend to increase the likelihood that the bereaved will search for meaning. Storytelling can be a useful tool to help the bereaved make sense of the circumstances of death and the retelling of the story can help keep memories alive and provide an outlet for emotional tension. Folkman emphasizes the impact of positive emotion on meaning making and coping, acknowledging that positive emotions affects the way people reappraise the event, the energy and resources available for coping and the meaning they attribute to unfavourable outcomes. There are five common approaches to meaning-focused coping:

1. Finding the Benefit: Seeking the benefits that come out of misfortune (e.g. growth, patience, greater appreciation for life)  
2. Benefit Reminding: Making an intentional effort to recall benefits  
3. Adaptive Goal Processes: Reappraising goals in light of new circumstances  
4. Reordering Priorities: Placing more or less importance on facets of one’s life given new circumstances  
5. Infusing Ordinary Events with Positive Meaning: To experience more positive emotions a caregiver might consider caregiving activities (e.g. cleaning up messes) as a way of expressing love

Not everyone searches for meaning and the content of meaning making may change over time. After a loss, the bereaved will need those around them, including palliative care providers, to listen to their storytelling and provide support and empathy during meaning making.
Dignity in care, or dignity therapy, is based on work by Dr. Harvey Max Chochinov and the Manitoba Palliative Care Research Unit. Chochinov and his team found that health-care providers can have significant influence on the dignity of those who use health care services.19

A person’s sense of dignity is affected by how a person sees themselves and by how they believe they are seen by others. There is considerable anxiety associated with having an illness. Persons and families often judge their own experience and place in the health care system by how they believe they are seen by health care providers.20

Providing dignity in care has been found to improve the person’s experience and increase his or her satisfaction with care. Improved interactions can result in better health outcomes and contribute to job satisfaction for health care providers. Dignity therapy or care provides a framework to explore what it is that we need to know as care providers about the person to be able to provide the best possible care.

**OBSERVING THE INDIVIDUAL’S EXPERIENCE**

By observing the experiences of the person and family, the caregiver will be better able to provide care, resources and referrals that meet needs. Recognizing that grief is an individual and unique experience for each person is critical to providing quality care.

**Observing Grief**

**Anticipatory Grief**

Observable signs of anticipatory grief may include:

- Picturing/imagining (rehearsal of) the death
- Increased concern for the dying person
- Depression (Note: unlike clinical depression, this is reactive; a deep sadness)
- Attempts to prepare for the aftermath of death
- Avoidance of visiting the dying person

The anticipation of loss may intensify attachment and relationships may get closer and more honest, providing treasured memories following death. On the other hand, premature grieving can be problematic if the person is “written off” as already dead. Withdrawal can deprive individuals of opportunities to support one another through the dying process and can lead to the bereaved individual accusing him or herself of having abandoned the person prior to the death.21

**Healthy Grief**

**Physical signs and symptoms of healthy grief:**22 23

- Dry mouth and throat
- Uncontrolled trembling
- Sleep disturbances
- Loss of appetite
- Stomach pain
- Shortness of breath
- Tight chest
- Weak muscles, lack of energy or fatigue
- Numbness
- Sexual impotency
- Exhaustion

**Psychological signs and symptoms of healthy grief**

- Deep sadness
- Fleeting visual, tactile, olfactory, auditory hallucinatory experiences
- Anxiety
- Anger

**Social signs and symptoms of healthy grief**

- Social withdrawal, weeping, startling easily
- Relief
- Shock
- Loneliness
- Yearning

**Spiritual signs and symptoms of healthy grief**

- Anger at a higher power

**Practical signs and symptoms of healthy grief**

- Helplessness
- Hypersensitivity to noise
- Difficulty making decisions
- Lack of sense of purpose
- Sense of disorganization

**Unhealthy Grief**

Signs and symptoms of unhealthy grief include:24

- Avoiding thoughts or feelings about the death
- Significant preoccupation with the death many months after it occurred
- Large memory gaps
- Flashbacks, hallucinations, or nightmares that occur on a consistent basis
Chapter 10: Loss and Grief Domain

- A continuing, significant disinterest in the activities of daily life
- Calmly and methodically giving away possessions with no emotion and no personal attachment to any of the items. For example, giving away to anyone everything that remotely reminds the survivor of the deceased.
- Feeling consistently guilty about surviving when the loved one died
- Over-idealizing the person who died to the point where it interferes with daily life
- Severe irritability and outbursts of anger toward others in the family, coworkers, friends and/or medical professionals on a consistent basis
- Feeling out of control and unable to cope for an extended period of time
- Using alcohol and/or drugs to keep from experiencing the pain of the grief process
- Detachment and withdrawal from significant others
- Avoiding all relationships for fear another loss will occur
- Flat affect; no emotion, even after the first few weeks following the death
- Continuing tension and insomnia that isn’t relieved with relaxation techniques
- Ongoing physical symptoms such as heart palpitations, severe startle reflexes, cold sweats, and breathing difficulties
- The development of new problems related to sleeping, eating, or relaxing that weren’t occurring previously
- Talking about or planning suicide

Complicated Grief

If any of the following symptoms are present, the person is at risk and may be in need of intensive counselling:

- Long term functional impairment
- Exaggerated, prolonged and intense grief reactions
- Significant neglect of self-care
- Frequent talking about loss
- Idealization of the deceased
- Impulsive decision-making or loss of decision-making power beyond the initial phase of grief
- Major personality changes
- Onset of new chronic health problems
- Mental disorders e.g. drug or alcohol dependency, depression (as diagnosed by a physician), feelings or expressions of suicide
- Post-traumatic stress disorder-like symptoms e.g. recurring nightmares, flashbacks, sleep problems, trouble concentrating, hyper vigilance, avoidance of people places and experiences related to the stress

Children and Grief

Death is a reality that children can learn to live with. Even before the death of a close family member occurs, parents can begin to introduce the idea of death as a part of everyday life. The nightly news, a trip past the cemetery, or a dead plant or bird may spark conversation about death.

One feature of grief demonstrated by most children is that they do not sustain grief over continuing periods of time, but tend rather to dip in and out of their grief - jumping in and out of puddles, rather than wading through the river of grief. Children will learn about grief and expressing grief from the adults around them, and should be allowed to express their grief in their own way, be it through play, artwork, or acting.

When applying Worden’s Four Tasks of Mourning to the experience of bereaved children, one must understand that children may revisit the tasks when they reach developmental milestones. Examples could include school graduations, getting a driver’s license, transition to high school, weddings, or births of their own children.

Chart 10.2 outlines the various reactions to grief a child may experience at different ages.
<table>
<thead>
<tr>
<th>Age</th>
<th>Characteristics</th>
<th>View of Death and Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newborn to 6 months</td>
<td>• Basic needs must be met</td>
<td>• No concept of death</td>
</tr>
<tr>
<td></td>
<td>• Cries if needs aren’t met</td>
<td>• Can sense disruption in routine</td>
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<td></td>
<td>• Needs emotional and physical closeness of a consistent caregiver</td>
<td>•</td>
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<tr>
<td></td>
<td>• Views caregiver as source of comfort and all needs fulfillment</td>
<td>•</td>
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<tr>
<td></td>
<td>• Developing trust</td>
<td>•</td>
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<tr>
<td>6 months to 2 years</td>
<td>• Begins to individuate</td>
<td>• May see death as reversible</td>
</tr>
<tr>
<td></td>
<td>• Remembers the face of the caregiver when absent</td>
<td>• Experiences true grief only to death of significant person in child’s life</td>
</tr>
<tr>
<td></td>
<td>• Demonstrates full range of emotions</td>
<td>• Screams, panics, withdraws, becomes disinterested in food, toys, activities</td>
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<tr>
<td></td>
<td>• Identifies caregiver as source of good feelings and interactions</td>
<td>• Reacts in concert with distress experienced by caregiver</td>
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<tr>
<td></td>
<td></td>
<td>• No control over feelings and responses</td>
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<tr>
<td></td>
<td></td>
<td>• Anticipate regressive behaviour</td>
</tr>
<tr>
<td>2 to 5 years</td>
<td>• Egocentric</td>
<td>• Sees death like sleep, that is, reversible</td>
</tr>
<tr>
<td></td>
<td>• Cause – effect not understood</td>
<td>• Has a sense of loss</td>
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<tr>
<td></td>
<td>• Developing conscience</td>
<td>• Curiosity, questioning</td>
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<tr>
<td></td>
<td>• Attributes life to objects</td>
<td>• Believes in magical causes</td>
</tr>
<tr>
<td></td>
<td>• Feelings expressed mostly by behaviours</td>
<td>• Anticipate regression, clinging</td>
</tr>
<tr>
<td></td>
<td>• Can recall events from the past</td>
<td>• Aggressive behaviour is common</td>
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<tr>
<td></td>
<td></td>
<td>• Worry about who will care for them</td>
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<tr>
<td>5 to 9 years</td>
<td>• Attributes life to things that move</td>
<td>• Begin to see death as irreversible, death is final and frightening</td>
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<td></td>
<td>• May fear the dark</td>
<td>• Personify death as ghosts and bogeymen; fear being alone</td>
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<tr>
<td></td>
<td>• Begin to develop intellect</td>
<td>• Interested in biological aspects of life and death</td>
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<tr>
<td></td>
<td>• Begin to relate cause and effect</td>
<td>• May see death as punishment; may feel responsible</td>
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<tr>
<td></td>
<td>• Understand consequences</td>
<td>• Problems concentrating on tasks</td>
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<tr>
<td></td>
<td>• Literal, concrete</td>
<td>• May deny or hide feelings</td>
</tr>
<tr>
<td></td>
<td>• Decreasing fantasy life, increasing control of feelings</td>
<td>• Vulnerable, fear being alone, worry that family members will die</td>
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<tr>
<td></td>
<td></td>
<td>• Developmental delays or regression to previous developmental stage</td>
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<tr>
<td></td>
<td></td>
<td>• Fighting and angry behaviour both at school and at home</td>
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<tr>
<td>9 to 12 years</td>
<td>• Individuation outside the home</td>
<td>• Everyone will die, sense of own mortality</td>
</tr>
<tr>
<td></td>
<td>• Identify with peer group but need family attachment</td>
<td>• Death is permanent</td>
</tr>
<tr>
<td></td>
<td>• Understand life processes</td>
<td>• Strong emotional reaction</td>
</tr>
<tr>
<td></td>
<td>• Can verbalize feeling</td>
<td>• Anger and aggression at many people including the person who died</td>
</tr>
<tr>
<td></td>
<td>• Begin to physically mature</td>
<td>• May somaticize e.g. headaches, stomach aches, trouble sleeping</td>
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<tr>
<td></td>
<td></td>
<td>• May intellectualize or have morbid preoccupation with death</td>
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<tr>
<td></td>
<td></td>
<td>• May experience loyalty conflicts between friends and family</td>
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<tr>
<td></td>
<td></td>
<td>• School work may be neglected or done poorly</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• May isolate themselves</td>
</tr>
</tbody>
</table>
Age | Characteristics | View of Death and Response
---|---|---
Teenage years | • Physical maturation continues  
• Need peer approval  
• Engage in search for meaning and purpose in life  
• Attempting to develop a personal identity | • Death is real but will not happen to me!  
• They may feel that their deep and powerful emotions are not experienced by anyone else  
• May experience wide mood swings, depression, extreme sadness, loneliness, anger, hostility  
• May cover up feelings with sarcasm or joking  
• May have identity confusion - “Now that my dad is dead, I must be the man in the house”  
• May prefer peers over family members  
• May test limits  
• May experiment with (or increase use of) alcohol and/or drugs  
• May become sexually active  
• May withdraw from friends and family  
• Ability with school work may decrease | • Coping mechanisms of individuals & family  
• Health conditions of family members  
• Gender; men & women grieve in different ways  
• Nature of the death  
• Social value of relationship to the deceased (e.g. death of a lover in a extramarital affair, miscarried or aborted fetus)

As the child grows and develops, certain life tasks need to be accomplished. Through the accomplishment of these life tasks and through life experiences, a person acquires skills that determine how he or she will react to different events, including the death of a loved one or his or her own impending death. Since every person has unique life experiences and skills, caregivers will observe many different grief reactions. There is no right or wrong way to grieve.

**INTERACTING WITH THE INDIVIDUAL, FORMAL/INFORMAL CAREGIVERS**

There are many factors which influence how families and individuals cope with death, dying, and loss. To ensure the best possible care for the family it is important for the caregiver to understand how the family copes. This understanding should drive the interaction and effective communication with the family.

Some of the factors that may affect how families interact with care providers and cope with the palliative experience are:

- Past death experiences, past grief experiences
- Deceased person’s role in family (e.g. wage earner, primary homemaker)
- seriousness and length of illness e.g. prolonged illness is emotionally and financially taxing, creates guilt
- Presence of family and outside social support
- Financial situation
- Cultural differences (e.g. willingness to accept help, expression of emotions)
- Relationship to the deceased
- Age of the deceased
- Age of the family member; children grieve differently than adults
- Coping mechanisms of individuals & family
- Health conditions of family members
- Gender; men & women grieve in different ways
- Nature of the death
- Social value of relationship to the deceased (e.g. death of a lover in a extramarital affair, miscarried or aborted fetus)

Grief is a natural and healthy response to any loss. Every person grieves in his or her own unique way. The caregiver needs to accept the uniqueness of each survivor – where he or she is in the grief process and what helps that particular person.

Grief is a healthy process that enables the bereaved to live in a world without the loved one. There is no right or wrong way to grieve, but it must be done.

Children may do poorly in managing their grief if they are not allowed to express it in ways that are healthy for them.

The pain may change from the acute pain experienced when the loss initially occurred, however grieving is never really over. Individuals will experience moments and times when an occasion or object revives feelings of loss, as if it just happened yesterday.

**PROVIDING SUPPORTIVE CARE STRATEGIES**

**Supportive Care Strategies for the Family Prior to the Death**

When someone in a family is diagnosed with a terminal illness, everyone begins to grieve. This anticipatory grief process can be confusing and challenging. On the one hand, family members are attending to the needs of the ill
person and maintaining involvement with him or her. On the other hand, they may begin to invest emotional energy into planning for life after the person dies. Health care providers can help to ease some of the strain that family members feel by being supportive in ways that help the family members to cope. Chart 10.3 describes some issues that family members may have to deal with in advance, and some of the supportive care strategies that the caregiver can suggest.

Chart 10.3

<table>
<thead>
<tr>
<th>Issue</th>
<th>Supportive Care Strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fluctuating from denial to acceptance of the illness and death.</td>
<td>Some denial of reality is healthy and necessary for a family to function. It allows them to take in information at a more tolerable pace, and gives them a break from the emotional stress of a situation. Acceptance may not necessarily bring peace. Health care providers need to accept the family members regardless of the coping strategy being utilized. An attitude that hopes for the best and plans for the worst is most often helpful.</td>
</tr>
<tr>
<td>Establishing a relationship with health professionals.</td>
<td>A family may need to learn how to be assertive and how to deal with frustration constructively. Having the family keep a journal of questions and concerns and providing consistent answers can help avoid confusion and conflict. Family and caregiver conferences can help to reduce anxiety by opening communication lines and providing timely information.</td>
</tr>
<tr>
<td>Meeting the needs of the dying person.</td>
<td>As the illness progresses, the person’s physical and emotional needs will change. Family members can be counseled to give the person as much independence and control as possible for as long as possible. Keeping the lines of communication open and frequently assessing the needs of all family members can help to keep the plan on track. It is important to avoid placing too much burden on any one person.</td>
</tr>
<tr>
<td>Maintaining a functional family unit.</td>
<td>When someone is ill, it means that everyone takes on new roles and responsibilities. At the same time, it is important to maintain some of the normal family routines in order to give some sense of security in the midst of chaos. Encouraging family members to take time to care for themselves and one another is important. The wisdom of the dying person can be transmitted to others in a variety of ways. Sharing knowledge maintains dignity and allows the person to continue to contribute to the family.</td>
</tr>
<tr>
<td>Living with the emotions of anticipatory grief.</td>
<td>Throughout the journey, both the person and family experience intense swings of emotion. Having information about these feelings and being aware of the normalcy of such reactions will help relieve feelings of guilt. It is important to communicate with one another, however there may be things that each member of the family will prefer to discuss with someone outside the family. Soul friends or hospice volunteers are extremely valuable resources for both the person and individual family members.</td>
</tr>
<tr>
<td>Dealing with people outside the family.</td>
<td>Family members may have little energy at this time for outside relationships and may find that other’s reactions are unpredictable. For example, friends avoid the sick person and may not understand what the person and family are going through. It is natural to resent others’ stability and good fortune. Setting up a Share the Care® team may assist in bringing friends together with a common purpose in support of the family.</td>
</tr>
<tr>
<td>Anticipating the family’s new reality after the death.</td>
<td>It is impossible to predict the future. Estate planning, dealing with different kinds of unfinished business, and building in emotional supports are things that can help people to prepare. Reassure the family members that they are doing the best that they can in the circumstances.</td>
</tr>
</tbody>
</table>
### Supportive Care Strategies Following the Death

There are many ways a caregiver can support family members to deal with grief and loss. There are different types of support available through which the bereaved can receive assistance with their grief work. Some persons will benefit from one-to-one assistance; others may respond better to a group setting. Some general tips a caregiver can share with the family include:

- Get adequate sleep; if sleep is not possible attempt to rest and relax, listen to soothing music
- Eat balanced meals; several small meals and snacks with healthy food choices may be easier than trying to eat 3 larger meals
- Drink lots of water
- Exercise; a short walk is better than no walk
- Cry as often as needed
- Reach out for help: reaching out is not a sign of weakness but rather a sign strength and insight
- Consider joining a support group
- If possible, avoid making any major changes for the first year after the death
- Plan ahead for special, potentially challenging occasions such as birthdays, holidays, weddings, etc.
- Avoid use of potentially harmful substances such as tobacco, drugs and alcohol; they only mask the grief
- Attend to the personal belongings of the dead loved one when ready; there is no specific time frame for accomplishing this task.

### Grief Rituals

Grief rituals are another strategy that can help the family deal with the death of a loved one and move towards healing. The value of creating “grief rituals” is in promoting a sense of tenderness, thanksgiving for the relationship, forgiveness, peace and acceptance. Too often, bereaved persons feel they must “hold on” to the pain in order to be faithful to the loved one. It is important for the bereaved either individually, or as a family, to create personal rituals that have meaning and significance. Grief rituals can include:

- Buy a very special candle and light it at times that are special to your loved one’s memory (e.g. birthday, Father’s Day, anniversaries, etc.)
- Write special notes in balloons and let them go
- Feed the hungry/homeless at Thanksgiving, holidays, etc. in memory of the loved one

<table>
<thead>
<tr>
<th>Issue</th>
<th>Supportive Care Strategy</th>
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<tbody>
<tr>
<td>Finding appropriate hope.</td>
<td>What a family hopes for throughout the illness trajectory often changes. Providing accurate and consistent information will assist in decision-making and prioritizing goals. As the disease progresses, treatment goals aimed at prolonging life are often changed to goals aimed at comfort. Helping the person and family adjust to a focus on comfort, can lead to acceptance of the inevitability of death.</td>
</tr>
<tr>
<td>Allowing the dying person to be at risk.</td>
<td>Allowing the dying person independence and control may sometimes mean refusal to take medications or accept personal help. Family members and health care providers may have difficulty allowing the person to be at risk. As long as the person’s choices do not place others at risk, the person’s informed decisions must be honoured. Health care providers have an obligation to provide information so that decisions are informed.</td>
</tr>
<tr>
<td>Making decisions for the dying person.</td>
<td>There may come a time when the person is unable to make any clear decisions. Prior discussions of the person’s goals, values and wishes will help substitute decision-maker(s) to make decisions that represent the person’s goals and best interests. Health care providers play an important role in encouraging advance care planning and discussions about goals, values and wishes as well as the role of the substitute decision-maker(s).</td>
</tr>
<tr>
<td>Care for the caregiver.</td>
<td>When members of the family are focused on caring for the dying person, they may neglect their own health needs. Encouraging them to build in time for self-care is crucial. Providers should encourage recognition of caregiver needs - physical, emotional and spiritual – and offer information about strategies to reduce stress.</td>
</tr>
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</table>
• Create a scrapbook of memories, photos
• Create ancestor rituals e.g. sprinkle rose petals around the pictures of deceased relatives as a part of other ceremonies e.g. weddings
• Plant a strong, healthy tree or rosebush in a loved one’s name
• Create a memorial garden and add a new plant on an anniversary
• Find a tree and tie a yellow ribbon around it. Go there to remember. This is especially helpful when ashes have been scattered and there is no grave site.
• Offer a scholarship in a loved one’s name
• On birthdays, holidays, anniversaries buy a gift in memory of your loved one and donate it to someone in need.
• At special religious times of year, bring out a special item in remembrance of your loved one
• Have wedding ring made into a new setting (e.g. a necklace, bracelet, etc.)
• Have a birthday celebration for your loved one and invite guests to wear the deceased’s favourite colour and enjoy his or her favourite food.
• Have a family “memory” evening where you share pictures, reminisce about special times, or create a scrapbook of memories, etc.

Grief rituals are an important supportive care strategy that can be repeated day after day, week after year after year. The funeral, celebration of life or memorial service is an example of a ritual that frequently marks in a social way the letting go of the person after death.

There are many reasons for having funerals/rituals to mark the death of a loved one and regardless of the culture, those reasons tend to be consistent. According to Rando, funerals/death rituals:28

• Confirm and reinforce the reality of the death
• Assist in the acknowledgement and expression of feelings of loss
• Offer the bereaved an opportunity to express their feelings
• Stimulate the recollection of the deceased loved one, which is a necessary part of grief
• Assist the bereaved to begin to accommodate to the changed relationship between themselves and their deceased loved one
• Validate the life of the deceased
• Allow for input from family and friends that serves as a living memorial and helps to form an integrated image of the loved one
• Allow family and friends to give the bereaved person(s) vital social support
• Begin the process of reintegrating the bereaved person back into society with a new identity
• Provide meaningful structured activities to counter the loss of predictability and order that frequently accompanies the death of a loved one

So long as the wounds of loss need mending, the work of ritual will continue. Mourning rituals do not repair reality; they repair the survivor, but only partially. For the bereaved the world remains forever changed and forever broken: they do not magically heal from the “slings and arrows of outrageous fortune”. And yet, through the ongoing, creative process of mourning, those wounded by loss can find hope, healing, and a way forward in their journeys in grief.29

Many religions and cultures have rituals that can be meaningful for those who are grieving regardless of their culture or religion.

Self Help

Grief can be a very private and profound process. This is a time when the bereaved person will need the support of compassionate and empathetic friends and family. Many self-help strategies/complementary therapies such as art, yoga, meditation, massage, may be found helpful. Reading about how others in similar situations coped with grief can also provide insights.

Grief Companions/Hospice Volunteers

Grief companions do not attempt to change the bereaved person’s perceptions or attitudes. They encourage the bereaved to work through their grief as a natural process that is necessary in order to learn to live with it. Often times the bereaved person will have been seen by a grief companion for a few sessions and will then join a grief support group for further support.

Support Groups

A support group involves persons who are bereaved sharing their grief stories. In the telling of their stories, they are affirmed that the emotions they are feeling are for the most part normal and healthy. Group members can provide encouragement, information, and practical suggestions to cope with each other’s grief. Grief support groups frequently meet for exercise or for social outings and often long term friendships are created.

Professional Assistance

At times a person may become “stuck” in his or her grief. As discussed in this chapter, grief may become complicated for many reasons. A person who experiences complicated grief should seek professional therapy. A professional therapist will attempt to intervene and work with the bereaved to identify and work through conflicts that are preventing the bereaved from living successfully with his or her grief. The
therapist needs to have in-depth knowledge of personality patterning and psychodynamics.

**Supportive Care Strategies Specifically for Children**

Supportive care strategies for children dealing with grief and loss may look a bit different than those for adults. Include the child in remembrance rituals, recognize and support the child's unique style and pace through grief, and expect periodic returns to grieving at significant transitions in the child's life. (Victoria Hospice Bereavement Program) Below (chart 10.4) are some practical supportive care guidelines that a caregiver can share with a family to help children cope with the death of someone close to them.30

**Chart 10.4**

<table>
<thead>
<tr>
<th>Age</th>
<th>Supportive Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth to 6 months</td>
<td>• Progressively disengage the child from primary caregiver if possible</td>
</tr>
<tr>
<td></td>
<td>• Introduce new primary caregiver</td>
</tr>
<tr>
<td></td>
<td>• Nurture and comfort</td>
</tr>
<tr>
<td></td>
<td>• Anticipate and provide for physical and emotional needs</td>
</tr>
<tr>
<td></td>
<td>• Maintain routines</td>
</tr>
<tr>
<td>6 months to 2 years</td>
<td>• Provide continual support and comfort</td>
</tr>
<tr>
<td></td>
<td>• Avoid separation from significant others</td>
</tr>
<tr>
<td></td>
<td>• Maintain close physical and emotional connection to significant others</td>
</tr>
<tr>
<td></td>
<td>• Maintain daily structure and schedule of routine activities</td>
</tr>
<tr>
<td></td>
<td>• Support caregiver to reduce distress and maintain a stable environment</td>
</tr>
<tr>
<td></td>
<td>• Acknowledge sadness that loved one will not return - offer comfort</td>
</tr>
<tr>
<td>2-5 years</td>
<td>• Remind the child that loved one will not return</td>
</tr>
<tr>
<td></td>
<td>• Reassure the child that he or she is not to blame</td>
</tr>
<tr>
<td></td>
<td>• Give realistic information</td>
</tr>
<tr>
<td></td>
<td>• Answer questions honestly</td>
</tr>
<tr>
<td></td>
<td>• Involve child in farewell ceremonies</td>
</tr>
<tr>
<td></td>
<td>• Keep home environment stable and structured</td>
</tr>
<tr>
<td></td>
<td>• Help put words to feelings; reassure and comfort</td>
</tr>
<tr>
<td></td>
<td>• Reassure the child about who will take care of them</td>
</tr>
<tr>
<td></td>
<td>• Provide ways to remember the loved one</td>
</tr>
<tr>
<td></td>
<td>• Create opportunities for play</td>
</tr>
<tr>
<td></td>
<td>• Be a consistent and nurturing presence</td>
</tr>
<tr>
<td></td>
<td>• Do not scold the child for any regressive behavior - be patient – this is the child's way of coping</td>
</tr>
<tr>
<td>5-9 years</td>
<td>• Give clear and realistic information</td>
</tr>
<tr>
<td></td>
<td>• Include children in funeral ceremonies if they choose</td>
</tr>
<tr>
<td></td>
<td>• Give permission to express feelings and provide opportunities</td>
</tr>
<tr>
<td></td>
<td>• Reduce guilt by providing factual information</td>
</tr>
<tr>
<td></td>
<td>• Provide structure for the child. Don't give the child too many choices at first, gradually introduce more choices</td>
</tr>
<tr>
<td></td>
<td>• Encourage the child to talk of feelings through words, play or drawings</td>
</tr>
<tr>
<td></td>
<td>• Notify the school for additional support</td>
</tr>
</tbody>
</table>
Supporting children through the loss of a loved one can be a difficult task for family, friends and relatives. Having children grieve who are at various ages and stages while the adult is also grieving can leave a parent feeling overwhelmed. It is common for children to feel a range of emotions and need support to understand that grief. Allowing children to share their questions, thoughts and concerns as they live through their loss helps them to make sense of what is happening. Grief involves many feelings such as sadness, guilt, worry, relief, anger and numbness. Children will need to be able to bring those feelings out in the open so that they can recognize these emotions and have their experience validated. Grief impacts children and teens in the same aspects as it does adults (i.e. emotionally, spiritually, physically and mentally).

It can take more time for children and teens to find the words or organize their thoughts and feeling. Encourage healthy ways to share feelings such as through art, craft, music, sports, writing or talking to someone. To help children discuss their thoughts and feelings, talk openly and honestly when answering questions, using the words died, dying or death instead of the confusing euphemisms such as ‘passed away’. Encourage families to share their own emotions to help children understand that the feelings they are experiencing are normal.

Encourage consistency as much as is possible to help children and teens help cope with loss and understand that although much has change, life goes on. Children may appear to move in and out of grief, feeling sad one minute then playing happily the next. Family members may find it difficult to support and take care of children and teens while experiencing their own grief. Encourage self-care so that families and friends are able to provide the support needed to their young family members.

**WORKING AS A TEAM**

Persons and families living with life-limiting illness and the associated loss and grief require the support and skills provided through the diverse talents found in an interdisciplinary team. The team includes the person and family who share their reaction to the illness and their ability to cope. No one member of the team is any more important than another as they are all working towards a common goal.

The physician’s primary responsibility is to manage the disease process and control the person’s pain and other symptoms. These symptoms must be controlled before any end-of-life grief work can begin.

The nurse on the team helps the family cope with the effects of the illness. The role of the nurse in hospice palliative care is further developed in the Comprehensive Advanced Palliative Care Education Program for nurses (CAPCE). Nurses establish therapeutic relationships with families and engage in countless encounters in which they assess, share information, support decision making, plan care, deliver care and confirm that goals are being met and that the person and family are satisfied with the care.

Social Workers bring skills that aid in the empowering the person and family to identify and express their needs and
goals. By focusing on the effects of life-limiting illness on the family system and engaging in honest communication, fear and anguish can be reduced. Social workers are invaluable in helping persons and family members cope with ever increasing losses and changing circumstances along the illness trajectory. They also provide practical resources, information, and referral related to practical, financial, and legal issues.

Chaplaincy can assist persons and families to find meaning and purpose in illness and death. Meaningful end-of-life rituals can be a source of support and encouragement as the person and family face the ultimate loss. Dealing with issues of regret and guilt can promote a peaceful letting go. Remember that denominational clergy, parish nurses, traditional healers, soul friends, spiritual advisors and others may be included under chaplaincy.

Personal Support Workers are in frequent and close contact with the person and family. This close contact provides an opportunity to get to know who each member is as a person. This relationship allows early recognition of changing symptoms and needs. By reporting observations, PSWs are paramount in promoting timely interventions by other team members. PSWs support compliance with the plan of care by reinforcing information provided by the professional members of the team. They support the person and family through their empathic and compassionate care as the family cope with the losses they encounter along the trajectory.

Hospice Volunteers are the team members who act as companions on the journey and bring opportunities to enhance quality of life to the person and family. They come from all walks of life and due to the serious nature of the work are carefully chosen to work with vulnerable people. Volunteers are screened, trained and then supported as they accompany families in the dying process. Volunteer matches are made by comparing the skills, talents and desires of the volunteer with the needs and social interests of the person and family. These invaluable members of the team are able to follow the survivors through bereavement.

Occupational therapy (OT) can help the person throughout the journey as they move from being totally independent to being completely dependent. The chaotic feelings that accompany the losses along the trajectory are the result of an assault on self-esteem. OTs can help the individual to identify as well as to analyze their feelings and reactions and can redirect the person toward an attitude of positivism and control.

Nutritional Therapy is of great value along the journey as goals change in relation to disease progression. The dietitian can offer advice related to loss of appetite and other changes such as mouth sores, diarrhea, nausea and vomiting, and changes in taste related to the disease and / or its treatment. Addressing such issues ultimately supports the person in the grieving process related to the many losses experienced over time. At end of life, the dietitian supports the team in helping the family to understand that loss of appetite is a normal part of the dying process. The benefit of artificial nutrition and hydration needs to be weighed against the burdens and risks. This information from a dietitian may help to relieve the family of any guilt surrounding the issues of feeding.

Physiotherapy is aimed at reducing the degree to which disabilities caused by the disease or its treatment interferes with everyday life. The person who has become dependent due to loss of mobility and function with the assistance of the physiotherapist may be able to regain some sense of control as well as enhanced comfort.

Speech language therapy can be helpful when losses related to speech and communication are experienced. They can offer advice to the team, person and family related to communication strategies. In addition, they can offer advice around feeding when the ability to swallow is diminishing.

Clinical psychology is concerned with the well-being of the whole team. Experiencing loss through death is one of the most stressful events in life. Psychologists have the skills to encourage expression of thoughts and emotions. Through counseling and skilled communication they help the person, family members and other team members to cope.

**Psychology and Grief**

The DSM 5 edition of the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM) is due for publication in 2013 and is currently in consultation, planning and preparation. In the DSM 4 edition, the bereaved are excluded when diagnosing a major depressive disorder. There is considerable discussion around the issue of including bereavement due to a fear that healthy grief will become a medical issue. Pies and Zizook, though they agree with the exclusion, believe that too little attention has been paid to the features that distinguish healthy grief and bereavement from psycho-pathological states, such as complicated grief or major depressive disorder. In healthy grief and bereavement, the person maintains emotional connection with others; believes that the grief will some day end; maintains self-esteem;
and experiences positive feelings and memories along with painful ones. If guilt is present, it is related to “letting down” the deceased person, rather than on being “worthless” or useless. Loss of pleasure is related to longing for the deceased loved one, as opposed to the pervasive anhedonia (loss of pleasure) often seen in severe depressions. Suicidal feelings are related to longing for reunion with the deceased rather than to thoughts of not deserving to live. The person is capable of being “consoled” by friends, family, music, books etc.

In severe depression, the person tends to be extremely “self-focused”; feels outcast or alienated from friends and loved ones; has the sense that the grief will “never end”; experiences profound self-loathing and guilt; experiences few if any positive feelings or memories; and is often inconsolable.

Hopefully by including bereavement as a risk factor for a major depression a “medicalization” of grief will not ensue. Rather, it may encourage team members who observe the signs of potentially serious depressive illness during bereavement to refer the person for further help. All health care professionals need to be astute in observing, assessing, sharing information about grief in order to make the grief process as healthy as possible. When treating the bereaved, premature prescription of antidepressants (e.g., within the first week of depression) should be avoided with consideration given to grief counseling or psychotherapy as the first-line treatment for short-lived, mild-to-moderate depression.

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Chapter 11

Occupational Wellness
UNDERSTANDING THE FUNDAMENTALS

Those who work in hospice palliative care are witness to and engage in an endless tide of illness, death and bereavement. Everyone is touched by involvement with the dying and bereaved and the impact leaves us with an appreciation of each and every day as well as a real awareness of the fragility of life. The challenge that caregivers have is to find a way to be emotionally involved in their work; to use their empathy, helping motivations, commitments and idealism without succumbing to stress related illnesses.

What attracts staff to Hospice Palliative Care?

A study conducted in New Zealand identified the following five themes related to choosing to work in the field of hospice palliative care:¹

- Previous death of a close family member, with either a positive or negative experience. An exceptionally good experience can lead to a desire to be part of something that provides exemplary support at a vulnerable time in people’s lives. On the other hand, deaths that involve extreme pain or other unmanaged symptoms can lead to a desire to improve the care of the dying.
- Some may choose hospice palliative care as part of a career development path wanting to become more specialized in this particular field of practice.
- Some appreciate the work environment. e.g. are drawn to the holistic nature of the care and value being a member of an interdisciplinary team.
- Some are drawn to hospice palliative care because the values and philosophy espoused in hospice palliative care align with their personal values.
- Some choose hospice palliative care for personal lifestyle reasons e.g. spiritual calling, service to others, flexibility in hours, shifts, work close to home.

Nurses and physicians in hospice palliative care practice in the following two ways:²

1. Striving to adopt a well-organized and purposeful approach which included the following:
   a. Using a scientific classification system (diagnosis and interventions)
   b. Working within the limits set by policy
   c. Developing a professional attitude: focusing on identified tasks, on the clarity and completeness of information sharing as opposed to the emotional impact of the message
   d. Striving to remain objective and consciously avoid allowing feelings to impact the response to situations
   e. Being task orientated and measuring outcomes of interventions
   f. Avoiding emotional stress by remaining professional and detached
   g. Embracing a practitioner-focused perspective which is characterized by a distant approach to care and a well-developed self-awareness to work on personal development as a professional

2. Striving to increase the well-being of the individual involved the following approaches:
   a. Using professional capabilities (e.g. being sensitive to the person’s concerns) and adapting the approach to the individual
   b. Adopting a humble attitude in which personal considerations were put aside in an effort to show availability without expecting anything of the person in return
   c. Giving attention to the person and his or her experience as evidenced by efforts to discover and understand what the person is experiencing and the reason for particular reactions
   d. Sharing information based on the premise that adequate and complete information leads to informed decision making
   e. Being available or truly present and trusting intuition
   f. Valuing a caring attitude based on an authentic relationships with each person
   g. Remaining attentive and thoughtful and adopting a person centered attitude
   h. Trying to accept and cope with emotional strain as part of the reality instead of avoiding the strain; remaining authentic even if problems could not be fully alleviated

In another study, it is proposed that comfort in working with the dying is preceded by a growth and development process that involves the following stages of adaptation:³

- Intellectualization
- Emotional survival
- Depression
- Emotional arrival
- Deep compassion
- The Doer

In order to become the “Doer” and practice the art as well as the science of palliative care, mentors are invaluable.

Occupational Stressors

A stressor is any experience that disrupts homeostasis. Positive stressors are rewarding or adaptive while negative stressors are harmful and threatening yet frequently are the impetus that prompts change. Ongoing negative stressors can contribute to stress related illnesses.
Stressors arise from both internal and external sources. Internal stressors are linked to balancing home responsibilities with work life, self-expectations and struggling with the continuous formation and loss of relationships. External stressors are linked to inadequate training or support to deal with the cumulative impact of death and grief, conflict in the workplace, or discrepancies in the values, beliefs and goals within the care team. The discrepancy between one’s vision of good hospice palliative care and the reality of the care provided at the bedside can be a major cause of distress.4

Some of the distressing issues that health care providers involved in the current health system contend with include:

- Lack of respect from other team members
- Team conflict
- Ruthless obstinacy, aggressive treatment when burden outweighs benefit
- Demanding consumers
- Lack of physicians, nurses and other caregivers
- Aging of the workforce
- Experienced clinicians reaching retirement age
- Increasing costs
- Inadequate resources
- Increasing accountability
- Job insecurity
- Aging of the population (increasing number of older adults, increasing numbers of individuals with cancer and other progressive life-limiting illnesses)
- New treatments that lead to living longer with chronic illness
- Increased complexity of care and treatment related to a person having more than one chronic illness
- Shift to community based care from traditional institution based care

Vachon and Huggard5 present a model for understanding occupational stress. The framework includes six areas of work-life.

1. Workload

Excessive workload exhausts the health care provider and emotional work is especially draining when the job requires the individual to display emotion inconsistent with feelings. Current issues with the nursing shortage and fiscal restraint all have an impact on worklife.

2. Control

Control is related to insufficient control over the resources necessary to do the work or insufficient authority to pursue the work in what is believed to be the most effective manner. Lack of communication skills and / or management skills and expectations to assume responsibility with inadequate training can lead to difficulty in functioning. Other issues of control can involve safety, the timing of referrals, feeling responsible for symptom management when the person with authority to address the issue is unresponsive to the need, and emotional involvement without sufficient supervision or support.

3. Rewards

Salary or benefits that are not commensurate with achievements or lack of social rewards when work is not appreciated by others can lead to dissatisfaction. Intrinsic rewards e.g. doing something of importance and doing it well can counterbalance the mismatch.

4. Community

When team members are ordered about without consultation or participation, they will not give their best efforts. Conflict among staff members contributes to emotional exhaustion and depersonalization. Manageable shifts, informal support from peers, adequate orientation, management of staff conflict, and feedback that acknowledges that you are doing a good job have been reported as valued initiatives.

5. Fairness

Fairness communicates respect, confirms self-worth and in the work environment may be the tipping point between engagement and burnout. Rivalries between staff and programs as well as unfair reimbursement systems continue to be issues.

6. Values

Being able to work in an area in which values are consistent with personal values aids in job satisfaction. Respondents in the study talked of the sense of purpose and the sacredness of the work, making a difference, loving the job and passion for what I do; all indicators of how meaningful and rewarding hospice palliative care can be.

How health care providers involved in hospice palliative care respond to the stressors in their work lives will vary according to personal, professional and environmental differences. Factors that affect response include:

- Level of training in dealing with dying, death and grief
- Organizational support and commitment .e.g. designated time for collaborative work, opportunity for team review and evaluation, flexibility and openness to new ideas
Chapter 11: Occupational Wellness

- Team support e.g. access to expertise, respect for the skills of each team member, synergy and camaraderie
- Communication and conflict resolution
- Life experiences
- Personality
- Coping strategies

When distress is overwhelming and coping mechanisms are ineffective the health care provider can succumb to one of the stress related syndromes. There are many names given to the syndromes that result from workplace distress e.g. compassion fatigue, moral distress, burnout, vicarious trauma, or battle fatigue.

- Compassion Fatigue is a danger for all those in the helping professions. Symptoms include having no energy, feeling empty, having nothing left to give, feeling depleted in every dimension, and having too many questions and no answers. 
  Compassion fatigue symptoms are closely related to those of post-traumatic stress disorder, however it applies to those who are emotionally affected by trauma to another.
- Moral Distress occurs when various options for action are available but there are competing and not easily reconciled values and beliefs of right and wrong underlying the choices. Having to act contrary to personal or professional values undermines authenticity and integrity.
- Burnout is a consequence of being stressed over a protracted period of time. Burnout impairs the quality of the social environment at work and is seen as the final step in a progression of unsuccessful attempts to cope with a variety of negative stress conditions.
- Vicarious Trauma is the process of change that happens due to caring about other people who have been hurt, and feel committed or responsible to help them. Over time this process can lead to changes in psychological, physical, and spiritual well-being.
- Battle Fatigue is a term that originated in WW II and today would be called post-traumatic stress disorder. The person with PTSD is typically numb with symptoms of depression, excessive irritability, survivor guilt, recurrent nightmares, flashback to the traumatic scene, and overreaction to sudden noises.

Compassion fatigue and burnout share similar characteristics, however those suffering from compassion fatigue are able to continue caring. Re-emergence is possible; the despair and sense of hopelessness can be addressed if caregivers are open to each other’s care and concerns.

Chart 11.1: Symptoms of Stress Related Illness

<table>
<thead>
<tr>
<th>Cognitive</th>
<th>Emotional</th>
<th>Behavioural</th>
<th>Spiritual</th>
<th>Personal Relations</th>
<th>Somatic</th>
<th>Work Performance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lowered concentration</td>
<td>Powerlessness</td>
<td>Impatient</td>
<td>Questioning the meaning of life</td>
<td>Withdrawal</td>
<td>Shock Sweating</td>
<td>Low morale</td>
</tr>
<tr>
<td>Decreased self esteem</td>
<td>Anxiety</td>
<td>Irritable</td>
<td>Loss of purpose</td>
<td>Decreased interest in intimacy or sex</td>
<td>Rapid heartbeat</td>
<td>Low motivation</td>
</tr>
<tr>
<td>Apathy</td>
<td>Guilt</td>
<td>Withdrawn</td>
<td>Lack of self satisfaction</td>
<td>Mistrust Isolation from others</td>
<td>Breathing difficulties</td>
<td>Avoiding tasks</td>
</tr>
<tr>
<td>Rigidity</td>
<td>Anger</td>
<td>Moody</td>
<td>Pervasive hopelessness</td>
<td>Overprotection as a parent</td>
<td>Obsession about details</td>
<td>Apathy</td>
</tr>
<tr>
<td>Disorientation</td>
<td>Regression</td>
<td>Depression</td>
<td>Anger at God</td>
<td>Protection of anger or blame</td>
<td>Apathy Negativity</td>
<td>Lack of appreciation</td>
</tr>
<tr>
<td>Perfectionism</td>
<td>Sleep disturbances</td>
<td>Nightmares</td>
<td>Questioning prior religious beliefs</td>
<td>Insolence</td>
<td>Detachment</td>
<td>Lack of commitment</td>
</tr>
<tr>
<td>Minimization</td>
<td>Fear</td>
<td>Appetite changes</td>
<td>Loss of faith in a higher power</td>
<td>Intolerant</td>
<td>Poor work commitments</td>
<td>Staff conflicts</td>
</tr>
<tr>
<td>Preoccupation with trauma</td>
<td>Helplessness</td>
<td>Hyper vigilance</td>
<td>Greater skepticism about religion</td>
<td>Loneliness</td>
<td>Absenteeism</td>
<td>Absenteeism</td>
</tr>
<tr>
<td>Thoughts of self harm or harm to others</td>
<td>Sadness</td>
<td>Elevated startle response</td>
<td>Loss of faith in a higher power</td>
<td>Increased interpersonal conflicts</td>
<td>Increased</td>
<td>Exhaustion</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td>Accident proneness</td>
<td>Greater skepticism about religion</td>
<td></td>
<td>Other somatic complaints</td>
<td>Irritability</td>
</tr>
<tr>
<td></td>
<td>Emotional roller coaster</td>
<td>Losing things</td>
<td></td>
<td></td>
<td>Impaired immune system</td>
<td>Withdrawal from colleagues</td>
</tr>
</tbody>
</table>
Job engagement, which is the opposite of burnout, involves energy, involvement and effectiveness; high levels of activity and pleasure characterize it. Schaufeli and Bakker define engagement as a positive, fulfilling, work-related state of mind that is characterized by vigor, dedication, and absorption. Vigor is characterized by high levels of energy and mental resilience while working, the willingness to invest effort in one's work, and persistence also in the face of difficulties. Dedication can be defined as a sense of significance, enthusiasm, inspiration, pride, and challenge. Absorption refers to being fully concentrated and happily engrossed in one's work, whereby time passes quickly and one has difficulties with detaching oneself from work. Maintaining job engagement requires a sustainable workload, feelings of choice and control, appropriate recognition and reward, a supportive work community, fairness and justice, as well as meaningful and valued work.

**Hardiness**

Dr. Susan Kobasa conducted research in the stress hardiness field in the 1970s. Commitment, control and challenge are the characteristics of hardiness.  

- **Commitment:** The hardy individual is one who is involved with life and life's activities such as work, family, and friendships.
- **Control:** The hardy individual has a sense of control over things that happen in his or her work and personal life.
- **Challenge:** The hardy individual tends to see a challenge where others may perceive a threat.

Cognitive hardiness has been a predictor of the ability to manage job stress, anxiety, daily hassles and to maintain a healthy lifestyle. Cognitive hardiness refers to a specific set of attitudes or beliefs about work and life that are relatively enduring from day-to-day. A sense of commitment and strong interest toward work, family, hobbies, or projects that you are involved in on a day-to-day basis as well as having things that you look forward to doing are indications of cognitive hardiness. A sense of belonging with friends, work, and family are other components of cognitive hardiness.

When cognitive hardiness is present, daily life changes are seen as being challenging rather than threatening. Change affords hidden opportunities for new experiences and growth as opposed to being a hindrance to work and life satisfaction. The belief that you have control over your life, that what you do is directly related to what you achieve, and that success in work and life is a result of individual behavior rather than luck, fate, or chance demonstrate cognitive hardiness. A belief that you can effectively achieve success in both work and life appears to buffer the potentially damaging impact of stress on well-being and directly generates effective coping behaviours.

Stamm notes that those with more time to sustain relationships and basic self-care tasks seem to be less at risk for experiencing the negative effects of caregiving.

Resilience is another means of preventing, minimizing or overcoming the damaging effects of adversity. Resilience is the product of a complex relationship of specific psychological inner strengths and environmental social supports throughout a person's life that determines the response to adversity. Resiliency springs from within and is also integrated with the quality of relationships and positive experiences that help people of all ages acquire hope, motivation, mastery, values and a sense of purpose. Developing resiliency is now recognized as a vitally important requirement for the health and well-being of everyone. The promotion of resilience lies in “encountering stress at a time and in a way that allows self-confidence and social competence to increase through mastery and appropriate responsibility”.

Caring does not come without cost. Experiencing the fear, pain and suffering of others has an impact on caregivers. The most effective therapists are the most vulnerable because of their enormous capacity for feeling and expressing empathy. True service is not a relationship between an expert and a problem; it is far more genuine than that. True service is a relationship between people who bring the full resources of their combined humanity to the table and share them generously.

Hospice palliative care requires a balancing act. Caregivers need to grieve. Those who do not grieve losses are at risk; however, caregivers cannot allow their hearts to become so filled with loss that they have no room left to care.

Caregivers want to experience compassion satisfaction; a sense of efficacy and happiness. When caregiver efforts are making the world in which they live a reflection of what they believe it should be, they experience fulfillment and live a life that is characterized by enthusiasm, dedication, energy, involvement, and effectiveness.

**SUPPORTIVE CARE STRATEGIES**

There are many factors that contribute to the personal and/or team distress of those working in the current health care system. While organizations have some responsibility for ensuring job satisfaction and competency, health care providers are also accountable for their own personal and professional well-being. Each team member can benefit from learning how to constructively deal with issues and conflicts. Incorporating proven stress management techniques into daily life will benefit both the individual and the team as a whole.
Vachon and Huggard identify that care strategies can be enabled at four different levels as follows:19

- **The Palliative Care Community** (e.g. develop and maintain networks at local, regional, provincial, national and international levels)
- **Organizational** (e.g. recruitment and orientation, accurate job descriptions, competencies linked to performance appraisals, human resources policies and procedures, training opportunities and support for study, communication channels, critical incident debriefing, regular feedback and acknowledgement of personal pressures)
- **Professional** (e.g. collegial support, reflective practice, professional development, effective communication, maintain motivation, prioritize workload, manage time, taking meal breaks, humour, attend to grief work)
- **Personal** (examples provided below)

Primary coping mechanisms can be defined as a sense of commitment, control and pleasure in one’s work.20 Other characteristics identified by researchers in the field of stress include a sense of coherence (a feeling of confidence that one’s life is orderly, manageable and meaningful), a sense of congruence (a feeling of rapport within oneself, a sense that the internal and external aspects of one’s being are in agreement with one another), as well as the personality construct of hardiness.

**Self-Care**

The following list is examples of self-care strategies for health professionals.

**Diversion**

- Spend time alone. See a movie. Daydream.
- Take a class. Read. Join a club.
- Play an instrument. Sing. Listen to music.
- Play a game. Go out with friends.

**Family**

- Balance time at work and home. Accept the good with the bad.
- Look for win/win solutions.
- Build good family feelings. Focus on strengths. Take on new family roles. Stay open to change.
- Develop friendships with other families. Make use of community resources
- Take time to be together. Build family traditions. Express affection.

**Interpersonal**

- Believe in yourself. Trust others. Give compliments.
- State your needs and wants. Say “no” respectfully.
- Make new friends. Really listen to others. Touch if appropriate.
- Show feelings. Share feelings.
- Accept others’ boundaries. Drop some involvements.
- Share problems with others. Ask for support from others.

**Mental**

- Look for the humour. Anticipate the future.
- Set clear goals. Plan for the future.
- Take charge. Make order. Don’t let things pile up.
- Solve it yourself. Seek outside help. Tackle problems head-on.
- Change perspective. Look for good in a bad situation.
- Focus on top priorities. Work smarter, not harder.

**Physical**

- Listen to your body. Know your physical limitations.
- Take short stretch breaks throughout your day.
- Eat for health. Limit use of alcohol.
- Tense and relax each muscle. Take a warm bath. Breathe deeply.
- Energize your work and play. Strive for self-improvement.

**Spiritual**

- Take up a worthy cause. Invest yourself meaningfully.
- Find purpose and meaning. Share beliefs with others.
- Let go of problems. Learn to live with the situation.
- Set priorities. Be consistent. Spend time and energy wisely.

**Developing Resiliency**21

The following strategies have been shown to help health care providers develop resiliency within their work.

- Develop a playful, childlike curiosity. Ask lots of questions and enjoy yourself as children do. Have a good time almost anywhere. Wonder about things, experiment, make mistakes, get hurt and laugh. Ask: “What is different now? What if I did this? Who can answer my questions? What is funny about this?”
- Constantly learn from experience. Rapidly assimilate new or unexpected experiences and facilitate being changed by them. Ask “What is the lesson here? What early clues did I ignore? The next time that happens I will....”
- Adapt quickly. Be mentally and emotionally flexible. Be comfortable with contradictory personality qualities. Think in

181
negative ways only to reach positive outcomes e.g. “What could go wrong, so it can be avoided?”

• Have self-esteem. Self-esteem determines how much you learn after something goes wrong. It allows you to receive praise and compliments. It acts as a buffer against hurtful statements while being receptive to constructive criticism. “I like, appreciate, and love myself...”

• Be self-confident; it is your reputation with yourself. Self-confidence allows you to take risks without waiting for approval or reassurance from others. You expect to handle new situations well because of your past successes. “These are my reliable strengths...”

• Have good friendships, loving relationships. Research shows that people in toxic working conditions are more stress resistant and are less likely to get sick when they have a loving family and good friendships. Loners are more vulnerable to distressing conditions. Talking with friends and family diminishes the impact of difficulties and increases feelings of self-worth and self-confidence.

• Express feelings honestly. Experience and express anger, love, dislike, appreciation, grief—the entire range of human emotions honestly and openly. Choose to suppress feelings when you believe it would be best to do so.

• Expect things to work out well. Be optimistic guided by internal values and standards. Have a high tolerance for ambiguity and uncertainty. Working without a job description is a good model of professionalism. Expecting things to work out well has a synergistic effect; it brings stability to crises and chaos. Ask “How can I interact with this so that things turn out well for all of us?”

• Read others with empathy. See things through the perspectives of others, even antagonists. Develop a win/win attitude when conflicts arise. Ask “What do others think and feel? What is it like to be them? How do they experience me? What is legitimate about what they feel, say, and do?”

• Use intuition and creative hunches. Accept subliminal perception and intuition as valid, useful sources of information. Ask “What is my body telling me? Did that daydream mean anything? Why don’t I believe what I’m being told? What if I did this?”

• Defend yourself well. Avoid and block attacks and fight back. See through and side-step cons, “games,” and manipulations that others attempt. Find allies, resources, and support.

• Learning lessons in the school of life is the antidote to feeling victimized. Convert a situation that is emotionally toxic for others into something emotionally nutritious for them. Learn good lessons from bad experiences; convert misfortune into good luck and gain strength from adversity. A good indicator of exceptional mental health is when a person talking about a rough experience says “I would never willingly go through anything like that again, but it was the one of best things that ever happened to me.” Ask “How can I turn this around? Why is it good that this happened? What is the gift?”

• Get better and better every decade. Become increasingly life competent, resilient, durable, playful, and free. Enjoy life more and more. It is important for caregivers to remember to care for themselves so that they can care for others. They are encouraged to create a community of care rather than feeling solely responsible for meeting the needs of others; to connect to whatever is personally meaningful and be playful and attentive to the spirit.

Meaning Making

Searching for meaning when caring for those who are facing death can help to sustain our well-being. We have discussed the importance of meaning making for caregivers but it is important to also recognize how this process can assist healthcare providers in coping with the work they do. Positive emotions in this work come from finding a sense of purpose, reframing the experience and creating meaningful narratives or interpretations of the care provided. Meaning making can assist healthcare providers in finding energy, hope and refocus when feeling overwhelmed. Creating that sense of purpose, problem solving and recognizing one’s role in solving a problem allows palliative care providers to construct meaning and identify the reward in care giving. Meaning making supports the values, goals and beliefs of both the care provider and organization, and allows for personal growth and a shared purpose in the work of the team/organization.

“Perhaps real wisdom lies in not seeking answers at all. Any answer we find will not be true for long.

An answer is where we fall asleep as life moves past us to the next question.

After all these years I have begun to wonder if the secret of living well is not in having all the answers but in pursuing unanswerable questions in good company.”

— Naomi Remen
References


Chapter 12

Assessment Review

Fundamentals Enhanced
UNIVERSITY PHYSICAL ASSESSMENT

Purpose

Assessment is the starting point of the nursing process and critical thinking in all care interactions. A thorough assessment includes the collection and gathering of data through reviews of health history, records, functional and laboratory assessments, and concludes with the physical examination. An assessment enables the nurse to interpret data collected and supports review and evaluation of conditions and plans of care.

In palliative care a comprehensive assessment of the person and family is critical to establishing and adapting an appropriate plan of care. Needs change throughout the course of the illness and attention to the changes and implications on the person’s and families experiences are an important tenant in palliative care. To establish goals of care, a comprehensive assessment (crossing all domains) must be completed, communicated and documented. Quality of life indicators for the person and family in their illness experience are crucial to examine as the disease progresses and particularly at four significant points in their journey: time of diagnosis, during active treatments, after active treatments have been discontinued and during active dying.

Physical Assessment Review

Assessment involves understanding the pre-existing conditions, diseases and symptoms of the person. For a physical assessment nurses are actively curious to verify previous information, to identify what is a new symptom or challenge for the person, and to explore all dynamics related to each issue. Both existing and anticipated issues are explored. Nurses are always considering how each issue and symptoms impacts the quality of life of both the person and his or her family.

Assessment requires an understanding of systems (e.g. integumentary, cardiovascular, pulmonary, gastrointestinal, neurological systems etc.) Using system knowledge in an assessment aids in defining, interpreting and identifying and managing the issue(s) at hand, as well as assists in the critical communication and teaching aspects of the nursing role.

Chart 12.1

<table>
<thead>
<tr>
<th>Assessment Techniques</th>
<th></th>
</tr>
</thead>
</table>
| **Inspection:** critical observation | • Vision, touch, smell, hearing data  
• General survey (head to toe)  
• Can be done alone or in combination with other assessment techniques but always comes first |
| **Palpation:** light and deep touch | • Texture, moisture, areas of tenderness, skin temperature, organ or mass location and size  
• Light touch to start, slow and systematic  
• Warm hands and calm gentle approach  
• Follows inspection  
• Back of hand: skin temperature  
• Finger tips: texture, swelling, lumps, pulsation  
• Base of fingers: or ulnar surface-vibration |
| **Percussion:** sounds produced by tapping body’s skin | • Produces different sounds or vibrations  
• Used to determine location, size and density  
• Can establish borders, indicate air filled, fluid filled or solid  
• Examples of descriptors: dull, resonant, flat, tympanic, etc.  
• Sound differentiated by amplitude (loud, soft)  
• Pitch (frequency), quality (timbre) and duration |
| **Auscultation:** listening to body sounds | • Direct auscultation: sounds are heard without stethoscope  
• Indirect auscultation: uses stethoscope  
• Identify sound characteristics (frequency, pitch intensity, duration, quality)  
• Quality of stethoscope and fit of earpiece important  
• Be alert to hear subtle changes  
• Flat diaphragm: high-pitched sounds such as breath, bowel, normal heart sounds  
• Bell: soft, low pitched sounds such as heart murmurs  
• Use against skin, warm the stethoscope end prior to use |
Assessment involves the senses (i.e. touch, smell, sight and hearing). It is always best to inspect by looking and comparing prior to touching. For example, observations can be made as the person walks down the hall towards us or as they are sitting in the chair. Touch is a critical skill in a physical assessment. Ensuring warm hands, using a light ‘touch’, and saving tender and sore areas to the later part of the exam all communicate care and respect. Specific techniques to conduct a physical exam include inspection (look before you touch!), palpation with warm hands, percussion and auscultation. See chart 12.1. However, when assessing the abdomen, the order of these techniques is inspection, auscultation, palpation and percussion.

Assessment skills include organizational abilities. Nurses need to consider privacy, warmth, and comfort along with having the proper equipment (i.e. stethoscope, disposable flashlight or one that can be sterilized, tongue depressor, measurement tool, etc.) at hand prior beginning an assessment. Being organized and having a personal approach (i.e. calm, organized, methodical) helps to communicate the importance of the task and show respect for the individual.

Nurses obtain data through observation, interviewing and examination. Health care organizations typically have a documentation form to follow for completing a health assessment that nurses have to utilize and follow in their work place. Forms can provide cues on the details that should be collected and documented during assessment.

**Head to Toe Assessment Review**

Assessment data is combined with the collection of history through interviewing and chart review. When appropriate, laboratory test results can add to a more fulsome picture of the person’s illness journey. To conduct a full physical assessment, it is important to identify and recognize the impact of physical changes or the diagnosis on the person’s broader experience (coping, emotional, spiritual, social, communication, employment etc.). Assessment changes as a person moves along the disease trajectory. It is therefore critical to be alert to the goals and needs of the person and how the approach to assessment impacts the individual.

Observational cues enable assessments to begin during the first meeting with the person. The following (chart 12.2) is a **guide** to conduct a complete baseline head-to-toe physical assessment. Having baseline data enables health care teams to create person-centered care plans, set goals and identify complex and changing needs. Assessment is always done in the context of and in respect of the person’s illness and his or her point in the journey. This checklist is not appropriate for example when a person is in the active dying phase of his or her illness.

### Chart 12.2

<table>
<thead>
<tr>
<th>General</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical appearance</strong></td>
<td></td>
</tr>
<tr>
<td>□ Appears stated age</td>
<td>□ Skin colour</td>
</tr>
<tr>
<td>□ Level of consciousness</td>
<td>□ Facial features, symmetry</td>
</tr>
<tr>
<td>□ Body language</td>
<td>□ Hygiene</td>
</tr>
<tr>
<td>□ Posture</td>
<td></td>
</tr>
<tr>
<td><strong>Body structure</strong></td>
<td></td>
</tr>
<tr>
<td>□ Evidence of malnutrition (e.g. temporal wasting)</td>
<td>□ Symmetry</td>
</tr>
<tr>
<td></td>
<td>□ Positioning</td>
</tr>
<tr>
<td><strong>Skin</strong></td>
<td></td>
</tr>
<tr>
<td>□ Colour (Jaundice, pallor, cyanosis)</td>
<td>□ Surgical sites healed</td>
</tr>
<tr>
<td>□ Skin condition</td>
<td>□ Rashes</td>
</tr>
<tr>
<td>□ Temperature, moisture</td>
<td>□ Turgor or evidence of other issues (edema, lesions, bruising, gout, rash)</td>
</tr>
<tr>
<td>□ Moles</td>
<td>□ Evidence of pruritis</td>
</tr>
<tr>
<td></td>
<td>□ Lymphorrhea (in edematous limbs)</td>
</tr>
<tr>
<td><strong>Weight</strong></td>
<td></td>
</tr>
<tr>
<td>□ Compare with previously known weight if possible</td>
<td>□ Intentional changes?</td>
</tr>
<tr>
<td><strong>General</strong></td>
<td></td>
</tr>
<tr>
<td>□ Aches / pains</td>
<td>□ Cramps</td>
</tr>
<tr>
<td>□ Muscle twitching / tingling</td>
<td>□ Sleep patterns / problems</td>
</tr>
<tr>
<td></td>
<td>□ History of broken bones/ major illness/ surgeries</td>
</tr>
</tbody>
</table>
Vital sign monitoring (if appropriate given the person's status) | □ What are you going to do with the information?
--- | ---
**Head & Neck**

### Head
- ☐ Symmetry
- ☐ Enlarged lymph nodes or thyroid

### Hair
- ☐ Texture
- ☐ Fullness
- ☐ Shine
- ☐ Dandruff

### Complexion
- ☐ Skin conditions
- ☐ Scars
- ☐ Makeup

### Mind
- ☐ Alert / oriented to person, time and place
- ☐ Capacity for decision making
- ☐ General mood
- ☐ Speech / language / vocabulary
- ☐ Ability to read
- ☐ Memory / attention span

### Senses

#### Sight
- ☐ Visual acuity
- ☐ Glasses / contacts
- ☐ Redness, itching, puffiness, icterus
- ☐ Eye drop usage
- ☐ Conjunctiva
- ☐ Sclera
- ☐ Lids: incomplete closure, ptosis, entropion, ektopion
- ☐ Pupils: equal, round, reactive to light (accommodation)

#### Hearing
- ☐ Deficits
- ☐ Use of aids
- ☐ Tinnitus
- ☐ Dizziness
- ☐ Pain
- ☐ Excess Wax / signs of infection

#### Smell
- ☐ Ability
- ☐ Presence of nasogastric tube/oxygen per nasal prongs

#### Taste
- ☐ Alterations in sense of taste

### Nose
- ☐ Nose bleeds
- ☐ Discharge/mucous
- ☐ Pain

### Mouth
- ☐ Teeth / gums / tongue
- ☐ Mucous membranes/Oral Cavity
- ☐ Dental hygiene
- ☐ Dryness (xerostomia)
- ☐ Sores / infection
- ☐ Dentures / bridges
- ☐ Pain

(Reminder: Use a flashlight for thorough inspection for this critical area. Issues to be alert for include xerostomia, candidiasis (thrush), dental caries, and sores. This impacts intake, pain and quality of life.)

### Lips
- ☐ Dry or cracked
- ☐ Fever blisters or cold sores
<table>
<thead>
<tr>
<th>Neck</th>
<th>□ Quality and clarity of voice</th>
<th>□ Swollen lymph nodes</th>
<th>□ Carotid pulses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ Range of motion</td>
<td>□ Venous distension</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Pain</td>
<td></td>
</tr>
<tr>
<td>Chest and Spine</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lungs</td>
<td>□ Rate/rhythm of respirations</td>
<td>□ Tongue obstruction (try jaw thrust or positioning)</td>
<td>□ Orthopnea</td>
</tr>
<tr>
<td></td>
<td>□ Accessory muscle use</td>
<td>□ Shortness of breath</td>
<td>□ Cough / sputum</td>
</tr>
<tr>
<td></td>
<td>□ Presence of respiratory rattle</td>
<td>□ Dyspnea on exertion</td>
<td>□ Shape of chest</td>
</tr>
<tr>
<td></td>
<td>□ Adventitious sounds (crackles, wheezes)</td>
<td>□ Pain</td>
<td></td>
</tr>
<tr>
<td>Heart / Cardiovascular</td>
<td>□ Rate / rhythm / extra heart sounds / murmurs</td>
<td>□ Blood pressure</td>
<td>□ Presence of pacemaker or defibrillator</td>
</tr>
<tr>
<td>Breasts</td>
<td>□ Appearance</td>
<td>□ Discharge</td>
<td>□ Pain / tenderness</td>
</tr>
<tr>
<td></td>
<td>□ Lumps</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spine</td>
<td>□ Deformities</td>
<td>□ Flexibility</td>
<td></td>
</tr>
<tr>
<td>Shoulders and Arms</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shoulders and Arms</td>
<td>□ Range of motion</td>
<td>□ Swelling</td>
<td>□ Reflexes</td>
</tr>
<tr>
<td></td>
<td>□ Strength</td>
<td>□ Joint/muscle pain or stiffness</td>
<td>□ Venous access (if this is different from access devices)</td>
</tr>
<tr>
<td></td>
<td>□ Dexterity</td>
<td>□ Neuropathies</td>
<td>□ Access devices</td>
</tr>
<tr>
<td></td>
<td>□ Coordination</td>
<td>□ Changes in sensation</td>
<td>□ Condition of nails</td>
</tr>
<tr>
<td></td>
<td>□ Crepitus</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Deformities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abdomen</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General</td>
<td>□ Appearance</td>
<td>□ Surgery scars</td>
<td>□ Palpation for tenderness, masses, rebound tenderness (begin with a light touch and then deepen if it is indicated)</td>
</tr>
<tr>
<td></td>
<td>□ Distension (gather abdominal history such as diet, appetite, belching, indigestion, pain, alcohol intake, diabetes etc.)</td>
<td>□ Percussion for resonance (i.e. hyperresonant, dull)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Auscultation of bowel sounds</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stomach</td>
<td>□ Usual diet</td>
<td>□ Nausea/Vomiting</td>
<td>□ History of problems such as Peptic Ulcer Disease, belching, pain, motion sickness, Nausea &amp; Vomiting with pregnancy</td>
</tr>
<tr>
<td>(In addition to physical assessment)</td>
<td>□ Appetite</td>
<td>□ Vitamin use</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Caffeine intake</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liver (In addition to physical assessment)</td>
<td>□ Alcohol intake</td>
<td>□ History of hepatitis</td>
<td>□ Evidence of hepatomegaly (enlarged liver)</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>-----------------</td>
<td>------------------------</td>
<td>--------------------------------------</td>
</tr>
<tr>
<td></td>
<td>□ Substance use</td>
<td>□ Liver function tests</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Pancreas (In addition to physical assessment)</th>
<th>□ History of diabetes, pancreatitis</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Gall bladder (In addition to physical assessment)</th>
<th>□ History of indigestion, pain</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Bowels (In addition to physical assessment)</th>
<th>□ Normal habits / changes (i.e. colour, form, consistency, laxative use, gas, diet etc.)</th>
<th>□ Auscultation for bowel sounds (i.e. hypo or hyper)</th>
<th>□ Rectal bleeding</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ Diarrhea / Incontinence / Constipation</td>
<td>□ Pain</td>
<td>□ Hemorrhoids</td>
</tr>
<tr>
<td></td>
<td>□ Fat &amp; fibre in diet</td>
<td>□ Hemoccult tests / regular Health care Provider rectal / exams / colonoscopy</td>
<td>□ Family history of bowel cancer</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Legs &amp; Feet</th>
<th>□ Range of motion</th>
<th>□ Weakness/ paralysis</th>
<th>□ Dryness</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ Strength</td>
<td>□ Deformities</td>
<td>□ Cellulitis</td>
</tr>
<tr>
<td></td>
<td>□ Crepitus</td>
<td>□ Reflexes</td>
<td>□ Venous stasis</td>
</tr>
<tr>
<td></td>
<td>□ Ability to walk; how far?</td>
<td>□ Changes in sensation / temperature</td>
<td>□ Skin discoloration</td>
</tr>
<tr>
<td></td>
<td>□ Gait</td>
<td>□ Edema</td>
<td>□ Condition of toenails</td>
</tr>
<tr>
<td></td>
<td>□ Coordination</td>
<td>□ Pedal pulses</td>
<td>□ Neuropathies</td>
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<td></td>
<td>□ Balance</td>
<td></td>
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</tbody>
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<thead>
<tr>
<th>Pelvis</th>
<th>□ As with abdomen, inspect, percuss (if indicated), and palpate</th>
<th>□ Color and quantity of urine output</th>
<th>□ Frequency of urination</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ Presence of foley catheter</td>
<td>□ Pain</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Urine</th>
<th>□ Digital rectal exam</th>
<th>□ Evidence of scrotal and/or penile swelling</th>
<th>□ Circumcised</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ Strength of voiding stream</td>
<td></td>
<td>□ Chancre or other lesions?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Male</th>
<th>□ Vaginal discharge</th>
<th>□ Dryness / odour / infection</th>
<th>□ Chancre or other lesions?</th>
</tr>
</thead>
<tbody>
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<td></td>
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<td></td>
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<table>
<thead>
<tr>
<th>Female</th>
<th>□</th>
<th>□</th>
<th>□</th>
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Chapter 12: Assessment Review (Fundamentals Enhanced)
It is the nurse’s role to assess, document, communicate, intervene and evaluate as they interact with the dying person. The burdens associated with any potential treatments must be considered. The two most important assessment questions that nurses can ask the person and family, regardless of phase or focus of assessment are: “What is your greatest concern?” and “How can I help?”

**Conclusion**

A detailed and comprehensive assessment is essential at time of diagnosis, during treatments, after treatments, as the illness progresses and during active dying.

Once physical assessment data is gathered, the greatest temptation can be to initiate suggested treatment solutions. To truly enable person-centered hospice palliative care, the context of the goals of care must be considered before choosing the most appropriate recommendations. Remember that body, mind and spirit are intertwined so physical assessment is but one step in determining the person’s experience.

**UNDERSTANDING SYMPTOM ASSESSMENT**

In module three of the Fundamentals Core program both the Palliative Performance Scale (PPSv2) and the Edmonton Symptom Assessment System-revised (ESAS-r) were introduced as tools that aide in consistency and communication in palliative care.

**Screen – ESAS-r**

The Edmonton Symptom Assessment System (ESAS-r) is a tool to assist in the screening of nine symptoms that are common in people living with a life-threatening illness: pain, tiredness, drowsiness, nausea, lack of appetite, depression, anxiety, shortness of breath, and well-being. There is also a blank scale for a person-identified symptom. Module three of the Fundamentals program includes the information on completing the ESAS-r. The revised Edmonton Symptom Assessment System (ESAS-r) replaces the ESAS, offering improvements related to understanding and completion.

See Edmonton Symptom Assessment System (ESAS-r), in the Tool section at the end of this guide, for a copy of the ESAS-r and instructions for its use. Note that the ESAS-r in the Fundamentals text is a GreyBruce version where permission was given by the authors to include bowel function in the symptom listings.

The ESAS-r is intended to provide a profile of symptom severity at a point in time as identified by the person or caregiver (when the person’s perspective cannot be obtained).

Repeated use of the tool may help to track changes in symptom severity over time. The ESAS-r is only one part of a holistic clinical assessment. It is not a symptom assessment in itself but rather a screening tool. It is also important to note that the numbers people assign to their symptoms have to be understood within that person’s context. What is 2 out of 10 for one person may be another person’s 8 out of 10. One cannot assume that a level of two is an acceptable level without first understanding the impact of that number on that specific person. Symptom management must be based on the specific context for each individual person.

The ESAS-r is completed by the person on the ESAS-r numerical scale and the results transferred to an ESAS-r graph by the nurse. Using the ESAS-r numerical scale first prior to plotting on the graph is important; subsequent graphing of the ESAS-r symptom severity scores allows for tracking of trends and effectiveness of interventions at a glance. ESAS-r is a reliable and valid communication tool that allows the nurse to understand what is most important to that particular person. It is a useful representation of symptom control and trends that can provide a consistent form of communication between teams and settings.

It is often the nurse’s role to explain the ESAS or ESAS-r tool to individuals and their families. Introducing the tool early allows for the person and family to become familiar with the tool and how it is used to understand the person’s perspective, monitor changes over time, evaluate effectiveness of interventions and enable focused care.

The ESAS-r is only a first step in assessing a person’s needs or goals. The ESAS-r does help screen for particular symptoms and concerns but it is then critical to proceed to a more robust assessment of the particular issue(s) as identified. ESAS-r can assist in focusing assessments by allowing the person to pinpoint the issue(s) of most concern to be addressed first. ESAS-r supports care goal setting, evaluating the efficacy of an intervention (e.g. 7/10 pain managed with goal of treatment being 3 / 10 score) and fosters a common language between health care team members. In essence the rating of severity on an ESAS-r tool is a call to action on the part of a nurse.

**Assessment – OPQRSTUv**

The Symptom Assessment Acronym OPQRSTUv is used to guide a systematic assessment of identified symptoms. This tool can help ensure consistent and comprehensive symptom assessment in palliative care. See OPQRSTUV Symptom Assessment Acronym, in the Tool section at the end of this guide, for a copy of the tool.

It is essential that nurses thoroughly assess each symptom
identified by the person during history taking and physical examinations. Keep in mind that a person may have 3 different areas or types of pain and each of these need to be assessed individually.

There are many tools to guide in-depth assessments. The elements of the OPQRSTU Symptom Assessment Acronym are often represented in those tools and consideration should be given to ensuring that the tool being used includes these elements.

**Assessment using Acronym O, P, Q, R, S, T, U and V**

O**nset**
When did it begin? How long does it last? How often does it occur?

P**rovoking and Palliating**
What brings it on? What makes it better? What makes it worse?

Q**uality**
What does it feel like? Can you describe it?

R**egion / Radiation**
Where is it? Where does it spread?

S**everity**
What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right now? At best? At worst? On average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom?

T**reatment**
What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments? What medications and treatments have you used in the past?

U**nderstanding/Impact**
What do you believe is causing this symptom? How is this symptom affecting you and/or your family?

V**alues**
What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?

This level of assessment is the foundation of being able to understanding the symptom, cause, impact and effectiveness of interventions for an individual. This tool allows for a standardized way to collect data and aids in communication between teams and team members. Once a screening tool such as the ESAS-r has identified an issue, then a complete comprehensive and consistent assessment is required. Documentation should be reflective of the details gathered in the assessment process.

**Communication – PPSv2**

The Palliative Performance Scale (PPSv2) is a reliable and validated tool used by health care providers to measure a person’s performance status in 10% increments. PPSv2 is enables tracking and identification of needs as disease progresses. The 100% to 0% PPS levels are further subdivided into general stages such as Stable -- 100-70%; Transitional -- 60-40% and End of life -- 30-0%. See **Palliative Performance Scale (PPSv2) Version 2 And Instructions For Use**, in the Tool section at the end of this guide, for a copy of this tool and instructions for its use.

The PPSv2 has been utilized in a number of ways within the palliative care community. As a workload measure, it can allow for adjustment of staffing levels in accordance with the level of care required. For example, if a nurse is assigned 10 patients and 3 of them have a PPS of 30% or lower, then an adjustment can be made to the assignment to allow for the time needed to be able to attend to the dying persons’ care needs.

PPSv2 scores have been embedded in some workplaces and the scores trigger specific interventions such as introducing the ESAS-r, discussing place of death, reviewing advance care wishes etc. The PPSv2 score can also trigger services such as bringing a Symptom Response Kit into the home, consulting a CCAC care coordinator for reassessment care needs or supports, alerting physicians to consider home visits etc.

As a communication tool for the team the PPSv2 score can serve as a reminder for healthcare providers to engage in conversations with individuals and families about changing needs, or to revisit goals of care. Collaborative Care Plans developed by Cancer Care Ontario are one example of work that is based on the functional performance as defined by the Palliative Performance Scale (PPSv2). (e.g. stable, transitional, and end-of-life stages) These Care Plans can be found at www.cancercare.on.ca.
Although the tool was initially designed for use in the cancer population, there continues to be ongoing research and validation of this tool being applied to different palliative populations. Many members of the palliative care team can use PPSv2. It is also important to note that PPS levels are determined not by what the person “is doing” but by what person “could do”. In other words, being in bed is not the physical limit but a practical limit. Some care settings (e.g. LTC) have less opportunity for independent functioning, which may not be reflective of what the person's actual level of function is. Victoria Hospice, the developer of this tool, has a detailed instruction and information booklet that addresses questions regarding assigning of levels. This tool is available on the Victoria Hospice website, www.victoria-hospice.org.

**Conclusion**

Effective communication, ability to facilitate a change and effective group function are foundational concepts in palliative care and particularly important throughout the assessment process. Embedding reliable, validated tools such as PPSv2, ESAS-r and the OPQRSTU acronym into organizational protocols not only ensures a consistent approach, but it also enhances communication across care settings and among providers as we strive to provide person-centered goals of care.

**References**


Chapter 13
Pharmacological Review
Fundamentals Enhanced
UNDERSTANDING THE PRINCIPLES OF PHARMACOLOGY

An understanding of the basic principles of pharmacology is essential for nurses working within palliative care. Administering medications safely requires that nurses be knowledgeable about the medications that they are administering and be able to clinically assess the individual for both expected and unexpected reactions to medications.\(^1\)

The science of pharmacology refers to the study of drug actions within the body.\(^2\) Simply put, there are two aspects of pharmacology that must be considered: Pharmacokinetics and Pharmacodynamics. Pharmacokinetics refers to what the body does to medications once they have been administered, and pharmacodynamics refers to what effect the medication has on the body.

This module is a brief overview aimed at introducing the learners to the basic concepts of pharmacology as it relates to hospice palliative care. First, the basic principles of pharmacokinetics and pharmacodynamics will be discussed. Then issues of clinical assessment will be considered in a hospice palliative care context. In order to provide high quality care, the nurse must be able to combine his or her knowledge of pharmacology with a clinical assessment of the person’s status and therapeutic needs. Finally, considerations specific to the pharmacological management of pain are explored. Learners are encouraged to seek further in-depth information by referring to pharmacology-specific textbooks for nursing. The CAPCE program has integrated the Pallium Palliative Pocketbook\(^3\) as reference material.

Pharmacokinetics

Pharmacokinetics refers specifically to what the body does to medication (i.e. the effect of biological systems on the drugs themselves). This includes mechanisms of absorption and distribution, the chemical changes of the substance within the body and the routes of excretion.\(^4\) Knowledge of pharmacokinetics helps one to understand more specifically the body’s role within the pharmacological interaction.

This is often understood through the ‘ADME’ scheme, which breaks it down into four discrete phases:

- Absorption is the movement of the medication into the bloodstream
- Distribution refers to movement of the medication from the bloodstream into the cells
- Metabolism is the breakdown of the medication into byproducts or metabolites
- Excretion refers to the body’s disposal of the metabolites

Age-related changes in the body can affect the pharmacokinetic processes. For example, in the elderly decreased liver and kidney function can affect drug metabolism and distribution.\(^5\) The total dosage and dosing interval often needs to be adjusted to account for these changes.

Drug Half-life refers to the length of time required for the body to eliminate half of the medication from the body. Different medications have different half-lives due to multiple factors such as distribution, rate of metabolism and elimination. It is important to understand medication half-lives so that an effective and safe interval for dosages can be prescribed. For example the half-life of subcutaneous fentanyl is 10 hours, and the half-life of the Fentanyl Patch is 20-27 hours.\(^6\)

Steady State is the point at which there is a consistent level of the drug in the individual’s body (i.e. the amount of medication being absorbed and distributed is equal to the amount being metabolized and excreted). When a medication is given on a routine schedule, it generally takes 5 half-lives to achieve steady state.\(^7\) For example, since the half-life of immediate-release oral hydromorphone is approximately 4 hours, it will take approximately 20 hours for the medication to achieve steady state, and even longer in an elderly person, or someone with impaired liver function. The effectiveness of a particular medication and dosage can only be properly assessed once steady state has been achieved.

Pharmacodynamics

Pharmacodynamics refers to the biological, chemical and physiological effects that the medication has on the individual’s body.\(^8\) Specific factors, such as age can influence the pharmacodynamics of a medication. For example, older adults may experience enhanced analgesic effects from opioids. It is important to understand the pharmacodynamics of a medication, as this determines the therapeutic benefit and potential adverse effects. More specifically, the effect of medications is determined by which cell receptor it attaches to; different receptors produce different effects. Medications that stimulate a cell to behave a certain way are called ‘agonists’; those that prevent a cell from being activated are called antagonists or blockers. For example, Nalbuphine and butorphanol bind to the kappa opioid receptor sites acting as an agonist (capable of producing analgesia) and simultaneously to the mu receptor sites acting as an antagonist (reversing agonist effects).\(^9\)
UNDERSTANDING SYMPTOM MANAGEMENT

For an effective approach to symptom management, the following principles can be used:

- Avoid delays in treatment
- Apply the World Health Organization (WHO) ladder to guide the selection of appropriate medications
- Choose oral preparations whenever possible
- Establish a routine medication schedule for those experiencing continuous symptom distress
- Have proper breakthrough medication dosages available to address breakthrough symptoms
- Tailor the plan to meet the individual’s needs and goals
- Address the physical, psychological, spiritual and social factors contributing to suffering
- Monitor the individual response to the analgesic regime on a daily basis until symptom(s) is/are managed
- Titrate medication orders based on assessment of the individual’s response
- Treat the underlying cause of the symptom whenever possible

Critical thinking and symptom management

It is important to note that, although certain medications require drug levels and laboratory measurements to be done to ensure safety of the individual, for the vast majority of medications it is the clinical assessment of the individual that is most important. Most of the time, clinical assessment is how the palliative care team is able to tell if a drug is having a positive or negative effect for the individual and whether that drug needs to be titrated, changed or discontinued.

Critical thinking skills are an essential competency for nurses who wish to effectively manage symptoms. This process requires the nurse to use comprehensive reasoning and problem solving, in which their judgments are based on evidence, thus enabling effective clinical decision-making.

The bedside nurse must know what the likely effects of a drug are for the individual and monitor the person to see what they actually experience. The nurse often spends more time with the person than does anyone else on the team. Therefore his or her observations of the person’s pain level, comfort, dyspnea, nausea or any other distressing symptom and the person’s overall well-being are critical to assessing whether a certain medication is having the desired effect.

It is imperative that the care team make decisions within the context of the person’s goals of care. For example, furosemide may be given subcutaneously to treat volume overload in the dying person. In this context we would likely not draw blood work to check their potassium level. If, however, the goal is comfort with the expectation that we also treat reversible conditions, it would make sense to check the electrolytes periodically. Critical thinking ensures that we balance the burden associated with our treatment plan to the goals of the person.

Drug Formulations and Application to Practice

Short-acting or Immediate Release oral formulations are preferred when initiating opioid treatment, rotating opioids, or treating a pain crisis or breakthrough pain. Someone who is opioid-naive (i.e. they have never had an opioid or have not had repeated dosing for two to three weeks) would be given the short acting/immediate release formulations. These formulations may be ordered every hour as needed if trying to establish an individual’s opioid requirements.

Long-acting, Sustained Release (SR) or Controlled Release (CR) oral formulations can be used when the level of pain management is stable. These formulations are not used in response to a pain crisis, and rarely would they be given to those who are opioid-naive. A tablet form (designed to be swallowed whole) is often administered to prevent rapid absorption. This ensures the person is not getting too much of the substance too quickly. Most long-acting formulations are administered every 12 hours; however, some maybe given every 8 hours. An exception is the 24-hour release formulation of morphine called Kadian.

Routes of Administration and Application to Practice

The route of administration will affect the rate of absorption, metabolism and excretion of the medication (pharmacokinetics). Oral/by mouth (PO) takes the longest, followed by subcutaneous (SC), intramuscular (IM) and then intravenous (IV) which is the fastest.

Oral (PO)

Oral is the preferred route for those who can still swallow. Capsules should be taken after consuming a small amount of liquid, followed by approximately 100 ml more liquid to prevent getting capsules stuck in the esophagus.

Enteral Feeding Tube - G/GJ, NG/NJ

Some medications come in liquid formulations that can easily be administered through enteric feeding tubes for people who can no longer safely take medications orally.
Additionally, sustained release capsules (example M-Eslon) can be opened and the small little pellets inside the capsule can be mixed with water and injected through a feeding tube. Note: Care must be taken not to crush the pellets or the medication that was designed to be slowly absorbed due to the coatings on the pellets will be absorbed all at once and can cause an overdose.

**Parenteral – Intramuscular (IM), Subcutaneous (SC), Intravenous (IV)**

The intramuscular route is avoided whenever possible, due to the discomfort it typically causes. Sometimes it is used in allergic reactions or during seizures if intravenous access is not available. Subcutaneous administration of medications is more comfortable compared to intramuscular. When a medication is to be administered frequently via the subcutaneous route, the nurse will often choose to insert an intermittent subcutaneous infusion port, often referred to as a subcutaneous butterfly. Such infusion ports should be changed on a regular basis. If a stable dose of medication is no longer providing its usual benefit, the nurse should change the infusion port prior to suggesting an increased dose; sometimes the decreased benefit is caused by poor absorption from the current subcutaneous site.

Due to the medications going directly into the bloodstream and bypassing the absorption phase, intravenous administration, or subcutaneous administration is often the preferred route when a drug must take effect quickly. Some drugs can only be given intravenously; however, intravenous access can lead to complications such as infection, embolism and difficulty with access.

**Transdermal**

The transdermal route, often in the form of patches (e.g. fentanyl) is often administered once stable well-managed pain is achieved. The medication is absorbed through the skin, therefore avoiding first-pass liver metabolism and gastric upset. Patches are generally easy to apply and, depending on the medication, may be changed every 3 days. Some individuals do experience a topical reaction to the patch, or sometimes the patches do not adhere well to the skin. It is important to remember that the Fentanyl Patch is only recommended for persons experiencing well-managed pain and should never be given to a person who is opioid naïve.

**Sublingual and Buccal**

Some medications such as lorazepam, fentanyl, and methadone are well absorbed sublingually. However, sublingual tablets do not absorb well if the oral cavity is too dry. Some opioids are given buccally, however there are some limitations to this. If the person is unable to hold volumes (1.5-2 mL) in his or her mouth for long enough, absorption will be limited.

**Topical**

There have been case reports that suggest the application of topical opioids & NSAIDs can be effective when applied to painful joints or ulcers.

**Nebulized**

Some evidence has shown that nebulized opioids have been effective in some cases for the treatment of dyspnea; however, this is not highly recommended due to the inconsistency of its bioavailability.

**PHARMACOLOGICAL MANAGEMENT OF PAIN**

**Titration and Rotation of Medications in Pain Management**

Titration refers to adjusting the dosage of the medication that a person in currently taking. This can refer to both an increase or decrease in the dosage. The goal of titration is to find optimal pain relief balanced with manageable or tolerable side effects.

**Titration upward** may occur when adjusting for efficacy after initiating a dose, when pain is increasing, if a person becomes tolerant and requires more of the medication to cover the pain, and to allow for assessment of side effects and reactions as one looks to achieve a therapeutic level. The current opioid dose, the use of breakthrough doses, and the severity of the pain are all considered before adjusting titration in an effort to avoid over- or under-dosing. Calculation methods include: a) increasing the scheduled dose by factoring in the amount of breakthrough doses used; b) increasing the scheduled dose by a specific percentage; or c) a combination of both. The person’s clinical factors such as age, co-morbidities and frailty also need to be factored into titration. Titration is done until either the person’s goals are met or side effects become intolerable. It is not appropriate to increase the scheduled dosing if the person has not required breakthrough doses.
**Titration downwards** may occur if the person has undergone a treatment that assists in the reduction of pain. Radiation, palliative surgery, chemotherapy with the intent to palliate a symptom, or the addition of an adjuvant analgesic may improve pain management and require a subsequent decrease in the opioid. In some instances, as the body systems begin to shut down at the end of life, the reduction of medication is also required to avoid over-medication, and the buildup of metabolites.

To safely titrate medications, the nurse must have a sound understanding of pharmacokinetics, routes of administration, opioid characteristics, and dosing intervals. Most importantly, titration is a highly individualized calculation, which factors in a person's individual response to medications and overall condition. Once pain has stabilized then a switch to a sustained release formulation with appropriate breakthrough is advised.

**Rotation of opioids** refers to switching from one opioid to another (e.g. morphine to hydromorphone) or from one route to another (e.g. sc to po). Rotation of opioids may be used when there is opioid toxicity, when there is a lack of pain management despite appropriate dose titrations, when one route is causing a side effect which could be managed using a different route, and when dosing has become impractical to continue to administer (i.e. rotating from a large dose to managing the pain with a smaller equianalgesic dose). An equianalgesia chart provides approximate dosing units of opioid medications that are equal to each other (e.g. 5mg of morphine equivalent to 1mg of hydromorphone).

Rotation requires an understanding of tolerance and incomplete cross-tolerance. Tolerance refers to the decreased effects of a drug at a particular dose or conversely, the need for a higher dose of the drug to maintain effect. Tolerance should not be confused with addiction and it is not a predictor of abuse. The term does not apply when a decrease in the drug's effect can be attributed to disease progression.

Tolerance to the non-analgesic effects of an opioid drug (i.e. side effects) occurs. The rate of developing tolerance to each of the non-analgesic effects of opioid drugs varies. For example, people usually develop tolerance to mental clouding and nausea within days or weeks; however, they rarely develop a tolerance to constipation. Tolerance to respiratory depression also develops rapidly, usually within days of opioid administration, although an overdose (lack of careful titration of the opioid) may lead to a lethal dose for the individual.

Tolerance to analgesic effects is managed by increasing the opioid dose; however, when an increased dose brings intolerable & unmanageable side effects, another option is to switch to an alternative opioid drug. When switching to another opioid, the clinical implications of a phenomenon called cross-tolerance must be considered. For example, if a person who is tolerant to morphine is switched to hydromorphone, it is extremely important to assume that cross-tolerance will be incomplete. This means that the starting dose of a new opioid must be reduced by 20 – 50% of the calculated equianalgesic dose to prevent overdosing. This is also why it is so important to provide adequate and appropriate breakthrough pain doses. The dose may then be gradually increased as needed to the point of pain relief and tolerable and manageable side effects.

Rotation requires consideration of side effect management, factors of opioid selection (convenience, availability, cost, and individual preference) and close monitoring of the person's response through the process. Knowledge of equianalgesic dose conversions along with the potential for variability of individual reactions is critical.

**Rotation of route** involves the switching from one route to another (e.g. iv/sc to po). Absorption, side effect potential, safety of route and excretion all influence the decision to choose a particular route. The medication dosage will change depending on the route selected (e.g. if 2 mg of sc hydromorphone is rotated to the oral route, the dose would change to 4 mg).

**Opioid Addiction, Physical Dependence and Tolerance**

One of the biggest barriers to adequate pain management is the perception that the administration of opioids for pain management causes addiction. The overwhelming majority of people taking opioids to manage pain will not become addicted provided the appropriate doses are used to treat physical pain. As would be expected, opioids are not effective in the treatment of psychological or spiritual pain; thus, the nurse must take a thorough pain history keeping in mind factors contributing to total pain, and ensure appropriate pain management strategies are employed. The risk of addiction for people with preexisting addiction issues does not mean that a practitioner does not treat the pain. Treatment for people at risk of addiction should be given utilizing precautions such as screening, education, contracts and close monitoring.

**Addiction** is a primary, chronic, neurobiological disease with genetic, psychological, and environmental factors influencing its development and manifestations. It is
characterized by behaviours that include one or more of the following: impaired control over drug use, compulsive use, continued use despite harm, and craving. True addictions need to be distinguished from pseudo-addiction caused by under-treatment of pain, behavioral/family/psychological dysfunction, and drug diversion with criminal intent. Pseudo addiction mimics the behaviours that one would see with psychological dependence and is caused by under-medication of pain.

Physical dependence is a state of adaptation that often includes tolerance and is manifested by a drug class-specific withdrawal syndrome that can be produced by abrupt cessation of the medication, rapid dose reduction, decreased absorption of the drug, and or administration of an antagonist.25 This normal response can occur with the persistent use of opioids, beta blockers, corticosteroids, antidepressants and other medications that are not associated with addictive disorders. When no longer needed, drugs that induce physical dependence should be carefully tapered. Abruptly discontinuing an opioid may result in withdrawal symptoms such as tachycardia, hypertension, diaphoresis, piloerection, nausea, vomiting, diarrhea, body aches, abdominal pain, psychosis, and/or hallucinations. If the dose is lowered too quickly and withdrawal symptoms occur, a transient increase in the opioid dose, treatment with clonidine, or a small dose of a benzodiazepine (for example lorazepam) may be necessary to settle distressing symptoms.

Pharmacologic tolerance is a state of adaptation in which exposure to a drug induces changes that result in a diminution of one or more of the drug’s effects over time. The region of the CNS where tolerance is thought to occur is anatomically and functionally separate from the brain pathways related to addiction.26 When increasing doses of analgesic are required, first suspect a worsening of the disease before assuming pharmacologic tolerance.

It is important to appreciate the differences between these concepts. Fears and misconceptions about opioids can lead to inappropriate dosing and treatments offered to a person living with pain. These fears and misconceptions can also be held by the person and family. Support and education is a critical factor in alleviating worries of addiction as a person’s illness progresses.

Decision Making Process for Pharmacological Interventions for Pain

The World Health Organization (WHO) has outlined a stepwise ‘ladder’ to be followed when choosing appropriate pain medications (diagram 13.1). According to the WHO Ladder, administration of pain medications should follow this order:

![Diagram 13.1](image)

1. **Nonopioid ± adjuvant**
   - ASA
   - Acetaminophen ± NSAIDS/COX-2s ± Adjuvants

2. **Opioid for mild-to-moderate pain ± nonopioid ±adjuvant**
   - Codeine Tramadol Oxycodone ± NSAIDS/COX-2s ± Adjuvants

3. **Opioid for moderate-to-severe pain ± nonopioid ±adjuvant**
   - Oxycodone
   - Morphine
   - Hydromorphone
   - Fentanyl
   - Methadone ± NSAIDs/COX-2s ± Adjuvants

Adapted from the World Health Organization 1996

Non-opioids (aspirin and acetaminophen); Mild opioids (codeine); Strong opioids (morphine) until adequate pain management is achieved.27

The following steps outline how a nurse might use the WHO Ladder and their own critical reasoning to treat pain:

1. If pain is rated by the person as mild, the WHO recommends the use of non-opioid analgesics such as Aspirin, acetaminophen and non-steroidal anti-inflammatories (NSAIDs).
2. If pain is rated by the person as moderate or is not responsive to Step 1, the WHO recommends the use of weak opioids such as codeine or Tramadol. One must remember that approximately 10% of the population lacks the enzyme necessary to convert codeine into morphine, thus achieving no therapeutic benefit from the codeine (however they may still experience the adverse effects).
3. If pain is rated as severe or is not responsive to Step 2, the use of strong opioids such as morphine, hydromorphone, oxycodone, fentanyl, or methadone is recommended. Most people in a hospice setting will need a Step 3 (strong opioid) medication +/- adjuvant medication to achieve pain management.

*At each of the 3 steps on the ladder, the selection of specific adjuvant analgesics as first- or second-line treatments should be considered. NSAIDs, corticosteroids, tricy-
clic antidepressants and anticonvulsants are a few examples of medications that could be used as adjuvant analgesics depending on the specific pain type. Additionally, it must be noted that when treating people with cancer, the use of radiation therapy, chemotherapy or surgery may decrease the level of pain. This may lead to instances when the dose/strength of the opioid needs to be reduced.

In summary, when making decisions regarding pharmacological interventions for pain management, the following should be considered:

- Understand the person's and family's goals and expectations, values, and beliefs
- Assess how consistently the person is taking the medication (Does the medication regime meet the specific needs of the person?)
- Choose the appropriate analgesic based on the pain type, the etiology of the pain, the condition of the person, concurrent medical conditions, response to prior or present medications, and cost to the person
- Choose an appropriate starting dose based on the severity of the pain, the age and condition of the person, and the particular properties of the medication
- Determine the dosing schedule based on the timing and duration of the pain (scheduled versus PRN versus prior to painful activities)
- Determine the appropriate drug preparation based on the severity of the pain, the need for rapid titration, and ease of administration
- Choose the appropriate route of administration based on the needs of the person, skill of the caregivers and ease of administration
- Discuss interventions with the team, including the person and family
- Determine an evaluation process to measure the efficacy of interventions
- Develop a process whereby the medication may be rotated or the dosage titrated to meet the person's needs.

**Conclusion**

This review of important pharmacological principles, concepts and terms is important for the nurse working in hospice palliative care. The combined understanding of pharmacokinetics, pharmacodynamics, formulations, routes, titration, rotation, and individual considerations all impact the decision-making process. Above all else, the nurse must apply critical thinking skills to all pharmacological decisions.

References


Glossary
GLOSSARY

Activities of daily living

Daily personal care activities, including ambulation, bathing, toileting, feeding, dressing and transfers. May also include cooking, cleaning, laundry, banking, shopping.

Advance directives

A term that may be used to imply a person’s formal or informal expression of wishes concerning expectations of care and choice of treatment options in response to potential illnesses or conditions (legal connotations vary by jurisdiction; may also be referred to as a living will).

Accountability

The fiduciary and professional responsibility to those receiving care and the community.

Alternate, complementary, integrative therapies

Terms often used to describe independent healing systems outside the realm of conventional medical theory and practice.

Assess

To identify, describe, evaluate and validate information.

Autonomy

The state of being self-governed.

Beneficence

The provision of benefits and the balancing of harms and benefits for the purpose of doing the most good.

Care

All interventions, treatments and assistance to the person and family.

Caregiver

Anyone who provides care.

- Informal caregivers are not members of an organization. They have no formal training, and are not accountable to standards or conduct or practice. They may be family members or friends.

Confidentiality

The protection and control of information privy to persons.

Discrimination / prejudice

Any act by another that inhibits a person’s ability to fully participate in society, especially when related to age, gender, national and ethnic origin, geographical location, race, colour, language, creed, religion, sexual orientation, diagnosis, disability, availability of a primary caregiver, ability to pay, criminal conviction, family status.

Essential services

The critical services required to implement the plan of care.

Essential step

Any activity that is required to meet a stated objective.

Expectations

Issues, hopes, and fears identified by the person and/or family that require attention in the plan of care.

Family

Those closest to the person in knowledge, care and affection. May include the biological family, the family of acquisition (related by marriage/contract), the family of choice and friends (including pets), the person defines who will be involved in his or her care and/or present at the bedside.

Goal

A desired future condition.

Grief

Sorrow experienced in anticipation of, during and after a loss.

Hospice palliative care

Care that aims to relieve suffering and improve the quality of living and dying.
Illness

Absence of wellness due to disease, another condition, or aging.

- An acute illness is one that is recent in onset and likely to be time-limited. If severe, it could be life threatening.
- A chronic illness is likely to persist for months to years. With progression it may become life threatening.
- An advance illness is likely to be progressive and life threatening.
- A life-threatening illness is likely to lead to death in the near future

Interdisciplinary care team (related to person / family care)

A team of caregivers who work together to develop and implement a plan of care. Membership varies depending on the services required to address the identified issues, expectations, needs and opportunities. An interdisciplinary team typically includes one or more physicians, nurses, social workers/psychologists, spiritual advisors, pharmacists, personal support workers, and volunteers. Other disciplines may be part of the team if resources permit.

Justice

The fair treatment of all individuals, without discrimination or prejudice.

Life closure

The process of putting personal, social (including financial and legal), and spiritual affairs in order, giving of gifts (e.g. personal treasures, money, etc), creation of a legacy, reminiscence, and saying goodbye in preparation for death. This usually occurs close to the end of a person’s life.

Measure

To find out the extent, size, quantity, capacity, etc.

Mission

A short statement of an organization’s purpose; what it is and what it does.

Needs

Issues identified by caregivers that require attention in the plan of care.

Nonmaleficence

The avoidance of doing harm.

Norm

A statement of usual or average practice. Less rigid than a standard.

Objective

A desired accomplishment or hoped for result

Outcome

A measurable end result or consequence of a specific action or essential step.

Pain

An individual, subjective, unpleasant sensory and emotional experience that is primarily associated with tissue damage or described in terms of tissue damage, or both.

Person

The person living with an acute, chronic, or advanced illness. The person is a contributing member of the interdisciplinary team.

Plan of care

The overall approach to the assessment, management, and outcome measurement to address the expectations and needs prioritized as important by the person and family.

Policy

A course of action selected from alternatives and in light of given conditions to guide and determine present and future decisions.

Preferred practice guideline

The recommended approach to guide the provision of care related to a particular issue. Must be flexible to take into account the exceptions/variations needed to meet the wide range of person and family expectations and needs. May be consensus or evidence based.
Principle

A fundamental truth.

Provider

A formal caregiver who is a member of an organization and accountable to defined norms of conduct and practice. The provider may be a professional, support worker, or volunteer.

Program

An organization with a number of component parts. It may be part of a larger host organization, or independent. It may or may not have its own governance structure.

Proxy

A person or agency of substitute recognized by law to act for, and in the best interest of the person.

Quality care

The continuous striving by an interdisciplinary team/program to meet the expectations and needs of the persons and families it serves.

Quality of life

Well-being as defined by each individual. It relates both to experiences that are meaningful and valuable to the individual, and his/her capacity to have such experiences.

Regional team

Regional teams are functional units within hospice palliative care organizations designed to provide formal caregivers and oversight to multiple patients/family care teams within a given population/region/setting of care.

Risk

A measure of the presence of variables that are likely to contribute to the development of an undesirable illness or condition.

Setting of care

The location where care is provided. Settings for hospice palliative care may include the person’s home, and acute, chronic, or long-term care facility, a nursing home/skilled nursing facility, a hospice or palliative care unit or free-standing facility, a jail or prison, the street, etc.

Service

An organization providing assistance or service to others. Services tend to be part of a larger organization (e.g., a host organization or a program). They have one or more component activities. Most will not have their own governance structure.

Spirituality

An existential construct inclusive of all the ways in which a person makes meaning and organizes his/her sense of self around a personal set of beliefs, values and relationships.

This is sometimes understood in terms of transcendence or inspiration. Involvement in a community of faith and practice may or may not be a part of an individual’s spirituality.

Standard

An established measurable condition or state used as a basis for comparison for quality and quantity.

Strategies

The specific methods, processes, or steps used to accomplish goals and objectives. Strategies impact resources (inputs) in some positive or negative way. They are executed in a tactical manner so as to link goals and objectives to day-to-day operations.

Suffering

A state of distress associated with events that threaten the intactness of a person. It may be accompanied by a perceived lack of options for coping.

Therapeutic relationship

A relationship between skilled caregivers and the person and family that aims to change the person’s and family’s experience of illness and bereavement. It combines the art and science of the process of providing care with the knowledge and skills needed to deliver a wide range of therapeutic interventions.

Total pain

Suffering related to, and the result of, the person’s physical, psychological, social, spiritual and practical state.
Truth-telling

The communication of what is known or believed to be true without deceit or falseness. Persons may voluntarily decline to receive information and designate someone else to receive information on their behalf, as long as there is no evidence of coercion.

Unit of care

Those who are the focus of a plan of care. In hospice palliative care this is typically the person and his/her family.

Value

A fundamental belief on which practice is based.

Vision

A short statement of an organization’s aspirations; what it hopes to become and achieve.

Volunteer

A person who freely gives of his/her time, talent, and energy. Volunteers are members of an organization and accountable to that organization’s standards of conduct and practice.
Tools
**TOOL: EDMONTON SYMPTOM ASSESSMENT SYSTEM (ESAS-R) INSTRUCTIONS FOR USE (MODIFIED AND REVISED)**

Please circle the number that best describes how you feel NOW:

<table>
<thead>
<tr>
<th>Symptom</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Worst possible</th>
</tr>
</thead>
<tbody>
<tr>
<td>No pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>pain</td>
</tr>
<tr>
<td>No tiredness (Tiredness = lack of energy)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>worst possible tiredness</td>
</tr>
<tr>
<td>Not drowsiness (Drowsiness = feeling sleepy)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>worst possible drowsiness</td>
</tr>
<tr>
<td>No nausea possible</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>worst possible nausea</td>
</tr>
<tr>
<td>No lack of appetite</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>worst possible lack of appetite</td>
</tr>
<tr>
<td>No shortness of breath</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>worst possible shortness of breath</td>
</tr>
<tr>
<td>No depression (Depression = feeling sad)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>worst possible depression</td>
</tr>
<tr>
<td>No anxiety (Anxiety = feeling nervous)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>worst possible anxiety</td>
</tr>
<tr>
<td>Best welling (Well-being = how you feel overall)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>worst well-being</td>
</tr>
<tr>
<td>Normal bowl function</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>worst possible bowel function</td>
</tr>
<tr>
<td>No _________ (for example: dry mouth)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>worst possible _________</td>
</tr>
</tbody>
</table>

Person’s Name _____________ Date ___ Time ___

*Used and modified with permission, Regional Palliative Care Program, Edmonton Zone, Alberta Health Services, 2011.*
Body Diagram

Please mark on these pictures where it is you hurt.
Completion of the ESAS-r

The Regional Palliative Care Program of Edmonton, Alberta (2010) recommends the following when completing the ESAS-r:

It is recommended that the person complete the ESAS-r with guidance from a health care professional especially on the first occasion.

The person should be instructed to rate the severity of each symptom on a 0 to 10 scale, where 0 represents absence of the symptom and 10 represents the worst possible severity. The number should be circled on the scale.

<table>
<thead>
<tr>
<th>No pain</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Worst pain</th>
</tr>
</thead>
</table>

The person should be instructed to rate each symptom according to how he or she feels now. The health care professional may choose to ask additional questions about the severity of symptoms at other time points e.g. symptom severity at best and at worst over the past 24 hours.

Definitions have been added to items that have been found to be more problematic for people to understand or rate. You can review these with the person:

- Tiredness: lack of energy
- Drowsiness: feeling sleepy
- Depression: feeling sad
- Anxiety: feeling nervous
- Well-being: how you feel overall
- With the previous version of the ESAS, people often reversed the scale for appetite i.e. they considered “0” as “no appetite” and “10” as “best appetite”. The scale has now been relabeled as “lack of appetite”. Coaching people on the correct direction of the scale is recommended
- The body diagram on the reverse side of the ESAS-r can be used to indicate sites of pain
- The circled numbers can be transcribed onto the ESAS-r graph
TOOL: OPQRSTUV SYMPTOM ASSESSMENT ACRONYM

The Symptom Assessment Acronym is a tool to aid in a systematic assessment approach to whatever hospice palliative care symptom you are reviewing. Other aids are available however; in Fraser Health we found this Symptom Assessment Acronym helpful. We recommend this tool for our Fraser Health care providers to guide a consistent and comprehensive symptom assessment in hospice palliative care.

Assessment using Acronym O, P, Q, R, S, T, U and V1,2,3,4,5,6,7,8,9

O

nset
When did it begin? How long does it last? How often does it occur?

P

rovoking and Palliating
What brings it on? What makes it better? What makes it worse?

Q

uality
What does it feel like? Can you describe it?

R

egion / R

adiation
Where is it? Where does it spread?

S

everity
What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right now? At best? At worst? On average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom?

T

reatment
What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments? What medications and treatments have you used in the past?

U

nderstanding/Impact
What do you believe is causing this symptom? How is this symptom affecting you and/or your family?

V

values
What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?

* Physical Assessment (as appropriate for symptom)

References


TOOL: PALLIATIVE CARE TEAM MEMBER ROLES

All team members are responsible to advocate, participate as a team member, identify issues and report.

Case Manager

- Conducts a thorough assessment (in the person’s home, hospital, or other appropriate setting), determine eligibility for CCAC services and to work with the person and family to determine the person’s needs, and goals of care.
- Provides information about and link to CCAC services and other appropriate community resources (i.e. hospice) and to assist the person and family to navigate through the health care system.
- Works with the person and family to determine what services are required to meet the person’s and family’s goals of care in each domain as outlined by the A Model to Guide Hospice Palliative Care.
- Sets up a service plan based on the person’s needs and refer to contracted service providers (e.g. nursing, physiotherapy, occupational therapy, speech language pathology, dietitian, social work, and personal support worker).
- Ensures that appropriate supplies and medical equipment are made available.
- Collaborates with the client’s interdisciplinary individualized care team to monitor and reassess needs.
- Ensures that the service plan remains up-to-date and revise the plan as needed.
- Ensures that the care team is aware of the person’s death and that equipment is removed from the home.
- Provides information and referral for bereavement support as appropriate.

Clergy / Spiritual Pastoral Care

- Assesses the spiritual needs of the person and support the person as he or she searches to find meaning and hope in changing circumstances.
- Provides opportunity for the person to experience meaningful rituals, sacramental ministry, and prayer.
- Participates with the team in ethical decision-making.
- Provides grief and bereavement support for the person and family and caregiver team.

Hospice/Palliative Care Volunteers

- Provides practical assistance in meeting the complex needs of the person.
- Provides support across various settings.
- Listens to the cares and concerns of the person, provide information regarding services available and advocate for access to services that will meet the person’s expressed wishes.
- Shares information disclosed with appropriate service providers and/ or volunteer coordinator

Nurse

- Functions within the scope of practice of the College of Nurses of Ontario.
- Performs a holistic assessment of the person and support network to identify issues in each of the domains of issues as outlined in the Model to Guide Hospice Palliative Care.
- Engages in therapeutic encounters that include assessment, information sharing, decision-making, care planning, care delivery, and confirmation related to each identified issue.
- Collaborates with other team members to provide the most appropriate services and maximum quality of life for the person and family.
- Performs delegated medical therapies.
- Collaborates with the physician to monitor and manage disease symptoms and the effects of medical therapy.
- Fosters the autonomy, empower and advocate for the person.
- Promotes efficient utilization of resources.
- Promotes opportunities for debriefing and resolution of grief among professional and volunteer caregivers.

Role of the Palliative Pain and Symptom Management Consultant Secondary or Tertiary Clinical Consultant

- Provides palliative care and pain and symptom management consultation for team members.
- Educates, train and mentor primary clinicians as needed.
- Provides up to date, research based and best practice information and guidelines related to palliative care and pain and symptom management on request.
- Assists communities to develop hospice palliative care services that will meet local needs.
- Promotes networking of existing palliative care resources throughout the district.
- Advocates for the person in need of pain and symptom management.

Secondary Expert:

- Is expert in hospice palliative care.
- Is an experienced member of a designated hospice palliative care team/unit or program.
- Supports primary providers in every setting where persons and families receive care.

Tertiary Expert:

- Is an expert practitioner and researcher in hospice palliative care.
- Consults with secondary experts and primary providers on difficult to manage cases.
• Educates secondary and tertiary experts.
• Conducts research.
• Develops advocacy strategies.

**Occupational Therapist**

- Determines the person’s desired self-care, productivity and leisure goals and assists the person to maintain quality of life through enabling him or her to achieve personal objectives/goals.
- Assesses loss of mobility (i.e. ambulation, bed mobility, transfers, assistive devices, home safety, fall risks, and range of motion).
- Recommends and teaches the use of assistive devices and specialized equipment to facilitate optimum physical function and comfort.
- Ensures that the person is safe within his or her environment.
- Anticipates the person’s changing status and makes appropriate recommendations to minimize changes to care routine.
- Provides advice regarding energy conservation techniques to maximize limited energy resources to meaningful activity.
- Provides recommendations for pain and pressure relief or reduction.
- Increases the ease of handling of the person by supporting caregivers and promoting safety for the person.

**Personal Support Worker and Health Care Aide**

Role of the Personal Support Worker/Health Care Aide:

- To assist with activities of daily living as required: personal care, nutrition, light housekeeping, laundry, respite.
- To observe and report to professional service providers and/or supervisors any changes in physical symptoms and emotional responses of the person.
- To participate, as a valued member of the health care team, in development and implementation of the care plan.
- To assist and support caregivers in the provision of care to the person.
- To provide holistic support and advocate as necessary to ensure that the person’s needs are met.
- To communicate effectively with team members.
- To document observations.

**Pharmacist**

- Prepares, dispenses and distributes medications to meet the person’s specific needs.
- Reviews medication profile and completes a medication assessment.
- Collaborates with the person, family, and other service providers to ensure that the person’s medication needs are met.
- Provides education about medications to the person, family and caregivers in order to optimize medication use and adhere to and to minimize potential risks of toxicity.
- Develops and implements a pharmacy care plan based on symptom management and drug related needs, with follow-up and outcome monitoring.
- Advocates on behalf of the person for optimal medication use.
- Acts as an easily accessible resource for medication and therapy-related questions.

**Family Physician**

- Several physicians may be involved in the care of the person throughout the illness trajectory. It is important to the person’s well-being that the family physician be aware of the condition, needs and expectations of the person as the disease progresses. The family physician is the most appropriate person to coordinate the medical care during the end-of-life stage of a life threatening illness. One of the most fundamental and urgent needs of the dying person is to have a physician who will not only assume responsibility for medical care but is also prepared to offer a listening ear and to serve as a skilled and sensitive professional in a situation of great sadness for all involved.
- Assesses the medical care needs of the person and family and provides ongoing care, support and guidance that fulfills the person’s/family’s goals.
- Offers compassion and respect.
- Helps the person and family cope with physical, psychological, social and spiritual needs and relieves unnecessary suffering.
- Advocates for meaningful and/or realistic goals of care involving early discussion of diagnosis and prognosis and the potential benefits, burdens, and risks associated with various therapies and with the refusal of therapy.
- Understands the impact of culture and religion on the person’s personal choices.
- Asks about and incorporates the person’s and family’s choices, values, beliefs and goals in decisions for end of life.
- Actively participates in case conferences.
- Encourages the discussion of the importance of advance care planning and, as the illness progresses, reassesses with the person and family on an ongoing basis.
- Ensures that other members of the care team are informed about treatment decisions relating to resuscitation and life support and that discussions are carefully documented in the health record.
- Collaborates with other members of the team in devising a plan of care.
- Communicates in a timely manner with the person and family concerning treatment options, assessment of options made by the health care team, supportive services and palliative care resources.
- Facilitates access to interdisciplinary pain and symptom management, palliative and supportive care.
- Allows the person to experience as dignified a death as
possible.
• Endeavors to honour the last wishes of the person wherever it is possible to do so.
• Designates a substitute physician whenever he or she is not available, ensuring that such designate is appraised of the situation.
• Attends to the certification of the death, facilitate the removal of the body, and provide emotional support to the bereaved within a reasonable time after death has ensued.
• Plans for bereavement follow-up care as appropriate to family needs.

Role of the Palliative Care Physician Consultant

• Acts as the medical advisor/consultant on the agency/facility/community Palliative Care Team and acts as a liaison between the medical staff and the Palliative Care Team.
• Acts, whenever necessary, as an advocate for the person and family referred to the Palliative Care Team.
• Participates in team meetings/case conferences as required.
• Promotes and participates in palliative care education of all services providers/caregivers.
• Encourages the emotional, psychosocial, and spiritual well-being of staff, volunteers and others working in palliative care.

Physician Assistant

• Support physicians in a range of health care settings. They work alongside physicians, nurses, nurse practitioners and other members of the interdisciplinary health care team. The specific duties of the PA vary depending on the individual competencies of the PA, the supervising physician’s area of practice, and the types of duties that the supervising physician chooses to assign. Examples include:
  » Conducts patient interviews and take medical histories
  » Performs physical examinations
  » Performs certain controlled acts delegated to them by a physician
  » Initiates and interpret tests, analyze data, implement and evaluate plans of care. Effectively manages the plan of care for each person based on clinical knowledge, data, patient preference and benefits to the patient
  » Provides counseling

Physiotherapist

• Acts as a complementary part of the professional team, and help set and achieve the person’s goals.
• Assesses circulation, chest status, edema, DVT, skin breakdown due to loss of mobility, and pain.
• Manages symptoms, reduces pain and provides support with the use of appropriate modalities.
• Improves mobility by assessing for proper aids, teaching transfers and teaching strengthening exercises.
• Deals with respiratory function with the use of vibrators, breathing techniques, mucociliary clearance, and/or oxygen saturation testing with exercise.
• Improves skin integrity via the use of support or compression bandaging, use of compression pump and use of wound management techniques.
• Teaches relaxation techniques.

Recreation Therapist

• Provides activities/programs/social visits to residents commensurate with and appropriate to their mental and physical status.
• Coordinates with care plan team to provide maximum opportunities to enhance quality of life.
• Promotes activities that involve the search for meaning, confronting fears, dealing with the loss of control, and other issues of loss.
• Addresses the dying person’s negative feelings; threats to self esteem and helps restore a sense of control, contributing to an improved quality of life.
• Reduces boredom, fosters a sense of accomplishment and enhances psycho-social supports within the person’s community.
• Informs, invites and provides special escort to activities and programs of choice.
• Modifies activities/programs/social visits offered to match resident’s mental and physical changes.
• Provides guidance and support to families and staff as to appropriate recreational activities.
• Provides for “final wish” opportunities to residents as tolerated and feasible.

Registered Dietitian

• Assesses nutritional status, history and goals of the person develops an individual nutritional care plan with the person based on factors affecting adequacy of intake, therapeutic issues and physiological state.
• Educates and supports the person, caregivers and other service providers.
• Monitors the effect of interventions, disease progression, concerns of the person and adapts the care plan as required.
• Advises the person of available funding for the use of supplements or equipment.
• Assists the person in decisions regarding nutrition support and alternative nutrition strategies.

**Respiratory Therapist**

• Assists in developing a plan to address respiratory insufficiency – thus optimizing comfort through appropriate intervention with oxygen therapy, inhalation therapy, and suction.
• Provides counseling in breathing techniques, mucociliary clearance, activity tolerance, and medication – as appropriate.
• Advises the person/family/caregivers of available funding – as well as discussing possible alternatives where no funding sources exist i.e. self pay.
• Revises the care plan as the disease progresses.
• Instructs the person, caregivers and services providers in the operation, maintenance and precautions of appropriate equipment/care plan.
• Communicates effectively with team members in case conferences, with timely report, assessment and other related documentation.
• Available on a 24 hour emergency basis to address equipment malfunctions.

**Social Worker**

• Assesses psychosocial needs and develops a care plan to meet identified needs.
• Explore emotional basis for intractable pain and assists person in developing coping strategies for the management of such pain.
• Assists team members with interactions with clients.
• Provides assistance with practical issues such as finances, will, Power of Attorney and funeral planning.
• Provides individual and family counselling as necessary.

**Speech-Language Pathologist**

• Assesses present and future communication needs and/or swallowing needs of the person, educates the person, caregivers and service providers and assists in developing a plan and teaching strategies to meet future communication and/or swallowing needs.

**References**

1. Palliative Care Team Member Roles (Revised 2011): Grey Bruce Palliative Care Manual. Grey Bruce Palliative Care Committee in collaboration with local service providers; 1999.
## TOOL: PALLIATIVE PERFORMANCE SCALE (PPSv2) VERSION 2 AND INSTRUCTIONS FOR USE

<table>
<thead>
<tr>
<th>PPS Level</th>
<th>Ambulation</th>
<th>Activity &amp; Evidence of Disease</th>
<th>Self-Care</th>
<th>Intake</th>
<th>Conscious Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>100%</td>
<td>Full</td>
<td>Normal activity &amp; work No evidence of disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>90%</td>
<td>Full</td>
<td>Normal activity &amp; work Some evidence of disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>80%</td>
<td>Full</td>
<td>Normal activity with effort Some evidence of disease</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>70%</td>
<td>Reduced</td>
<td>Unable normal job/work Significant disease</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>60%</td>
<td>Reduced</td>
<td>Unable hobby/house work Significant disease</td>
<td>Occasional assistance necessary</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>50%</td>
<td>Mainly Sit/ Lie</td>
<td>Unable to do any work Extensive disease</td>
<td>Considerable assistance required</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>40%</td>
<td>Mainly in Bed</td>
<td>Unable to do most activity Extensive disease</td>
<td>Mainly assistance</td>
<td>Normal or reduced</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>30%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity Extensive disease</td>
<td>Total Care</td>
<td>Normal or reduced</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>20%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity Extensive disease</td>
<td>Total Care</td>
<td>Minimal to Sips</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>10%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity Extensive disease</td>
<td>Total Care</td>
<td>Mouth care Only</td>
<td>Drowsy or Coma +/- Confusion</td>
</tr>
<tr>
<td>0%</td>
<td>Death</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

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Instructions for Use of PPS (see also definition of terms)

PPS scores are determined by reading horizontally at each level to find a 'best fit' for the individual that is then assigned as the PPS% score.

Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that individual. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.

Example 1: The person who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious with good intake would be scored at PPS 50%.

Example 2: An individual who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although this person may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The person may have normal intake and full conscious level.

Example 3: However, if the person in example 2 was paraplegic and bed bound but still able to do some self-care such as feed self, then the PPS would be higher at 40% or 50% since he or she is not 'total care'.

PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that person.

Definition of Terms for PPS

Some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall 'best fit' using all five columns.

Ambulation

- The items 'mainly sit/lie', 'mainly in bed,' and 'totally bed bound' are clearly similar. The subtle differences are related to items in the self-care column. For example, 'totally bed bound' at PPS 30% is due to either profound weakness or paralysis such that the person not only can't get out of bed but is also unable to do any self-care. The difference between 'sit, lie, and bed' is proportionate to the amount of time the person is able to sit up versus need to lie down.
- 'Reduced ambulation' is located at the PPS 70% and PPS 60% level. By using the adjacent column, the reduction of ambulation is tied to inability to carry out their normal job, work occupation or some hobbies or housework activities. The person is still able to walk and transfer independently but at PPS 60% needs occasional assistance.

Activity & Extent of Disease

- 'Some', 'significant', and 'extensive' disease refer to physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply 'some' disease, one or two metastases in the lung or bone would imply 'significant' disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcemia or other major complications would be 'extensive' disease. The extent may also refer to progression of disease despite active treatments. Using PPS in AIDS, 'some' may mean the shift from HIV to AIDS, 'significant' implies progression in physical decline, new or difficult symptoms and laboratory findings with low counts. 'Extensive' refers to one or more serious complications with or without continuation of active antiretrovirals, antibiotics, etc.
- The above extent of disease is also judged in context with the ability to maintain one's work and hobbies or activities. Decline in activity may mean the person still plays golf but adjusts from playing 18 holes to 9 holes, or just a par 3, or to backyard putting. People who enjoy walking will gradually reduce the distance covered, although they may continue trying, sometimes even close to death (e.g. trying to walk the halls).

Self-Care

- 'Occasional assistance' means that most of the time the person is able to transfer out of bed, walk, wash, toilet and eat by his or her own means, but that on occasion (perhaps once daily or a few times weekly) minor assistance is required.
- 'Considerable assistance' means that regularly every day the individual needs help, usually by one person, to do some of the activities noted above. For example, the person needs help to get to the bathroom but is then able to brush his or her teeth or wash at least hands and face. Food will often need to be cut into edible sizes but the person is then able to eat of his or her own accord.
• ‘Mainly assistance’ is a further extension of ‘considerable’. Using the above example, the person now needs help getting up but also needs assistance with washing, but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.

• ‘Total care’ means that the person is completely unable to eat without help, toilet or do any self-care. Depending on the clinical situation, the person may or may not be able to chew and swallow food once prepared and fed to him or her.

Intake

• Changes in intake are quite obvious with ‘normal intake’ referring to the person’s usual eating habits while healthy. ‘Reduced’ means any reduction from that and is highly variable according to the unique individual circumstances. ‘Minimal’ refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

Conscious Level

• ‘Full consciousness’ implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc. ‘Confusion’ is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies. ‘Drowsiness’ implies fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor. ‘Coma’ in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period.

Scoring of PPS scores should be initiated when there are no further interventions whose goal is cure or remission available to the person with a life-threatening illness.

In the home setting: Good practice is to complete the PPS at each visit.

In the hospital or palliative care unit setting: Good practice is to complete the PPS at the same time each day.

In a long-term care home setting: Good practice is to complete the PPS on admission, quarterly, and daily when a score of 30% is not maintained concurrently for 72 hours and daily for scores of 20% and lower.
## TOOL: PAIN INTENSITY SCALES

<table>
<thead>
<tr>
<th>Scale</th>
<th>Description</th>
<th>Advantages – each point represents research/studies on the scale</th>
<th>Disadvantages – each point represents research/studies on the scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual Analogue Scale (VAS)</td>
<td>A vertical line of 10 cm (or 100mm) in length anchored at each end by verbal descriptors (e.g., no pain and worst possible pain). The person is asked to make a slash mark or X on the line at the place that represents the amount of pain experienced.</td>
<td>Positive correlation with other self reported measures of pain intensity and observed pain behaviors. Sensitive to treatment effects and distinct from subjective components of pain. Qualities of ratio data with high number of response categories make it more sensitive to changes in pain intensity.</td>
<td>Scoring may be more time-consuming and involve more steps. Person and family may have difficulty understanding a VAS measure. Too abstract for many adults, and may be difficult to use with elderly, non-English speaking and persons with physical disability, immobility. Or reduced visual acuity, which may limit their ability to place a mark on the line.</td>
</tr>
<tr>
<td>Numeric Rating Scale (NRS)</td>
<td>The number that the person gives represents his/her pain intensity from 0-10 with the understanding that 0=no pain and 10=worst pain possible.</td>
<td>Validity and demonstrated sensitivity to VAS. Verbal administration to individual allows those by phone or who are physically and visually disabled to quantify pain intensity. Ease in scoring high compliance, high number of response categories. Scores may be treated as interval data and are correlated with VAS.</td>
<td>Lack of research comparing sensitivity to treatments impacting pain intensity.</td>
</tr>
<tr>
<td>Verbal Descriptor Scale (VDS)</td>
<td>Adjectives reflecting extremes of pain are ranked in order of severity. Each adjective is given a number which constitutes the person’s pain intensity.</td>
<td>Short, ease of administration to person, easily comprehended, high compliance. Easy to score and analyze data on an ordinal level. Validity is established. Sensitivity to treatments that are known to impact pain intensity.</td>
<td>Less reliable among illiterate individual and persons with limited English vocabulary. Patients must choose one word to describe their pain intensity even if no word accurately describes it. Variability in use of verbal descriptors is associated with affective distress. Scores on VDS are considered ordinal data; however, the distances between its descriptors are not equal but categorical.</td>
</tr>
<tr>
<td>Scale</td>
<td>Description</td>
<td>Advantages – each point represents research/studies on the scale</td>
<td>Disadvantages – each point represents research/studies on the scale</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Faces Scale (Wong Baker)</td>
<td>The scale consists of six cartoon-type faces. The no pain (0) face shows a widely smiling face and the most pain (10) shows a face with tears. The scale is treated as a Likert scale and was originally developed to measure children’s pain intensity or amount of hurt. It has been used in adults.</td>
<td>Validity is supported by research reporting that persons from many cultures recognize facial expressions and identify them in similar ways. Simplicity, ease of use, and correlation with VAS makes it a valuable option in clinical settings. Short, requires little mental energy and little explanation for use.</td>
<td>Presence of tears on the “most” pain face may introduce a cultural bias when the scale is used by adults from cultures not sanctioning crying in response to pain.</td>
</tr>
<tr>
<td>Faces Pain Scale – Revised</td>
<td>The Faces Pain Scale Revised (FPS-R) was adapted from the FPS in order to make it compatible with a 0-10 metric scale. The FPS-R measures pain intensity consist of six oval faces ranging from a neutral face (no pain) to a grimacing sad face without tears (worst pain).</td>
<td>Easy to administer. Oval shaped faces without tears or wide smiles are more adult-like in appearance, possibly making the scale more acceptable adults.</td>
<td>Facial expressions may be difficult to discern by patients who have visual difficulties. The FPS-R may measure other constructs (anger, distress and impact on pain on functional status) than just pain intensity.</td>
</tr>
<tr>
<td>Pain Thermometer</td>
<td>Modified vertical verbal descriptor scale which is administered by asking the patient to point to the words that best describes his/her pain.</td>
<td>Increased sensitivity. Preferred for patients with moderate to severe cognitive deficits or those with difficulty with abstract thinking and verbal communication.</td>
<td>Allow for practice time to use this tool.</td>
</tr>
</tbody>
</table>

TOOL: TUCKMAN’S STAGES OF TEAM DEVELOPMENT¹

**Stage 1: Forming**

Whenever a person’s needs are identified as appropriate for hospice palliative care, a new team takes shape with the person and family at the center of the team.

| Feelings                               | • Excited                     |
|                                       | • Eager                       |
|                                       | • High positive expectations  |
|                                       | • Anxiety about how they will fit in and whether they will measure up |
| Behaviours                             | • Lots of questions           |
| Team Tasks                             | • Create a clear structure, goals, direction and roles |
|                                       | • Build trust                 |

**Stage 2: Storming**

The team begins to discover that they may not be able to meet all their expectations. Team members are attempting to see how the team will handle differences and conflict.

| Feelings                               | • Frustration and anger       |
|                                       | • Express concerns about being unable to meet goals |
| Behaviours                             | • Less polite; frustration about constraints may be leveled at other team |
|                                       | • Members, team leadership   |
|                                       | • Disagreement about goals, expectations, roles and responsibilities openly expressed |
|                                       | • Team members may argue or become critical |
| Team Tasks                             | • Refocus on goals           |
|                                       | • Break larger goals into smaller achievable steps |
|                                       | • Develop both task related skills, group process and conflict management skills |
|                                       | • Redefine teams goals, roles, tasks |

**Stage 3: Norming**

During the Norming stage of team development, team members begin to resolve the discrepancy they felt between their individual expectations and the reality of the team’s experience. The team is successful in setting more flexible and inclusive norms and expectations.

| Feelings                               | • An increased sense of comfort in expressing their “real” ideas and feelings |
|                                       | • Feel an increasing acceptance of others on the team, recognizing that the variety of opinions and experiences makes the team stronger and its product richer. |
|                                       | • Constructive criticism is both possible and welcomed. Members start to feel part of a team and can take pleasure from the increased group cohesion |
### Stage 4: Performing

#### Behaviours
- Members making a conscious effort to resolve problems and achieve group harmony
- More frequent and more meaningful communication among team members and an increased willingness to share ideas or ask teammates for help
- Refocus on established team ground rules and practices and return their focus to the team’s tasks
- Teams may begin to develop their own language (nicknames) or inside jokes

#### Team Tasks
- Members shift their energy to the team’s goals
- Show an increase in productivity, in both individual and collective work
- An appropriate time for an evaluation of team processes and productivity

#### Feelings
- Satisfaction in the team’s progress
- Share insights into personal and group process
- Aware of their own (and each other’s) strengths and weaknesses
- Attached to the team as something “greater than the sum of its parts”
- Satisfaction in the team’s effectiveness
- Confidence in both individual abilities and those of their teammates

#### Behaviours
- Able to prevent or solve problems in the team’s process or in the team’s progress in meeting goals
- A “can do” attitude is visible as are offers to assist one another
- Roles on the team may have become more fluid, with members taking on various responsibilities as needed
- Differences among members are appreciated and used to enhance the team’s performance

#### Team Tasks
- Significant progress made toward meeting goals
- Commitment to the team’s mission is high
- Competence of team members is high
- Continued deepening of team member’s knowledge and skills
- Work to continuously improving team development
- Accomplishments are measured and celebrated

### Stage 5: Termination/Ending

Palliative Care Teams do come to an end, when death occurs. Their work with a specific family is ended. The nursing team may remain the same but there will be different partners in the next case; a different person and family at the centre, a different physician, a different group of PSWs and volunteers. While not part of Tuckman’s original model, it is important for any team to pay attention to the end or termination process.
### Feelings
- Members may carry a variety of feelings for the person who has died
- Members may have concerns about the family members and their abilities to cope
- Members may have some anxiety because of uncertainty about their future responsibilities
- Sadness or a sense of loss about the death and separation from the family
- A sense of deep satisfaction at the accomplishments of the team or a sense of frustration if the death did not go well
- Individual members might feel all of these things at the same time, or may cycle through feelings of loss followed by feelings of satisfaction. Given these conflicting feelings, individual and team morale may rise or fall throughout the ending stage. It is highly likely that at any given moment individuals on the team will be experiencing different emotions about the death

### Behaviours
- Some team members may become less focused on the team’s tasks and their productivity may drop
- Alternatively, some team members may find focusing on the task at hand is an effective response to their sadness or sense of loss and their task productivity may increase

### Team Tasks
- Need to acknowledge the upcoming transition and the variety of ways that individuals and the team may be feeling about the death
- During this stage, the team should focus on three tasks:
  - Completion of any deliverables and closure on any remaining team work
  - Evaluation of the team’s process and product, with a particular focus on identifying “lessons learned”
  - Creating a closing celebration/ritual that acknowledges the contributions of individuals, acknowledges the accomplishments of the team, formally ends this particular team’s existence

### References
P2P
Peer-to-Peer Exchange
**PEER-TO-PEER EXCHANGE**

**Objectives**

- To understand how far along each learner is with respect to his or her self-directed reading and e-Learning Module content
- To assist the learner articulate his or her own key take-aways and to benefit from hearing someone else's perspective
- To identify and discuss some of the more challenging content and flag any possible barriers to learning
- To help the learners support each other to develop their problem solving skills
- To provide learners with an informal environment to share their observations, reflections and barriers’ challenges with content and begin to explore these issues
- To enable learners to provide emotional/social support to each other, build relationships, support collaborative learning and shared solution finding and to identify and mitigate risks to successful learner experiences

**Process**

At the beginning of the Fundamentals program you will be placed in a group with 1-2 other Fundamentals learners. You will connect with your peer-to-peer groups bi-weekly via telephone, skype or in-person.

Use the following steps to guide your Peer-to-Peer Exchanges throughout the program:

**STEP 1:** Share where each of you are currently at in the program content.

**STEP 2:** Take turns identifying what key concepts or content highlights were most meaningful to you, and why you think that is.

**STEP 3:** Identify any barriers or challenges you had with the content and discuss why that might be.

**STEP 4:** Identify any outstanding questions you have.

**STEP 5:** Identify strategies you will implement to overcome those barriers and find answers to your questions.
Reflective Activity
REFLECTIVE ACTIVITY

Meaning Making: Reflective Activity Objectives

- To individually reflect on meaning making in one’s life.
- To reflect on the impact of spirituality on living with a progressive life-limiting illness.

Meaning Making: Reflective Activity Instructions

Complete the following activity between weeks 5-6.

Read: Dr. Balfour Mount, one of the pioneers of hospice palliative care in Canada, tells the story of a 25-year-old man who had been a football star in university, obtained great marks, had abs of steel, was considered to be good looking! He was diagnosed with a terminal illness and died a year later. On his deathbed he told Dr. Mount that this was “the most wonderful year of my life”. Dr. Mount asked, “How could this year of pain and suffering be the most wonderful year of your life?” His response was his dying taught him about truly living, because he had the opportunity to slow down, to balance being and doing, to reappraise his values, to rest and nourish his soul.

For most of us, our days are consumed by the multiple “doing” tasks required of us because of our various roles, (e.g., being a parent, a sibling, a health care provider, a friend, a volunteer). We don’t often take the time to slow down, find the balance in being and doing, or rest and nourish our souls.

Activity: Reflect on and record your answers to the following questions:

1. Who am I? What is my core belief related to the essence of who I am? Am I a physical body only? Consciousness that lives on when the body dies?
2. What is the meaning and purpose of my life?
3. What activities bring meaning to my life?
4. In what circumstances do I feel an uplifting of my spirit?
5. What provides me with the courage / strength to carry on in difficult times?
6. If I were diagnosed tomorrow with a life-threatening illness that impacted my ability to engage in my current activities how would I likely react?
FUNDAMENTALS CASES

CASE 1: ADITI & MALIKA / CAMILLE & BIANCA

Aditi & Malika: Part 1

Aditi and Malika were 5-years-old and not only cousins, but best friends. One summer at the cottage, the girls were playing in the water and Malika drowned. Aditi was immediately sent home with family members while her parents stayed several days to help find the body. Aditi’s parents wanted to protect her and did not give her an option to attend the funeral.

Camille & Bianca: Part 1

After a long battle with COPD, Camille’s 68-year-old father passed away. At the funeral home Camille’s husband did not want their teenage daughter, Bianca, to see the body. Camille argued that it was Bianca’s choice. She told Bianca she was welcome to come in with her if she wanted. Bianca was unsure but followed her Mom. Camille stroked her father’s hair and invited Bianca to do whatever she was comfortable with. Bianca hesitated but soon began stroking her grandfather’s cheek, a gesture she had always done to wake him up from naps.

Aditi & Malika: What Really Happened

As Aditi grew through her childhood, she never spoke Malika’s name. She became obsessive with her schoolwork in elementary school and had difficulty making close friends and developing relationships. She hated visiting her extended family because she was concerned her presence was bringing up painful memories for her favourite uncle. She started sleeping for shorter and shorter periods of time. In her teens Aditi still avoided discussions about death and never went to funeral homes. In her 20’s Aditi had multiple panic attacks that affected her ability to drive. On her own initiative, Aditi went to counseling for several years and found outlets for her emotions. Aditi now can admit that Malika’s death had great impact on her life.

Camille & Bianca: What Really Happened

After watching her father in pain for so long, Camille felt relieved to see him resting peacefully. Camille and her husband asked Bianca later that night how she felt about seeing her grandfather. She shared that she was glad to have had the opportunity to say goodbye.

CASE 2: RAVI

Ravi: Part 1

A palliative care nurse received the following information about a new man, Ravi, who is scheduled to participate in her palliative clinic the next day.

“Patient is an ex-con who has AIDS. He is recently out of jail and has a history of drug abuse”.

Ravi: What Really Happened

The nurse constructed a mental image of Ravi and based on that image, was afraid and worried to have him in her clinic. She put these fears aside. When she met Ravi the next morning, they connected immediately. Because of Ravi’s history with drugs, he was monitored closely. Ravi was someone the team could respect, support and work with throughout his illness. When he died, the nurse ended up assisting in the funeral celebration of his life.

CASE 3: JACOB

Jacob: Part 1

Jacob is in his mid 30’s and is the single father of a 13-year-old son. Jacob has both ALS and cancer of the bowel but has not talked to his son about his illnesses. They live in the country and have no family or friends that visit. Jacob has nausea, constipation and dyspnea. He has been having increased difficulty walking, preparing meals for his son and taking care of himself. Jacob is no longer able to drive and is struggling with depression. Jacob is stoic. He doesn’t complain to his son but winces when he moves.

Jacob: Part 2

Jacob’s PPS score is 60%. His ESAS-r scores are as follows:

- Pain 7/10
- tiredness 3/10,
- nausea 5/10
- drowsiness 0/10
- lack of appetite 6/10
- shortness of breathe 5/10
- depression 8/10
- anxiety 3/10
- best well-being 7/10
- normal bowel function 5/10
Jacob: What Really Happened

Three volunteers were introduced to support Jacob and his son. One volunteer provided spiritual support through assisting Jacob and his son to make connections to their faith group, another volunteer was able to provide practical support to Jacob’s son while his dad rested for an afternoon a week and the third volunteer helped to address his psychological state by sharing music and conversation for one morning a week. PSWs were added to the team and came in to help John with food preparation and personal care. Nursing began weekly visits in regard to his physical/symptom needs.

CASE 4: SANDY

Sandy: Part 1

Sandy is a 27-year-old woman living with MS. She is on pain medication but hospice volunteers observe and report that in spite of the analgesic, Sandy was still showing non-verbal cues of pain including restlessness and anxiety. The palliative care nurse was called in for support.

Sandy: Part 2

The nurse is briefed about Sandy’s life history, which includes information about her conservative background, estrangement from her large family and an abortion she had in her teens. Sandy knows the nurse is aware of her history.

Sandy: Part 3

The nurse sits with Sandy and says “I am worried that your pain is something we can’t reach with medication” She speaks with Sandy for a while and soon asks, “Where do you hurt the most”. Sandy replies, “in my heart.”

Sandy: What Really Happened

Sandy shared that her estrangement from her family was due to her abortion. The nurse asked if there was someone in the family Sandy would like to speak to. Sandy asked to speak to one of her sisters and had her sister write a letter to the rest of the family asking for forgiveness. The whole family attended Sandy’s care conference. Sandy ended up dying reconciled.

CASE 5: CHARLIE

Charlie: Part 1

Following a cardiac arrest, Charlie has arrived at the intensive care unit from a long-term care home. Vital signs have remained absent for several minutes. After some response, Charlie is intubated and ventilated. He is declared profoundly comatose.

Charlie has a 94-year-old wife, four children and eight adult grandchildren. Following a 49-hour period of no noted neurological recovery, the medical team has suggested a withdrawal of treatment (ventilation and intubation).

Charlie: Part 2

A care conference is scheduled with Charlie’s family to discuss the poor prognosis and the possibility of withdrawing aggressive treatment (ventilation and intubation). All are present except Charlie’s wife. All other family members are actively involved and tell the medical team that their mother is “too old for all of this.” Charlie’s eldest son shares that, though his mother is the highest ranked substitute decision maker, she would be comfortable with him making the decision. All present at the meeting agree with this and staff consults with Charlie’s wife to confirm this understanding.

Charlie: What Really Happened

Charlie’s son is accepted as substitute decision maker. He agrees to the withdrawal of treatment (ventilation and intubation) and it is withdrawn. Charlie dies with the supports in place to allow for a comfortable death.

CASE 6: DAVID

David: Part 1

David is a 44-year-old engineer who has been living with brain cancer. His prognosis indicates he will dement, most likely in his frontal lobe. This may cause him to be belligerent and hard to care for. David lives with his partner Henry and has been cared for at their home by the same visiting community service team for the last several years. Though Henry is devoted and willing to help care for David, David does not want to become a burden and has decided that at the end-of-life he would like to be transitioned to another setting as he does not want to die at home. His PPS is 60%.

David: Part 2

As David’s illness progressed his nausea and pain increased, along with a decrease in his and Henry’s ability to cope
with the challenges and changes in David's personality and behaviors. Over a period of one-month David's PPS fell to 40% and he was transferred to the residential hospice. Henry was David's only visitor after this transition.

**David: What Really Happened**

David's PPS continued to decline over the next few days after his admission to hospice. He stopped taking sips of fluid, had a decreased awareness of his surroundings and slept most of the time. David became restless and his breathing patterns changed to periods of shallow breathing with longer gaps between breaths. Henry commented that David's skin colour looks poor and that he is no longer able to get any response to his attempts at conversation. Though David's restlessness was upsetting to Henry, his presence and soothing music seem to help them both. Hospice staff continued to address this and other symptoms for David, and provide support for Henry's emotional journey. David died with Henry at his bedside holding his hand.
FEC
Fundamentals Enhanced Coaching
The Fundamentals Enhanced Program includes two opportunities for learners to engage with CAPCE Coaches. It is expected that the learner will review the associated questions before each coaching session. The CAPCE Coach will use the questions provided to guide a focused discussion. Questions may be tailored, at the coach's discretion, to meet the individual needs of the learner.

**Purpose of coaching:**
- To provide support and guidance for nurses to utilize their skills and knowledge more effectively
- To learn from the experiences of practiced hospice palliative care leaders in a relaxed, safe and informal learning environment
- To discuss possible future learning opportunities

**COACHING SESSION 1: ORIENTATION**

**Purpose:** To review the goals of the learner, introduce the learner to the program format and provide an opportunity to discuss the real-life application of the CAPCE Resource Nurse role.

**Coaching Questions:**

**Section 1: Learner Goals**
1. Why did you choose to take the Enhanced program?
2. What are your learning goals?

**Section 2: Learner Experience**
1. Do you have any questions about the Enhanced course and your responsibilities?

**Section 3: The Role of the CAPCE Resource Nurse**
1. Do you have any questions about the role of the CAPCE Resource Nurse?

**COACHING SESSION 2: LOOKING FORWARD**

**Purpose:** To review and discuss the questions the learner has completed as part of e-Learning Modules L and M. The intent is that by the end of this session, the CAPCE Coach will be able to judge if the learner has successfully completed the Enhanced program and if they are an appropriate candidate for the CAPCE Program.

**Coaching Questions**

**Section 1: Check in**
1. Do you have any questions related to the content that you’ve covered in the last few weeks?

**Section 2: Assessment**
1. Think about the person with a past history of diabetes, congestive heart failure, and recent diagnosis of lung cancer. His PPS is 40% and his ESAS-r scores indicate:
   - Pain – 6/10
   - Tiredness – 5/10
   - SOB – 8/10
Taking into consideration the information in the previous slides and knowing the person’s PPS and ESAS-r scores, what would you do to further assess this person?

2. A person with CHF, diabetes and cancer of the lung has received 4 chemotherapy treatments and his ESAS-r for nausea and vomiting is 7/10 and appetite is 9/10. What are the most important elements of the comprehensive assessment that you would initiate in this case?

3. A woman has ovarian cancer and has not had a bowel movement for 5 days. She has had a sudden decline of PPS from 60% to 30%. Her ESAS-r scores are:
   - Pain – 8/10
   - Fatigue – 8/10
   - Appetite – 10/10
   - Nausea and Vomiting – 8/10
   - Bowels – 10/10

What are the most important elements of the comprehensive assessment that you would initiate in this case?

**Section 3: Pharmacological Review**

1. In your current role, what three challenges do you experience as it relates to applying the principles of symptom management to persons in your care?

2. What routes of administration are used most frequently in your practice. Provide a rationale for why these routes are chosen?

3. What’s wrong with an order that states, Hydromorphone 4 mg PO or SC q4h?

**Section 4: Enhanced Wrap Up**

1. Do you feel you’ve met your identified goals? If not, what else do you feel you need to get you there?

2. Given what you’ve learned in this program, what will you do differently as of tomorrow? What do you think will change?

3. Based on your experience with the Fundamentals and Fundamentals Enhanced Programs, what else would you like to learn about?