The Comprehensive Advanced Palliative Care Education

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 Comprehensive Advanced Palliative Care Education Program. The content in this Program Guide is intended to supplement and compliment the resources outlined in the list of the CAPCE Required and Recommended Learner Resources, including but not limited to the Pallium Palliative Pocketbook, Registered Nurses Association of Ontario Best Practice Guidelines and resources from Cancer Care Ontario.

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
- Practical Applications
- In-person Case-Based Learning Sessions
- Coaching

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Introduction to CAPCE
Program Overview

The Comprehensive Advanced Palliative Care Education (CAPCE) initiative is designed to align with the Model to Guide Hospice Palliative Care and supports the outcomes of the Palliative Care stakeholder planning day November 27, 2002. CAPCE is sponsored by the Ministry of Health and Long-Term Care through the Palliative Care Initiatives of Ontario.

Eligibility Criteria

In order for the Nurse Practitioner (NP), Registered Nurse (RN) or Registered Practical Nurse (RPN) to be eligible to participate in the CAPCE program, the following attributes/experience will be considered:

- A minimum of 1 year experience, (or equivalent as determined by the CAPCE coordination office), caring for people with a progressive, life-limiting illness
- Ability and interest to function as a leader and mentor, providing primary level support and enhanced-level knowledge and skills for care team members in his or her organization
- Ability and interest to coach others, facilitate change and be a role model
- Sensitivity to the impact of attitudes, behaviours, life experiences, values, thoughts and feelings on the well-being and quality of life from the perspective of all partners in care
- Ability to listen, learn from others, to question self and others, and identify new approaches
- Ability to solve problems and take action to provide the best care possible
- Ability to learn and develop, both personally and as part of a team and organization
- Ability to engage in self-directed study and independent research using resources such as libraries, the Internet, peers and subject matter experts

To help ensure his or her success, the NP, RN or RPN also requires the following from his or her organization:

- A commitment of leadership to support and enable improvements to hospice palliative care
- Ongoing support and encouragement from those in leadership positions as well as peers (e.g., support for pain assessment, management and staff education)
- Removal of barriers to learning i.e., work with the most appropriate physician to be a part of the team, scheduling of staff to facilitate attendance at education sessions
- Assistance with the transfer of new skills and knowledge to the work place

Additionally, the NP, RN or RPN must:

- Have access to an Internet-enabled computer
- Have working knowledge of basic computer programs (e.g. Power Point, Word, Internet Explorer)
- Be a part-time or full-time employee currently caring for persons requiring hospice palliative care
- Have completed The Fundamentals of Hospice Palliative Care program (including the Enhanced Modules developed in 2013) or equivalent as determined by the CAPCE Program Team
- Be available to complete all components of the program
- Connect with the CAPCE Coach, throughout the program duration (via teleconference, one-to-one, etc.)

Performance Objectives

Following active participation in all components the CAPCE learner will practice as a competent hospice palliative care Resource Professional and support the development of skills among his or her peers. To demonstrate an understanding of the essential and basic steps of a therapeutic encounter, the CAPCE learner will:

1. Serve as a resource nurse sharing knowledge by engaging in the following activities to the extent that he or she is able to:
   a. Collaborate with peers in problem solving and the development of an individualized plan of care that responds to the identified needs of the person/family
   b. Identify gaps in care delivery both at the bedside and within the organization, and considers strategies in response to identified gaps and needs
   c. Communicate organizational gaps and issues and possible problem solving strategies to management in an effort to enhance delivery of hospice palliative care within the organization
   d. Advocate for improved delivery of hospice palliative care within the organization

2. Complete an assessment to the extent he or she is able to:
   a. Utilize appropriate screening questions and assessment tools in data collection related to the domains of issues
   b. Complete a comprehensive history of the person detailing information about health and symptom status, potential cause, associated expectations, needs, hope and fears, and the perceived benefits and burdens of any previous therapeutic interventions for issue or opportunity (including the disease), as well as information about adverse events and allergies
   c. Organize and think critically about the assessment findings to prepare for information sharing
3. Share information to the extent he or she is able to:
   a. Determine, document and respect confidentiality limits defined by the person
   b. Determine what the person and family caregivers already know
   c. Assess and document the desire and readiness for information sharing
   d. Develop a process and documents a plan for sharing information in a timely manner in a setting where privacy can be ensured, and in a language and manner understandable and acceptable to the person and his or her family
   e. Determine and document the need for translation
   f. Observe and document the physical and emotional reaction to information provided
   g. Assess the understanding of information shared with the person and family
   h. Determine and document the desire for additional information

4. Assists in the decision-making process to the extent that he or she is able to:
   a. Demonstrate through documentation that the components of consent, disclosure, capacity, and voluntariness have been met
   b. Assess and document decision-making capacity regularly
   c. Determine and document the legal substitute decision-maker and verifies knowledge of substitute decision-making legislation
   d. Determine who the person wants to include in the information sharing and decision-making processes
   e. Encourage discussion related to values, goals and wishes
   f. Discuss and document current wishes and clarifies the person’s and/or family’s goals for care on a regular basis
   g. Collaborate with the person and/or family to prioritize identified issues
   h. Offer and explain therapeutic options in order to obtain informed consent as the person’s condition changes
   i. Discuss and document requests for withholding or withdrawing therapy; therapy with no potential benefit; medical assistance in dying with the person and family
   j. Develop a plan for conflict resolution when needed

5. Engages in care planning to the extent that he or she is able to:
   a. Determine and document wishes related to the person’s preferred setting of care
   b. Develop a process to negotiate and determine a plan of care that:
      » Addresses issues and opportunities and delivers chosen therapies

6. Engages in care delivery to the extent that he or she is able to:
   a. Support family and friend caregivers in their potential role as part of the care team
   b. Support formal caregivers so they may be competent and confident to provide care
   c. Document that care is aimed at meeting the goals of the person and family
   d. Identify team members who will provide leadership, coordination, facilitation and support
   e. Organize learning strategies to meet the needs of caregivers
   f. Identifies community resources including secondary level consultants/educators and demonstrates knowledge of how to access and utilize services
   g. Develop a written plan of care
   h. Ensure that mechanisms are in place to communicate the plan of care and information among all health care providers and family caregivers and across all settings of care
   i. Regularly review care delivery and adjusts the care plan to compensate for changes in the person’s and his or her family’s status and choices

7. Confirms understanding of, and satisfaction with the treatment plan to the extent that he or she is able to:
   a. Document the person’s and his or her family’s understanding of the disease process and the expected course of the illness
   b. Document the level of satisfaction of the person in relation to the plan of care and the delivery of care
   c. Determine the perceived complexity of the treatment regime and document concerns, questions and issues raised
   d. Determine and documents any expressed level of stress
   e. Determine and documents the ability of health care providers and family caregivers to participate in the plan of care
   f. Document the therapeutic interventions and advocate for further intervention when goals and expectations are not met
The National Model to Guide Hospice Palliative Care

The practice of hospice palliative care is relatively recent in Canada, emerging in the 1970s out of a recognized need to provide specialized care for the dying. It's evolution eventually led to the development of the Hospice and Palliative Care Association’s (HPCA) Model to Guide Hospice and Palliative Care: Based on National Principles and Norms of Practice (referred to as “the model” herein). Over the past ten years through the collaboration of experts from across Canada, the model was developed to help guide individuals and institutions in the provision of effective palliative care. The hope for the model was to change the understanding of hospice palliative care from simply “care for the dying,” towards “care that aims to relieve suffering and improve quality of life throughout the illness and bereavement experience, so that patients and families can realize their full potential to live even when they are dying.”

The Model to Guide Hospice and Palliative Care was built on an understanding of health, the illness and bereavement experiences, and the role hospice palliative care plays in relieving suffering and improving quality of life.

The model recognizes the need for an understanding of how people experience health and illness, and how the healthcare system responds. As illness dramatically alters the lives of the person and his or her family through the experience of suffering, loss and quality of life, there are multiple complex issues that must be considered. These can be categorized into 8 domains: physical, psychological, social, spiritual, practical, disease management, end of life care/death management, and loss/grief.

The model has defined hospice palliative care as a practice that aims to relieve suffering and improve the quality of living and dying. Although the role of hospice and palliative care arose out of a need to provide caring for those at end of life, it must be available to the person and family throughout the experience of illness and bereavement. Each person is an individual, who defines his or her own quality of life. The model views both life and death as providing opportunities for growth, learning and strengthening communities.

The key principles guiding the model are person and family focused care; quality, safety and effectiveness; adequate and accessible resources; collaborative care from knowledgeable staff; advocacy; and research-based practice. In addition to this, the three foundational concepts: effective communication, effective group function, and the ability to promote and manage change, enable hospice palliative care to meet the needs of the person and family.

This model is the underlying framework for the CAPCE program. It enables clinicians to be competent at identifying issues faced by the person and his or her family, skilled at providing the core competencies of hospice palliative care based on best practice guidelines, effective at outcomes assessment and documentation. CAPCE uses this model to ensure a consistent and comprehensive approach to developing the skills and competencies for the development of a nurse leader and mentor in hospice palliative care.

Foundational Concepts of Hospice Palliative Care

Hospice palliative care is based on three foundational concepts: effective communication, effective group function, and the ability to promote and manage change:

1. Effective Communication

Effective communication is fundamental to the process of providing care. Though acquiring skill is critical to the delivery of hospice palliative care, skill is not enough. Communication involves dynamic interactions, of which clinicians are not entirely in charge. How the person understands and views the world and his or her communication styles will have a profound effect on any given interaction.

Clinicians are, at the very least, bi–cultural in communication styles. In childhood communication is shaped by cultural experience including a blend of ethnicity, national origin, generation, and gender. When clinicians are trained they are introduced to a new subculture with its own particular communication styles.

To be effective communicators in hospice palliative care, we must:

- Share a common language and understanding of the terms used in the process of providing care
- Use a standardized protocol to communicate, to actively listen to, and to respond to the reactions that information creates
- Collect data that documents the person’s and family’s status and provides a record of each therapeutic encounter
- Educate persons, families, and caregivers using strategies that are built on the principles of adult education

2. Effective Group Function

Effective group function is dependent on effective communication, negotiation and discussion, and requires each member of the team to be willing to consider the viewpoints of others. By working together, the members of the interprofessional team can form a composite picture of the person and his or her family whose care they have undertaken.
The family is the centre of the team and at the same time is the focus of care. A person’s life threatening illness affects the whole family; however, the stresses on the family are different than the stresses on the person. Therefore the needs of each must be assessed independently.

In addition to the person and family and the interdisciplinary team of primary providers, hospice palliative care includes regional teams of hospice palliative care secondary level consultants/educators. Each organization’s management team, committees and workgroups as well as local committees and regional networks support the system in which care is delivered.

3. Ability to Facilitate Change

Hospice palliative care providers aim to help those living with life threatening illness manage the challenges and opportunities that are encountered on the journey. The nurse has the opportunity to affect change in long-term care homes and agencies as well as in the experience of illness for persons and families. The nurse is frequently a navigator throughout the illness trajectory of a life-threatening disease.

The nurse cannot directly change the experience of illness for the person; however, the nurse can, through ongoing therapeutic encounters, enable the person to live and to die with as much quality the person is capable of experiencing.

We can advocate for the best that medical science has to offer in easing the physical suffering, promote referral to colleagues with expertise in other aspects of caregiving, and share the wisdom garnered from the experience of having cared for others in their dying.

Developing knowledge and skill in the art and science of hospice palliative care promotes a greater sensitivity to the holistic needs of the person and family. Pain, suffering, and loneliness do not have to characterize the experience of dying. The nurse plays an important role in delivering person centered care that can lead to a peaceful end-of-life transition into death and a healthy grief process for the family and the community.

Recall the book Tuesdays with Morrie where Morrie, a dying professor, acted as a coach and mentor for his learner, Mitch Albom. During the course of their career, health care providers will have the opportunity to meet dying people who live and die like Morrie and others who choose not to live and die like Morrie. Some people will inspire health care providers to continue their own personal growth in an effort to live their lives more fully open to love, patience, honesty, and compassion; others may help solidify personal views on how not to live and die. Regardless, everyone has a lesson to impart.

A Framework for Development of Hospice Palliative Care Expertise

The Framework for the Development of Hospice Palliative Care Expertise describes the settings, qualifications and role expectations of health care providers practicing as primary caregivers, resource professionals, secondary consultants and educators, and tertiary consultants and educators. When primary providers encounter care issues and situations beyond their level of confidence and expertise, they must be able to seek help and support from practitioners with greater knowledge and expertise.

This framework has been adapted from the Canadian Hospice Palliative Care Association “A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice” which outlines the roles of providers involved in delivery of hospice palliative care and was produced after 10 years of collaboration and consensus building.
# Chapter 1: Introduction to CAPCE

## Chart 1.1

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<th>Palliative Care Expertise</th>
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| **Primary Caregivers**   | • Manage disease  
• Identify Issues  
• Provide core competencies  
• Advocate for person and family  
• Make referrals as needed |
| **Resource Professionals** | • Demonstrate proficiency in core concepts  
• Promote and champion hospice palliative care within their role and work setting  
• Assist mentors and peers in identifying issues and problem solving  
• Advocate for best possible care for the person and family |
| **Secondary Consultants/Educators** | **District:**  
• Experienced members of a designated hospice palliative care team/unit/program employed on a full time or part time basis in palliative care and associated with a secondary or tertiary level facility. (For example, Regional Palliative Pain and Symptom Consultants/Educators)  
• Qualifications: Discipline specific certification in hospice palliative care or equivalency in knowledge, Canadian Nurses Association Hospice Palliative Care Nursing Certification, skill and experience.  
• Minimum requirement: Comprehensive Advanced Palliative Care Education (CAPCE) for nurses or Learning Essential Approaches to Palliative and End-of-Life Care (LEAP)  

**Regional:**  
• Experienced member of a designated hospice palliative care team/unit/program in a large urban centre employed exclusively or primarily in Palliative Care.  
• Qualifications: Discipline specific certification in Hospice Palliative Care or equivalency in knowledge, Canadian Nurses Association Hospice Palliative Care Nursing Certification, skill and experience. |
| **Tertiary Care Consultants/Educators** | • Consult on difficult to manage cases  
• Educate and train secondary and tertiary experts and develop advocacy strategies  
• Design and conduct research |
CAPCE Program Guide

Notes


Introduction to the Nurse’s Role on the Team

A nurse accompanies the person and family throughout the illness trajectory. A nurse provides support and care for those with symptoms being investigated, receiving diagnoses, during surgical interventions, discussing prognostication and planning care. Often the nurse is at the bedside during periods of crisis and in the last hours of life.

Regardless of the setting in which hospice palliative care is being delivered, the person and his or her network of support are the focus of care. The person with the life-threatening illness determines who is part of their network, who will have access to information and be part of the decision-making process. The nurse’s role is to ensure that the standards of confidentiality are met and honour the person’s right to determine his or her own network. The nurse also helps to identify goals and work collaboratively to identify interventions that will help achieve those goals.1

With his or her advanced knowledge and skill in hospice palliative care, empathy and compassion, the CAPCE learner demonstrates leadership and engages in therapeutic encounters that over time build a therapeutic relationship of mutual trust. By ensuring that opportunities to actively participate in decision-making are provided to the person and family (with the person’s permission), the nurse empowers both the person and his or her family to inform and direct the shared hospice palliative care experience.

By being fully present, the nurse can actively listen and be mindful to the person and family. The nurse then will translate those insights into care strategies that will better meet the identified goals, and in doing so, can then help to bring some measure of peace and recognition of life’s meaning, provide comfort to family and friends and provide more person-centred and meaningful care.

Leadership

The nurse must practice within seven professional standards according to the College of Nurses of Ontario2 including: accountability, continuing competence, ethics, knowledge, knowledge application, leadership, relationships and professional relationships.

1. **Accountability:** Show accountability by sharing knowledge and expertise with staff, maintaining their competence, and facilitating, advocating and promoting the best care for the person.

2. **Continuing Competence:** Maintain competence by investing time and effort to increase knowledge and skill and advocating for change in the workplace.

3. **Ethics:** Follow the mandate to identify and report ethical issues and look introspectively to identify personal values and beliefs so to not conflict with professional practice.

4. **Knowledge:** Be knowledgeable of the roles on the interdisciplinary team, the health care system, the government legislation and standards. Use research to inform professional practice and the knowledge of where and who can be confided in as a resource for information and advice.

5. **Knowledge Application:** Recognize any abnormal response and take action utilizing best practice guidelines. Recognize professional limitations and create care plan that address the needs, wishes and hopes of the person and family.

6. **Leadership:** Model professional values, beliefs and attributes and provide coaching and mentoring to novice nurses. Advocate, collaborate and develop therapeutic relationships with the person and family.

7. **Professional Relationships:** Maintain collegial relationships and develop knowledge networks.

Leadership is defined as a relational process in which an individual seeks to influence others towards a mutually desirable goal.3 The Transformational Leadership Practices outlined by the Registered Nurses Association of Ontario include the ability to build relationships and trust, create an empowering work environment, create an environment that supports knowledge and skill development and integration, lead and sustain change, and, balance competing values and priorities.4

The nurse needs to continually develop his or her personal resources by exercising strong professional standards, by developing personal leadership characteristics, by developing leadership skills and mentoring others to do the same, and by engaging in professional and personal self-care.

**Coaching and Mentoring**

The CAPCE program integrates coaching and mentoring for nurses to help them embrace their professional standards and demonstrate leadership skills as they evolve into the leadership and mentoring role.

Developing leadership can be accomplished through coaching and mentoring; these are two different methods that make up part of a nurse’s role when practicing.

**Coaching** can facilitate learning by providing support and guidance for nurses to utilize their skills and knowledge more effectively. Coaching involves a process of sharing knowledge and working with another as new skills are practiced in a supportive environment.5 It is often used to help the transfer of skill and knowledge into the workplace.
Coaching strategies can be utilized at all levels of experience. Less individualized than mentoring is, coaching can assist with career progression, coping with organizational changes, the development of new skills, and problem solving. Coaching is one of the most important methods of offering support to families and other caregivers.

Mentoring takes more of an advisory function and focuses more on collaborative problem solving and critical thinking than coaching. Mentoring results in the development of a relationship where both parties share, learn and grow together through four stages: initiation, separation and redefinition. Mentoring can be a lengthy process but can significantly enhance career development and is an important method to offering support and learning opportunities to other care providers.

A Nurse’s Role in a Therapeutic Relationship: Understanding the Therapeutic Relationship

Hospice palliative care is based on the development of a therapeutic relationship between skilled health care providers and the dying person and his or her family. The Registered Nurses Association of Ontario (RNAO) Best Practice Guidelines (2006) defines the therapeutic relationship as “an interpersonal process that occurs between the nurse and the client(s)”. The “therapeutic relationship is a purposeful, goal directed relationship that is directed at advancing the best interest and outcome of the client”. In hospice palliative care the therapeutic relationship can be understood as a creative process aimed to positively change the experience of illness and bereavement. The knowledge and skills needed to deliver a wide range of therapeutic interventions make up the art and science of palliative care nursing. Additionally, the development of successful therapeutic relationships requires continuity since relationships build over a period of successful encounters.

The therapeutic relationship that occurs within the context of hospice palliative care can be understood as a journey that brings many lessons to the dying person, family and health care providers. In his research and experience working with dying people, David Kuhl (2006) established that dying people want the same thing that living people want; central to the therapeutic relationship are the core concepts of reciprocity, self-awareness, awareness of boundaries, empathy and validation, and establishing trust and confidentiality. The concept of ‘therapeutic use of self’ can also help build the connection between the nurse, the dying person and his or her family, as the nurse draws on personal communication styles and individual strengths during interactions. The sense of connection, shared experience and understanding can have profound impact on the dying person, family and caregivers within the hospice palliative care context.

The Three Phases of Therapeutic Relationships

Understanding the sequencing or phases of a therapeutic relationship can be helpful in developing the therapeutic process in hospice palliative care. The RNAO Best Practice Guideline (2006) leverages nursing theorist Peplau’s understanding of the therapeutic process as taking place in three distinct phases: Orientation, Working and Resolution which are essentially the beginning, middle and end-of-the therapeutic journey.

Phase 1: Orientation – Initiating and Developing Therapeutic Relationships

WHAT – Characteristics and Considerations

In this phase of the therapeutic process the nurse, person and his or her family are getting to know one another. They each bring their own set of values, expectations and previous life experiences. This is the point in which relationship parameters and boundaries are set. Open communication, trust and respect help to establish a sense of partnership, thus setting the stage for deepening a therapeutic relationship. In this phase the Palliative Care Nurse gathers key information from the person and family, working collaboratively to prioritize and address that which is most important to the dying person and family.

HOW – approaches, qualities, competencies and skills

- Introduce yourself by name to the person and family, and ensure that you are addressing each of them by their preferred names and/or titles.
- Listen to the person with the intent to truly understand his or her feelings and experience, refraining from immediately giving advice.
- Gain a broad understanding of the person’s abilities, limitations and needs related to his or her health condition, as well as their level of knowledge, beliefs and wishes in order to help find the best possible care solution. (i.e. What does quality of life mean to this particular person at this stage in his or her life?)
- Establish and seek a mutual understanding, setting boundaries
at the onset of the therapeutic relationship. Based on the principle of information sharing discuss with the person and family or other caregivers, your role as a nurse and the perceived expectations of both the person and family and the nurse.

- Provide information about confidentiality and sharing information within the health care team, identifying the circle of care.
- Approach the relationship with self-awareness and continual self-reflection. Consider verbal and non-verbal communication, cultural values, biases and life experiences that may shape perspectives and impact the relationship. (i.e. What are the person's views about death? What fears might you yourself have about death?)

**Phase 2: Working – Maintaining Therapeutic Relationships**

**WHAT – Characteristics and Considerations**

Once the therapeutic relationship has been established, the nurse and the person and his or her family can move into a working partnership. Intervention typically takes place in this phase. The process is rarely linear, as positive change can alternate with resistance or lack of change. The nurse continues to establish a deeper level of trust through demonstrated commitment to work with the person and his or her family regardless of where they are in their personal journey. Assessment continues throughout this stage as therapeutic relationships develop, changes occur and new priorities emerge.

**HOW – approaches, qualities, competencies and skills**

- Actively listen, demonstrating understanding and respect for the values, opinions, cultural beliefs, concerns and on-going needs of the person and family. Integrate this into all aspects of care planning.
- Promote choice, preference and self-advocacy. Enable the person to make informed decisions. Actively including the person as a partner in care ensures that the person is considered the expert on his or her life.
- Recognize that all behaviour has meaning and seeking to understand behaviours that are out of the ordinary by looking beneath the surface. (i.e. Is the person in pain and unable to communicate this in a coherent way?)
- Demonstrate commitment and consistency, advocating for and acting on the person's concerns when appropriate (i.e. if pain is not being adequately addressed).
- Reflect on how stress can affect the therapeutic relationship. Manage stress and emotions through strategies and debriefing with colleagues.
- Maintain professional boundaries:
  - Help the person to understand when requests are beyond the limits of the therapeutic relationship
  - Avoid self-disclosure unless it meets an identified therapeutic need

- Ensure that any approach or activity that could be perceived as a boundary crossing is documented in the care plan
- Clarify personal role in the therapeutic relationship, especially in settings or situations where boundaries may be less clear to the person (i.e. providing care in a person's home, or accompanying a person to a funeral)
- If difficulty arises in establishing a therapeutic relationship seek support or request a therapeutic transfer of care if necessary

See Practice Standard on Therapeutic Nurse-Client Relationship from the College of Nurses Of Ontario (2006) for more information on Maintaining Boundaries.

**Phase 3: Resolution – Ending a Therapeutic Relationship**

**WHAT**

In the final phase of the therapeutic process, following the person's death, the nurse and the family must end the therapeutic relationship. Once care has been provided to the best of the nurse's ability or what has been defined within the scope of their role, there must be a natural and appropriate transition to end care. This ending is based on an agreement that goals have been met and understanding has been reached. In the hospice palliative care context this may include saying goodbye to the dying person and referring the family on to other individuals such as a grief counselor. This cessation of services may bring a sense of ambivalence, loss and feelings related to ending the relationship with the family. The nurse must balance professionalism with being sensitive in this situation.

**HOW – approaches, qualities, competencies and skills**

- Ensure that quality of life, dignity and needs of the person and family are being met by debriefing experiences with the family and other health care providers as appropriate.
- Discuss ongoing plans for meeting the family needs after the person has died for example, referral to other services and or community organizations.
- Reflect on boundary issues and the therapeutic relationship towards the end of the therapeutic process. (i.e. Is it appropriate to attend the persons funeral?)
- Reflect on interactions with the dying person and the health care team, and invest time and effort to continually improve communication skills.
Self-Care

Self-care means to take care of one’s self by reflecting on and participating in meaningful activities that promote health, well-being and life-balance (i.e. rest and relaxation, exercise, yoga, meditation, spiritual practice, spending time with people you care about etc.). There can be many benefits to engaging in regular; for example, stress reduction, improved coping skills, and more enjoyment and meaning in life. It can be difficult to take time out of a busy schedule for self-care, however a commitment to self-care can increase your energy and ability to focus on work, family and other meaningful aspects of your life.

Nurses need to develop their own self-care practices as a preventative measure and to maintain health and happiness. Taking care of one’s self enables one to be his or her best self. Not only does this benefit the individual, but it can also have an enormous impact on the quality of care that one provides to others.26

Often times those who spend their lives caring for others forget to take the necessary time to care for themselves. This can leave them vulnerable to stress, compromising health and happiness. Nurses and all those in healing professions are particularly at risk, as they are often exposed to stressful experiences with the person and family, as well as the challenges of the health care system. If a person is not taking care, these stressors may lead to feeling emotionally drained, burnt out and exhausted.

Compassion Fatigue

Also known as secondary traumatic stress, Compassion Fatigue (CF) can be defined as reduced physical, psychological and spiritual functioning resulting from the experience of caring for individuals who are suffering. As a consequence of providing empathic care, the nurse may absorb the experience of pain and suffering of the person and family.

CF is related to what is known as ‘burnout’, however there are some key differences. Sabo defines burnout as “a gradual wearing down of the individual over time, whereas CF has an acute onset”. Typically burnout is more a result of the work environment rather than a “consequence of caring for people who are suffering”, although burnout may lead to compassion fatigue. Someone who is suffering from burnout generally begins to withdraw emotionally, and loses the ability to be empathic.

Anyone who works in a healing profession, providing empathetic care is at risk of developing compassion fatigue. According to Sabo, “empathy becomes a double-edged sword for the nurse or clinician; on one hand, empathy facilitates caring work; on the other hand the act of caring leaves the nurse or clinician vulnerable to its very act.”

There are other factors that may leave some individuals more susceptible; some of these factors may include lack of time, less years of experience and or level of education and lack of institutional support. Other factors such as having a tendency to become over involved, not having a solid set of coping strategies, not regularly engaging in activities that replenish the self (physically, mentally, emotionally and spiritually) and having difficulty with learning new skills may also contribute to developing CF. In addition, those who bring unrealistically high expectations to a job are often at-risk.

Preventative Measures include assessing what it is that is affecting you, how it is affecting you and what might be done to improve the situation. Lombardo and Eyre believe self-assessment helps one to gain insight into stressors that contribute to CF, and may help with prevention and/or recovery. A recovery plan that includes personal reflection, identifying meaningful activities that are enjoyable and health promoting, and enhancing support systems is recommended. In addition, strengthening your communication and interpersonal skills can help you address issues and advocate for your own health and well-being in the workplace.

Moral Distress and Moral Residue

Moral Distress occurs when a person is unable to act in a way that they feel is ethical or appropriate as a result of the constraints that have been placed on them. These are often systemic barriers or decisions that are out of their control. Examples of situations that could cause moral distress include:

- The person is continued on life support even though it is not in their best interest
- Staffing is inadequate, people are over-worked and thus care is compromised

Moral Residue results from lingering moral distress. Epstein and Delgado explain that “when one's moral values have been violated due to constraints beyond one's control” there remains a wound that can be damaging to one’s view of self over time. Moral distress occurs as a reaction to an ethical conflict, whereas moral residue refers to the impact on the individual over time.

Preventative Measures include enhancing communication skills (i.e. speaking up and voicing concerns), accepting accountability and building stronger support networks. In addition to this, it can be helpful to focus more on system-level issues and policy rather than on individual situations.
Education and interprofessional collaboration also helps prevent moral distress/residue.39

**Hardiness and Resiliency**

Developing the traits of ‘Hardiness’ and ‘Resiliency’ is important for the nurse in order to protect oneself from CF and moral residue. Hardiness refers to one’s ability to remain healthy under life stress,40 whereas resiliency can be understood as one’s ability to bounce back from difficult experiences. Laskowski-Jones believes that the key to personal resilience involves “how we choose to let these distressing episodes affect us, as well as what we as individuals and members of the nursing profession do together to alleviate the damaging effects41 helps individuals to cultivate both hardiness and resiliency in order to cope with the demands of their job and the healthcare system”.

**Self-Care Strategies and Suggestions**

1. Set limits and stick to them. Learn what you need to feel well at work and how to communicate this with others. (i.e. a quiet space, a debriefing session, etc.)
2. Create an environment where you can get away (i.e. a quiet space at work or home) and build time into your routine that allows you to decompress.
3. Be kind to yourself: Eliminate “I should’s” – Instead try “I could”.
4. Engage in regular self-reflection – Ask yourself key questions (i.e. “How can I feel more relaxed and at peace?” “What activities make me feel good?” “What needs to change in my environment to promote more healing?”)42
5. Get to know yourself better and try not to confuse what you do with who you are.
6. Involve yourself with life outside of work; develop other skills and hobbies, and get involved with projects that are meaningful to you.
7. Listen more and strive to be less reactive.
8. Try to see challenges as learning opportunities.
9. Participate in activities that make you feel good. (i.e. try a yoga class, a creative writing course, reading a good book, spending time with family or in nature, or doing whatever it is that has meaning for you!)
10. Strengthen support systems by:
   - Seeking out a colleague or mentor at work: Who can I call (at 2 am? 6 am? 10 am? 10pm?) when I am in crisis? Who is a good listener?
   - Finding a counselor. Most hospitals have an Employee Assistance Program (EAP) that will provide you with professional support if you need it.
   - Speaking with pastoral care or a spiritual leader in your community.
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References


Chapter 2: The Nurse's Role


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3
Assessment
Therapeutic Encounter: Assessment

Assessment of the person and family is the first step in the therapeutic encounter. It is the foundation upon which all interventions are determined. The nurse uses assessment to determine the person's needs, actual and potential, what assistance the person and family may require, and the desired outcomes of the care to be provided. This is recognized as a starting point for establishing and determining the nature of the therapeutic relationship.

Both the process and content of assessment are important. Process includes communication paired with physical assessment skills, in order to establish a relationship and gather needed information. The content will vary with the person, but generally includes physical assessment, collection of diagnostic data, and assessment of the meaning of the illness experience, quality of life, symptoms, and cultural factors that may affect the person's well-being.

The nurse obtains information from:

- The person and family
- The health care record, including diagnostic results, lab results, and other clinical investigations
- Reports provided by unregulated health care providers and family caregivers
- Observation of the person's surroundings and space

The key to obtaining information from the person is to allow him or her to “tell the story” in his or her own words, taking care to observe the person's actions and behaviors, and nonverbal cues as well.

Thinking Critically and Conserving Dignity

A nurse conducting an assessment in palliative care will need to approach the task with two overarching concepts in mind.

1. Thinking critically
2. Conserving dignity

Thinking Critically

Critical thinking is a higher class of thinking using several advanced thinking skills in diverse ways. It differs from regular thinking in focus, activity and the goal. Critical thinking focuses on ideas, assumptions, biases, flaws in reasoning, point of view, context and implications in order to deepen and broaden questions and test the ways ideas are formed, interpreted and examined. The process of thinking critically in palliative care requires the deliberate and strategic application of criteria to help form a conclusion or evaluate thought processes. Thinking and assessing is logical and attentive to personal perspectives as well as the perspectives of others.

Some strategies that can help the nurse think critically throughout his or her assessment work include:

- **Think Deeply:** Look deeper into assumptions and values and broader when connecting theories to disciplines to challenge initial conclusions
- **Think Critically:** Develop questions and challenge initial conclusions
- **Think Systematically:** Think through your answers systematically (e.g. analysis, synthesis, interpretation, and evaluation) and engage in self-reflection (e.g. is that really true? Do I need to be more specific or detailed?)

The nurse needs to be thinking critically throughout history taking and assessment.

Conserving Dignity

“The secret of the care of the patient is in caring for the patient.”
- Francis W. Peabody

The person experiences a sense of dignity if they feel they are being treated with respect. It is most important for the nurse to value the person for both who they were and who they are. This type of care is sometimes classified as spiritual or psychosocial and as a result, health care providers may be cautious in providing this type of care claiming lack of knowledge, time or comfort.

A Canadian psychotherapist, Harvey Chochinov, identifies that all health care providers can improve the person's sense of dignity by following the A, B, C and D of dignity conserving care.

A:  Attitude

The nurse needs to look at his or her own beliefs and attitudes towards the person and ask the following questions:

- How would I be feeling in this person's situation?
- Could my attitude towards the person be based on something to do with my own experiences, anxieties, or fears?
B: Behaviours

The nurse needs to modify his or her behaviours based on this new understanding of how their beliefs and attitudes affect their perception of the person. Simple expressions of kindness, being attentive during conversations, asking permission to perform an exam or provide personal care indicates that you respect their opinions and needs.

C: Compassion

The nurse needs to reflect on his or her own feelings of suffering, illness and death. This reflection happens over time and often through life experiences, exposure to death in clinical settings and the reality of our mortality as we age. Taking the time to listen to personal stories, touching (with permission) and looking at the person can exhibit compassion.

D: Dialogue

The nurse, utilizing newfound skills, attitude, modification of behaviours and compassion, will find that communication will start to flow more freely. For example, simply stating: “This must be frightening for you” affirms and acknowledges their feelings. The most important question is “What should I know about you as a person to help me take the best care of you that I can?”

Chochinov has developed a therapy called Dignity Therapy. The purpose of this therapy is to provide for the person and family a written document that is a culmination of their most important life relationships, experiences and feelings. Dignity Therapy is now provided in Canada, the United States, Denmark, England, Scotland, Portugal, Spain, China and Australia. The therapists have found the conversations that inform the document to be profound.

Some examples of the questions asked in Dignity Therapy are as follows:

- Tell me a little about your life history; particularly the parts that you either remember most or think are the most important? When did you feel most alive?
- Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
- What are the most important roles you have had in life (e.g., family roles, vocational roles, community-service roles)? Why were they so important to you and what do you think you accomplished in those roles?
- What are your most important accomplishments, and what do you feel most proud of?
- Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?
- What are your hopes and dreams for your loved ones?
- What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your son, daughter, husband, wife, parents, or other(s)?

“This is no ordinary conversation you have just taken part in, nor ordinary disclosure you have just heard. They represent a lifetime’s accumulation of experiences and insights and, if you have done your job right, they have the potential to resonate across generations to come.”

– Harvey Chochinov

Understanding the Person and Family: The Process

Understanding the person and family are central to providing person-centred care. This understanding starts with a comprehensive history taking and the administration of a general assessment using tools such as the Edmonton Symptom Assessment System (revised) (ESAS-r). The individual characteristics of the person and each member of the family to be considered by the nurse include but are not limited to age, gender, relationships, culture, socioeconomic status, education and literacy, and disabilities.

The nurse needs to gain an understanding of the characteristics, needs, and expectations of family members as well as the person. It is important to remember that families suffer too. Many family members assume responsibilities of caregiving as the dying person deteriorates. They watch the person struggle with physical, emotional, social and spiritual pain. They become exhausted, neglect their own needs, grieve the many losses that become evident as illness progresses, and live in anticipation and fear of the ultimate loss. Both the person and the family experience reciprocal suffering; the suffering of the person amplifies the suffering of the family.

Taking a History

Central to developing an understanding of the person and family is the taking of a comprehensive history. Persons living with life-threatening illness are not a homogeneous group with the same views, needs, symptoms, goals and expectations. Every person who is dying is unique and has a past, a present and a perceived future. In taking a history, it is important to consider age, gender, relationships, culture, lifestyle education, socio-economic status and literacy level, and disabilities of both the person and the family.

The nurse needs to gain an understanding of the characteristics, needs, and expectations of the person and family.
Chapter 3: Assessment

Taking a person-centred approach to history taking and thinking critically about whom the person is should guide the next steps in how the assessment is approached.

There are five essential components for taking a comprehensive history:

- **Chief Complaint:** The person tells you, in their own words, why they are seeking medical help. If the person uses any medical terms, have them define the terms for you to make sure you understand the person’s perception and meaning of those terms. This process could be compared to the ESAS-r where a person identifies the issues that are most troublesome to them.

- **History of Present Illness:** The history includes what has changed in the last days or weeks in the person’s level of health that has led them to seek medical attention. It should answer the questions of what, when, how, where, which, who, and why in relation to their chief complaint. Basically, it will be the story of how they came to the medical situation they are in.

- **Past Medical History:** This is the assessment of the person’s health status before this illness. Include the following: past illnesses (don’t forget childhood illness), injuries or major accidents, hospitalizations (both medical and psychiatric), surgeries, allergies (food, drug, or environmental), immunizations, substance abuse, diet, sleep patterns, and current medications (both prescription and over-the-counter).

- **Family History:** Ask about the age and health of members of immediate family and include the age and cause of death of those who may be deceased.

- **Psychosocial History:** This includes information about education, life experiences, and personal relationships in the person’s life. It includes information about his or her lifestyle, who they live with, spiritual or religious beliefs, employment, and their outlook about their future in light of their diagnosis. The future that is perceived by the person will affect how the nurse is able to influence the dying process.

**Assessment Across The Domains**

Taking a thorough history and completing a physical assessment that crosses all domains is the most important first step when treating physical symptoms. The nurse will need to reassess throughout the illness trajectory as new symptoms or concerns arise, or existing ones may worsen. Changes in the person’s condition can occur rapidly; especially as the disease progresses and the PPS score decreases. The assessment will evolve as the nurse gains the trust of the person and family.

After the nurse has taken a history of both the person and family, there are three key assessment tools that generally should be completed:

1. **Edmonton Symptom Assessment Scale (revised):** The ESAS-r should be documented as part of the history and assessment, and baseline scores established for future comparison. Attention should be given immediately to any scores above 4/10; however all scores are assessed in the current context. For some people, a rating of 1 or 2 may require just as much assessment.

2. **PPS:** The Palliative Performance Scale is a reliable and valid tool that will quickly describe the person’s functional status. The PPS has prognostic significance, and will help guide care planning.

3. **Fraserhealth Symptom Assessment Acronym (OPQRSTUV):** The symptom assessment tool will aid in a systematic approach to assessment of any palliative care symptom.

   - **O**nset
   - **P**rovoking/Palliating
   - **Q**uality
   - **R**egion/Radiation
   - **S**everity
   - **T**reatment
   - **U**nderstanding/Impact on You
   - **V**alues

To be effective at relieving suffering and improving quality of life, the nurse must be able to identify and respond to the complex and multiple issues that the person and family may face. If an issue is missed, it can compound one on another, leading to increased distress and further complications.

The issues commonly faced by persons and families can be categorized into 8 domains, each of which is of equal importance during an assessment. Many tools are available to assess physical symptoms such as pain. The following questions, address the other 7 domains of issues and should guide the nurse’s critical thinking and enhance his or her understanding of the person and family.

**Disease Management:**

- What are the primary and secondary diagnoses?
- What is the PPS score? What does it mean?
- Are there unmanaged symptoms that might influence decision-making?
- Are there any allergies to any medications /environmental?
Psychological:

- What do I need to know about the person to take the best care of them that I can? For example, what crisis have the person and family encountered throughout their life? How did they cope?
- Has the person been treated for depression, anxiety or other psychiatric illness in the past?
- Given what I know about the person, what questions can I ask that will help me understand what he or she is thinking and feeling?

Social:

- Are there relevant developmental issues that require particular expertise such as pediatrics or gerontology?
- Who does the person consider to be part of his or her family, what roles do they have and how has the illness affected them?
- Is there anyone with whom the person wishes to be reconciled?
- Does the person have any concerns regarding sexuality, intimacy or privacy?
- What are the patterns of communication and decision-making in the family?
- What experiences have the person and family already had with illness, disability, death and loss?
- What routines are important to be aware of in terms of personal care?
- What leisure activities, recreation or hobbies add to the person’s sense of well-being?
- What is/was the person’s vocation? Does the person have any financial concerns?
- Are there any outstanding legal issues causing the person concern?
- Have guardianship and custody issues been addressed?
- Does the person have a Power of Attorney for Personal Care? For Property?
- Has the person engaged in Advance Care Planning? Is there a document in which the person has identified wishes? Is the Substitute Decision-Maker and family aware of the wishes?
- Does the person have a will?
- Has the person considered organ donation or what will happen to his or her body after death?
- Would Hospice services be of benefit to the person and or family?

End-of-Life and Death Management:

- Are there any medications, treatments, or tests that should be discontinued?
- Do the person and family understand the reasons for withdrawing or withholding treatments?
- Has there been ongoing information sharing with person and family about what to expect at end-of-life?
- Are the person’s lips and mouth dry or coated? Is the person a mouth-breather?
- Is pain managed?
- Are all symptoms well managed?
- Is there potential for escalation of any symptoms?
- Are medications on hand to address symptoms that commonly present at the end-of-life? (For example, has the Symptom Response Kit been ordered and is in the home?)
- Is there a plan in place for an alternate route for medication administration?
- Is there a high risk for skin breakdown?
- Does the person need a special pressure-relieving surface?
- Does the person find comfort with massage?
- Is incontinence of bowel or bladder an issue?
- Would a Foley catheter prevent skin breakdown and conserve caregiver energy?
- Would the use of incontinent briefs be appropriate to the person?
- Is the person or family anxious or fearful?
• Are there rites and rituals that should be included in the plan of care?
• Do the person and family have access to spiritual care?
• Is there anyone the person wishes to see? For example, does the person want to or need to say goodbye to specific persons?
• Does the person and family want visitors restricted?
• Do the family members want respite? Are they taking care of themselves?
• Is a plan in place for a funeral or memorial service?
• Are there any signs of complicated grief reactions among family members?
• Is the case been coordinated by the CCAC Complex Care Coordinator?
• Is the most appropriate team of nurses caring for the person?
• Has end-of-life care planning been initiated by the nurse team?

Loss and Grief:

• Who will grieve this person’s death?
• What is the relationship between the dying person and the grieving loved ones?
• What are the specific things the person and family is losing throughout the illness? (Anticipatory grief)
• Is this death a risk factor for complicated grief? For example the death of a child, a traumatic death, elderly male widower
• Is the nurse experiencing grief or grieving, what can he/she do to work through the grief as she/ he continues to work skillfully at her/his job?

* The Bereavement Risk Assessment Tool, or BRAT, is a psychosocial assessment tool used by care team members to communicate personal, interpersonal and situational factors that may place a caregiver or family member at greater risk for a significantly negative bereavement experience. This information can be collected prior to the death of the person and used to inform the care team of any immediate concerns regarding caregivers or family members, and may also facilitate the allocation of scarce bereavement services after the death.

Continuing the Conversation

In addition to taking a history and completing a comprehensive assessment, there are a series of conversations the nurse should continue to facilitate with the person and family to better understand their values, beliefs, goals, fears and expectations associated with the disease and subsequent treatments.

For example, the nurse can help the person and family discuss the disease and treatment options, goals, values, beliefs and expectations, fears and concerns throughout the illness trajectory. Through this exploration the nurse can help discern how the person wants to live and die, the wishes of the primary caregiver, and the caregiver burden. With this knowledge the nurse can provide person and family-centred care that will best meet their needs.

The nurse who assists the person and family to identify goals of care provides an important service. It can be difficult for the person and family to conceptualize and articulate goals; the nurse needs to nurture the process sensitively and in an ongoing way. Some examples of goals include:

- Living to the last possible second
- Living until the burden becomes too great
- Living at home with family avoiding medical interventions
- Living as comfortably as possible until death
- Avoiding medical interventions unless they have meaningful outcomes

Once a big picture goal has been identified, the nurse together with the person, family and other team members can begin to identify interventions that will help achieve the goal.

Once the nurse has collected the subjective and objective data, the nurse has to prioritize the needs of the person in order to be prepared for information sharing (the next step in the therapeutic encounter). The nurse accompanies the person and family on the journey. With his or her knowledge and skill, empathy and compassion, the nurse engages in therapeutic encounters that over time build a therapeutic relationship of trust and even affection.

Assessment Tools

There are many tools and frameworks to guide assessment and subsequent information sharing and decision-making. The nurse can use these tools to help collect subjective and objective data, understand the person current state, and anticipate the person’s future state. Refer to the Tools section of this program guide for the tools mentioned in this chapter and many others to support assessment.
References


Therapeutic Encounter: Information Sharing

It is a patient’s and family’s right to be informed about hospice palliative care and what can be offered throughout the illness and bereavement experiences.1

The nurse must be fully informed as to what hospice palliative services are available and, through information sharing, explore with the person and family their readiness and willingness to accept these services.

Information sharing takes place in the context of the person’s current condition with attention also paid to situations that may present in the future. In order to make informed choices, the person must have a clear understanding of his or her disease and progression. Gentle truth telling is advocated.

Most people are willing and able to enter into collaborative decision-making with their health care team. There may be times when a capable individual will designate an alternate decision-maker to receive information and make decisions for them. In such cases it is acceptable for the nurse to share information with the alternate decision-maker. The treatment plan however must be presented to the person if he or she is capable for final consent.

The nurse will work with the person and his or her family (with the person’s permission) to identify questions that need to be asked, to ensure an understanding of the disease, its prognosis, treatment options, the potential benefits, risks, and burdens of each treatment option, and the consequences of the decision to consent to or reject the treatment. If a care conference is scheduled, the nurse will bring forward knowledge of the person’s goals and wishes, as well as other information to help ensure that the physician is as informed as possible prior to meeting the person and family.

By having ongoing therapeutic discussions with the person and family the nurse can ascertain their level of understanding and clarify the meaning of any information provided.

Communication, Conflict and Culture and Information Sharing

Information sharing requires effective communication with the person, family and other members of the care team including the sensitive navigation of conflict resolution and respectful attention to cultural preferences. By practicing effective communication and conflict management skills and by being person-centred, the nurse can effectively remove the barriers to understanding the information being shared.

Effective information sharing enables informed decision-making about care.

Understanding Communication in Hospice Palliative Care

Effective communication has been identified as one of the three foundational concepts of hospice palliative care2 and is essential to the provision of person-centered care to positively impact areas such as decision-making, conflict-resolution, care planning, and person, family, and caregiver satisfaction.

To effectively communicate, the nurse will initiate a therapeutic relationship with the person and family based on the underlying principles of trust, respect, professional intimacy, and empathy.3

- **Trust:** Trust is the foundation of all interpersonal relationships. The nurse must maintain the confidence of the person by following through on agreements. Open and honest communication promotes this trusting relationship.
- **Respect:** Nurses need to ensure the person's dignity by appreciating their unique attitude, feelings, beliefs, and values despite their situation.
- **Professional Intimacy:** Nurses must abide by the *Freedom of Information and Protection of Privacy Act* when providing any type of care or service. This could include but is not limited to personal, spiritual, psychological or social care.
- **Empathy:** Nurses need to validate and echo the illness experience identified by the person. Empathy also includes promoting healthy professional boundaries.
- **Knowledge:** Nurses must understand that because of their knowledge of the health care system the nurse-client relationship is unbalanced. The nurse must use this knowledge appropriately by collaborating with the person to meet his or her needs.

The standards of therapeutic communication can be met through the following strategies that summarize the establishment, maintenance and end of the nurse-client relationship.4 Over the course of the relationship the nurse will:

- Introduce and explain their role on the team.
- Address the person by their preferred name.
- Provide the person time to express their feelings.
- Inform the person that information will be shared with the interprofessional team.
- Be self-aware of personal verbal and nonverbal communication styles.
- Identify the person’s literacy, language, developmental and cognitive status in order to modify communication accordingly.
Work with the person to find the best interventions by considering individual preferences and advocating for the person.

- Provide accurate information promoting informed decision-making.
- Understand and integrate the person’s ethnic and cultural beliefs and values into the care process and plan.
- Include the family and significant others in the plan of care if consistent with the persons wishes.
- Bring closure to the relationship by discussing ongoing plans for meeting the person's/family's needs.
- Assist the person and family to identify other necessary resources with other team members for provision of their ongoing needs.

In addition, The Model to Guide Hospice Palliative Care states that to be effective communicators, health care providers must:

- Share a common language and understanding of the terms used in the process of providing care.
- Use a standardized protocol to communicate, to listen to, and to respond to the reactions that information creates.
- Collect data that documents the person’s and family’s status and provides a record of each therapeutic encounter.
- Educate persons, families, and caregivers using strategies that are built on the principles of adult education.

Developing effective communication skills takes time, observation and practice. The nurse needs to know him or herself in order to better understand, anticipate and temper his or her natural emotions and reactions. The skilled communicator in hospice palliative care should excel at the following:

- Gentle Truth Telling
- Being Comfortable with Silence
- Active Listening
- Being Self-Aware

**Gentle Truth Telling**

Dying is a highly personal, non-medical journey. The person’s autonomy is particularly important during this time, and the nurse can foster autonomy in the art of gentle truth telling. Combining truth with hope and comfort can be very difficult, but deceit, no matter how kindly motivated, leads to despair. Gentle truth telling takes courage; the nurse must be willing to enter into a relationship of professional intimacy and compassion, while encouraging strength and individuality.

**Being Comfortable with Silence**

Silence has an energy to it like no other source, yet it is sometimes felt as awkward, uncomfortable, and time wasting. It is often confused with nothingness or a void. In reality, silence is an important communication skill; learning to use silence wisely in the therapeutic relationship takes time and practice. Silence is not a sense of emptying ourselves, but rather, filling ourselves, and allowing thoughts to focus inward, gaining the power needed to refuel our minds. Silence allows time for true introspection, and this is often when the deepest thoughts and feelings emerge. The ancient Persian poet, Rumi, wrote: “In silence there is eloquence. Stop weaving and see how the pattern improves” (Rumi, 1207-1273).

**Active Listening**

Active listening helps the nurse to obtain important information to engage in a meaningful therapeutic encounter, it allows for the identification of important psychosocial issues with the person and family, and when done well, is an important foundation in a successful therapeutic relationship. Active listening is not a passive activity. It is a learned behavior that is deliberate, intentional, and requires skill and practice. There are five steps to improving your active listening skills:

1. **Concentrate on the person speaking:** Sit close enough to the person to see their face and observe body language. Most communication is non-verbal. Make eye contact; even when it’s not your turn to speak, continue to listen with your eyes.
2. **Avoid trying to think of an answer:** When someone is speaking, give your full attention to what they’re saying, instead of thinking of what you’ll say next.
3. **Eliminate distractions:** Time constraints and pressure are unavoidable, but make every effort to dedicate time and attention to the person and family. Put cell phones and pagers on vibrate, and do not fill out charts or paperwork when the person or family is speaking.
4. **Be respectful:** The person and family have the same goal as you—quality care given and received with dignity and compassion. Listen with a sense of caring to identify the person’s needs and immediate concerns. Validate concerns, and treat the person and family with the same respect you would want if the situation were reversed.
5. **Pay attention to vocal inflections:** The tone of a person’s voice will often tell you more than their words. It may help to identify depression, anger, or may point to physical symptoms, such as pain.
Active listening is a learned behavior, important in the art of hospice palliative care nursing. Active listening will help the nurse fully engage with person and family, make informed decisions, and ultimately, provide better care.\textsuperscript{12}

**Being Self-Aware**

On a personal and professional level, developing self-awareness is an important skill. The foundational basis of good nursing can’t be achieved until the nurse knows himself or herself. Becoming self-aware is a conscious, intentional process by which the nurse enriches the understanding of who he or she is, helping to identify strengths, as well as areas to develop, personal barriers, parameters and limitations. This self-knowledge will enable the nurse to better help others.\textsuperscript{13}

Self-awareness will also help the nurse present professionally in the therapeutic relationship, better recognizing personal knowledge and skills, as well as the limitations that affect the ability to care for others. The self-aware health care provider realizes he or she is knowledgeable and expert in some areas, while acknowledging that he or she is still a learner in others.

Building self-awareness is an ongoing, sometimes painful process, as aspects of self are revealed. Despite personal uncertainties, the nurse is expected, at all times, to act professionally. Strength and courage can be found in self-awareness. Jean Watson stated, eloquently: “To care for someone else, I must know who I am. To care for someone else, I must know who the other person is. To care for someone else, I must be able to bridge the gap between myself and the other person.” (As cited by Anderson, CNO 2004).

**Understanding Conflict in Hospice Palliative Care**

When working in hospice palliative care, given the emotionally laden situations and the significance of the end-of-life decisions that are encountered, conflicts can be complex. Conflicts can arise between health care members and the person and/or family members. As well, conflicts may occur between family members or between health care providers involved in the care.

The environment of hospice palliative care involves a number of challenging factors that can often generate intense emotions, such as:

- Life or death choices
- Views about the quality and meaning of life

- High costs
- Moral principles
- Legal rights
- Family dynamics

It is important to accept that conflict is not necessarily bad, nor should it be avoided. We usually think of conflict as producing frustration, discomfort, and stress. Yet, working through conflict may also contribute to growth and positive change.\textsuperscript{14} Some conflicts may be anticipated and averted; in other situations, effective conflict resolution can have positive outcomes for all involved.

Being self aware of personal response to conflict will better prepare the nurse to manage conflict when it occurs.\textsuperscript{15}

**Strategies to Manage Conflict**

Addressing situations of conflict in the health care setting require large amounts of time. Everyone is affected by conflict within a health care team, regardless of the source. By evading conflicts, there is a risk of the matter escalating or worsening. Health care teams can experience frustration, caregiver burnout, and intra-team conflict due to muted tension or the polarization of opinion. All involved suffer unrecoverable losses of time, emotional depletion, stress, and often professional or personal regard.

Health care providers involved in hospice palliative care need knowledge and skills in conflict management. Many of these skills are transferable to establishing patterns of balanced communication, consensus building, and well-functioning teams.

The nurse can help to mitigate conflict by considering the following tips: \textsuperscript{16}

- Know and take care of yourself by understanding your perceptions, biases and triggers and creating a healthy environment for yourself.
- Clarify the personal needs threatened by the dispute (may be substantive, procedural or psychological needs).
- Identify the consequences of not resolving the conflict.
- Establish ground rules for discussion.
- Identify a safe place for negotiation (consider an appropriate space for discussion, mutual consent and agreement to time, roles of supportive group members).
- Practice active listening in the interaction.
- Assert your needs clearly and specifically, using ‘I’ messages as tools for clarification.
- Approach problem solving with flexibility.
- Manage impasse with calm demeanour, patience and respect.
- Clarify feelings and take breaks as needed.
Planning and Conducting a Family Care Conference

Family conferences are an effective and powerful tool for achieving a number of important goals in the shortest amount of time. There is an opportunity to share important information, assess information needs, assess the family system and observe family dynamics, identify vulnerable family members, and to deal with family conflicts. A multidisciplinary approach allows for a shared understanding of diagnosis, prognosis, and management goals. As well, feelings and concerns can be discussed and the foundations of trust can be established.

A family care conference can be arranged:

- After the diagnosis is made.
- Any time an issue causes significant difficulties; it 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.

Understanding Culture in Hospice Palliative Care

Understanding and integrating culture is central to providing person-centred care. Learning the customs, rituals, cuisines and languages of various ethnic groups can be helpful; however, cultural variations exist within religions, ethnic backgrounds and groups who share national origins. Learning from the person and family is paramount to providing person-centred, culturally sensitive care.

Considering the uniqueness of the person’s goals, wishes and expectations, the best approach to understanding the person and his or her culture is one of sensitive inquiry. Inquiry and sharing of information provides an opportunity for the dying person to reflect on personal attitudes and beliefs and to consider any observances, rituals, or customs that would bring meaning to living and dying.

Sharing Information in order to Provide Culturally Sensitive Care

In any Therapeutic Encounter, the person’s culture and the health care provider’s culture both affect the relationship. To provide culturally sensitive care, a first step for the nurse is to recognize in what way his/her values and beliefs are similar to, as well as different from, the individual’s and to reflect on how these values and beliefs impact on this relationship.

It is unrealistic to expect that the nurse will have complete knowledge of the various cultures. Instead, it is possible to obtain a broad knowledge of how culture may influence beliefs and values. Cultural competence is defined as an ability to develop working relationships across lines of difference. This process involves self-awareness, intercultural communication skills and knowledge acquisition.

The nurse should consider four elements during information sharing to help eventually plan for and provide culturally sensitive care: self-reflection, acquiring cultural knowledge, facilitating client choice, and communication.

6. Self-reflection

To provide appropriate care, a health care provider needs to consider and understand his or her personal culture and that of his or her discipline. Self-reflection helps to consider how personal belief systems affect interactions with others. This understanding also helps to identify or anticipate the values and biases that may contribute to the selection of approaches and interventions.

7. Acquiring Cultural Knowledge

Acquiring cultural knowledge begins with the acknowledgement that behaviours and responses that are viewed one way in one cultural context may be viewed another way, or may have a different meaning, in another cultural context.

Communication with the person and family is necessary to determine specific values and beliefs that are relevant to the provision of care – the steps of the Therapeutic Encounter will guide the nurse through this process. Assessment, Information Sharing, and Decision-Making may be most significant from a cultural care context.

8. Facilitating Client Choice

Cultural assessment, cross-cultural communication, cultural interpretation, and appropriate intervention are skills to be acquired. An important role of the nurse is to help a person meet his or her specific goals. This involves exploring the person’s view or request and trying to understand the meaning behind it.
9. Communication

Verbal Communication:

An effective Therapeutic Encounter is based on meaningful communication between the health care provider and the person. An assessment of verbal communication involves identifying the language spoken in the home, how the person likes to communicate, and the person’s speaking and reading ability. A person may return to his or her most familiar language as a disease progresses. The tenor of the voice or the silence may have different meanings among cultural groups.21

Non-verbal Communication:

Non-verbal behaviours are important in every culture but will have different meanings depending on cultural norms. In some cultures, eye contact may communicate warmth; whereas a lack of eye contact communicates rudeness, low self-esteem, and dishonesty. In other cultures, eye contact may be seen as a lack of respect or unacceptable between different genders.

Touch may be a powerful tool that makes connections, decreases loneliness, and reassures others or it may be perceived as an invasion of personal space and privacy and can suggest a subservient relationship. Cultural interpretations of personal space vary. Misinterpretations of intent can happen easily – where a person stands or sits may demonstrate different messages. In Euro-American culture, there are three variations: the intimate zone (0-18”), the personal zone (18-36”), and the social/public zone (3’-6”).22 In Euro-American culture, standing or sitting within the personal zone may show caring but may be considered aggressive and disrespectful in other cultures.

The nurse must understand how complex the combination of social, cultural, and other factors is for each person and family in order to avoid ethnocentrism (i.e. that one’s own ethnic group is ‘natural’ or ‘right’) and stereotyping.

Sharing Information about Disease, Pain and Other Symptoms

Information sharing takes place in the context of the person’s current condition with attention also paid to situations that may present in the future. In order to make informed choices, the nurse must have a clear understanding of the person’s disease process so they can anticipate symptoms and plan accordingly for decisions and care.

Understanding Disease in Hospice Palliative Care

The general principles of providing good palliative care, including communication, ethical decision-making and specific symptom management that apply to cancer patients also apply to non-cancer patients. The types and frequency of various symptoms and the nature of different problems may vary from disease to disease, but in general, the needs of terminally ill non-cancer patients are similar to those of dying cancer patients.

– Pallium Palliative Pocketbook

In order to facilitate informed decision-making, the nurse must have knowledge and/or seek out knowledge of both cancer and non-cancer diseases including clinical presentation, anticipated symptoms, management strategies, and possible co-morbidities. The following are some of the non-cancer diseases that are important for the nurse to be knowledgeable of and are described in the Pallium Palliative Pocketbook and the Registered Nurse Association of Ontario Best Practice Guidelines (RNAO BPG, available online at www.rnao.ca) as outlined in the recommended reading list at the end of this program guide:

- Chronic Obstructive Pulmonary Disease
- End-stage Heart Failure
- End-stage Renal Failure
- Dementia
- Stroke
- Amyotrophic Lateral Sclerosis (ALS)
- Multiple Sclerosis (MS)
- Diabetes
- Hypertension

Understanding Symptoms in Hospice Palliative Care

There are numerous symptoms and conditions that can affect the person’s disease trajectory and thus are important for the nurse to have knowledge of to support information sharing and understanding. The following symptoms are described in the Pallium Palliative Pocketbook, the Registered Nurse Association of Ontario Best Practice Guidelines (RNAO BPG, available online at www.rnao.ca) and the Cancer Care Ontario guidelines (available at www.cco.org) as outlined in the recommended reading list at the end of this program guide:

- Anorexia/Cachexia
Sharing Information About Treatment Options

Through the information sharing process, the expectations, fears, hopes, needs, and goals of the person and family will emerge and be considered in decision-making.

The Pallium Palliative Pocketbook is an important resource for the nurse to support information sharing regarding pain management and the treatment of other symptoms as they relate to disease.

Effective information sharing regarding treatment options will be enhanced by a strong working knowledge of pain management in particular. The following information focuses on information related to pain management that does not appear in the Pallium Palliative Pocketbook.

A Note about Meperidine

When controlling pain on a chronic basis, oral Demerol® and Demerol® IM are contraindicated. In 2004, the Institute for Safe Medication Practices Canada concluded that there were only three potential uses for Meperidine; in all other situations, it would not be considered the first line opioid.

Understanding Calculations

When sharing information about pain management with the person and family to assist in decision-making, the following concepts need to be addressed and understood: Initiating an opioid

- Managing breakthrough pain
- Determining an appropriate route of administration
- Titrating/rotating opioids
- Managing procedural or incident pain
- Managing intractable pain
- Managing adverse effects

The following tools related to pain management are included in the Tools section of the program guide.

- Equianalgesic Dosing Chart
- Guidelines for Calculating Breakthrough Dosing
- Opioids Frequently Use in Palliative Care
- Formula for Titration/Rotation of Opioids

Titrating/Rotating Opioids

In addition to the information in the Pallium Palliative Pocketbook, the CAPCE program has developed a worksheet (see W-2) to rotate the opioids that will be central to the nurse’s practice for pain management.

When increasing the regular opioid dose, rotating from one opioid to another or from one route to another, follow these steps:

1. **Total in 24 hours of each opioid**

   Calculate the total amount of each route of opioid drug given in the previous 24 hours including the regular and the PRN doses.

2. **Consider cross-tolerance and calculate the reduction IF APPLICABLE**

   Take into account cross-tolerance. Cross-tolerance is the development of tolerance to the effects of other pharmacologically related drugs, particularly those that act at the same receptor site. In other words, a person who is tolerant to morphine may also be tolerant to hydro- morphine or fentanyl. However, when rotating from one opioid to another, it is important to consider that cross-tolerance may be incomplete. This means that a person who has developed tolerance to one opioid analgesic may not be equally tolerant to another. Therefore when rotating to a new opioid, the person should be started on 20-50% less than the equianalgesic dose.
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of the new opioid. Another clinical implication of cross tolerance is that a person receiving morphine may have developed tolerance to nausea, but when rotated to the new opioid may experience increased nausea. It is very rare that a person will ever develop a tolerance to constipation therefore a daily laxative is recommended.

3. One Route

Using route conversions ratio (i.e., oral: parenteral of 2:1), convert to one route of administration.

4. One drug Current Total

Using DRUG conversion ratios, (i.e., morphine 10 mg po = Hydromorphone 2 mg po), rotate to one drug. Choose the medication you plan to use for regular dosing, rotate and add together.

5. Choose scheduled dosing times:

To choose new regular (ATC) dose, divide the new total 24-hour amount by the appropriate interval i.e. q 24 h divide by 1; q 12 h divide by 2; q 4 h divide by 6; q1h divide by 24.

6. Calculate the breakthrough dose (BTD)

Calculate approximately 10% of the total daily dose of the scheduled opioid

Steady State/ Half Life

The nurse should allow steady state to be reached and evaluate efficacy at steady state before titrating. Steady state is the time it takes for the drug to plateau in the plasma. The time it takes for half of the drug to be metabolized is referred to as the half-life of a drug. The half-life of an oral or parenteral opioid is 4 hours and it takes 4-5 half lives to reach steady state; therefore it takes 16-20 hours before the full effect of the opioid is realized.

Titrates the dose upwards until goals are met or side effects become intolerable.

When pain has stabilized, rotate to a sustained-release preparation.

End of Dose Failure

Approximately 10% of persons who are taking long acting opioids for pain may experience that returns towards the end of the dosing interval on a consistent basis. This is termed end of dose failure. A thorough pain assessment needs to be conducted to eliminate any other causes of the pain. The most common cause of end of dose failure is inadequate dose of the regular opioid regime. If it has been determined that the person is experiencing end of dose failure, increase the dose according to the protocol for titration of opioids, keeping the dosing interval the same (i.e. q12h). If after 1-2 dose increases the person is still experiencing end of dose failure, than the person is likely metabolizing the opioid rapidly and requires shorter dosing intervals (i.e. q8hr in the case of long acting morphine, hydromorphone, oxycodone or codeine, and q48hr in the case of transdermal fentanyl).

Breakthrough Dose

Breakthrough dose (BT) should ideally be the same opioid but the immediate-release preparation ordered q1h PRN. Ideally titration of long acting opioids can be considered every 2 – 3 days. The titration of a long acting opioid is based on the amount of opioid used in a 24-hour period. It is not appropriate to increase the ATC dose without having given breakthrough doses, making sure that the BT dose is the proper dosage, and evaluating the reason BT doses was taken (i.e. person may have taken more BT doses on a particular day due to an event that would not be normally be part of their daily routine).

Fentanyl Patch

When considering effective treatment in pain management, variables, such as age, disease, dysphagia, and extent of disease progression differ from person to person. The choice to use a transdermal opioid, such as TD fentanyl, should be made with individual variables considered, including malnutrition, cachexia, fat stores, temperature, skin thickness, permeability, and metabolic clearance. TD fentanyl is 50 to 100 times as potent as Morphine, and bioavailability after skin absorption has been reported as a mean of 92%. Fever can increase the absorption of TD fentanyl up to 33% and hypothermia can decrease the concentration of TD fentanyl in the body. Titration ability is a concern with TD fentanyl; titration should be made only every 3 days if necessary, and a new dose may not reach therapeutic levels for a full 6 days. Disease progression can cause increased pain and acute pain episodes, and TD fentanyl is not appropriate for acute pain episodes; it is intended for use in chronic pain situations only.

“Transdermal fentanyl has become a standardization of pain control that in every situation, especially that of palliative care, must be individualized for quality of life.”

– M. Sopalski


 Decision Making
Therapeutic Encounter: Decision-Making

It is the person’s right to make informed decisions and determine goals of treatment and symptom management. The nurse’s role, in collaboration with other team members, is to advocate for full discussion of disease-related options. All treatments and their risks and benefits, as well as alternative courses, need to be discussed and weighed in context of the person’s values, culture, beliefs, goals, expectations, and fears.

Shared decision-making is a concept in health care delivery that asks health care providers to engage in evidence-based conversations with the person and family about the risks and benefits of the treatment options. It is important that palliative care options be communicated clearly among the person, family, and health care providers so that all choices are understood. Shared decision-making is defined as:

- The involvement of the person and a health care provider (at least two participants);
- Information sharing between the parties;
- Expression of treatment preferences by person and health care team; and
- A consensus over a treatment plan.

Shared decision-making balances the primary values of beneficence: the health care provider’s responsibility to act in the best interest of the person and family, and autonomy: the person’s right to make informed choices about his or her own treatment. A person’s autonomy is based on the level of information he or she is given, the pertinent situation, as well as the person’s readiness and ability to take responsibility for his or her health care decisions. Decision-making must always rest with the person, as far as possible for as long as possible. Shared decision-making in hospice palliative care communication creates exceptional moments in the human experience of death and dying.

Understanding Decision-Making in Hospice Palliative Care

There are many parameters in hospice palliative care that can provide the nurse with the guidance, wisdom, and insight needed to respect and advocate for the rights and dignity of the person as decisions are made about care.

Regardless of these parameters, in the provision of care, the nurse will encounter different legal and ethical dilemmas. Although some decisions might be defensible under ethical principles, they might not be permissible under the law. Laws provide a framework to guide certain decisions or practices and can impose limits on decisions.

There are a number of decisions to make along the journey in hospice palliative care that will affect the plan of care as it evolves. The complexity of the journey is illustrated in the figure below. Some of the most significant decisions that will impact the person’s journey include:

- Advance Care Planning
- Cardio Pulmonary Resuscitation
- Sedation for intractable symptoms
- Medical Assistance in Dying (MAiD)

Advance Care Planning and Health Care Consent

Advance Care Planning is a process of reflection and communication about an individual’s personal health care choices should the time come when he/she is not capable of consenting to or refusing treatment or other care. A person may express “wishes” about future health treatment, particularly about end-of-life care; however these are only wishes and not consents to those future treatments or refusal of treatments.

Advance Care Planning involves understanding who would be the Substitute Decision Maker (SDM). In Ontario, a person can choose someone (or more than one person) to be the SDM by preparing a Power of Attorney for Personal Care Form (the legal requirements for preparing this document are in the Ontario Substitute Decisions Act), or the law provides a SDM using a ranking list (hierarchy) that the health care provider must turn to for consent or refusal of consent to any treatments. The hierarchy is embedded in the Ontario Health Care Consent Act.

Advance Care Planning includes conversations about the person’s wishes, values and beliefs as it relates to personal care such as:

- Health care services, for example physicals, diagnostic tests
- Medical treatments, for example ventilation, CPR
- Nutrition, for example TPN
- Shelter, consider care setting such as home, hospice, LTCH, hospital

The Ontario Health Care Consent Act does not use the terms, “advance directive” or “living will” but refers to the same issue as “care wishes”. The advance care wishes must be honoured by a health practitioner in an emergency situation if he/she is made aware of these wishes. Although advance care wishes are a good starting point for discussion about possible health care options, advance care planning is NOT consent; wishes are NOT decisions. The consent to treatment or refusal of treatment must come from a person, not a piece of paper, and relate to the person’s current condition. The nurse can play a valuable role in Advance
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Care Planning by:

• Sharing tools and resources; for example referring persons to such organizations as the Advocacy Centre for the Elderly (ACE), the National Initiative for the Care of the Elderly (NICE), the Canadian Hospice Palliative Care Association
• Promoting education about Advance Care Planning in Ontario
• Encouraging individuals to engage in communicating their wishes and goals
• Encouraging individuals to determine their SDM(s) (default or name in POAPC).

Cardio Pulmonary Resuscitation (CPR)

CPR is a decision that people may struggle with at times of crisis. The nurse is often the first health care provider the person talks to regarding this decision. This can be an uncomfortable conversation if the health care provider does not know how to manage the discussion. An algorithm for the development of a plan of treatment related to CPR and completion of the Do Not Resuscitate confirmation form has been established to assist health care providers with the process and the conversation (Grey Bruce Integrated Health Coalition, 2010). The algorithm includes information regarding the following points of discussion: capacity to consent, hierarchy of substitute decision-makers, CPR discussion planning, guiding principles, elements of consent and the DNR confirmation form, physician assessment related to CPR and discussion points when CPR is being offered and when it is not. Each step of the process respects the Health Care Consent Act, The Substitute Decisions Act, the Criminal Code of Canada and the Personal Health Information Protection Act.

The algorithm is available in the Tools section of this program guide.

Sedation for Intractable Symptoms

Canada did not have a standardized ethical framework for Continuous Palliative Sedation Therapy (CPST), otherwise known as sedation for intractable symptoms, although there were several regional and institutional guidelines used in practice. The Canadian Society for Hospice Palliative Care Physicians took on the task of developing a national framework to standardize practice. The literature review identified the following five standards: indications, aim, decision-making, drugs and their administration, and monitoring outcomes.

CPST is an ethically charged treatment option. The nurse needs to understand the ethical obligations to the person and family when CPST is being considered. According to the Nursing Ethics Practice Standards nurses are responsible for maintaining the following values when providing care: client well-being, client choice, privacy and confidentiality, respect for life, maintaining commitments, truthfulness and fairness.

The Latimer Ethical Decision Model is recognized by Fraserhealth and the Pallium Palliative Pocketbook as a valid, reliable, researched tool for use in establishing goals of care, including the option of CPST. The nurse must ensure they understand the model, that they follow the process, and that the decisions are documented and implemented.

The Richmond Agitation Sedation Scale (RASS) tool is recommended to assess level of sedation and can be accessed at www.fraserhealth.ca (Refractory Symptoms and Palliative Sedation Therapy Guideline).

Medical Assistance in Dying

A nurse may be asked by a patient about medical assistance in dying and should be aware of the legislation changes from June 2016 that has legalized this as an option in Canada. Nurses are also encouraged to consult and review the College of Nurses information entitled 'Guidance on Nurses Roles in Medical Assistance in Dying.'

Criteria to be eligible for MAiD is the person must be a capable adult, eligible for publicly funded health care services in Canada and have a “grievous and irremediable” medical condition. If a request is made it must be voluntarily, not a result of pressure and the person must provide valid informed consent. Three stages in Medical Assistance in Dying include; determining eligibility, ensuring safeguards are met and providing medical assistance in dying.

Consider this six-step approach to requests for medical assistance in dying:

1. Clarify the request
2. Assess underlying causes
3. Inform person of process (i.e. notify family Dr. of request)
4. Affirm your commitment to care for the person
5. Respond to persistent requests and make an effective referral
6. Consult with colleagues and secondary level palliative care expert or team.

Ethics in Hospice Palliative Care
The ethics of care requires a delicate balance between the conventional practice of medicine and the wishes of the patient, appreciating that each human situation is unique.\(^{15}\)

When issues involving differences of opinions arise, legal and ethical principles provide a framework to work through the issues in a way that respects the rights of both the person and family and the health care providers. A therapeutic conversation then needs to begin with those involved—the person, the family (if the person consents), and the health care providers involved. Involvement of a bioethics committee may be useful to structure the discussion. The nurse needs to participate in these discussions to provide his or her perspectives, to advocate for the person and family, and to respect the therapeutic relationship.

There are many approaches proposed by ethicists for the analysis and resolution of challenging situations. Principles are balanced and weighed in each particular ethical situation. When two or more ethical values apply to a situation, but these values support diverging courses of action, an ethical conflict or dilemma exists.\(^{16}\)

The following principles are shared by common approaches to resolving ethical dilemmas:

- Respect for autonomy
- Beneficence
- Non-maleficence
- Justice
- Double effect

**Respect for Autonomy**\(^{17}\)

Respect for autonomy recognizes the right and ability of an individual to make decisions based on his or her own values, beliefs and life span, without prejudice. This principle implies that the person may choose a treatment that might differ from the advised course of care. A person’s decision should be fully informed (according to criteria) and well-considered, reflecting his or her values which requires truth telling and exchange of accurate information about status, goals of care, options and expectations. Respect for autonomy allows for refusal of options. For example a person may refuse a certain therapy according to his own religious beliefs.

**Beneficence**\(^{18}\)

Beneficence requires that harm be prevented or removed while doing or promoting good and is the most commonly used principle in the application of care. The principle implies that the health care team should do positive acts in maximizing the benefits of treatment for the person, for example: delivering effective and beneficial treatments for pain or other symptoms; providing sensitive support; and assisting persons and families in any way possible.

**Non-Maleficence**\(^{19}\)

Non-maleficence supposes that one ought not to inflict harm deliberately, including violations such as offering information in an insensitive way, providing inappropriate treatment of pain or other symptoms, continuing aggressive treatment not suitable to the person’s condition, providing unwanted sedation or prematurely withholding or withdrawing treatment.

**Justice**\(^{20}\)

Justice relates to fairness in the application of care and implies that the person receives the care to which they are entitled medically and legally. This principle can be translated into “give to each equally” or “to each according to need” or “to each his due” and requires a consideration for a common or societal good.

**Double-Effect**

The principle of double effect applied to palliative care states that, if desired by a terminally ill person or a surrogate decision-maker, medications intended solely to provide relief from severe or intractable symptoms may be used even at the risk of foreseeable, but unintended side effects. For example, high-dose opioids may be given to relieve severe pain or dyspnea even at the risk of foreseeable but unintended sedation, hypotension, respiratory depression, and even hastening of death. The issue of what is intended in the action is the key to whether it is morally defensible.\(^{19}\)

**Laws that Support Decision-Making in Hospice Palliative Care**

Formed by the values of society, laws are a reflection of a societal consensus on particular issues. Legal frameworks define requirements that need to be fulfilled in order to avoid liability. In end-of-life care, laws, particularly those relevant to the person’s rights, help to ensure that these rights will be respected despite physical and mental vulnerabilities.

Ontario laws most relevant to advance care planning and end-of-life decision-making are:


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5 Grey Bruce Integrated Health Coalition. Algorithm for Development of a Plan of Treatment related to CPR and Completion of the DNR Confirmation Form; 2011.


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6
Care Planning
Chapter 6: Care Planning

Therapeutic Encounter: Care Planning

Once the nurse has collaborated with the person and family to complete an assessment, engaged in information sharing, and assisted in decision-making, development of a person-centered plan of care is the next essential step. The plan of care is negotiated and developed with the person, family, and other interprofessional team members. The plan aims to address the goals and expectations of the person and family by taking into account the personalities and cultures of those involved. It must be customized, flexible, and support the person and family’s desire for control and autonomy, allowing them to be cared for in the setting of their choice with the supports they require.

Critical thinking skills are imperative in this part of the therapeutic encounter; nurses must apply skillful reasoning as a guide to develop interventions and actions for the person and family. The development of person-centered plans of care requires nurses to think systematically and logically with openness to question, and reflect on the reasoning process used to ensure quality care. In developing the care plan, the nurse must ensure a process is in place for ongoing assessment, monitoring, and documenting the efficacy of all interventions. The effectiveness of symptom management should be reviewed regularly and adjusted in response to changes in the person’s status and/or choices.

Additionally, the nurse must ensure that all team members, including the person and family, understand and report any observations or progression of symptoms that may signal complications or deterioration. Where necessary, the nurse is responsible to educate the person and family so they understand what symptoms need to be reported immediately.

Effective reporting and collaboration with team members are essential in a person-centered plan of care, and it needs to include details regarding when and how to provide reports to other team members, especially the physician. Included in the plan of care should be information for the person and family regarding access to the expertise of other members of the interprofessional team, such as social workers, psychologists, and complementary therapists. The nurse must ensure that the plan of care is well-documented on the health care record and is kept current at all times.

Settings of Care

Planning for care in different settings requires knowledge of those settings including:

- Long-term care
- Hospital
- Community/retirement home, community living supported housing
- Residential hospice
- Palliative Care Unit
- Person’s home

Long-term care

Although not formally identified as such, long-term care homes are the largest palliative care units in our province. Every resident can benefit from a palliative approach. A palliative approach aims to improve the quality of life for individuals with a life-threatening illness and that of families, by reducing their suffering through early identification, assessment and treatment of the domains of issues as outlined in the Model to Guide Hospice Palliative Care. In this approach care is most effectively provided by interprofessional care-teams. The team can include a family physician, nurses, PSWs, volunteers, recreation therapists, physiotherapists, spiritual care providers, social workers, dietitians and aides.

Persons living in long-term care reflect diverse cultures, religions and ethnicities. Long-term care homes face unique and significant challenges when providing care. Many of those living in long-term care have a dementia, have multiple co-morbidities requiring multiple medications and are increasingly frail thereby needing increased nursing care.

Access to clinical support is somewhat limited; the long-term care home provides blood work and doctors visit once weekly. The homes provide a degree of management for chronic pain and symptoms. Medications can be provided orally and via subcutaneous butterfly; however, intravenous infusions are possible in very few homes. In most cases residents are transferred to the hospital to receive intravenous infusions or other treatment options not provided by the long-term care home.

Too often, the physician’s decision to “declare a resident palliative” is done very late, within days of the resident’s death. This makes preparation for the death rushed and hurried, not only for the care team but for the family as well. Residents most often live with one or more chronic illness making their health status a gradual decline in functional ability and health. It can be shocking for some family
members to be told that their loved one is now at the end of their life. They were unaware that their loved one was so close to death. This is a symptom of our chronic disease culture of death denial and belief that we are not going to die.

Nurses need to be aware of the chronic disease specific symptoms related to end-of-life to help plan for death in a more timely fashion in the long term care setting. Using specific tools such as PPS, PPI, PaP and Clinical Indicators of Decline help to guide the nurse to make informed decisions as to where the resident is on his or her illness trajectory (see Tools section in this resource guide).

Hospital

Hospitals provide acute pain and symptom management, which could include chemotherapy, radiation therapy, surgery, intravenous therapy, or pain pumps. Some hospitals have specialized palliative care consultation teams, others may consult from their community. Some hospitals have designated palliative care beds or units while others do not. Persons living in the community who frequent the emergency department cost the health care system millions of dollars a year. Often these emergency visits occur when the person is very close to death and the home situation has become unbearable for either the person or family, or symptoms have not been well managed and have escalated to the point that they cannot be managed at home. The person could die while in the emergency department. It is also common for the person to be admitted with the expectation of receiving acute care, are admitted to an acute bed but are in reality requiring palliative services. It is imperative that staff recognize and identify these people as they transition from acute to palliative care, have the appropriate discussions with the person and family, and make changes in the care plan accordingly.

Community/retirement homes, community living supported housing

When the person is asked where he or she wants to die, often he or she will respond: home. Home is where the person may feel most comfortable. Unfortunately, there is no provision for 24-hour home care unless the person privately pays. The LHIN Home and Community Support offers home care based on the needs and functioning of the person and family. The home care team could include: physician, home care nursing, PSWs, volunteers, physiotherapy, occupational therapy, social work and speech therapy. Spiritual care is individual for every person and is provided as the person dictates. If the person belongs to a religious organization he or she may be comfortable addressing spiritual needs within that religion. Hospice services can also provide invaluable spiritual support guiding the person and family to find value and meaning in life. Spiritual advisors, life coaches may also play an important role in the person’s spiritual journey.

Preplanning for end-of-life issues is crucial in the community. On-going communication with the person and family and/or substitute decision-maker, if necessary, and health care providers is extremely important especially at the end-of-life stage of the illness. Team meetings both for the family and health care providers should increase in frequency at the end-of-life stage. It is important for the nurse to have knowledge of the resources available in the community and facilitate coordination of them. For example, in advance, the nurse should be aware of the pharmacy capability and capacity to provide the medication required, physician coverage, prn medications to be ordered and ready for use, and equipment needs. Nurses need to have the knowledge and skill regarding how to manage symptoms experienced by persons who are at, or nearing the end of their life, to assist them in providing quality end-of-life care. Especially in the community, nurses are challenged in their practice to be generalists, but also need to have specialized knowledge and skills meet the needs of a widely diverse population. The community nurse needs to ascertain who on the nursing team has the palliative care expertise and advocate for that team member to have a lead role.

Residential hospice

Residential Hospices are non-profit organizations that provide a home like environment with 24-hour care free of charge to the public. The number of beds available at each hospice varies. Usually the persons PPS would be 30% or lower therefore the residential hospice is generally geared for those persons who are at the end of their life. The team could consist of: physicians, nurses, PSWs, social workers, spiritual care, and volunteers. The team expert in Hospice Palliative Care knowledge and the environment is relaxed and comfortable. Care is provided as it would be in the persons own home as much as possible. Hospices are not available in every community but are becoming more prevalent in Ontario and across Canada.

Palliative care unit

Palliative care units within the acute care system would have all the benefits of the acute care system including quick turn around times for test results, 24 hour medical, nursing and allied health care. This unit is for persons who require acute care involving palliative radiation, chemotherapy or surgery. A typical case, for example, might be one where the person has a fractured hip related to bone metastasis due to prostate cancer and needs orthopedic surgery. Because these
beds are within the acute care system, occupancy is crucial to sustaining their presence.

Palliative Care Units within the continuing care hospital system offers a sub-acute care system. This environment provides basic and complex care in end-of-life pain and symptom management utilizing a team of health care providers. This team might include: physicians, nurses, physiotherapy, occupational therapy, spiritual care, volunteers, music therapy, recreational therapy, and social work. Occupancy is also important in this setting and often beds are used for those with a longer prognosis. Depending on the site these beds may come at a cost similar to long term care.

Acknowledging and understanding the difference between settings is extremely important for nurses to know. Nurses need to educate the person and family so they know what to expect while they are in the different facilities. This allows for smoother transitions and more satisfying outcomes.

**Thinking Critically about Your Community**

The nurse needs to understand the services and supports available in his or her community in order to be a resource for the person and family in care planning. In order to think critically about the local context, the following questions can be considered by the nurse:

- Who can take on the responsibility of being the primary care giver?
- Are the family members aware of the provision of Compassionate Leave through the Employment Insurance Program?
- Is there a network of extended family, friends, community, church or hospice volunteers that would be willing to assist with support of the family, provision of practical assistance and provision of respite?
- Is there support for the family?
- What services are available through the LHIN Home and Community Support?
- Does the person have insurance coverage that will finance additional care?
- Are there personal finances available to purchase professional or personal support services?
- Are there financial constraints that are or could impact optimum care of the person?
- If the finances are available, are the human resources available?
- What other possibilities for care exist? Could the person move in with another family member?
- Is there a residential hospice and is there a bed available?
- Is hospital admission possible if needs become complex and overwhelm the family caregivers?
- Is respite care available?
- Is admission to a long-term care facility a possibility due to the expectation that the dying trajectory will be gradual and death is not imminent?
- What bereavement support is available for the family?
- What supports are in place for the nurse caring for the person who is dying?

**Developing a Plan of Care**

Developing a comprehensive plan of care as a nurse includes considering many facets of the person’s life, including but not limited to:

- Dependents
- Backup coverage
- Respite care
- Emergencies

**Dependents**

The practical needs of a person throughout their illness trajectory requires the nurse to have the advanced knowledge and skill regarding how to manage symptoms and issues that will occur along the way. For example, the nurse needs to be able to identify, assess and manage different types of pain. He or she must be able to select and administer appropriate medications and both anticipate and monitor side effects.

The family needs the knowledge and ability to manage symptoms such as fatigue, nausea and vomiting, edema, wound care, and mouth ulcers and they need to know who to call if symptoms become unmanageable. The family is usually in charge of the meal preparation, feeding and methods of hydration. They are often responsible for all physical and personal hygiene including turning and positioning of their loved one. Their ability to identify emergency situations and impending death are vital to maintaining their loved one at home. The nurse needs to ensure that the family are fully informed and understand what is being asked of them. For example the family may be taught to give subcutaneous (SC) injections through a SC port; however, if they do not understand what to look for if the site becomes interstitial the person receiving the medication will suffer.

The nurse needs to determine if the family is capable and able to provide this type of care. Is the family member frail and elderly? What training or education might they require to fulfill the needs of their loved one? Education can occur while the person is still hospitalized prior to discharge, or in the home setting. Ongoing access and availability of professional assistance and the ability and willingness of the family
to learn and navigate the health care system is essential.

It has been shown that family caregivers have expressed a desire for more written information regarding: disease progression, available nursing and other resources in the community, nutrition, positioning, and bathing. It is important for the nurse to work with the person and family to develop a written care plan that the person or family can refer to. The care plan should be flexible to allow for the many changes that will occur along the illness trajectory.

In addition to the care of the person, the family may face many other challenges. For example, the family may need to manage a new financial landscape (i.e. if the person dying and/or the care provided by the family has resulted in a lost income). Caregivers may be eligible to receive financial support through the Compassionate Care Benefit offered through the Government of Canada.3 The person and family may require more intensive planning depending on their needs and wishes. They may need help from social assistance. The case coordinator could be a resource to help navigate the person and family through the system.

Community volunteer models such as Share the Care can also be utilized to provide a wide range of interventions.4 The family may be faced with trying to support their loved one in an institution and find themselves feeling helpless, or overwhelmed wanting to care for the person. It is essential for the nurse to identify the specific needs of the family and provide opportunities for them to provide as much care as permitted (e.g. teaching the family to provide mouth care). This small task can allow the family to demonstrate love and commitment while not being responsible for all the care.

Nurses must also be aware of and acknowledge the burden the family is carrying. Just as nurses can become burned out, so can family members providing end-of-life care. It may be difficult for the family to recognize or acknowledge feelings of burnout. Families often feel that handing the care to another, or taking a break is unthinkable. Nurses need to observe for signs of burnout and help the family understand the options available to ease the family’s care giving burden.

It is important that support for children be appropriate for their age group and is not forced upon them. Finding the appropriate resources that work specifically with children living with anticipatory grief is critical. Hospice programs may offer support for children at any age. The nurse must have knowledge of these resources and gain permission to arrange for services. Children need to be told the truth in an age-appropriate way utilizing gentle truth telling. There are many resources available online for the nurse regarding supportive care strategies for children dealing with grief such as including the child in remembrance rituals, recognizing and supporting the child’s style and pace as they work through their own grief, and anticipating periodic returns to grieving at significant transitions in the child’s life. The six-year old boy whose father died may go through an acute grief phase at age 16 when he gets his license to drive a car and remembers sitting on his dad’s lap when they were pretend driving in the driveway. For more information on children and grief refer to the Fundamentals of Hospice Palliative Care Program Guide.

“Dependents” also includes pets. It is important for the nurse to know if the person would like to see his or her pet, particularly if they are admitted to a long-term care home, hospital or residential hospice. Often there are policies that accommodate bringing a pet in to the institution.

Back-up Coverage

The discussion related to the care plan should always focus on the most desirable outcomes for the person. Regrettably, the preferred plan is not always successful or possible. When planning care, it is essential for the team to address this reality and encourage the person to identify an alternative option to the preferred plan. This reassures the person and family, and the team that if the preferred plan fails the person has a viable care option to turn to, rather than entering a crisis or ending up in emergency. Back-up coverage could include: LHIN Home and Community Support referral; Share the Care model; respite; transfer to Palliative Care Unit, Residential Hospice or the person’s local hospital.

Respite Care

Respite care is short term, temporary relief provided to families caring for their loved ones at home. It can be provided on a planned or emergency basis. The goal of respite is to provide short, time-limited breaks for families and other unpaid caregivers in order to support and maintain the primary care-giving relationship.

Many families, committed to the goal of caring for the person in the home setting, cannot anticipate or prepare for the emotional and physical toll around-the-clock care requires. There are different models of respite care available:

1. In-Home Respite Service: Care is provided in the home by a volunteer or paid caregivers through the LHIN Home and Community support.
2. Centre-Based Respite Service: Palliative Care Day Programs
are an example of centre-based respite service. Family caregivers bring the care recipient to a setting outside the home to receive care and support.

3. **Hospital-Based Programs**: Some hospitals designate respite beds for the sole purpose of providing 24 hour care by qualified health care providers.

4. **Assisted Living or Long-Term Care Home Respite Services**: Similar to hospital-based programs, some assisted living or long term care homes will offer temporary care for respite.

5. **Caregiver Supports**: Respite care provided by friends, other family, neighbours, volunteers, or faith-based groups.

6. **Hospice Volunteer Visiting Programs**: Many are able to offer the services of skilled hospice palliative volunteers in blocks of time.

Respite care, in many cases, prevents placements to outside facilities, as the break from care allows caregivers a chance to relax, refocus, and rejuvenate. Respite has been shown to help sustain caregiver health and well-being, avoid unnecessary placements, and reduce incidence of abuse or neglect.5

**Emergencies**

In Hospice Palliative Care, where death is the expected outcome, emergencies are those situations, if left untreated, that will severely threaten the quality of life remaining (given that prolonging life is not a realistic goal). As such, when they occur immediate and aggressive symptom management is required.

Once the emergency has been identified, the nurse needs to consider if the situation can be reversed and if the situation should be reversed. For example, hypercalcemia may or may not be appropriate to treat in the last days/hours of life, but the symptoms can be managed.

For palliative care emergencies, there is a two-tiered decision-making process:5

1. **What is the best solution for this problem/situation?**
2. **Is the solution appropriate for the person at this time and do the person and/or family agree?**

Some of the most common emergencies that arise in Palliative Care are:

- Spinal cord compression
- Pain crises or crises involving other symptoms
- Catastrophic hemorrhage
- Superior vena cava syndrome
- Cardiac tamponade
- Hypercalcemia
- Seizures
- Airway obstruction
- Agitated delirium
- Complete Bowel Obstruction

Emergencies in Hospice Palliative Care seldom arise unexpectedly. It is very important for the nurse to have a thorough understanding of the person’s diagnosis and possess a high suspicion index, which will allow him or her to anticipate potential emergencies. Putting a plan in place to prevent emergencies or intervene quickly and effectively, and sharing that plan with the family, is important. For more information on these emergency symptoms, refer to Information Sharing chapter in this program guide and the Pallium Palliative Pocketbook.

**Planning and Facilitating Care Setting Transitions**

Transitional care promotes the safe and timely passage of people between levels of health care and across care settings. This may be from hospital to community (home or residential Hospice, retirement home, supportive community living housing) or hospital to long-term care. It could also be from the community or long-term care to hospital. High-quality transitional care is especially important for persons with complex health issues, as well as for their family caregivers. These persons typically receive care from many providers, and frequently transition within the health care system. Successful transitional care is dependent on care providers who commit themselves to intentional conversations and attention to detail in order to facilitate the movement through care settings for the person and family receiving palliative care services.

**Information Sharing**

Once decisions have been made by the person, family and other care providers to change care settings, the sharing of this information is the critical first step in successful transitional care. By sharing important information about the future care setting, the nurse will allow the person and family not only to develop realistic expectations, but will also alleviate the fear and anxiety, which often accompany a move from an environment that is secure and trusted to one filled with unfamiliar faces and routines. Even a transition back to a familiar home can be intimidating, especially if the goal is to return to their home to die.

**Discharge Planning**

In every successful discharge plan, no detail is too small to escape close attention. Many well-intentioned transitions have gone awry because of poor “handoffs” from one care setting to another. This is most important when planning for the transition from a care setting that is staffed with
around-the-clock care providers to the home setting, where family caregivers will assume duties that may be new and possibly frightening for them. Looking back at information sharing, families must be given accurate, realistic information about providing 24-hour care to a loved one who is dying. Another key to successful discharge planning is in the timing; discharging a person and family too soon, especially to the home setting, can contribute to adverse events, poor symptom management, and increased re-hospitalization.

The person and family anticipating a transition from one care setting to another will miss hearing important information and details, so the nurse should write everything out, as well as go over the details in conversation. Finally, the best discharge plans are created with efficient communication between health care providers. The lack of communication between the care providers at either end of the transition is frequently one of the greatest challenges in transitional care.

Medications

The nurse has an important role in ensuring successful transitional care for the person and family with regards to medications. Information sharing, once again, is essential. The person and family will need detailed information regarding medication names, purpose, dosage strengths, dosage times, side effects and expected adverse reactions. The nurse must also be aware which medications are not covered by ODB and may present a financial strain on the person and family if they must purchase the medication out of pocket (even for future reimbursement by a third party insurance company). The nurse should remember that residential hospices are considered community care settings, and some medications will not be covered.

Attention to detail regarding medication administration by family caregivers is important. First of all, the nurse should ascertain, with the person, which family caregivers will be giving medications, either orally, by injection, or perhaps even, rectally. If in a hospital setting the administration of SC injections should be taught well in advance and family caregivers given ample opportunity to “practice” and gain familiarity prior to discharge. The nurse must never assume that family caregivers have the desire or ability to administer medications by any route, and careful planning, teaching and communication must take place to ensure safe, effective medication administration. The nurse’s role also involves securing the required prescriptions from the physician and facilitating communication with the person’s pharmacy and pharmacist. The nurse should also ensure the person and family have well-written information and instructions, even if transitioning to a care setting staffed by health care providers.

Plan for Death and Funeral

Facilitating therapeutic conversations about the person’s death and funeral requires sensitivity. Some people are very comfortable talking about death, even their own, when anticipated, as well as their funeral plans, if already made; whereas others will not possess the same level of comfort.

In the context of transitional care, planning for the death is most important when transitioning to the home setting. The person and family who do not understand the dying process or know what to expect may be filled with anxiety and fear, which is sometimes manifested as anger or frustration with care providers, and most often, the nurse. Just as with medication administration, the nurse must never assume that family caregivers have any level of comfort with the dying process or possess any amount of knowledge. The nurse should also remember that expected deaths do occur unexpectedly, and conversations with the family around such possibilities should take place, including detailed, written instructions for the family to follow if a health care provider is not present when the death occurs. If funeral plans have not been made, the nurse should encourage the person and/or family to at least choose a funeral home and have an introductory conversation with a funeral director, as this is not an easy decision to make after a death has occurred. Intentional, well-directed therapeutic conversations, conducted with sensitivity and caring around the death and funeral of a person, can help contribute to successful transitional care.

Care Needs

When transitioning from one care setting to another, the nurse must possess situational awareness around the care needs of the person and the family. Cognizant of the emotional reality of the care transition, the nurse must observe the person and family prior to discharge from the present care setting, and be aware of the physical, emotional, practical, and spiritual needs that arise, tending to those needs as he/she is able, and accessing the help of additional team members whenever needed. To prepare for transition to a home setting, the nurse should thoroughly assess the needs of the family caregivers as early in the discharge planning process as possible, to allow for appropriate teaching and coaching to occur.

Transitional care is an important, key role for the nurse. It takes patience, attention to detail, and knowledge about available services and care across all sectors. Smooth transitioning between care settings is one of the greatest gifts a nurse can give any person and family receiving hospice
palliative care services.

**End of Life and Death Management**

Understanding end-of-life care begins by connecting the physical, psychosocial, and spiritual needs of the person and must be pursued as energetically, purposefully, and vigorously as one would in an intensive care unit. Each dying person is entitled to receive optimum, intensive and comprehensive hospice palliative care.

Determining when a person enters the end-of-life phase can be achieved by completing an assessment using the following tools (available in the Tools section of this program guide):

- PPS
- ESAS-r
- Registered Nurse Association of Ontario Best Practice Guides for End of Life Care During the Last Days and Hours (2011)

Regardless of the tools used, care delivered at this stage of the illness is as important as at any other stage. Aggressive pain and symptom management interventions need to be continued. The nurse monitors the effectiveness of the current pain and symptom management plan even more frequently in the last phase of life and responds quickly to changes in comfort level, as pain and symptoms can escalate quite rapidly as the person is actively dying. Protocols should be maintained and/or modified if symptoms escalate.

One of the major decisions to be made early in the end-of-life stage of the illness is to determine the setting in which care will be provided during this part of the illness trajectory. The dying person needs to receive care in an appropriate setting and to be reassured that the treatment plan will be honoured if he or she needs to move across settings. If the person is at home, the ability of family and other caregivers to manage the end-of-care needs should be assessed frequently. The plan should be flexible to accommodate any changes made in response to the needs of the dying person and the ability of the caregivers to cope with more complex care.

Decisions related to organ donation, autopsy, cremation or burial, traditional funeral or memorial service, public or private service, are all issues to be considered at the time of death if they have not been dealt with previously.

The nurse will need to educate and share information to caregivers of what to expect as dying approaches including how to interpret the signs and symptoms of impending death.

Since pain or symptom crises can occur in the last hours, the nurse needs to anticipate the medications needed if a crisis does occur and have a standing order from the physician with the medication in place. In some areas the Symptom Response Kit (SRK) is available for those who have a PPS of less than 50%, have a treatment plan in place, wish to die in their home and have completed a DNRC form.

The SRK is a kit that has specific medications that one may need for most palliative emergencies. The nurse would still have to obtain specific medication orders from the physician for each medication to be used from the kit.

The possible need for alternate routes of medication delivery will necessitate having a plan in place. If the possibility of a symptom becoming intractable exists, discussion involving the person and family and palliative care team related to sedation for intractable symptoms should take place prior to a crisis developing.

If the person has to be transferred to another care setting, the nurse must ensure that the details of the treatment plan accompany the person to promote continuity of care.

The nurse and other health care providers present at the moment of death should take a moment to privately grieve or debrief with a colleague. Often health care providers are so focused on the care of the family, they forget that they also need to support and heal each other and themselves.

**Bereavement Care**

The nurse who recognizes that family support throughout the illness and particularly in the last days and hours promotes healthy grieving, will ensure that issues and challenges commonly experienced along the journey are identified and pre-empted or managed in a timely fashion. Successful therapeutic encounters prevent unnecessary suffering for both the dying person and the family. Quality end-of-life care incorporates the cultural and spiritual rites and rituals that have meaning for the family in an attempt to facilitate healthy grieving and bereavement following the death.

In hospice palliative care, bereavement support is regarded as an integral part of the service provided. Nurses are paid to care for the living. Consequently, when the person has died, nurses may consider that his or her responsibility for care is over. However, the family members who are part of the unit of care are still alive; they are an extension of the deceased person and deserve attention from the health care system and health care providers. Nurses are also often in the best position to be aware of the risk factors present for
complicated grief with the surviving family members.

The nurse’s care for the family does not end with the death of the person. Support for family caregivers continues through the processes of grief and bereavement to facilitate a positive transition through loss. Nurses are key people in handling bereavement; families feel comfortable with nurses and will turn to them for support.

Some ways a nurse can help a grieving or bereaved family include:

**Before the Death:**

- **Actively Listen:** The best support a nurse can give is to listen carefully and allow family members to express their feelings and talk about their loved one.
- **Be Honest:** As a nurse, you won’t have all the answers. You may not even know what to say to a family. It’s okay to say, “I don’t know”. And, if you make a mistake, admit it and start over again.
- **Be Non-Judgmental:** Most family members will manage the stress of the illness and grieve in their own way.
- **Be Consistent:** Families, in the midst of grief and sadness, will ask different nurses the same questions. Be consistent with your answers and explanations with different family members. As well, be consistent with your colleagues; this will facilitate trust and ease anxiety.
- **Be the Advocate:** Grieving families are often too distraught to think clearly, especially when the death occurs. Be ready to suggest choices, options, and alternatives that are available and explain.

**After the Death:**

- **Facilitate Mourning:**
  - Tell the family their loved one has died. Use the word “died” or “death”.
  - Involve the family in decisions to be made. Even with an expected death, the shock of the reality may prevent them from being able to make decisions; give them the information they need in simple, clear language.
  - Allow the family private time with their loved one. If the death occurs in a setting other than home, allow the family to pack up their loved ones’ belongings, if they wish.
  - You can provide the atmosphere to let family members express their emotions. At the same time, remember it’s appropriate for you to express your own emotions, as well, and show them you care.
- **Share Information:** Provide verbal and written information to the family about bereavement services in the region in which they live. Even if you do not sense unhealthy grieving or anticipate problems, grief is a journey, and family members may want information in the future. It’s best to provide the information prior to the closure of your professional relationship.
- **Say Goodbye:** When leaving the family for the final time, say goodbye. Bringing closure to a therapeutic relationship with the family will be healthy for them and for the nurse, because neither will be a “stranger” ever again. The Palliative Care Nurse can thank the family for the privilege of caring for their loved one. The Palliative Care Nurse should also graciously accept the family’s thanks and compliments, when given (this can be difficult for some nurses to do).
References


3 More information regarding these benefits can be found at the following website: http://www.servicecanada.gc.ca/eng/ei/faq/faq_compassionate_care_individuals.shtml

4 More information regarding Share the Care model can be found at the following website: http://www.sharethecare.org/


Therapeutic Encounter: Care Delivery

Care delivery is the follow-through phase of the therapeutic encounter. It is based on the decided plan of care, which is specific to the person and family and focuses on their needs and achievable outcomes. Actions involved in care delivery include: requests for initial evaluation and ongoing follow-up, implementation of decisions, and the delivery of chosen therapies, equipment and supplies.1

An interprofessional care team, comprised of family caregivers, health care providers, as well as community resources (as requested by the person and family), provides care, and the person and family can be as active in the delivery of care as desired. Family and friends are educated about their potential role and supported in their decision to become caregivers; the nurse plays a role in providing training and support to facilitate their role.

Implementation of the individualized plan of care takes place in the setting of the person's choice, which is maintained to be safe, comforting, and provide opportunity for privacy and intimacy.2

There is no timeline for care delivery. Implementation occurs over the course of hours, days, weeks, or even months.

The Care Team

One of the foundational concepts in Hospice Palliative Care is effective team functioning.3 There are different groups that nurses must perceive as a team. The person and family are the unit of care and the essential core to the team. Nurses need to understand the dynamics and roles and culture within the family to best utilize the resources and networks within it. This process involves assessment, information sharing and guided decision-making.

Essential to the team are the interprofessional health care team members. This team supports the person and family by providing care based on values, beliefs and informed decisions. Care planning is done in collaboration with the person and family and the interprofessional care team. It is in the sharing of information and open discussion of possibilities that allows the team to arrive at realistic, achievable and viable goals culminating in an individualized plan of care. The nurse may have a role to support the coordination and collaboration with the interdisciplinary team; LHIN care coordinators are often in a lead role.4

The person's decisions inform the plan of care, which in turn determines the care team roles required to fulfill care delivery. The nurse needs to understand the role of each caregiver and health care provider contributing to the team and identify any areas where education or additional supports are needed. Any issues such as medications, transfer to another setting, or equipment needs to be addressed promptly, guided by the nurse.

Anticipating and planning for, including coping strategies and self-exploration of death and dying, is important preparation as a member of the care team. The nurse plays an integral role in ensuring that members on the team are supported (physically and emotionally) as they care for the dying.

There are times when the team is very small and/or collaborating using technology. It is in these instances critical thinking and knowledge of the resources is crucial. In rural and remote areas, a small team or a team connecting from different geographic areas may be the only option, further reinforcing the need for effective team function, effective communication and the development of therapeutic relationships.

Regional teams of Hospice Palliative Care providers are available in some of these instances and use of Ontario Teleconferencing Networks are a possibility to support consultation.

Knowing when to Expand the Care Team

The nurse can make referrals to and advocate for the appropriate referrals to interprofessional team members and/or Hospice Palliative Care Consultation Teams when:

- Symptoms are not managed effectively,
- The present interventions are not working,
- Side effects are unacceptable,
- The person requires care that is out of the scope of practice of the hospice palliative care nurse, or if
- The care needs increase or change.5

Nurses practicing these standards foster the coordination of care across the continuum. The nurse is expected to assist the person and family to navigate the health care system, improve their quality of life and their experience at end-of-life.
Therapy Delivery Considerations for the Palliative Care Nurse

Protecting Medication in the Home

Many people receiving hospice palliative care services in the home are taking numerous medications, including opioids. Opioids can be stolen from homes and abused. Opioid misuse and abuse accounts for thousands of deaths every year. The person and his or her family are responsible to keep prescribed medications, including opioids, safe and protected in their home. Part of the nurse role is to instruct the person and family about safeguarding medications.

The following are some tips to share with the person and family:6

1. Do not share your medication with anyone
2. Limit access to your medications to you and your caregiver/nurse only
3. Lock your medications in a lock box or cabinet and secure the key or combination
4. Do not keep your medications in a kitchen cupboard or bathroom cabinet (these rarely lock and are the first place people look when searching for opioids and other medication)
5. Make sure you have the correct number of pills when you get a prescription and count the number you have left on a regular basis; if you are ever short, discuss it with your caregiver or nurse immediately
6. If you are missing any medications, change the location of where you keep the locked container, as well as the key/combination and report to your nurse

Errors

It is without a doubt that every nurse will make some errors over their career. It is expected that the nurse take responsibility for his or her errors and take the appropriate action to ensure the safety of the person and family.7

Accountability ensures that not only the person is provided the necessary follow-up care but that the nurse learn from mistakes and become better care providers. Admitting mistakes also promotes a trusting, therapeutic relationship.

Reference

8 Confirmation
Chapter 8: Confirmation

Therapeutic Encounter: Confirmation

Confirmation, the final step in the Therapeutic Encounter, encompasses the evaluation of the individualized, person-centered plan of care. It is crucial to determine, after participating in the development of a plan of care, as well as the implementation, whether the expectations of the person and family were met.

During confirmation, the nurse, along with the interprofessional team, assesses the overall understanding satisfaction, level of stress, sense of complexity, concerns, questions, and desire for additional information related to the domains of issues during each therapeutic encounter. Additionally, the team ensures that the plan either meets the person and family’s goals and expectations, or every effort is made to adjust the plan to improve the outcomes.

The nurse acts as an advocate for the person and family until the goals are achieved. Effective communication between team members, both written and verbal, is just as important in this phase of the therapeutic encounter as any other. Paramount to the success of the care plan is knowledge of the outcomes. Most important to remember is that confirmation is a continuous process, as it completes the circle of the Therapeutic Encounter, which is an ongoing, evolving process in the delivery of hospice palliative care.

Evaluation of Care

The nursing process is similar to the steps in the therapeutic encounter. The evaluative step of the nursing process coincides with the confirmation step in the therapeutic encounter. Confirmation is the assessment of the person, family and caregivers related to:

- Satisfaction with the process of providing care
- Perception of the complexity of the situation
- Perception of the level of stress
- Concerns, questions and desire for more information

Confirmation determines the person’s response to the care plan interventions. This could be accomplished by utilizing validated clinical tools such as the ESAS-r in screening for symptoms (e.g., the person’s ESAS-r pain score went from a 10 to a 2 with the care plan regime of medications). It could also be described in the completion the person’s goal (e.g., because the person’s pain was well managed they were able to attend the wedding of their daughter or the person was able to reunite with a long lost relative to make their peace).

Confirmation is also a time of assessing the effectiveness of the team’s ability to collaborate and intervene on the issues the person and family was facing to produce a positive outcome. Consider a situation where a spiritual care provider in the hospital setting had an influx of referrals and communicated that he would not be able to respond to a last referral in a timely fashion. Assessment of that situation may reveal that ideally, a spiritual care provider from the community would be part of the interprofessional team and would have been aware of where the person was in the illness trajectory and been able to accommodate a timely response to the referral. Alternatively, if there was no such person on the team, confirmation may confirm that the nurse needed to advocate on behalf of the person so that his or her spiritual needs were met in a timely manner.

The concept of assessing and confirming is closely linked to the need to revise the plan of care when the plan is not producing the desired outcomes, and like other steps in the Therapeutic Encounter, may be done repeatedly throughout the illness trajectory. And in addition to this ongoing cycle of assessment and confirmation, the nurse must also assess the stress level of the care team surrounding the person. If the stress on the team is too great, the care for the person will be less effective and the nurse would need to respond by revising or advocating for the revision of some plan of care aspect(s).

Confirmation is the gathering of data and communicating the outcomes of the interventions, with the person and family and with other members of the interprofessional team. Quality practice includes evaluation and this is best done as a group in reflection after the death of the person (“debriefing session”). These debriefing sessions can address what went well and what did not go well for the person and the members of the care team, and lessons learned from this case. The phrase retrospective sense making involves looking at what was done in a situation and giving meaning to that situation. A very important part of any debrief are the lessons learned from the experience and the changes or modifications one would do when working with the next person in a similar situation.
A Note to the CAPCE Learner

From the day you entered nursing school, you likely were besieged with warnings, advice, and strategies. Organizations, desperate to maintain human resources, offer in-services and education around, compassion fatigue, and burnout. Research and scholarly articles are abundant; there is no end to information available to nurses who want to know how to care for themselves in their professional role.

It is a false assumption that hospice palliative care nurses burn out faster than other nurses due to the challenging nature of the work. Simply because death and dying are the end results, research has shown that burnout or compassion fatigue will not necessarily occur at a greater rate than in other sectors of care."^2

Many hospice palliative care nurses have been doing their work for years and find it challenging and exhausting (at times), but overall, rewarding and fulfilling. What is the key to longevity in this specialized area of nursing? Support. Nurses cannot work in isolation as they care for persons and their families.

In hospice palliative care nursing the person and the family are a single unit of care, and you will find yourself caring not only for the person but for members of the family as well. Over time, you will learn to navigate through family dynamics complicated by the painful reality of death and dying.

It is exhausting work, physically, emotionally, spiritually, and mentally. It takes its toll, but it also gives great rewards, as well. As the nurse, not only will you need the support of the interprofessional team, but the support of colleagues, as well. Challenging, ethical decisions are made every day in hospice palliative care, and you will need the support and presence of other team members who do the same work and understand the intricacies, challenges, and joys of accompanying persons on their final journey.

Together as nurses, we are called to an extraordinary task. It is a great privilege to stand at the bedside of a person you have cared for, along with their family, as they take their final breath. To do this work day after day and year after year takes a great love and respect for others, as well as a commitment to self. It takes laughter and tears, mingled with occasional frustration, frequent happiness, and constant compassion. The successful nurse will always see possibility where others see problems.

“When both care providers and care receiver are co-participants in caring, the release can potentiate self-healing and harmony in both. The release can allow the one who is cared for to be the one who cares, through the reflection of the human condition that in turn nourishes the humanness of the care provider. In such connectedness they are both capable of transcending self, time and space. Neither stands above the other."^3
Reference


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**TOOL: OPIOID Rotation Calculation Worksheet**

<table>
<thead>
<tr>
<th>Formula</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total in 24h of EACH opioid</strong></td>
<td>Calculate the total amount of each route of each opioid given in the previous 24 hours, including regular and prn doses.</td>
</tr>
<tr>
<td><strong>Consider cross tolerance and calculate the reduction if applicable.</strong></td>
<td>To account for lack of complete cross tolerance, calculate and subtract 20% to 50% reduction of the 24h dose of any opioid being rotated to a new (different) opioid. Clinical judgment is used in determining the degree of reduction. Always confirm with a resource expert if you are unsure.</td>
</tr>
<tr>
<td><strong>One route</strong></td>
<td>Using ROUTE conversion ratio (i.e., po to SC/IV of 2:1), convert to one route of administration.</td>
</tr>
<tr>
<td><strong>One Drug Current Total</strong></td>
<td>Using DRUG conversion ratio (i.e., morphine 10 mg po = hydromorphone 2 mg po), rotate to one drug. Choose the medication you plan to use for regular dosing, rotate and add together for a new 24h total.</td>
</tr>
<tr>
<td><strong>Choose scheduled dosing times.</strong></td>
<td>To choose new regular (ATC) dose, divide total 24h amount by appropriate interval based on product to be used. For example: divide by 6 for q4h dose; divide by 2 for q12h dose; divide by 24 for hourly infusion</td>
</tr>
<tr>
<td><strong>Calculate the breakthrough dose: (BT)</strong></td>
<td>Calculate approximately 10% of the total daily dose of the scheduled opioid. Example calculations for breakthrough opioids delivered by:</td>
</tr>
<tr>
<td>» <strong>Mouth:</strong></td>
<td></td>
</tr>
<tr>
<td>10% of 30 mg = 3 mg (max dose) po q1h prn</td>
<td></td>
</tr>
<tr>
<td>» <strong>SC:</strong></td>
<td>morphine 10 mg q4h SC = 60 mg SC/24h</td>
</tr>
<tr>
<td>10% of 60 mg = *6 mg (max dose) SC q1h prn or *3 mg SC q30min prn</td>
<td></td>
</tr>
<tr>
<td>» <strong>CSCI:</strong></td>
<td>morphine 2.5 mg q1h SC continuous infusion = 60 mg SC/24h</td>
</tr>
<tr>
<td>10% of 60 mg = *6 mg (max dose) SC q1h prn or *3 mg SC q30min prn or *1.5 mg SC q15min prn</td>
<td></td>
</tr>
<tr>
<td>* clinical judgment may indicate the need to lower the calculated dose</td>
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</tbody>
</table>
TOOL: EQUIANALGESIC DOSING CHART

All equivalencies are approximate; use this chart as a guideline only.

**Oral Routes:**

<table>
<thead>
<tr>
<th>Morphine 10 mg = Percocet 1 tab (5/325) = Oxycodone 5 mg</th>
<th>Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morphine 10 mg = Codeine 100 mg = 3 Tylenol #3 tabs (90/900)</td>
<td>1:10</td>
</tr>
<tr>
<td>Morphine 10 mg = Hydromorphone 2 mg</td>
<td>5:1</td>
</tr>
</tbody>
</table>

**Oral to Subcutaneous Routes: Ratio 2 (po): 1 (sc)**

<table>
<thead>
<tr>
<th>Morphine 10 mg po = Morphine 5 mg sc</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hydromorphone 10 mg po = Hydromorphone 5 mg sc</td>
</tr>
</tbody>
</table>

**Subcutaneous Equianalgesia:**

| Morphine 10 mg sc = Hydromorphone 2 mg sc |

**Conversion to Transdermal Fentanyl:**

(CPS 2013, page 931, table 2)

CPS Recommended Conversion:

E.g. Morphine 60-134 mg po/24h = Fentanyl 25 mcg patch q72h

Note: this range of morphine is very broad which may result in significant under dosing. Clinical judgement prevails.

Note: There are various accepted methods used when switching to or from Transdermal Fentanyl. Whatever formula is used it will remain consistent with the Pallium Pocketbook 2nd edition 2016.

To account for lack of complete cross tolerance, calculate and subtract 20% to 50% reduction of the 24h dose of any opioid being rotated to a new (different) opioid.

**Guidelines for Calculating Breakthrough Doses (BT)**

Calculate approximately 10% of the total daily dose of the scheduled opioid and administer it as needed for uncontrolled pain.

The breakthrough dose is calculated in the same way no matter what route of administration is being used (Pallium Pocketbook 2nd edition 2016)
For opioids taken by mouth:

e.g. Morphine 15 mg q12h po = 30 mg po/24h total
    10% of 30 mg = 3 mg (max. dose) po q1h prn for breakthrough pain

For opioids taken sc:

e.g. Morphine 10 mg SC q4h = 60 mg SC/24h
    10% of 60 mg = 6 mg (max. dose) SC q1h prn for breakthrough pain

For CSCI:

e.g. Morphine 2.5 mg q1h CSCI = 60 mg/24h
    10% of 60 mg = 6 mg (max. dose) SC q1h prn* or 3 mg q1/2h prn for breakthrough pain

*Clinical judgment may indicate the need to lower the calculated dose.

CAPCE Program. Revised 2013, second edition 2017. © SWO PPSMCP
TOOL: ALGORITHM FOR INFORMED CONSENT FOR A PLAN OF TREATMENT RELATED TO CPR AND COMPLETION OF THE DNR CONFIRMATION FORM

Algorithm for Informed Consent for a Plan of Treatment related to CPR and Completion of the DNR Confirmation Form
Algorithm for Conflict Resolution regarding CPR Decision

**Physician assessment related to CPR**

1. Explain the goal is to respect the patient's informed choice and to make accurate information, planning for appropriate care, including discussion on the patient's unique values and goals, and thereby provide medical information.
2. Explain what CPR is and includes: process (waking dependent), compressions, mouth to mouth, electric shock, intravenous medications, including/with sedation.
3. Explain what is involved in CPR and that:
   - How the CPR works depends on the health of the person (where information such as the CW/CPR Decision Aid for Patients and Their Families) and the different types of emergency. Charges for survival depend on the health of the person and location or place where they are injured.
   - CPR is an effective procedure and will not improve the outcome that causes the heart attack.
   - CPR requires immediate CPR be taken immediately and the emergency call to be conducted with the emergency response service. CPR is an effective procedure in improving the chance of survival from heart attack. Benefits of CPR are particularly seen in patients who suffer from sudden cardiac arrest.
4. CPR will not help those who are at the natural end of their lives due to a progressive illness/limiting illness.
5. Inform consent discussions may differ slightly by location, e.g.: hospital care CPR more specific options can be offered.
6. Discuss this:
   - Limiting circumstances CPR can save life (yes).
   - After 5 minutes without a heartbeat, serious brain and organ damage take place which can lead the person in a state of pain and dependent on machines which breath for the person. Blood vessels are open and blood is flowing into the brain. Even if CPR is started the person known presenting CPR before the time the machine inbreathing for the brain. Depending on the severity of the brain damage, the machine for breathing may not be able to be removed.

**CPR Decision Points when CPR is not being offered as a treatment option**

1. Follow Steps 1 to 5 in Box H.
2. Inform and share assessment with the person/SDM that CPR would not be beneficial and would cause harm, explaining that the physician is recommending that CPR not be included in the plan of treatment.
3. Answer any further questions but do not continue to press your points.
4. If the person/SDM agrees with the physician’s recommendation/decision, refer to Algorithm step 9(i)(ii).
5. If the person/SDM does not agree with the physician’s recommendation/decision, refer to Algorithm for Conflict Resolution.

**References**

- College of Nurses - Consent Practice Guideline (2009)
- College of Physicians & Surgeons of Ontario (CPSO) policy statement #5-16, Planning for and providing Quality End-of-Life Care, May 2016
- Ontario Health Care Consent Act, 1990
- Ontario’s Selection of Treatment Act, 2006
- Ontario Critical Care Resuscitation (CCR) - A Decision Aid for Patients and Their Families - www.healthOntario.ca, June 2010
- Do not Resuscitate Conformation Reference Document for Paramedics, Firefighters, Nurses & Physicians, May 2007, Version 15.1
**TOOL: BEREAVEMENT RISK ASSESSMENT TOOL**

This tool is shown as a sample only and is not be used without complete instructions and permission. For complete instructions and permission please purchase the Bereavement Risk Assessment Tool Manual with CD

### Bereavement Risk Assessment Tool © Victoria Hospice Society 2008

<table>
<thead>
<tr>
<th>Assessment Date</th>
<th>Assessed by</th>
<th>ID#</th>
<th>Patient / Deceased Name</th>
<th>Bereaved Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aug-08</td>
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</table>

#### Risk Indicators and Protective Factors

**I. Kinship**
- a) spouse/partner of patient or deceased
- b) parent/parental figure of patient or deceased

**II. Caregiver**
- a) family member or friend who has taken primary responsibility for care

**III. Mental Health**
- a) significant mental illness (e.g., major depression, schizophrenia, anxiety disorder)
- b) significant mental disability (e.g., developmental, dementia, stroke, head injury)

**IV. Coping**
- a) substance abuse / addiction (specify)
- b) considered suicide (no plan, no previous attempt)
- c) has suicide plan and a means to carry it out OR has made previous attempt
- d) self-expressed concerns regarding own coping, now or in future
- e) heightened emotional states (anger, guilt, anxiety) as typical response to stressors
- f) yearning/pining for the deceased OR persistent disturbing thoughts/images > 3 months*
- g) declines available resources or support
- h) inability to experience grief feelings or acknowledge reality of the death > 3 months*

**V. Spirituality / Religion**
- significant challenge to fundamental beliefs / loss of meaning or faith / spiritual distress

**VI. Concurrent Stressors**
- a) two or more competing demands (e.g., single parenting, work, other caregiving)
- b) insufficient financial, practical or physical resources (e.g., ↓ income, no childcare, illness)
- c) recent non-death losses (e.g., divorce, unemployment, moving, retirement)
- d) significant other with life-threatening illness / injury (other than patient/deceased)

**VII. Previous Bereavements**
- a) unresolved previous bereavement(s)
- b) death of another significant person within 1 year (from time of patient’s death)
- c) cumulative grief from > 2 OTHER deaths over past 3 years
- d) death or loss of parent/parental figure during own childhood (less than age 19)

**VIII. Supports & Relationships**
- a) lack of social support/social isolation (perceived or real - e.g., housebound)
- b) cultural or language barriers to support
- c) longstanding or current discordant relationship(s) within the family
- d) relationship with patient/deceased (e.g., abuse, dependency)

**IX. Children & Youth**
- a) death of parent, parental figure or sibling*
- b) demonstration of extreme, ongoing behaviours/symptoms (e.g., anxiety+, nightmares)
- c) parent expresses concern regarding his/her ability to support child’s grief
- d) parent/parental figure significantly compromised by his/her own grief

**X. Circumstances Involving the Patient, the Care or the Death**
- a) patient/deceased less than age 35
- b) lack of preparedness for the death (as perceived or demonstrated by bereaved)*
- c) distress witnessing the death OR death perceived as preventable*
- d) violent, traumatic OR unexplained death (e.g., accident, suicide, unknown cause)*
- e) significant anger with OTHER health care providers (e.g., “my GP missed the diagnosis”)
- f) significant anger with OUR hospice palliative care program (e.g., “you killed my wife”)

**XI. Protective Factors Supporting Positive Bereavement Outcome**
- a) internalized belief in own ability to cope effectively
- b) perceives AND is willing to access strong social support network
- c) predisposed to high level of optimism/positive state of mind
- d) spiritual/religious beliefs that assist in coping with the death

---

* denotes requirements for intervention
TOOL: DERMATOME MAP
TOOL: BRIEF PAIN INVENTORY (SHORT FORM)

STUDY ID# ___________________  DO NOT WRITE ABOVE THIS LINE

HOSPITAL # ___________________

Brief Pain Inventory (Short Form)

Date: __________/________/_______  Time: __________

Name: ___________________________  ___________________________  ___________________________

Last  First  Middle Initial

1. Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?

   1. Yes  2. No

2. On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.

3. Please rate your pain by circling the one number that best describes your pain at its worst in the last 24 hours.

   0  1  2  3  4  5  6  7  8  9  10  Pain as bad as you can imagine

   No Pain

4. Please rate your pain by circling the one number that best describes your pain at its least in the last 24 hours.

   0  1  2  3  4  5  6  7  8  9  10  Pain as bad as you can imagine

   No Pain

5. Please rate your pain by circling the one number that best describes your pain on the average.

   0  1  2  3  4  5  6  7  8  9  10  Pain as bad as you can imagine

   No Pain

6. Please rate your pain by circling the one number that tells how much pain you have right now.

   0  1  2  3  4  5  6  7  8  9  10  Pain as bad as you can imagine

   No Pain
7. What treatments or medications are you receiving for your pain?

8. In the last 24 hours, how much relief have pain treatments or medications provided? Please circle the one percentage that most shows how much relief you have received.

<table>
<thead>
<tr>
<th>Percentage</th>
<th>No Relief</th>
<th>Complete Relief</th>
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<tbody>
<tr>
<td>0%</td>
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<td>80%</td>
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<tr>
<td>90%</td>
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</table>

9. Circle the one number that describes how, during the past 24 hours, pain has interfered with your:

**A. General Activity**

<table>
<thead>
<tr>
<th>Number</th>
<th>Does not Interfere</th>
<th>Completely Interferes</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
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**B. Mood**

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<tr>
<th>Number</th>
<th>Does not Interfere</th>
<th>Completely Interferes</th>
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**C. Walking Ability**

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<thead>
<tr>
<th>Number</th>
<th>Does not Interfere</th>
<th>Completely Interferes</th>
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**D. Normal Work (includes both work outside the home and housework)**

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<th>Number</th>
<th>Does not Interfere</th>
<th>Completely Interferes</th>
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</table>

**E. Relations with other people**

<table>
<thead>
<tr>
<th>Number</th>
<th>Does not Interfere</th>
<th>Completely Interferes</th>
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<tbody>
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<tr>
<td>10</td>
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</tbody>
</table>

**F. Sleep**

<table>
<thead>
<tr>
<th>Number</th>
<th>Does not Interfere</th>
<th>Completely Interferes</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
<td></td>
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<tr>
<td>10</td>
<td></td>
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</tr>
</tbody>
</table>

**G. Enjoyment of life**

<table>
<thead>
<tr>
<th>Number</th>
<th>Does not Interfere</th>
<th>Completely Interferes</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
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<td></td>
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<tr>
<td>10</td>
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</tbody>
</table>
The Confusion Assessment Method (CAM)

By: Christine M. Waszynski, MSN, APRN, BC, Hartford Hospital

WHY: Delirium is present in 10%-31% of older medical inpatients upon hospital admission and 11%-42% of older adults develop delirium during hospitalization (Siddiqi, House, & Holmes, 2006; Tullmann, Fletcher, & Foreman, 2012). Delirium is associated with negative consequences including prolonged hospitalization, functional decline, increased use of chemical and physical restraints, prolonged delirium post hospitalization, and increased mortality. Delirium may also have lasting negative effects including the development of dementia within two years (Ehlenbach et al., 2010) and the need for long term nursing home care (Inouye, 2006). Predisposing risk factors for delirium include older age, dementia, severe illness, multiple comorbidities, alcoholism, vision impairment, hearing impairment, and a history of delirium. Precipitating risk factors include acute illness, surgery, pain, dehydration, sepsis, electrolyte disturbance, urinary retention, fecal impaction, and exposure to high risk medications. Delirium is often unrecognized and undocumented by clinicians. Early recognition and treatment can improve outcomes. Therefore, patients should be assessed frequently using a standardized tool to facilitate prompt identification and management of delirium and underlying etiology.

BEST TOOL: The Confusion Assessment Method (CAM) is a standardized evidence-based tool that enables non-psychiatrically trained clinicians to identify and recognize delirium quickly and accurately in both clinical and research settings. The CAM includes four features found to have the greatest ability to distinguish delirium from other types of cognitive impairment. There is also a CAM-ICU version for use with non-verbal mechanically ventilated patients (See Try This® CAM-ICU).

VALIDITY AND RELIABILITY: Both the CAM and the CAM-ICU have demonstrated sensitivity of 94-100%, specificity of 89-95% and high inter-rater reliability (Wei, Fearing, Eliezer, Sternberg, & Inouye, 2008). Several studies have been done to validate clinical usefulness.

STRENGTHS AND LIMITATIONS: The CAM can be incorporated into routine assessment and has been translated into several languages. The CAM was designed and validated to be scored based on observations made during brief but formal cognitive testing, such as brief mental status evaluations. Training to administer and score the tool is necessary to obtain valid results. The tool identifies the presence of delirium but does not assess the severity of the condition, making it less useful to detect clinical improvement or deterioration.

FOLLOW-UP: The presence of delirium warrants prompt intervention to identify and treat underlying causes and provide supportive care. Vigilant efforts need to continue across the healthcare continuum to preserve and restore baseline mental status.

MORE ON THE TOPIC:
- Best practice information on care of older adults: www.ConsultGeriRN.org
- The Hospital Elder Life Program (HELP), Yale University School of Medicine. Home Page: www.hospitalelderlifeprogram.org
- CAM Disclaimer: www.hospitalelderlifeprogram.org/private/cam-disclaimer

The Hartford Institute for Geriatric Nursing, New York University, College of Nursing is cited as the source. This material may be downloaded and/or distributed in electronic format, including PDA format. Available on the internet at www.ConsultGeriRN.org and/or www.ConsultGerIIX.org. E-mail notification of usage to: hartford.ign@nyu.edu.

T-12
The Confusion Assessment Method Instrument:

1. **[Acute Onset]** Is there evidence of an acute change in mental status from the patient’s baseline?
2A. **[Inattention]** Did the patient have difficulty focusing attention, for example, being easily distractible, or having difficulty keeping track of what was being said?
2B. **(If present or abnormal)** Did this behavior fluctuate during the interview, that is, tend to come and go or increase and decrease in severity?
3. **[Disorganized thinking]** Was the patient’s thinking disorganized or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject?
4. **[Altered level of consciousness]** Overall, how would you rate this patient’s level of consciousness? (Alert [normal]; Vigilant [hyperalert, overly sensitive to environmental stimuli, startled very easily]; Lethargic [drowsy, easily aroused]; Stupor [difficult to arouse]; Coma; [unarousable]; Uncertain)
5. **[Disorientation]** Was the patient disoriented at any time during the interview, such as thinking that he or she was somewhere other than the hospital, using the wrong bed, or misjudging the time of day?
6. **[Memory impairment]** Did the patient demonstrate any memory problems during the interview, such as inability to remember events in the hospital or difficulty remembering instructions?
7. **[Perceptual disturbances]** Did the patient have any evidence of perceptual disturbances, for example, hallucinations, illusions or misinterpretations (such as thinking something was moving when it was not)?
8A. **[Psychomotor agitation]** At any time during the interview did the patient have an unusually increased level of motor activity such as restlessness, picking at bedclothes, tapping fingers or making frequent sudden changes of position?
8B. **[Psychomotor retardation]** At any time during the interview did the patient have an unusually decreased level of motor activity such as sluggishness, staring into space, staying in one position for a long time or moving very slowly?
9. **[Altered sleep-wake cycle]** Did the patient have evidence of disturbance of the sleep-wake cycle, such as excessive daytime sleepiness with insomnia at night?

The diagnosis of delirium by CAM requires the presence of features 1 and 2 and either 3 or 4.

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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>Scale</th>
<th>Worst possible</th>
</tr>
</thead>
<tbody>
<tr>
<td>No pain</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible pain</td>
</tr>
<tr>
<td>No tiredness (Tiredness = lack of energy)</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible tiredness</td>
</tr>
<tr>
<td>Not drowsiness (Drowsiness = feeling sleepy)</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible drowsiness</td>
</tr>
<tr>
<td>No nausea possible</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible nausea</td>
</tr>
<tr>
<td>No lack of appetite</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible lack of appetite</td>
</tr>
<tr>
<td>No shortness of breath</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible shortness of breath</td>
</tr>
<tr>
<td>No depression (Depression = feeling sad)</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible depression</td>
</tr>
<tr>
<td>No anxiety (Anxiety = feeling nervous)</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible anxiety</td>
</tr>
<tr>
<td>Best well-being (Well-being = how you feel overall)</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst well-being</td>
</tr>
<tr>
<td>Normal bowel function</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible bowel function</td>
</tr>
<tr>
<td>No _______ (for example: dry mouth)</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Worst possible _______</td>
</tr>
</tbody>
</table>

Person's Name __________ Date____ Time____

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Regional Palliative Care Program,
Edmonton Zone, Alberta Health Services, 2011.

Complete by (check one)

☐ Person
☐ Family Caregiver
☐ Health care professional caregiver
☐ Caregiver - assisted
Body Diagram

Please mark on these pictures where it is you hurt.
SPIRITUAL ASSESSMENT TOOL – FICA®

Spiritual Assessment Tool

An acronym which can be used to remember what to ask in a spiritual history is:

F: Faith or Beliefs
I: Importance and Influence
C: Community
A: Address

Some specific questions you can use to discuss these issues are:

F: What is your faith or belief?
   Do you consider yourself spiritual or religious?
   What things do you believe in that give meaning to your life?

I: Is it important in your life?
   What influence does it have on how you take care of yourself?
   How have your beliefs influenced in your behavior during this illness?
   What role do your beliefs play in regaining your health?

C: Are you part of a spiritual or religious community?
   Is this of support to you and how?
   Is there a person or group of people you really love or who are really important to you?

A: How would you like me, your healthcare provider to address these issues in your healthcare?

General recommendations when taking a spiritual history:

1. Consider spirituality as a potentially important component of every patient’s physical well being and mental health.
2. Address spirituality at each complete physical exam and continue addressing it at follow-up visits if appropriate. In patient care, spirituality is an on-going issue.
3. Respect a patient’s privacy regarding spiritual beliefs; don’t impose your beliefs on others.
4. Make referrals to chaplains, spiritual directors or community resources as appropriate.
5. Be aware that your own spiritual beliefs will help you personally and will overflow in your encounters with those for whom you care to make the doctor-patient encounter a more humanistic one.

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Further References:

Spiritual Assessment in Clinical Practice, Christina Puchalski, Psychiatric annals; Mar 2006; 36, 3 Psychology Module pg 150
Taking Spiritual History Allows Clinicians to Understand Patients More Fully
Christina Puchalski, M.D. and Anna L. Romer, Ed.D; Journal of Palliative Medicine Volume 3, Number 1, 2000 Pgs 129 – 137
REFERENCES

2. Ibid: pg’s 661 - 663
3. Christina Puchalski; Spiritual Assessment in Clinical Practice; Psychiatric Annals; March 2006; 36,3 ; Psychology Module pg. 153
4. Puchalski Christina, M; A Time for Listening and Caring; Oxford University Press 2006, Page 10
5. Ibid; page 13 (Reed 1987)
6. Ibid; page 6,7,8
7. Christina Puchalski; Spiritual Assessment in Clinical Practice; Psychiatric Annals; March 2006; 36,3 ; Psychology Module pg. 152 (Ehman)
8. Ibid pg 151
9. Ibid pg 150 (Viktor Frankl)
10. Puchalski, Christina and Romer, Anna; Taking a Spiritual History allows clinicians to understand patients more fully. Journal of Palliative Medicine Vol 3 No. 1, 2000 p.129
11. Ibid pg 130

TOOL: GENERALISED ANXIETY DISORDER ASSESSMENT

Generalised Anxiety Disorder Assessment (GAD 7)

This easy to use self-administered patient questionnaire is used as a screening tool and severity measure for generalised anxiety disorder.\[1\]\[2\]

**Generalised Anxiety Disorder Questionnaire (GAD-7)**

Over the last 2 weeks, how often have you been bothered by any of the following problems?

<table>
<thead>
<tr>
<th>Problem</th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling nervous, anxious or on edge?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Not being able to stop or control worrying?</td>
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<tr>
<td>Worrying too much about different things?</td>
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<td></td>
<td></td>
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<tr>
<td>Trouble relaxing?</td>
<td></td>
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<tr>
<td>Being so restless that it is hard to sit still?</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Becoming easily annoyed or irritable?</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Feeling afraid as if something awful might happen?</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Total= \[
\]

\[21\]
The GAD-7 score is calculated by assigning scores of 0, 1, 2, and 3, to the response categories of “not at all,” “several days,” “more than half the days,” and “nearly every day,” respectively, and adding together the scores for the seven questions. [3]

Scores of 5, 10, and 15 are taken as the cut off points for mild, moderate, and severe anxiety, respectively. When used as a screening tool, further evaluation is recommended when the score is 10 or greater. Using the threshold score of 10, the GAD-7 has a sensitivity of 89% and a specificity of 82% for generalised anxiety disorder. It is moderately good at screening three other common anxiety disorders – panic disorder (sensitivity 74%, specificity 81%), social anxiety disorder (sensitivity 72%, specificity 80%), and post-traumatic stress disorder (sensitivity 66%, specificity 81%). [4]

Further reading & references

1. Swinson RP; The GAD-7 scale was accurate for diagnosing generalised anxiety disorder. Evid Based Med. 2006 Dec;11(6):184.
3. IAPT Outcomes Toolkit 2008/9 NHS website

Original Author: Dr Huw Thomas
Current Version: Dr Huw Thomas
Last Checked: 26/10/2010
Document ID: 8736 Version: 10
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View this article online at www.patient.co.uk/doctor/Generalised-Anxiety-Disorder-Assessment-(GAD-7).htm.

Discuss Generalised Anxiety Disorder Assessment (GAD 7) and find more trusted resources at www.patient.co.uk.

EMIS is a trading name of Egton Medical Information Systems Limited.
**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 V**

<table>
<thead>
<tr>
<th><strong>Onset</strong></th>
<th>When did it begin? How long does it last? How often does it occur?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Provoking / Palliating</strong></td>
<td>What brings it on? What makes it better? What makes it worse?</td>
</tr>
<tr>
<td><strong>Quality</strong></td>
<td>What does it feel like? Can you describe it?</td>
</tr>
<tr>
<td><strong>Region / Radiation</strong></td>
<td>Where is it? Does it spread anywhere?</td>
</tr>
<tr>
<td><strong>Severity</strong></td>
<td>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?</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td>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?</td>
</tr>
<tr>
<td><strong>Understanding / Impact on You</strong></td>
<td>What do you believe is causing this symptom? How is this symptom affecting you and / or your family?</td>
</tr>
<tr>
<td><strong>Values</strong></td>
<td>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?</td>
</tr>
</tbody>
</table>

* Physical Assessment (as appropriate for symptom)
References


**TOOL: PAIN ASSESSMENT IN ADVANCED DEMENTIA (PAINAD) SCALE**

Pain Assessment in Advanced Dementia (PAINAD) Scale

<table>
<thead>
<tr>
<th>Items*</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathing</td>
<td></td>
<td>Normal</td>
<td>Occasional labored breathing.</td>
<td></td>
</tr>
<tr>
<td>Independent of</td>
<td></td>
<td>Short period of hyperventilation.</td>
<td>Noisy labored breathing. Long period</td>
<td></td>
</tr>
<tr>
<td>Vocalization</td>
<td></td>
<td></td>
<td>of hyperventilation. Cheyne-Stokes</td>
<td></td>
</tr>
<tr>
<td>Negative</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vocalization</td>
<td></td>
<td>None</td>
<td>Occasional moan or groan. Low-level</td>
<td></td>
</tr>
<tr>
<td>Facial expression</td>
<td></td>
<td></td>
<td>speech with a negative or disapproving</td>
<td></td>
</tr>
<tr>
<td>expression</td>
<td></td>
<td></td>
<td>quality.</td>
<td></td>
</tr>
<tr>
<td>Body language</td>
<td></td>
<td>Relaxed</td>
<td>Tense. Distressed pacing. Fidgeting.</td>
<td></td>
</tr>
<tr>
<td>Consolability</td>
<td></td>
<td>No need to console</td>
<td>Distracted or reassured by voice or</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>touch.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Unable to console, distract or</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>reassure.</td>
<td></td>
</tr>
</tbody>
</table>

**Total**

*Five-item observational tool (see the description of each item below).

**Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0=no pain* to 10=severe pain*).**

**Breathing**

1. Normal breathing is characterized by effortless, quiet, rhythmic (smooth) respirations.
2. Occasional labored breathing is characterized by episodic bursts of harsh, difficult or wearing respirations.
3. Short period of hyperventilation is characterized by intervals of rapid, deep breaths lasting a short period of time.
4. Noisy labored breathing is characterized by negative sounding respirations on inspiration or expiration. They may be loud, gurgling, or wheezing. They appear strenuous or wearing.
5. Long period of hyperventilation is characterized by an excessive rate and depth of respirations lasting a considerable time.
6. Cheyne-Stokes respirations are characterized by rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea (cessation of breathing).

**Negative vocalization**

1. None is characterized by speech or vocalization that has a neutral or pleasant quality.
2. Occasional moan or groan is characterized by mournful or murmuring sounds, wails or laments. Groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
3. Low level speech with a negative or disapproving quality is characterized by muttering, murmuring, whining, grumbling, or swearing in a low volume with a complaining, sarcastic or caustic tone.
4. Repeated troubled calling out is characterized by phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.
5. Loud moaning or groaning is characterized by mournful or murmuring sounds, wails or laments much louder than usual volume. Loud groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
6. Crying is characterized by an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.

**Facial expression**

1. Smiling is characterized by upturned corners of the mouth, brightening of the eyes and a look of pleasure or contentment. Inexpressive refers to a neutral, at ease, relaxed, or blank look.
2. Sad is characterized by an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.
3. Frightened is characterized by a look of fear, alarm or heightened anxiety. Eyes appear wide open.
4. Frown is characterized by a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.

5. Facial grimacing is characterized by a distorted, distressed look. The brow is more wrinkled as is the area around the mouth. Eyes may be squeezed shut.

**Body language**

1. Relaxed is characterized by a calm, restful, mellow appearance. The person seems to be taking it easy.
2. Tense is characterized by a strained, apprehensive or worried appearance. The jaw may be clenched (exclude any contractures).
3. Distressed pacing is characterized by activity that seems unsettled. There may be a fearful, worried, or disturbed element present. The rate may be faster or slower.
4. Fidgeting is characterized by restless movement. Squirming about or wiggling in the chair may occur. The person might be hitching a chair across the room. Repetitive touching, tugging or rubbing body parts can also be observed.
5. Rigid is characterized by stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and unyielding (exclude any contractures).
6. Fists clenched is characterized by tightly closed hands. They may be opened and closed repeatedly or held tightly shut.
7. Knees pulled up is characterized by flexing the legs and drawing the knees up toward the chest. An overall troubled appearance (exclude any contractures).
8. Pulling or pushing away is characterized by resistiveness upon approach or to care. The person is trying to escape by yanking or wrenching him or herself free or shoving you away.
9. Striking out is characterized by hitting, kicking, grabbing, punching, biting, or other form of personal assault.

**Consolability**

1. No need to console is characterized by a sense of well being. The person appears content.
2. Distracted or reassured by voice or touch is characterized by a disruption in the behavior when the person is spoken to or touched. The behavior stops during the period of interaction with no indication that the person is at all distressed.
3. Unable to console, distract or reassure is characterized by the inability to soothe the person or stop a behavior with words or actions. No amount of comforting, verbal or physical, will alleviate the behavior.


Excerpted from Frampton K. "Vital Sign #5. Caring for the Ages 2004; 5(5):26-35. &copy; 2004 Lippincott Williams &amp; Wilkins. All rights reserved. Reprinted with permission.
### Palliative Performance Scale (PPSv2) version 2

<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>

**Instructions for Use of PPS (see also definition of terms)**

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

2. 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 patient. In this way, ‘leftward’ columns (columns to the left of any specific column) are ‘stronger’ determinants and generally take precedence over others.

Example 1: A patient 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 level with good intake would be scored at PPS 50%.

Example 2: A patient who has become paralysed and quadriplegic requiring total care would be PPS 30%. Although this patient 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 patient may have normal intake and full conscious level.

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

3. 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 patient.

4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient’s current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

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Definition of Terms for PPS

As noted below, 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.

1. 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 patient 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 patient is able to sit up vs 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 on their own but at PPS 60% needs occasional assistance.

2. 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 reduces 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 (eg. trying to walk the halls).

3. Self-Care

‘Occasional assistance’ means that most of the time patients are able to transfer out of bed, walk, wash, toilet and eat by their own means, but that on occasion (perhaps once daily or a few times weekly) they require minor assistance.

‘Considerable assistance’ means that regularly every day the patient 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 patient is then able to eat of his or her own accord.

‘Mainly assistance’ is a further extension of ‘considerable.’ Using the above example, the patient now needs help getting up but also needs assistance washing his face and shaving, but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.

‘Total care’ means that the patient is completely unable to eat without help, toilet or do any self-care. Depending on the clinical situation, the patient may or may not be able to chew and swallow food once prepared and fed to him or her.

4. 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.

5. 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 either 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.
FAST FACTS AND CONCEPTS #19 (PDF)
Author(s): Bruce Ambuel PhD

Background  Illness raises fundamental questions – For what may I hope? Why do I suffer? Does my suffering have meaning? What happens after I die? When a physician stands with a patient as they face death, the physician inevitably plays a role in supporting the patient’s inquiry into these spiritual questions. In addition some patients have specific preferences or needs regarding medical care, death and dying that are based upon their religious beliefs. The physician often plays an important role in supporting a patient’s exploration of these issues. Taking a spiritual history is one way to support the patient in this exploration. Maugans (1997) presents a framework for taking a spiritual history; the interview below comes primarily from Maugans’ article with some modification based upon the other sources cited.

Taking a Spiritual History

S—spiritual belief system
- Do you have a formal religious affiliation? Can you describe this?
- Do you have a spiritual life that is important to you?
- What is your clearest sense of the meaning of your life at this time?

P—personal spirituality
- Describe the beliefs and practices of your religion that you personally accept.
- Describe those beliefs and practices that you do not accept or follow.
- In what ways is your spirituality/religion meaningful for you?
- How is your spirituality/religion important to you in daily life?

I—integration with a spiritual community
- Do you belong to any religious or spiritual groups or communities?
- How do you participate in this group/community? What is your role?
- What importance does this group have for you?
- In what ways is this group a source of support for you?
- What types of support and help does or could this group provide for you in dealing with health issues?

R—ritualized practices and restrictions
- What specific practices do you carry out as part of your religious and spiritual life (e.g. prayer, meditation, services, etc.)
- What lifestyle activities or practices do your religion encourage, discourage or forbid?
- What meaning do these practices and restrictions have for you? To what extent have you followed these guidelines?

I—implications for medical care
• Are there specific elements of medical care that your religion discourages or forbids? To what extent have you followed these guidelines?
• What aspects of your religion/spirituality would you like to keep in mind as I care for you?
• What knowledge or understanding would strengthen our relationship as physician and patient?
• Are there barriers to our relationship based upon religious or spiritual issues?
• Would you like to discuss religious or spiritual implications of health care?

T—terminal events planning
• Are there particular aspects of medical care that you wish to forgo or have withheld because of your religion/spirituality?
• Are there religious or spiritual practices or rituals that you would like to have available in the hospital or at home?
• Are there religious or spiritual practices that you wish to plan for at the time of death, or following death?
• From what sources do you draw strength in order to cope with this illness?
• For what in your life do you still feel gratitude even though ill?
• When you are afraid or in pain, how do you find comfort?
• As we plan for your medical care near the end of life, in what ways will your religion and spirituality influence your decisions?

References

Fast Facts and Concepts are edited by Drew A. Rosielle MD, Palliative Care Center, Medical College of Wisconsin. For more information write to: drosiell@mcw.edu. More information, as well as the complete set of Fast Facts, are available at EPERC: www.eperc.mcw.edu.


Disclaimer: Fast Facts and Concepts provide educational information. This information is not medical advice. Health care providers should exercise their own independent clinical judgment. Some Fast Facts cite the use of a product in a dosage, for an indication, or in a manner other than that recommended in the product labeling. Accordingly, the official prescribing information should be consulted before any such product is used.

ACGME Competencies: Interpersonal and Communication Skills

Keyword(s): Communication, Psychosocial and Spiritual Experience: Patients, Families, and Clinicians
TOOL: A COMMUNICATION ROADMAP FOR PATIENT CENTERED INTERACTION

A COMMUNICATION ROADMAP
FOR
PATIENT CENTERED INTERACTION

ATTITUDES

This list is meant to provide guidelines not a checklist. The points listed should provide a sense of the kind of behaviours the physician might employ in a patient interaction.

- Putting patients at ease
- Respecting and valuing the patient (especially when values clash)
- Identifying and acknowledging patient’s feelings
- Using a professional conversational style
- Encouraging discussion
- Providing the patient with opportunities to ask questions
- Encouraging feedback
- Seeking clarification & consensus
- Addressing disagreements
- Using constructive skills of refusal
- Facilitating and directing an interview without controlling it
- Keeping an open mind i.e. being aware of making assumptions

STYLES

Questioning
- appropriate use of open & close-ended questions

Active Listening
- picking up on verbal & non-verbal cues
- using the patient’s language
- use of silence
- not interrupting

Body Language
- awareness of body posture, body language & eye contact

TECHNIQUES

- REPEATING Repeating/restating what you have just heard using the patient’s words i.e. “You don’t want to see your husband suffer like this”

- REFLECTING (in the form of a question) Checking in with the patient and interpreting what you have heard i.e. “So you’re feeling like there is nothing in your life that makes you happy”
- **REITERATING**  This is a way of reinforcing and reviewing crucial information that has been previously discussed with the patient. "I’d like to reiterate the importance of taking all your medication until it’s finished"

- **PARAPHRASING** Using your own words to infer the patient’s thoughts and feelings e.g.: Patient: “I can’t go through this anymore”  
  Doctor: “You’ve really reached your limit”

- **THE FOUR TECHNIQUES ABOVE:**
  - provide an opening for a richer and more thorough response from the patient
  - allow the patient an opportunity to expand upon and clarify their position
  - afford the patient a chance to confirm and acknowledge their own feelings
  - are proof positive to the patient that you are listening closely

- **FACILITATING** The use of body language and nonverbal techniques (nodding, open posture, silences etc.) and encouraging phrases (e.g. “please go on..." “Help me understand...")

- **CLARIFYING** Checking in with the patient to verify facts, information, or feelings that have been expressed. "What I think I’ve heard you say is that you don’t want to go to hospital because then your husband would not have the support he needs right now. Is that accurate?"

- **QUANTIFYING** Get an accurate understanding of regimens such as medications, alcohol intake or smoking. “When you say you drink wine socially, can you tell me exactly how many glasses you have in a day? And how many on weekends?”

- **BRIDGING** Using transition statements to connect two parts of the interview-mapping the direction of the interview e.g. “I think I have a thorough understanding of your past health. Now I’d like to ask you about your current lifestyle”

- **LINKING**  Making a connection for patients between their condition, and the effect that their attitude or behaviour has on it. Linking management suggestions to the patient’s problem.  
  “Are you aware that heavy alcohol consumption can often cause changes in the liver that result in breast enlargement?”  
  Explaining why you are asking questions – especially with sensitive topics.  
  “In order to get a better understanding of your condition I need to ask some sensitive questions.”

- **NORMALIZING**  Statements intended to decrease patient anxiety and increase patient comfort/ease. “When a person is dying, one of the chief concerns is making them as comfortable as possible. Is this how you’re feeling?”  
  “Women in abusive relationships often blame themselves”
• **NEGOTIATING** Forging a mutual contract with the patient to improve outcomes. “If I told you that reducing your alcohol consumption would improve your current condition, would you be willing to try and cut back?”

• **ASKING PERMISSION** “In order to get a better understanding of your condition I’m going to need to ask some sensitive questions. Is that OK with you?”

• **SUMMARIZING** Brief frequent verbal reviews of the patient interview will help to maintain a mutual and accurate understanding of events. A final summary serves as segue to a shared plan.

Standardized Patient Program, University of Toronto  2004
# SBAR Report

**BEFORE CALLING/COMMUNICATING**

1. Assess the patient
2. Review the chart for the appropriate physician to call
3. Know the admitting diagnosis and comorbidities
4. Read the most recent Progress Notes and the assessment from the nurse on the prior shift/visit.
5. Have available: Chart, Allergies, Current Medication List, Lab Results as appropriate

---

### SITUATION

State your **name and unit/sector**
I am calling about: **(Patient Name & Facility)**
The **reason** I am calling is:

### BACKGROUND

State the pertinent **medical history/ any recent trauma/PPS**
A Brief Synopsis of the **treatment to date and effectiveness**

### ASSESSMENT

<table>
<thead>
<tr>
<th>Onset</th>
<th>Precipitating &amp; alleviating factors</th>
<th>Quality</th>
<th>Region &amp; radiation</th>
<th>Severity</th>
<th>Timing</th>
<th>U &quot;How is the pain affecting the patient?&quot;</th>
</tr>
</thead>
</table>

Any changes from prior assessments:

### RECOMMENDATION

**Do you think we should:**  
[ ] Order a new analgesic/medication/treatment?  
[ ] Come to see the patient at this time?  
[ ] Order **diagnostic tests**?  
[ ] Other ________________________________

**Are any tests needed?**  
[ ] Do you need any tests?  
[ ] XRAY

**If a change in treatment is ordered, then ask:**  
 [ ] If the patient does not improve, **when would you like to speak again?**
 [ ] Do you want contact with a secondary level palliative care expert if there is no improvement? (e.g. PC Team, PC Physician, PPSMCP etc.)

Document the details of communication & outcomes in patient record  
Adapted from WWHP Jan. 2011, June 2016
### Palliative Care SBAR Communication Tool

<table>
<thead>
<tr>
<th><strong>S</strong>ituation</th>
<th><strong>B</strong>ackground</th>
<th><strong>A</strong>ssessment</th>
<th><strong>R</strong>ecommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PPS</strong></td>
<td><strong>Diagnosis</strong></td>
<td><strong>Onset</strong></td>
<td><strong>Can you please visit to assess</strong></td>
</tr>
<tr>
<td><strong>ESASR</strong></td>
<td><strong>History of illness, related factors</strong></td>
<td><strong>Provoking/Palliating</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Symptom</strong></td>
<td></td>
<td><strong>Quality</strong></td>
<td><strong>Upon arrival can you please assess</strong></td>
</tr>
<tr>
<td>Date</td>
<td>Date</td>
<td><strong>Region/Radiation</strong></td>
<td></td>
</tr>
<tr>
<td>Date</td>
<td>Date</td>
<td><strong>Severity</strong></td>
<td></td>
</tr>
<tr>
<td>Date</td>
<td>Date</td>
<td><strong>Treatment</strong></td>
<td></td>
</tr>
<tr>
<td>Date</td>
<td>Date</td>
<td><strong>Understanding/Impact on you</strong></td>
<td></td>
</tr>
<tr>
<td>Date</td>
<td>Date</td>
<td><strong>Values</strong></td>
<td></td>
</tr>
<tr>
<td>Date</td>
<td>Date</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Symptom</strong></th>
<th><strong>Current Medications</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td></td>
</tr>
<tr>
<td>Tiredness</td>
<td></td>
</tr>
<tr>
<td>Drowsiness</td>
<td></td>
</tr>
<tr>
<td>Nausea</td>
<td></td>
</tr>
<tr>
<td>Lack of Appetite</td>
<td></td>
</tr>
<tr>
<td>Shortness of breath</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
</tr>
<tr>
<td>Well-being</td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
</tr>
</tbody>
</table>

I have concerns about: ____________________________

Name ____________________________ DOB MM/DD/YY

Health Card Number ____________________________ Gender ______

☐ The problem I am calling about is...  ☐ The reason for transfer is...

Allergies ____________________________

<table>
<thead>
<tr>
<th><strong>Symptoms</strong></th>
<th><strong>Current Medications</strong> (or attach medication sheet)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
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<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

☐ Can you please visit to assess

I recommend.../my thoughts are.../I wonder if...?

Nurse’s Name/Agency: ____________________________

Contact number: ____________________________

Date: ____________________________

Adapted from the Fraser Health Hospice SBAR Communication Tool by the Palliative Pain & Symptom Management Consultation Service for the SE Local Health Integration Network Aug2017
Early Identification & Prognostic Indicator Guide
Guidance for clinicians to support earlier identification of patients nearing the end of life and who could benefit from a hospice palliative care approach

Why is it important to identify people nearing the end of life?

About 1% of the population dies each year. Although some deaths are unexpected, many more in fact can be predicted. This is inherently difficult, but if we were better able to predict people in the final year of life, whatever their diagnosis, there is good evidence that they are more likely to receive well-coordinated, high quality care.

This Early Identification and Prognostic Indicator Guide aims to help family physicians, specialist physicians and nurse practitioners in earlier identification of those patients nearing the end of life who could benefit from a hospice palliative care approach.

The tool has been adapted from the Gold Standards Framework (GSF) Prognostic Indicator Guidance\(^1\) tool developed by the GSF Centre in the UK. The UK has been using the tool along with a comprehensive education program to support GPs, care homes and general hospital staff in identifying patients and placing them on a register to help trigger specific support.

Varying Disease Trajectories\(^2\)

Three triggers that suggest that patients could benefit from a hospice palliative care approach

1. The Surprise Question: ‘Would you be surprised if the patient were to die in the next year?’

2. General indicators of decline: deterioration, advanced disease, decreased response to treatment, choice for no further disease modifying treatment.

3. Specific clinical indicators related to certain conditions.

Definition of Hospice Palliative Care\(^3\)

Hospice palliative care is a philosophy of care that aims to relieve suffering and improve the quality of living and dying. It strives to help individuals and families to:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears;
- prepare for and manage self-determined life closure and the dying process;
- cope with loss and grief during the illness and bereavement;
- treat all active issues;
- prevent new issues from occurring;
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

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Early Identification & Prognostic Indicator Guide
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**Step 1**
Ask the Surprise Question
Would you be surprised if the patient were to die in the next year?
Refer to details below

- **NO**
- **NOT SURE**
- **YES**

**Step 2**
Do they have General Indicators of Decline?
Refer to details below

- **YES**
- **NO**

**Step 3**
Do they have Specific Clinical Indicators?
Refer to details below

- **YES**
- **NO**

**IDENTIFY** Flag in patient’s medical record with identified palliative care needs
Refer to community Palliative Care supports or program

**ASSESS** Assess patient and family needs (i.e. disease management, physical, psychosocial, spiritual, functional status, goals of care)
Record goals of care/advance care planning discussions

**PLAN** Participate as a member of the primary level palliative care team
If patient/family needs meet complexity criteria, discuss role of secondary level palliative care specialists, i.e. consultation, collaborative care/shared care, direct care

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Early Identification & Prognostic Indicator Guide

Guidance for clinicians to support earlier identification of patients nearing the end of life and who could benefit from a hospice palliative care approach

More details of indicators – the intuitive surprise question, general decline and specific clinical indicators

The Surprise Question

For patients with progressive life-limiting illness – Would you be surprised if the patient were to die in the next year?

The answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient’s quality of life now and in preparation for possible future needs?

General Indicators of Decline

Are there general indicators of decline and increasing needs?

- Advancing disease – unstable, deteriorating complex symptom burden
- Decreasing response to treatments, decreasing reversibility
- Choice of no further disease modifying treatment
- General physical decline
- Declining functional performance status (e.g. Palliative Performance Scale (PPS) ≤60, reduced ambulation, increasing dependence in most activities of daily living)
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity
- Weight loss - >10% in past six months
- Repeated unplanned/crisis hospital admissions
- Sentinel event, e.g. serious fall, bereavement, retirement on medical grounds
- Serum albumin <25g/l

Specific Clinical Indicators

Flexible criteria with some overlaps, especially with those with frailty or other co-morbidities

a. Cancer - rapid or predictable decline

- Metastatic cancer
- More exact predictors for cancer patients are available e.g. PPS, ECOG, PPI, PaP
- The single most important predictive factor in cancer is performance status and functional ability - if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less

b. Organ failure - erratic decline

<table>
<thead>
<tr>
<th>Lung Disease (COPD)</th>
<th>Heart Disease (CHF)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease assessed to be very severe (e.g. FEV1 &lt;30% predicted)</td>
<td>CHF NYHA Stage 3 or 4 - shortness of breath at rest on minimal exertion</td>
</tr>
<tr>
<td>Recurrent hospital admissions (≥3 in last 12 months due to COPD)</td>
<td>Repeated hospital admissions with heart failure symptoms</td>
</tr>
<tr>
<td>Fulfills long term oxygen therapy criteria</td>
<td>Difficult physical or psychological symptoms despite optimal tolerated therapy</td>
</tr>
<tr>
<td>MRC grade 4 to 5 – dyspnea after 100m on the level or confined to house</td>
<td></td>
</tr>
<tr>
<td>Signs and symptoms of right heart failure</td>
<td></td>
</tr>
<tr>
<td>More than 6 weeks of systemic steroids for COPD in preceding 6 months</td>
<td></td>
</tr>
</tbody>
</table>

**Early Identification & Prognostic Indicator Guide**

Guidance for clinicians to support earlier identification of patients nearing the end of life and who could benefit from a hospice palliative care approach

<table>
<thead>
<tr>
<th>Renal Disease (CKD)</th>
<th>Liver Disease</th>
<th>Neurological Diseases</th>
<th>General</th>
</tr>
</thead>
</table>
| Stage 4 or 5 Chronic Kidney Disease (CKD) whose condition is deteriorating | Advanced cirrhosis with one or more complications in past year:  
- diuretic resistant ascites, hepatic encephalopathy, hepatorenal syndrome, recurrent variceal bleeds  
- Liver transplant contraindicated  
- Child-Pugh Class C | Progressive deterioration in physical and/or cognitive function despite optimal therapy |  
- Marked rapid decline in physical status  
- First episode of aspirational pneumonia  
- Increased cognitive difficulties  
- Weight Loss  
- Significant complex symptoms and medical complications  
- Low vital capacity (below 70% of predicted using standard spirometry)  
- Dyskinesia, mobility problems and falls  
- Communication difficulties |
| Patients choosing the ‘no dialysis’ option or discontinuing dialysis (by choice or due to increasing frailty, co-morbidities) |  
- Symptomatic Renal Failure – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload | Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure |  
- Speech problems: increasing difficulty in communications and progressive dysphagia |
| Patients with difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy |  |  |  |
| Symptomatic Renal Failure – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload |  |  |  |

Early Identification & Prognostic Indicator Guide
Guidance for clinicians to support earlier identification of patients nearing the end of life and who could benefit from a hospice palliative care approach

c. Frailty/Dementia - gradual decline

Frailty

- Multiple co-morbidities with significant impairment in day to day living and:
- Deteriorating functional performance status
- Combination of at least three of the following symptoms: weakness, slow walking speed, significant weight loss, exhaustion, low physical activity, depression

Dementia

- Unable to walk without assistance and
- Urinary and fecal incontinence, and
- No consistently meaningful verbal communication and
- Unable to do self-care without assistance
- Reduced ability to perform activities of daily living

Plus any of the following:
- Weight loss, urinary tract Infection, severe pressures sores (stage 3 or 4), recurrent fever, reduced oral intake, aspiration pneumonia

Stroke

- Persistent vegetative or minimal conscious state or dense paralysis
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment / post-stroke dementia

References:

Case Based Learning

The case studies used are not presented as, nor are they meant to be perfect scenarios. They are taken from actual events and do not in some instances reflect best practice. The purpose for these case studies is to allow a complete and thorough analysis of each case, to consider possible solutions, apply critical thinking that reflects best practice and to undergo retrospective sense making that can be applied to each case.
Case Based Learning

CBL 1 ~ CASE 1: Deepa

Deepa, a well known and experienced Nurse Practitioner, who until recently worked full time with the Palliative Care Team. Deepa has been diagnosed with metastatic ovarian cancer. She is undergoing chemotherapy and the community nurse visits once a week for PICC line dressing changes.

Deepa developed a low grade fever and told the visiting nurse she chooses not to go to the hospital as she feels she can manage the fever on her own.

Within 24 hours, Deepa’s fever has spiked to over 39 and her husband took her to the Emergency Department. Deepa was diagnosed with neutropenic infection and has been admitted to the ICU in critical condition.
CBL 1 - CASE - 2: Mary

Mary worked night shift on a medical unit at the local hospital and cared for a patient in a pain crisis. She completed a pain assessment and notified the attending physician.

Mary reported that this 75 year old man admitted from home 2 days prior with a diagnosis of end stage adenocarcinoma of the gallbladder had excruciating pain in his right upper quadrant. He rated it as a 10/10 and stated it was the worst pain he had ever had. He was febrile and jaundiced. The admitting physician in the ED had ordered Tylenol #3 1 to 2 tabs q4h prn for pain with no effect.

The attending interrupted her and inquired what Mary would like him to do. Mary then requested a different analgesic to manage the pain. He retorted, give him 50 mg of morphine s/c every hour till he is comfortable. Mary repeated 50? 5-0? He said yes and hung up. Mary did not feel that the order was appropriate, but transcribed the order and administered the morphine.

The unit was busy and Mary returned to check on the patient after 90 minutes. When she entered the room, he was not breathing. She initiated the code, started CPR but despite their efforts, the patient died.

After the death, the chart and care provided were reviewed. The physician denied giving the order for that quantity of morphine. Colleagues recalled Mary calling the physician but did not know the exact conversation. Her colleagues also indicated they were not approached to review the order.

Mary blamed herself for being afraid to further clarify the order with the physician and neglecting to review it with colleagues.

Mary was so distraught by the occurrence that she terminated her employment and never worked as an RN again.
CBL 1 ~ CASE 3: Michael

Michael an RN working in long term care home provided care for a resident named Mrs. Baxter. Mrs Baxter, 82, with advanced dementia had a recurrent CA of breast with metastasis to bone and had been experiencing severe pain for many weeks. Her pain ranged from 4/10 to 9/10, and she had frequent episodes of incident pain.

Michael worked closely with his team to assess and manage Mrs. Baxter’s pain, but her daughter Mary was reluctant to agree to opioids, as she believed them to be addictive and dangerous. Mary did agree to Tylenol #3, 1-2 tabs po q4-6h PRN, but ONLY if her mom requested it.

Mrs. Baxter’s pain continued, and after a comprehensive reassessment, Michael asked the physician to rotate the analgesic to an opioid.

During a team meeting the following day, Michael reported on the progress with Mrs. Baxter’s pain management with the addition of hydromorphone, and Karen, one of Michael’s colleagues, looked at him and said, “You can’t put her on hydromorphone; she’s not palliative yet!” Michael tried to explain to Karen that a routine dosing of hydromorphone was important for Mrs. Baxter’s pain management, and being on opioids has nothing to do with ‘being palliative’. Karen got up and left the team meeting.

The following morning, Michael arrived to find a note on his clipboard from Karen: “Mrs. Baxter and her daughter do not want hydromorphone. She wants to continue taking Tylenol #3.” Confused and concerned, asked her about the note. Karen said, “Last evening before supper her daughter asked me about the new pain medication. I told her that when my Granny was in a nursing home, they put her on hydromorphone, and two days later she died. I told them I didn’t think Mrs. Baxter was sick enough to take a drug that strong.”
CBL 2 ~ CASE 1: Kim & Shelly

Kim & Shelly: Part 1

A concerned woman in a small rural community was worried that her neighbor Kim and partner Shelly had become reclusive. Kim had a diagnosis of cancer and had not left the house in the last few months. Lately, when the neighbor went to call she was not invited in and only received vague responses from Shelly at the door. The neighbor has kept others in the neighborhood ‘up to date’ on Kim and Shelly’s activity. Any attempts at health system support had been refused by Kim and Shelly.

The neighbor was becoming increasingly concerned and reached out to her friend who was a local rural nurse, to check-in on Kim and Shelly as a personal favor. The nurse received permission from Shelly that she could come to the house. Shelly met the nurse at the door and immediately Kim began yelling from the kitchen using abusive language that no one was to see her.

Kim & Shelly: Part 2

The situation has changed. The nurse received a referral from the health system. The patient initially refused a visit but changed her mind and later accepted service.

When the nurse arrived for the visit she was told Kim would only allow her to enter under the condition that no hands-on examination would occur. The nurse agreed.

After making her way past many cats and through refuse on the floor the nurse found Kim in the kitchen sitting on a stool. Kim was morbidly obese and though she wore a blouse, only had a sheet covering from her waist down. Her exposed legs had gross edema with massive thickening of tissues at the knees and ankles and were weeping copious amounts of serous drainage. Purulent discharge came from areas of broken skin. Kim’s arms were covered with scratches, some of which appeared to be infected. Kim was very short of breath and explained that she was only able to sit on the stool or lay on the couch a few steps away. She was not able to use a toilet herself, but rather had to have Shelly place a pail underneath her while she held onto the counter.

Kim shared with the nurse that she was diagnosed with stomach cancer one year ago. She was being treated at the local cancer center but it was extremely difficult for her to attend due to her obesity and pain. The few times she was able to go, Kim felt that all staff were repulsed by her obesity; in fact she was told that her weight was probably the cause of her cancer. Both Kim and Shelly were somber remembering how they were rushed through exams and never spoken to directly. Kim shared, “each time we went I felt violated. I couldn’t do it anymore and so I stopped going.” Around this time, Kim also “fired” her family physician for similar reasons. The cancer clinic called a few times afterwards but Kim refused to speak to them and there was no further follow up.

Kim revealed that she had become pregnant by her father at age 15 and had a miscarriage at 13 weeks gestation. She was now sure that the large growth coming out of her umbilicus was retribution for being a ‘bad person’. Kim would not let the nurse look at this growth because she told the nurse it was disgusting and humiliating.

Kim has felt hurt and judged by the health care system and her own community for both her obesity and her sexual orientation. The last few months Kim has refused help from anyone but Shelly.
Kim & Shelly: Part 3

The nurse listened quietly to Kim’s story and said, “as a health care professional, I want to apologize for the way you were treated and I am so sorry that the system let you both down.”

Kim and Shelly were surprised and touched. They told the nurse that no one had ever apologized before.

The nurse suggested that they learn from these experiences and together put things in place to safeguard this from happening again. Though Kim was becoming emotionally and physically exhausted, she consented to a more thorough physical exam. The nurse made the decision to examine the lungs and the umbilical tumor. She recognized that many identified issues were beyond her scope of practice and continued to encourage Kim and Shelly to consider more supports and services.

Assessment:

Lungs

- Decreased Air Entry (A/E) middle lobe. No A/E inferior lobe of (R) lung
- No A/E inferior lobe of (L) lung
- Crackles throughout both lungs
- Shortness of breath with any activity and after speaking a few sentences

Umbilical Tumor

- Painful pulsating fungating tumor with necrotic tissue sloughing off of abdomen. Foul odour discharge purulent drainage. Tumor > 6 cm in diameter.

After completion of this assessment, Kim agreed to have the nurse contact a doctor. Kim’s only stipulation was that if the doctor was to make a home visit, he was to come only with the nurse. Kim was becoming very short with her answers, and breathing was becoming an issue. It was apparent to the nurse that Kim was becoming fatigued, and assessment was stopped.

Kim & Shelly: What Really Happened

The nurse contacted the palliative care physician in her area and requested an urgent home visit for Kim. The doctor was reluctant but agreed to visit the next day.

The nurse and the doctor did a joint visit and developed and implemented a care plan. When the physician left the home he shared with the nurse that nothing could have prepared him for what he had witnessed.

The next day Shelly called to say that Kim had died. Kim had become severely short of breath but did not want anyone called. She had lots of pain in her chest and her lips turned blue. Kim’s cats climbed on her bed and stayed with her. Kim died holding onto Shelly.
John: Part 1

John is an 82-year-old man who has been living with heart failure for the last few years. Over the past two weeks has experienced increasing dyspnea and pain. He has had a weight gain of five pounds in the last week and has a troublesome dry cough. After three emergency room visits, he was finally admitted to the local hospital two days ago with end stage heart failure. He has a medical history of mild hypertension and bronchial asthma, peripheral vascular disease (PVD), diabetes mellitus, and progressive heart disease. His PPs is 50% and NYHA classification is stage 3.

John is currently taking the following medications:

- Hydrochlorothiazide
- Albuterol and ipratropium inhalers prn.
- Furosemide
- Metoprolol
- Metformin
- Plavix
- Amlodipine
- ES Tylenol 2 tabs po q6h
- Digoxin

On admission, Johns’ respiratory rate was 22-26 per minute, pulse was 100 beats and pulse oximetry 90% on room air. He complains of breathlessness and physical exam reveals bilateral crackles with decreased A/E, and edema both legs. John had some mental clouding, and unable to rate is shortness of breath on the ESAS-r. His wife feels it is 9/10.

John: Part 2

In hospital, John’s dyspnea is treated with the following interventions:

1. oxygen at 3 L via nasal prongs
2. morphine 5 mg po q6h with BT of 5 mg q1h prn, titrated up during stay based on BTD dosing
3. inhalers
4. increased Lasix given per IV
5. heart medications at optimal doses.

John made an informed decision not to have CPR and a plan of treatment is documented in his medical record along with the completion of the DNR-C form. John would like to die in his home not in the hospital. John is discharged from hospital with a referral for nursing visits to provide end-of-life care.

Currently his dyspnea is well palliated (ESAS-r - SOB 5/10) on oral MS Contin 30 mg every 12 hours, BT medication is Statex 5 mg q1h prn, use of oxygen and prescribed inhalers. John also has Lorazepam 1 mg bid prn and an order for Lasix prn for weight gain 2-3 pounds in over 2 days. His PPS is 50%.

After 3 weeks, John has increased dyspnea and wheezing and has developed a cough. Nursing observations include: cachexia, appearance of acute discomfort (gripping side rails, sitting up - cannot speak more than 2 words at a time), while his wife comments that he frequently appears terrified. He is unable to rate his SOB. His PPS is 40% and NYHA classification is 3.

Physical exam reveals the following:

Face & Neck
- Jugular vein distention
Cardiac

- Galloping, erratic heart sounds

Lungs

- Decreased breath sounds (R) Lung-mid and lower lobes
- Crackles throughout

Abdomen

- Evidence of distention

Extremities

- Bilateral pedal edema

Evidence of Cachexia Syndrome

The SRK was not in the home, nor any injectable medication to treat the crisis. John was transferred to the hospital via ambulance. John was diagnosed with pneumonia and end stage heart disease. He was given IV antibiotics and after 2 weeks was discharged home.

John: Part 3

Three weeks later John’s visiting nurse reports that John is anxious, agitated, is having visual hallucinations and has had sleep-wake cycle disturbance. John rates his shortness of breath as 8/10. John’s PPS is now 30% and NYHA classification is stage 4. The SRK is now in the home with the appropriate accompanying orders. John has been having noisy breathing due to increased secretions. He has been increasingly anxious and John’s wife has been giving him more Lorazepam and BT Morphine.

His medications are as follows:

- MS Contin 45 mg po q12h
- IR morphine 5 mg q4h prn (has had 6 BT doses in past 24h)
- Lorazepam 1 mg tid and prn (has had 5 extra doses in the last 24h)
- Supplemental oxygen
- Hydrochlorothiazide
- Albuterol and ipratropium inhalers prn.
- Furosemide prn
- Metoprolol
- Metformin
- Plavix
- Amlodipine.

John: What Really Happened

John is now actively dying. All oral meds are discontinued. The Lorazepam has been discontinued and morphine rotated to hydromorphone. John is started on Haldol 1 mg SC q6h to reduce his agitation. To palliate his noisy breathing, John is placed in the left recumbent position and given Atropine drops orally as needed. John experienced severe air hunger and the Haldol was d/c and methotrimeprazine sc was initiated. Two days later, John has a cardiac arrest and dies at home with his family present.
CBL 3 ~ CASE 1: Lee

Lee: Part 1

Lee is a 70 year old man who recently moved to Long Term Care because his family could not provide the support he required at home. Lee has a diagnosis of Parkinson’s, Ca Prostate, and recently-identified bone metastases. Lee’s PPS is 40%, and his ESAS-r score for pain is 10/10. His pain regimen has included Hydromorph Contin 6 mg po q12h and Tylenol ES 2 tabs po q6h prn for breakthrough pain; his pain continues to escalate. Lee is distraught about his recent move and his declining health, and has been constantly asking, “Why did this have to happen to me?” He questions what he did wrong in his life to deserve this fate. He is angry at having to change physicians with the move, as well as his latest diagnosis. He has refused to see the medical director and has insisted to have his former family physician resume his care. Lee is currently seeing an oncologist at the regional cancer centre. He has not engaged in discussions with family or health care providers regarding goals of care or his wishes for end-of-life care.

Lee: Part 2

The medical director and the DOC of the long term care home met with Lee and his family to discuss his concerns about not having his family physician involved in his care. After a lengthy dialogue, Lee agreed that the medical director could direct his care in consultation with his previous family physician. Lee was adamant that he did not want to be admitted to the local hospital and wanted to remain at the long term care home. From the initial contact with the medical director, Lee identified that pain is the primary issue to address at this time.

Lee: Part 3

Lee experiences an acute pain crisis that could not be managed. Lee was admitted to the local hospital. Lee has told staff that he has already spoken to his oncologist about ‘putting him out for good’. He has had no discussion with the LTC medical director about his suffering.

Lee: What Really Happened

During his hospital stay, Lee’s pain management continued to be a very challenging issue. He repeatedly asked for sedation to put him out for good. The hospitalist ordered IV opioids to be given q20min, but this had little to no effect. Lee was also started on Midazolam IV q30min. After 1.5 hours of unrelenting pain, Lee became semi-comatose but would occasionally awaken and cry out. He was restless even in a semi-comatose state. Four hours later Lee called out his wife’s name and as she approached his bedside he grabbed her hand, looked at her and died.

Lee’s pain was never managed, palliative sedation for intractable symptoms was not initiated and his wife was left with the horror of watching her husband suffer and die a painful death.
CBL 3 ~ CASE 2: Maria

Maria: Part 1

Maria is a 66-year-old woman with advanced lung disease. She has been hospitalized 8 times in the past year for respiratory distress. Maria did not want CPR in her plan of treatment, which she communicated to her family, friends, family physician and nurses at the local hospital during each of her admissions. There is no informed consent for a plan of treatment for CPR documented, nor a DNR-C form completed.

Recently Maria developed extreme respiratory distress at home and her husband Bill called the ambulance. When paramedics arrived Maria was in respiratory arrest and Bill was extremely distraught and insisted that measures be taken to keep Maria alive. Maria then went into cardiac arrest. Without the DNR-C form in place, the paramedics proceeded with CPR and transferred Maria to the hospital. At the hospital, one of the nurses recognized Maria from previous visits. Maria’s family doctor was on holidays.

Maria: What Really Happened

Maria did not want CPR, as expressed in previous wishes, though her SDM indicated to continue. The doctor at the hospital, continued to perform CPR for 15 minutes until a heartbeat was detected. Maria was then transferred to a tertiary care hospital on life support. She had numerous seizures and was actively treated for this additional symptom. After 5 days a family/team conference was held and the family decided to discontinue life support and Maria died 1 week later. Maria’s wishes and plan of treatment were not respected.
P2P
Peer-to-Peer Exchange
PEER-TO-PEER EXCHANGE GUIDE

Objectives

• To understand how far along each learner is with respect to the self-directed reading and e-Learning Module content
• To help learners articulate their own key take-aways and to benefit from hearing someone else’s perspective
• To help identify and discuss some of the more challenging content and flag any possible barriers to learning
• To help 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 navigate 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.
• Discussion about when you will be connecting for the the next one or two P2P exchanges.

Process

At the beginning of the CAPCE program you will be placed in a group with 1-2 other CAPCE learners. You will connect with your peer-to-peer groups once every two weeks 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: Have a conversation around the “Practice It” reflections in the e-Learning modules. Share and discuss your answers to the questions asked in the e-Learning Modules that you have worked through so far. You will be prompted to discuss with your peers questions you answered from the following e-Learning Modules:

   » Module A: Introduction to CAPCE and the Role of the CAPCE Resource Nurse
   » Module C: Information Sharing
   » Module D: Decision-Making
   » Module F: Care Delivery and Confirmation

Step 4: Identify any barriers or challenges you have with the content and discuss why that might be.

Step 5: Identify any outstanding questions you have.

Step 6: Identify strategies you will implement to overcome those barriers and find answers to your questions.
COACHING SESSIONS

The CAPCE Program includes opportunities for learners to engage with CAPCE Coaches in 1-1 or small group settings. 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 educators in a relaxed, safe and informal learning environment
- To identify future learning or mentoring opportunities that assists the nurse in achieving their identified goals

COACHING SESSION 1: Lead From Where You Stand 1

Format: Email, Check-In or Phone Call (coach will indicate format in CBL #1)

Purpose:

To review the goals of the learner, confirm understanding of the program format, and to provide an opportunity to explore the potential to lead from where they stand.

Coaching Questions

Email your Coach a response to the following question:

1. What are the three learning goals you have identified for yourself in e-Learning Module A? Use and reflect on discussions, materials and frameworks shared in Case Based Learning session 1. Goals should include a goal statement, steps to achieve, and how you know that you have achieved them. Identify what leadership qualities you will use to achieve your goals.

2. Do you have any questions about your role as a nurse with enhanced knowledge of hospice palliative care?

COACHING SESSION 2: Introduction to Calculations

Format: Small Group (2 hours)

Purpose:

To learn and understand the core concepts of equianalgesia, calculation of breakthrough pain dose, titration of opioids, opioid rotation/switching, calculation of cross tolerance and use of TD Fentanyl.

Required resources:

- Equianalgesic Dosing Chart
- Opioid Analgesics used Frequently in Palliative Care
- Opioid Rotation Calculation Worksheet
- The Pallium Palliative Pocketbook
Coaching Questions

Section 1: Core Concepts of Equianalgesia

Coach will lead this section and share information on equianalgesia. Discussion on familiarity of content to you and your experiences will follow the information shared.

Section 2: Calculations

Using long acting (LA) opioid formulations:

1. A person is taking morphine 20 mg po q4h and is having difficulty with needing to awaken in the night to take the 4 am dose. Calculate an equivalent morphine po LA dose.

Equianalgesia:

2. Using the Equianalgesic Dosing Chart, calculate:
   a. the equivalency of morphine 100 mg po to hydromorphone po
   b. the equivalency of morphine 100 mg po to oxycodone po

Breakthrough Pain

3. Calculate the oral BT dose for a person with extensive metastatic bone disease who is on Hydromorph Contin 18 mg po q12h and experiences episodes of pain when she moves. What is your first step? Next?

Titration of opioids

4. Calculate the new total daily dose of morphine for a person who reports good pain management on morphine 20 mg po q4h plus 9 BT doses of morphine 10 mg po.
   a. Calculate the new long acting po dose.
   b. Calculate a new breakthrough po dose
5. What are the steps and considerations when initiating a TD fentanyl patch when the person’s pain is already managed on a regular dose of opioid?

Opioid Rotation/Switching

6. A person with end stage heart disease is managed on MS Contin 30 mg po q12h but loses the ability to swallow (PPS 20%). Calculate an equivalent 24h SC dose. What do you do first? Next?

7. A person who is on MS Contin 160 mg po q12h develops myoclonus. He is drinking sufficient fluids. A decision is made to rotate him to hydromorphone. His pain is well managed.

   a. Using the Opioid Rotation Calculation Worksheet calculate the new 24h total dose, 12h dose, and po breakthrough dose of hydromorphone using a 40% cross tolerance reduction.
### Formula Answer: Question #7.a

<table>
<thead>
<tr>
<th><strong>Total in 24h of EACH opioid</strong></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Calculate the total amount of each route of each opioid given in the previous 24 hours, including regular and prn doses.</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th><strong>Consider cross tolerance and calculate the reduction if applicable.</strong></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>To account for lack of complete cross tolerance, calculate and subtract 20% to 50% reduction of the 24h dose of any opioid being rotated to a new (different) opioid. Clinical judgment is used in determining the degree of reduction. Always confirm with a resource expert if you are unsure.</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th><strong>One route</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Using ROUTE conversion ratio (i.e., po to SC/IV of 2:1), convert to one route of administration.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>One Drug Current Total</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Using DRUG conversion ratio (i.e., morphine 10 mg po = hydromorphone 2 mg po), rotate to one drug. Choose the medication you plan to use for regular dosing, rotate and add together for a new 24 hr total.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th><strong>Choose scheduled dosing times.</strong></th>
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</thead>
<tbody>
<tr>
<td>To choose new regular (ATC) dose, divide total 24hr amount by appropriate interval based on product to be used. For example: divide by 6 for q4h dose; divide by 2 for q12h dose; divide by 24 for hourly infusion</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Calculate the breakthrough dose: (BT)</strong></th>
<th></th>
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</thead>
</table>
| Calculate approximately 10% of the total daily dose of the scheduled opioid.  
**Example calculations for breakthrough opioids delivered by:** |  |
| **Mouth:** |  |
| morphine 15 mg po q12h = 30 mg po/24h |  |
| 10% of 30 mg = 3 mg (max dose) po q1hr prn |  |
| **SC:** |  |
| morphine 10 mg q4h SC = 60 mg SC/24h |  |
| 10% of 60 mg = *6 mg (max dose) SC q1h prn or *3 mg SC q30min prn |  |
| **CSCI:** |  |
| morphine 2.5 mg q1h SC continuous infusion = 60 mg SC /24h |  |
| 10% of 60 mg = *6 mg (max dose) SC q1h prn or *3 mg SC q30min prn or *1.5 mg SC q15min prn |  |

* clinical judgment may indicate the need to lower the calculated dose
b. The person is now having difficulty swallowing (PPS 30%). Calculate the SC/24h dose for him.

c. Calculate the continuous SC infusion (CSCI) hourly dose.

d. Calculate a breakthrough dose for this new CSCI dose using the 24h equivalent from 7b.

e. If the person was in LTC, calculate a SC q4h dose.

f. Calculate a breakthrough dose.
8. Calculate a rotation from hydromorphone 64 mg po/24h to TD fentanyl including a new BT morphine and hydromorphone dose for this person using the manufacturer of Duragesic equianalgesic chart (Pallium Pocket Guide, chapter 5). Use a 50% reduction when factoring in cross tolerance.

Section 2: Review and Summary

- Practical Application 1: Complete Practical Application 1, Group A Questions (due at Coaching Session 3)
<table>
<thead>
<tr>
<th>Formula</th>
<th>Answer: Question #8</th>
</tr>
</thead>
</table>
| **Total in 24h of EACH opioid**  
Calculate the total amount of each route of each opioid given in the previous 24h, including regular and prn doses. | |
| **Consider cross tolerance and calculate the reduction if applicable.**  
To account for lack of complete cross tolerance, calculate and subtract 20% to 50% reduction of the 24h dose of any opioid being rotated to a new (different) opioid. Clinical judgment is used in determining the degree of reduction. Always confirm with a resource expert if you are unsure. | |
| **One route**  
Using ROUTE conversion ratio (i.e., po to SC/IV of 2:1), convert to one route of administration. | |
| **One Drug Current Total**  
Using DRUG conversion ratio (i.e., morphine 10 mg po= hydromorphone 2 mg po), rotate to one drug. Choose the medication you plan to use for regular dosing, rotate and add together for a new 24h total. | |
| **Choose scheduled dosing times.**  
To choose new regular (ATC) dose, divide total 24h amount by appropriate interval based on product to be used.  
For example: divide by 6 for q4h dose; divide by 2 for q12h dose; divide by 24 for hourly infusion | |
| **Calculate the breakthrough dose: (BT)**  
Calculate approximately 10% of the total daily dose of the scheduled opioid  
**Example calculations for breakthrough opioids delivered by:**  
» **Mouth:**  
morphine 15 mg po q12h = 30 mg po/24h  
10% of 30 mg = 3 mg (max dose) po q1hr prn  
» **SC:**  
morphine 10 mg q4h SC = 60 mg SC/24h  
10% of 60 mg = *6 mg (max dose) SC q1hr prn or *3 mg SC q30min prn  
» **CSCI:**  
morphine 2.5 mg q1h SC continuous infusion = 60 mg SC/24h  
10% of 60 mg = *6 mg (max dose) SC q1hr prn or *3 mg SC q30min prn or *1.5 mg SC q15min prn  
* clinical judgment may indicate the need to lower the calculated dose |
COACHING SESSION 3: In-Depth with Assessment

Format: Small Group (2 hours)

Purpose: To review answers to Practical Application, Group A and to practice the concepts of assessment and information sharing with changing variables.

Required Resources to bring to session:

- Equianalgesic Dosing Chart
- Opioid Analgesics used Frequently in Palliative Care
- Opioid Rotation Calculation Worksheet
- The Pallium Palliative Pocketbook
  » SBAR tool
  » CCO algorithm on depression
  » ESAS-r

Coaching Questions

Section 1: Review and take up the answers to Practical Application 1, Group A Questions

1. Review your completed PA 1, Group A answers

2. Complete the following calculation

   MS Contin 60 mg po q12h plus Dilaudid (hydromorphone) 4 mg po x 6 doses:

   a. Convert all to hydromorphone

   b. Factor 30% cross tolerance

   c. What would the continuous infusion dose be?
Formula Answer: Question #3.1

Total in 24h of EACH opioid
Calculate the total amount of each route of each opioid given in the previous 24h, including regular and prn doses.

Consider cross tolerance and calculate the reduction if applicable.
To account for lack of complete cross tolerance, calculate and subtract 20% to 50% reduction of the 24h dose of any opioid being rotated to a new (different) opioid. Clinical judgment is used in determining the degree of reduction. Always confirm with a resource expert if you are unsure.

One route
Using ROUTE conversion ratio (i.e., po to SC/IV of 2:1), convert to one route of administration.

One Drug Current Total
Using DRUG conversion ratio (i.e., morphine 10 mg po = hydromorphone 2 mg po), rotate to one drug. Choose the medication you plan to use for regular dosing, rotate and add together for a new 24h total.

Choose scheduled dosing times.
To choose new regular (ATC) dose, divide total 24h amount by appropriate interval based on product to be used.
For example: divide by 6 for q4h dose; divide by 2 for q12h dose; divide by 24 for hourly infusion

Calculate the breakthrough dose: (BT)
Calculate approximately 10% of the total daily dose of the scheduled opioid

Example calculations for breakthrough opioids delivered by:

- **Mouth:**
  - morphine 15 mg po q12h = 30 mg po/24h
  - 10% of 30 mg = 3 mg (max dose) po q1h prn

- **SC:**
  - morphine 10 mg q4hr SC = 60 mg SC 24h
  - 10% of 60 mg = *6 mg (max dose) SC q1h prn or *3 mg SC q30min prn

- **CSCI:**
  - morphine 2.5 mg q1h SC continuous infusion = 60 mg SC/24h
  - 10% of 60 mg = *6 mg (max dose) SC q1h prn or *3 mg SC q30min prn or *1.5 mg SC q15min prn

* clinical judgment may indicate the need to lower the calculated dose
Section 2: Lillian & Sheri

Lillian was admitted to a Long Term Care Home six months ago. Her diagnosis includes: OA, NIDDM, COPD, and advanced CHF. Since her admission you have learned that her husband died suddenly 7 years ago from an aortic aneurism, and she has four children; one daughter and son live in town, another daughter lives our East and another son lives in Texas. Increasingly over the last several weeks Lillian has been requesting to stay in bed. She doesn’t want to go to the dining room for meals. She looks sad and is increasingly resistant to care. She cries when the staff tries to get her to do activities.

Over and over again Lillian tells the PSW’s that she wishes she were back in her own apartment again. She misses her apartment, her things, her friends and her church. She also expresses a deep sadness for not being able to do as much for her as before.

Lillian questions: (based on questions from Module B; bring notes to coaching session)

1. What are the issues for Lillian you see from this case? (consider across domains)

2. How would you intervene?

Lillian case update

As you spend time with Lillian, you quickly discover that she misses her husband terribly, and misses the life they shared together. She says she is tired and life isn’t worth living anymore; she just wishes she could die and join her husband. She talks about her belongings and how hard it was to leave her apartment and move into Long Term Care, and she wonders if the people who got her precious things are taking care of them.

3. What tools are available to assist you in a more thorough assessment considering domains outside the physical?

Review the CCO algorithm on depression and share information on the 2016 RNAO Best Practice Guideline on Depression, Delirium and Dementia. Share any additional resources you have used and found helpful.

Sheri case reminder

Sheri was 50 years old, female, married, with two teenage children living at home. She led a very healthy life until diagnosed with breast cancer, for which she had a mastectomy, chemotherapy and radiation. She was declared ‘cancer free’ for two years. Previous chemotherapy treatments caused her to develop Type II Diabetes, but her blood sugars were well controlled with oral hypoglycemic medications. She started to experience increased diffuse abdominal pain, as well as continuous nausea. An abdominal CT showed a mass on the liver and deep needle biopsy identified that this was a metastatic lesion from her previous breast cancer.

The only treatment was oral Tamoxifen to arrest further growth of the cancer cells. Sheri prepared for her final Christmas a few months later and made it a really big deal by giving all her family members a unique gift that reminded her of them, along with a photo of herself and a hand written letter. As the next year progressed Sheri’s condition stabilized, but she struggled emotionally as she ‘waited to die’, and felt abandoned by her friends. The development of slurred speech, two falls led to the discovery of mets. to her brain and she died four weeks later in the Palliative Care Unit of her local hospital.
Coaching Sessions

Sheri questions: (based on questions from Module B, bring notes to coaching session)

4. Compare the eight Domains of Issues and the ESAS-r tool. Which domains of issues are identified by the ESAS-r tool and which ones are not?

5. What tool assists in the assessment of issues identified from an ESAS-r or in the encounter with the patient?

6. Considering the domains of issues and the OPQRSTUV mnemonic write one sample assessment question for each of the domains.

Section 3: Kim & Shelly

Kim and Shelly, a same sex couple in a small town, have been brought forward from the community as having social and health concerns. The couple are isolated and not connected to services and supports. (they have refused LHIN Home and Community Support involvement though offered)

A neighbor asked a local rural nurse to check-in as a personal favor. The nurse received permission from Shelly that she could come. Shelly met the nurse at the door and Kim began yelling in the background using abusive language that no one was to see her. The nurse did ask Shelly what she could do right now that would help them. Eventually Kim agreed to allow the nurse to enter under the condition that no hands-on examination was to be performed.

The nurse found Kim in the kitchen sitting on a stool. Kim was morbidly obese and wore a blouse with a sheet covering from her waist down. Her legs had gross edema with massive thickening of tissues at the knees and ankles and were weeping copious amounts of serous drainage. Purulent drainage came from areas of broken skin. Kim's arms were covered with scratches, some of which appeared to be infected. Kim was very short of breath and only able to sit on the stool or lay on the couch. She was not able to use a toilet, but has Shelly place a pail underneath her while she held onto the counter.

Kim was diagnosed with stomach cancer one year ago. She was treated at the local cancer center but it was extremely difficult for her to attend due to her obesity and pain. Kim felt that all staff were repulsed by her obesity; and she was told that her weight was probably the cause of her cancer. Both Kim and Shelly indicated they were rushed through exams and never spoken to directly. Kim shared, “each time we went I felt violated. I couldn’t do it anymore and so I stopped going.” Kim “fired” her family physician for similar reasons. The cancer clinic called a few times afterwards but Kim refused to speak to them and no further follow up was initiated.

Kim revealed that she had become pregnant by her father at age 15 and had a miscarriage at 13 weeks gestation. She was sure the growth at her as she felt it was disgusting and humiliating. Kim has felt hurt and judged by the health care system and her own community (obesity, sexuality). Kim has now refused help from anyone but Shelly.

The nurse listened to Kim’s story and said, “as a health care professional, I want to apologize for the way you were treated by the health care professionals and I am so sorry that the system let you both down.” They told the nurse that no one had ever apologized before. The nurse suggested that they learn from these experiences and together put things in place to safeguard this from ever happening again.

Though Kim was becoming emotionally and physically exhausted, she allowed the nurse to conduct a physical exam. With Kim's consent, the nurse made the decision to examine the lungs and the umbilical tumor. She recognized that many identified issues were beyond her scope of practice and continued to encourage more medical involvement.
Assessment:

Lungs

- Decreased Air Entry (A/E) middle lobe. No A/E inferior lobe of (R) lung
- No A/E inferior lobe of (L) lung
- Crackles throughout both lungs
- Shortness of breath with any activity and after speaking a few sentences

Umbilical Tumor

- Painful, pulsating fungating tumor with necrotic tissue sloughing tissue on abdomen. Foul odor draining purulent drainage. Tumor > 6 cm in diameter.

After the assessment, Kim agreed to have the nurse contact a doctor. Kim's stipulation was that if the doctor was to make a home visit, he was to come with the nurse. Kim was becoming very short with her answers, and breathing was becoming an issue, the conversation taking its toll.

The nurse called a local palliative care physician, described the situation and asked him to take Kim on. He reluctantly agreed to make a house visit with the nurse. The next day on a joint visit pain medication, home oxygen, puffers, Lasix and Aldactone, wound dressings were ordered. Kim agreed to LHIN Home and Community Support starting nursing and support services. Post visit the physician shared that nothing could have prepared him for what he saw.

The next day Shelly called to say that Kim had died. Kim had become severely short of breath, had chest pain, lips turned blue but was able to indicate she did not want anyone called. She died holding onto Shelly.

1. Complete the SBA portion of the SBAR tool with the assessment data above.

2. What would be the emergent concerns with pulsating, fungating umbilical tumor?

3. For those persons at risk for a major bleed, how might you prepare the person and family?

4. Review the medication and dosing protocol in Pallium.

5. Are you aware of your organization policy or protocol on management of massive bleeds (LTC, hospital, community, hospice)?
Section 4: Review and Summary

- Review Practical Application 1, Group B. This is due at Coaching Session 5 and contact the facilitator if any questions.
- Review pertinent timeline points – i.e. next CBL, next coaching session and check in that peer groups are engaged.
COACHING SESSION 4: In-Depth with Information Sharing

Format: Small Group Coaching (2 hours)

Purpose:
To practice the concepts of symptom/disease management with changing variables within the context of information sharing.

Required Resources to bring to session:
- Heart Card
- Pallium Palliative Pocketbook
- CCO Algorithms for Depression and Constipation

Coaching Questions

Section 1: Sam

Sam is a 76-year old retired engineer who is in end stage heart failure, NYHA classification Stage 4. His wife, Stella, is caring him for at home. He has nursing and PSW services in the home; none of Sam and Stella’s children live in the same town, but they have a good social support system. For dyspnea, Sam’s medications include MS Contin 30 mg po q12h with morphine 5 mg po q1h prn for extreme dyspnea. His ESAS-r scores are, as follows: Dyspnea: 8/10, Depression: 6/10, and Well-Being: 5/10

1. Sam’s wife has become his spokesperson and often speaks on his behalf. Stella has stopped giving Sam any breakthrough doses because he is severely constipated, and she is concerned about him becoming addicted to morphine. Instead, she is using more Lorazepam for his intractable shortness of breath and anxiety.
   a. How do you ensure understanding of use of opioids for pain and dyspnea?
   b. How do you effectively communicate with Sam and Stella in a situation such as this?

2. How is opioid-induced constipation prevented and managed?

3. What if Sam lives in long-term care and the nursing staff is withholding morphine, because they believe morphine will decrease his respirations to the point that he will die. As you consider this opportunity to lead and mentor, what could you do?
4. Why is it important to assess for depression?

5. How will you further assess Sam’s depression?

6. What would you do if, after you complete your depression assessment, Sam indicates that he has a plan in place to kill himself?

7. What are the risk factors for depression?

8. What would be the pharmacological management for Sam’s depression?

9. How else would you support Sam?

10. Stella asks you about starting artificial hydration because Sam is no longer eating or drinking (his PPS is now 20%). How might you respond to this request?

11a. What steps, planning and education will you share and initiate with Sam and his family at this point?

11b. What will your approach be while sharing this information?

Section 2: Review and Summary

- Practical Application 1: Complete Practical Application 1, Group B Questions (due at Coaching Session 5)
COACHING SESSION 5: Thinking Critically About Calculations

Format: Small Group (2 hours)

Purpose: To apply calculation skills and critical thinking as it relates to pain management in more complex situations

Required Resources to bring to session:

- Opioid Rotation Calculation Worksheet
- Equianalgesic Dosing Card
- Opioid Analgesics Used Frequently in Palliative Care
- Pallium Palliative Pocketbook

Coaching Questions

Section 1: Practical Application Review

- Review Practical Application 1, Questions 5 to 10.

Section 2: Scenarios

Scenario #1: Jared - Severe Oral Mucositis

Seven days after an autologous stem cell transplantation, Jared, a 36-year old man with acute lymphocytic leukemia has developed grade 3 mucositis and is unable to eat solids. Although he has little pain most of the time, severe mouth pain has prevented him from eating, and drinking has become very uncomfortable. He had been put on morphine 10 mg po q4h. Though this has helped with the pain, he is reluctant to take it because swallowing is very painful and he is unhappy at being drowsy some of the time.

a. What non-pharmacological treatment strategies would you recommend for this person? Why?

b. What pharmacological treatment strategies would you expect the physician to order? Why?

c. What would be the SC equivalent of the oral medication he is taking?

d. What would be the dose for SC q4h?

e. What would be the dose for a CSCI?

f. What would the breakthrough dose be?
Scenario #2: Sabrina - Difficult to Control Breakthrough Pain

Sabrina, with a primary breast tumor and metastases to bone, has been taking MS Contin 130 mg po q12h with BT being Statex 25 mg po q1h prn. She has had an average of 6 BT doses /24h and has been experiencing severe incident breakthrough pain for her metastatic cancer. Any increase in long acting medication causes excessive drowsiness. PPS is 50%.

a. What information, gathered from your assessment, is needed to identify specific interventions to manage Sabrina’s current breakthrough pain?

b. What interventions might be implemented to alleviate Sabrina’s pain?

Scenario #3: Giorgio - Dosing Intervals

Giorgio is taking Hydromorph Contin 12 mg po q12h with BT Dilaudid 2 mg po q1h prn. He has been experiencing end of dose failure.

a. How would you determine if this is end of dose failure and find the therapeutic dose for Giorgio?

Scenario #4: Fred - Pain Management in the Elderly

Fred, a 92-year-old man in fragile health has been having increasing pain in his hip due to a metastatic lesion. He has rated his pain at 8/10 for 2 weeks. He is opioid naïve and his PPS is 50%.

a. List the considerations, steps and scheduling to introduce a pain management regime for this person.

Scenario #5: Vladimir - Pain Management for Patients with History of Drug Abuse and Addiction

Vladimir is being treated for metastatic cancer of the liver and has a history of drug abuse and addiction. Pain has been rated as 12/10 for the past week.

a. What are the key elements for management of pain in a case like this?
Scenario #6: Faraji - Managing a Pain Crisis

Faraji has a diagnosis of prostate cancer with metastasis to rectum. His PPS is 40%. He has experienced a rapid increase in pain. He does not want to go to the hospital unless there are no other options.

a. What would be the next steps in assessing and managing Faraji’s pain?

Section 2: Review and Summary

- Practical Application 2: Introduction to Practical Application 2 (due at Coaching Session 8)
COACHING SESSION 6: Lead From Where You Stand 2

Format: individual call or meeting with coach (30 minutes) – order of format

Purpose:

To review the goals of the learner and provide an opportunity to discuss the real-life application of the nurse role.

Coaching Questions

Section 1: Learner Goals

1. At the beginning of the course you had identified three learning goals; do you feel like you are on your way to meeting these goals? Why or why not?

Section 2: Learner Experience

1. How is your experience so far in the CAPCE Program?

2. How far along are you in the content?

3. What are your questions, based on what you have read so far?

4. Do you have any questions about the CAPCE course and your responsibilities?

Section 3: Nursing Leadership and Mentorship

1. Based on your understanding of the role of leadership and mentorship, how do you see yourself facilitating positive change? What would be different from what you are doing now?

2. Do you foresee any challenges? What strategies need to be in place to support you?

3. What action do you need to take? Who do you need to talk to? What do you need to set up now in anticipation of you stepping into this role?
4. How will you make yourself available as a leader/mentor within your practice setting? How will you help your peers understand how you can support their work?

5. We’ve talked throughout the program about the impact of moral residue and importance of self-care. What are the indicators that you will recognize within yourself to alert you to the impact of moral distress. How will you manage your self-care?

Section 4: Review and Summary

- Reminder to complete Practical Application 2 for Coaching Session 8
- It is expected that all course components will be completed by Coaching Session 8.
COACHING SESSION 7:
In Depth with Decision-Making, Care Planning, Care Delivery and Confirmation

Format: Face-to-Face Small Group Coaching (2 hours)

Purpose:

To practice the concepts of decision-making, care planning, care delivery, and confirmation with changing variables based on decisions made in the care plan.

Coaching Questions

Section 1: Lee

Lee is a 70 year old man who recently moved to Long Term Care because his family could not provide the support he required at home. Lee has a diagnosis of Parkinson’s, Ca Prostate, and recently-identified bone metastases. Lee’s PPS is 40%, and his ESAS-r score for pain is 10/10. His pain regimen has included Hydromorph Contin 6 mg po q12h and Tylenol ES 2 tabs po q6h PRN for breakthrough pain; his pain continues to escalate. Lee is distraught about his recent move and his declining health, and has been constantly asking, “Why did this have to happen to me?” He questions what he did wrong in his life to deserve this fate. He is angry at having to change physicians with the move, as well as his latest diagnosis. He has refused to see the medical director and has insisted to have his former family physician resume his care. Lee is currently seeing an oncologist at the regional cancer centre. He has not engaged in discussions with family or health care providers regarding goals of care or his wishes for end-of-life care.

The medical director and the DOC of the long term care home met with Lee and his family to discuss his concerns about not having his family physician involved in his care. After a lengthy dialogue, Lee agreed that the medical director could direct his care in consultation with his previous family physician. Lee was adamant that he did not want to be admitted to the local hospital and wanted to remain at the long term care home. From the initial contact with the medical director, Lee identified that pain is the primary issue to address at this time.

Lee experiences an acute pain crisis that could not be managed. Lee was admitted to the local hospital. Lee has told staff that he has already spoken to his oncologist about ‘putting him out for good’. He has had no discussion with the LTC medical director about his suffering.

During his hospital stay, Lee’s pain management continued to be a very challenging issue. He repeatedly asked for sedation to put him out for good. The hospitalist ordered IV opioids to be given q30min. After 1.5 hours of unrelenting pain, Lee became semi-comatose but would occasionally awaken and cry out. He was restless even in a semi-comatose state. Four hours later Lee called out his wife’s name and as she approached his bedside he grabbed her hand, looked at her and died.

Lee’s pain was never managed, palliative sedation for intractable symptoms was not initiated and his wife was left with the horror of watching her husband suffer and die a painful death.

1. When considering an opioid for pain management what are the questions you must ask yourself?

2. You have completed your comprehensive pain assessment and have determined that Lee has somatic pain with a neuropathic component. What would your suggested pharmacological management of this class of pain be?
3. What if Lee complains of a tight pain like an elastic band that is wrapping around his stomach. What might your initial concern be?

4. What other symptoms confirm your suspicions?

5. What would you do next? What would you ask for?
Section 2: Maria

Maria is a 66 year old woman with advanced lung disease. She has been hospitalized 8 times in the past year for respiratory distress. Maria has expressed DNR wishes to her family, friends, family physician and nurses at the local hospital during each of her admissions. She does not have a plan of treatment for CPR nor has a DNRC been completed.

Recently Maria developed extreme respiratory distress at home and her husband Bill called the ambulance. When paramedics arrived Maria was in respiratory arrest and Bill was extremely distraught and insisting that measures be taken to keep Maria alive. Maria then went into cardiac arrest. The paramedics proceeded with CPR and transferred Maria to the hospital. At the hospital, one of the nurses recognized Maria from previous visits. Maria’s family doctor was on holidays.

Maria did not want CPR, as expressed in previous wishes, though her SDM contradicted this. The doctor at the hospital continued to perform CPR for 15 minutes until a heartbeat was detected. Maria was then transferred to a tertiary care hospital on life support. She had numerous seizures and was actively treated for this additional symptom. After 5 days a family/team conference was held and the family decided to discontinue life support and Maria died one week later. Maria’s wishes and plan of treatment were not respected.

The events in the Maria case, present an ethical dilemma for the nurses during the resuscitation. Difficult care situations often impact the professional position of health care providers resulting in moral distress. Let’s consider what you would do in a similar situation.

1. The nurses in this scenario felt moral distress due to the disrespect shown to Maria’s body and lack of dignity and respect for her wishes. What might the impact of this be on you as a nurse? What about on the family? What could the nurse do to address her moral distress?
Section 3: Health Care Consent

Scenario #1: Bob

Bob is a 70-year-old man with renal failure, coronary artery disease and osteoporosis. He has been receiving renal dialysis at the local hospital for the past year. He is very dependent on his wife Peggy for support and encouragement. In fact, he often defers health care decision-making to her because he says, “I don’t want to hear much information so I just let Peggy hear the details and I trust her, we've been married for 48 years”. It's your role to develop a plan or treatment for CPR.

a. What would you do initially?

b. How would you start the conversation?

c. What information would you give to Bob about CPR?

Scenario #2: Lena

Lena is an 83-year-old woman who suffered a stroke 3 years ago; the outcome of which was right-sided paralysis. Her medical history also includes advanced vascular dementia. Her only child, Ben, is her legal Substitute Decision Maker and he and his wife have been caring for her since she had her stroke. Lena did not indicate any wishes previously about her future health and personal care. You have been asked to develop a plan of treatment for CPR.

a. What would you do initially?

b. How would you start the conversation?

c. What information would you give to Ben about CPR?
Section 4: Communication

In an environment where communications and situations are emotion-laden, it is possible for misinterpretations or even misinformation to occur. Family members may respond to what they are told, what they are not told, or to the manner in which they are told.

1. How will you respond when conflict arises due to misinterpreted or miscommunicated information with a family member?

Section 5: Review and Summary

• Reminder to bring completed work on Practical Application 2 to final Coaching Session 8
• Reminder to complete all course components by Coaching Session 8 (Peer to Peer, reading, e-Learning modules, etc.)
COACHING SESSION 8: Thinking Critically About CAPCE Content

Format: Individual or small group session (2 hours)

Purpose:

To review Practical Application #2 work, observing for a demonstration of application and understanding of CAPCE content.

At the end of this session the CAPCE coach will confirm if the learner has successfully completed the CACPE program

Coaching Questions

Section 1: Review Multiple Choice Questions

1. Did anything surprise you when completing the multiple choice questions? Were any questions particularly challenging?

Section 2: Review Case Studies: Barb and Mateo

1. Share and discuss your completed work on the Barb and Mateo case studies.

Section 3:

1. Do you feel you have met your identified goals? If not, what else do you feel you need to get there?

2. At this point, what do you see as your next steps to function as a mentor/leader and change agent? What do you think will change now that you have completed this program? What will you do differently as of tomorrow?

3. Based on your experience with the CAPCE program, what else would you like to learn?
PRACTICAL APPLICATION 1: CALCULATIONS

PRACTICAL APPLICATION 1 - GROUP A (QUESTIONS 1-4):

Independently complete the following set of calculations, using your Equianalgesic Dosing Card. If you have any questions, bring these forward to your next Peer-to-Peer Exchange, or to your next CAPCE coaching session. Think critically about Calculations.

1. **Equianalgesic Dosing**
   
   For the purpose of these calculations, no cross tolerance needs to be considered

   1.1 morphine 10 mg po q4h ATC = ___________ total morphine po/24h

   1.2 morphine 30 mg po q12h/24h = ___________ total morphine po/24h

   1.3 morphine 45 mg po q12h + Statex 10 mg po x 5 doses = ___________ total morphine po/24h

   1.4 morphine 200 mg po/24h = ___________ total morphine SC/24h

   1.5 morphine 120 mg po q12h + Statex 20 mg po x 3 doses/24h = ___________ total hydromorphone po/24h

   1.6 morphine 400 mg po/24h = ___________ TD fentanyl patch/72h*

   1.7 Tylenol #3 - 2 tabs q4h (12 tabs)/24h = ___________ total morphine po/24h

   1.8 TD fentanyl Patch 25 mcg/72h = ___________ total morphine po/24h*

   1.9 Percocet 6 tabs/24h = ___________ total morphine po/24h

* Throughout this exercise we will refer to the Duragesic ® transdermal fentanyl to morphine po equianalgesic dose conversion table found in the Pallium Palliative Pocketbook, or the most current CPS.
Utilize the Opioid Rotation Calculation Worksheets that follow to answer questions 2 to 4, and questions 5-10.

More worksheets are available in the WS - Worksheet section of this Program Guide.

2. **OxyNeo 20 mg po q12h plus Statex (IR morphine) 10 mg po x 7 doses:**
   
a. Rotate to MS Contin po with Statex po BT, using 40% reduction for cross tolerance
### Formula

<table>
<thead>
<tr>
<th>Total in 24h of each opioid</th>
<th>Answer: Practical Application #2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Calculate the total amount of each route of each opioid given in the previous 24h, including regular and prn doses.</td>
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**Example calculations for breakthrough opioids delivered by:**

- **Mouth:**
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  - 10% of 60 mg = *6 mg (max dose) SC q1h pm or *3 mg SC q30min pm or *1.5 mg SC q15min pm

* clinical judgment may indicate the need to lower the calculated dose
3. Hydromorph Contin 18 mg po q12h plus Percocet tabs 12/24hr
   a. Rotate to Hydromorph Contin with IR hydromorphone BT, using 30% cross tolerance
**Formula**

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  - 10% of 30 mg = 3 mg (max dose) po q1h prn

- **SC:**
  - morphine 10 mg q4h SC = 60 mg SC/24h
  - 10% of 60 mg = *6 mg (max dose) SC q1h prn or *3 mg SC q30min prn

- **CSCI:**
  - morphine 2.5 mg q1h SC continuous infusion = 60 mg SC/24h
  - 10% of 60 mg = *6 mg (max dose) SC q1h prn or *3 mg SC q30min prn or *1.5 mg SC q15min prn

* clinical judgment may indicate the need to lower the calculated dose
4. **Case Scenario - Edith**

Edith is an 82-year old resident of a long term care home and has taken Percocet 1 tab q4hr for the past few months plus 4 doses of Tylenol ES 1000 mg daily for breakthrough pain. She has an old hip fracture, herniated disc, COPD and CHF. Her pain is 3/10 at rest but 6-7/10 on movement. She dislikes taking the pills, being constipated, being limited in her mobility and is discouraged with her constant pain. She is on no other analgesic or analgesic adjuvant. Your colleague asks you if she should get the doctor to order the TD fentanyl patch.

4.1 Determine if Edith can be rotated to TD fentanyl. Use the opioid calculation worksheet and give your rationale for the cross tolerance percentage used and your answer regarding the rotation to TD fentanyl.

   Use the Duragesic® transdermal fentanyl to morphine po equianalgesic dose conversion table found in the Pallium Palliative Pocketbook or most current CPS.

4.2 What is the major concern with this medication regime?

4.3 What assessment needs to be done at this point?

4.4 What analgesics could be used instead?
### Formula

<table>
<thead>
<tr>
<th><strong>Total in 24h of each opioid</strong></th>
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</tr>
</thead>
<tbody>
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| **Consider cross tolerance and calculate the reduction if applicable** | |
| To account for lack of complete cross tolerance, calculate and subtract 20% to 50% reduction of the 24h dose of any opioid being rotated to a new (different) opioid. Clinical judgment is used in determining the degree of reduction. Always confirm with a resource expert if you are unsure. | |

| **One route** | |
| Using ROUTE conversion ratio (i.e., po to SC/IV of 2:1), convert to one route of administration. | |

| **One Drug Current Total** | |
| Using DRUG conversion ratio (i.e., morphine 10 mg po = hydromorphone 2 mg po), rotate to one drug. Choose the medication you plan to use for regular dosing, rotate and add together for a new 24h total. | |

| **Choose scheduled dosing times** | |
| To choose new regular (ATC) dose, divide total 24h amount by appropriate interval based on product to be used. |
| For example: divide by 6 for q4h dose; divide by 2 for q12h dose; divide by 24 for hourly infusion | |

| **Calculate the breakthrough dose (BT)** | |
| Calculate approximately 10% of the total daily dose of the scheduled opioid | |
| **Example calculations for breakthrough opioids delivered by:** | |
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| * clinical judgment may indicate the need to lower the calculated dose |
5. Case Scenario - Mrs. Drake

Mrs. Drake has cancer of the right breast with metastases to lung and chest wall. Her pain escalated after her recent radiation treatments requiring a switch from po to SC. The switch managed her pain very well at the time. She is presently taking 4 mg hydromorphone q4h ATC SC. Her pain is well managed now and she would like to try oral dosing as she is tired of injections.

Calculate dose of oral Hydromorph Contin and an appropriate breakthrough hydromorphone dose.
**Formula**

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* **Clinical judgment may indicate the need to lower the calculated dose**
6. **Case Scenario - Sally**

Sally, age 43, with cancer of the breast and liver metastases (PPS 50%) is taking MS Contin 60 mg po q12h. Her pain is 5/10 most of the time, even when she takes the BT medication. Her BT medication is Statex 10 mg po q1h pm and she took 8 breakthrough doses each day for the past three days. Issues identified by Sally on ESAS-r include: Nausea 4/10, Appetite 7/10.

6.1 How would you further assess Sally with the information you have been given?

6.2 Her pain is not well managed. The physician wants to rotate the opioid to Dilaudid CSCI. Calculate the safe starting and BT dose. (Give your rationale for the calculation of the cross tolerance percentage chosen).
<table>
<thead>
<tr>
<th><strong>Formula</strong></th>
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7. **Case Scenario - George**

George, age 87, is taking MS Contin 90 mg po q12h as well as Dilaudid 8 mg po q8h and over the past 24 hours he has had Percocet 1 tab x 8 doses, which his wife has crushed and put in applesauce. The last 2 times he choked on the applesauce. His pain is rated as 8/10 at times and he is drowsy most of the time. George has cancer of the prostate with bone and rectal metastases and his PPS is 30%. He wants to remain at home for as long as possible.

7.1 **What medical orders do you need from the physician?**

7.2 **Rotate George to hydromorphone CSCI for pain management, using 40% cross tolerance calculation.**
### Total in 24h of each opioid

Calculate the total amount of each route of each opioid given in the previous 24h, including regular and prn doses.

### Consider cross tolerance and calculate the reduction if applicable

To account for lack of complete cross tolerance, calculate and subtract 20% to 50% reduction of the 24h dose of any opioid being rotated to a new (different) opioid. Clinical judgment is used in determining the degree of reduction. Always confirm with a resource expert if you are unsure.

### One route

Using ROUTE conversion ratio (i.e., po to SC/IV of 2:1), convert to one route of administration.

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To choose new regular (ATC) dose, divide total 24h amount by appropriate interval based on product to be used.

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### Calculate the breakthrough dose (BT)

Calculate approximately 10% of the total daily dose of the scheduled opioid

#### Example calculations for breakthrough opioids delivered by:

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*clinical judgment may indicate the need to lower the calculated dose*
8. Case Scenario - Sarah

Sarah is 86-years-old and her PPS has gone from 50% to 20% in the last month. Her diagnoses are COPD and HF. She also has stable chronic arthritic pain. She has been taking MS Contin 45 mg po q12h for months. The PSW has reported that Sarah is complaining that her pain is worse the past few days and she is also slightly confused at times. Her daughter reported that Sarah is more drowsy than usual and she falls asleep in mid sentence. The daughter has also noticed some jerky movements of her arms and legs.

8.1 Based on this information what do you think is causing Sarah’s symptoms?

8.2 Rotate Sarah to SC hydromorphone q4h. Use 40% cross tolerance for your calculation. Share what you think the rationale is for 40% cross tolerance.
**Formula**

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**One route**

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**One Drug Current Total**

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* clinical judgment may indicate the need to lower the calculated dose
9. Case Scenario - Yusuf

A 76 year old gentleman, Yusuf, has cancer of the prostate with diffuse bony metastasis, COPD, CHF and end stage dementia. Yusuf's Painad score yesterday was 3/10. Today he has not been able to swallow any of his medication. His PPS is presently 20%. His goal is to die at home. His Painad score today is 8/10. He is agitated, trying to get out of bed. His caregiver is exhausted and wants him to be comfortable and safe but not sedated. His analgesia regimen over the past 6 months has been the following: Hydromorph Contin 21 mg q12, morphine IR 20 mg q1h prn, Percocet 2 tabs q6h prn and extra strength Tylenol 500 mg 2 tabs daily. He has been taking his morphine IR breakthrough dose on average 5 times daily up and his Percocet tid daily.

Use the worksheet to rotate to hydromorphone CSCI and give your rationale for the cross tolerance percentage you chose to use in your calculation.

9.1 What additional interventions would you consider in Yusuf's case?
<table>
<thead>
<tr>
<th>Formula</th>
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10. Case Scenario - Aleena

Aleena's pain is well managed with MS Contin 100 mg po q12h and she takes morphine IR 20 mg po once in 24 hours for breakthrough. She is experiencing ongoing nausea so she is switched to TD fentanyl with the appropriate morphine dose for BT. Use the Duragesic® transdermal fentanyl to morphine po equianalgesic dose conversion table found in the Pallium Palliative Pocketbook, or the most current CPS. Calculate using a 30, 40 and 50% cross tolerance.

10.1 What are some things to remember when switching to TD fentanyl?

10.2 Calculate the dose of TD Fentanyl that Aleena would require.
<table>
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<tr>
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PRACTICAL APPLICATION 2: CAPCE REVIEW

CAPCE learners will independently complete the following three sections of this assignment to consolidate and apply the knowledge and skills learned in the CAPCE program before the last CAPCE Coaching Session:

1. Multiple Choice
2. The Barb Case
3. The Mateo Case

Section 1: Multiple Choice

Answer the following questions based on the content and resource materials from the CAPCE program. Bring forward any challenging questions to your last Coaching Session.

1. Which of the following opioids is not recommended for chronic pain management in people with advanced cancer?
   a. Meperidine
   b. Codeine
   c. Oxycodone
   d. Fentanyl

2. A 67-year-old man with prostate cancer has increasingly severe pain over the left hip. Over the past two weeks the pain has worsened requiring increasing doses of opioid analgesics. The pain is constant, aching and well localized; there is no referred pain. This man’s increasing pain most likely represents:
   a. Drug seeking behavior
   b. New onset depression
   c. Opioid addiction
   d. Opioid tolerance
   e. Worsening metastatic cancer

3. Pain that is described as “dull and achy” and is well localized, is best described as:
   a. Autonomic pain
   b. Neuropathic pain
   c. Somatic pain
   d. Vascular pain
   e. Visceral pain

4. From the list below which is the most appropriate adjuvant analgesic for use when treating somatic pain?
   a. Amitriptyline (Elavil)
   b. Clonidine (Catapres)
   c. Ibuprofen (Motrin)
   d. Lorazepam (Ativan)
   e. Neurontin (Gabapentin)

5. What is one of the most appropriate adjuvant analgesics used when treating neuropathic pain:
   a. Neurontin (Gabapentin)
   b. Clonidine (Catapres)
   c. Dexamethasone (Decadron)
   d. Ibuprofen (e.g. Motrin)
   e. Lorazepam (Ativan)
6. The single most important supplemental therapy to consider when starting a person on opioids for pain is:
   a. Amphetamines to increase alertness
   b. Antidepressants to supplement pain relief
   c. Antiemetic to treat nausea
   d. Laxatives to prevent constipation
   e. Non-steroidal (NSAID's) to treat inflammation

7. The most appropriate anti-emetic for opioid-induced nausea is:
   a. Gravol
   b. Maxeran
   c. Ondansetron
   d. Stemetil

8. A 45-year-old man with cancer and severe pain related to metastatic bone disease is in need of opioid for pain management. He is opioid naive. What would be an appropriate starting dose?
   a. MS Contin 30 mg po q12h and IR morphine 5 mg po q1h pm
   b. IR morphine 5-20 mg orally q4h and IR morphine 5 mg q1h pm
   c. IR morphine 5 mg po q4h and 5 mg po q1h pm
   d. IR morphine 5 mg po q1h pm
   e. IR morphine 5 mg po qid and 5 mg po pm

9. Neuropathic pain is often characterized by episodes of:
   a. Achy pain
   b. Colicky pain
   c. Gnawing pain
   d. Shock-like pain
   e. Squeezing pain

10. Approximately how long does it take for the first application of TD fentanyl to reach steady state?
    a. 6 hours
    b. 12 hours
    c. 24 hours
    d. 36 hours
    e. 48 hours
    f. 72 hours

11. The single most important feature that defines opioid drug addiction (psychological dependence) is:
    a. An increasing need for the drug over time
    b. Complaint of pain exceeding that expected for a given medical problem
    c. Development of a withdrawal syndrome when the drug is stopped
    d. Evidence of adverse life consequences from drug use
    e. Requesting a specific opioid by name
12. The single best predictive factor in determining prognosis in people with metastatic cancer is:
   a. Functional ability
   b. Number of metastatic lesions
   c. Presence of brain metastases
   d. Serum albumin
   e. Severity of pain

13. A woman with metastatic pancreatic cancer is losing weight and spending more than 75% of time in bed or lying down; no further anti-neoplastic treatments are planned. The person asks you: “how much time do you think I have?” The best approach is to say:
   a. “I believe time is short, only a few weeks to a few months”
   b. “I really can’t tell how much time you have left”
   c. “Life is mystery, you must not give up hope”
   d. “Only God can determine how long someone has to live”

14. Current evidence suggests that a feeding gastrostomy in advanced dementia, will:
   a. Improve quality of life
   b. Improve resistance to infections
   c. Increase the need to use physical restraints
   d. Prevent episodes of aspiration pneumonia
   e. Prevent the development of bed sores

15. A 72-year-old man with diagnosis of small cell lung cancer presents with some dyspnea, facial swelling and neck distension and a cough that has developed over the last 10 days. Considering the disease modality what might you suspect?
   a. Lung Infection
   b. Superior Vena Cava Syndrome
   c. Pericardial effusion

16. Which one of the following statements about treating terminal delirium is true:
   a. Family members should leave the room to help decrease the agitation
   b. Paradoxical worsening may occur after administration of a benzodiazepine
   c. Placing the person in a dark room will decrease sensory input and reduce agitation
   d. The drug treatment of choice is lorazepam (Ativan)
   e. The drug treatment of choice is an opioid analgesic

17. A 48-year-old man with refractory, advanced leukemia presents with mild delirium. He has mild cognitive impairment and is a little agitated. He is also experiencing some visual hallucinations. He is on a regular regime of oxycodone 20 mg orally every 4 hours. Which one of the following would be the most appropriate initial pharmacological management to control the delirium?
   a. Haldol 2.5 mg po or SC q12h and Haldol 2.5 mg q1h prn
   b. Valium 5 -10 mg po bid and 1 mg q1h prn
   c. Nozinan 12.5 mg po or SC q12h and 12.5 q1h prn
   d. Versed a bolus dose of 2.5 mg IV followed with a continuous infusion of 1 mg/h
18. Which one of the following statements about depression at end-of-life is true:

a. Clinical depression is a normal stage of the dying process
b. Depression associated with HIV is more difficult to treat than depression associated with cancer
c. Feelings of hopelessness/worthlessness are indicators of a clinical depression
d. The degree of appetite and sleep disturbance is predictive of response to anti-depressant medication
e. Tricyclic antidepressants are the first choice for drug therapy

19. Which one of the following statements is closest to the definition of “Medical Assistance in Dying”:

a. Discontinuing intravenous fluid administration in a person who can no longer take oral medication
b. Discontinuing tube feedings for a person with end-stage dementia
c. Raising the dose of intravenous morphine with the intent of depressing respiration to the point of death
d. Removing a respirator at the request of a decisional patient
e. Administering or prescribing a medication to a patient, at their request, that will cause death

20. Which of the following statements is true regarding capacity when making medical decisions?

a. A major psychiatric diagnosis does not prevent one from having the capacity to make medical decisions.
b. For emergency procedures, decision-making capacity must be confirmed by a psychiatrist or psychologist.
c. Refusing a recommended medical treatment indicates that the person does not have decision-making capacity.
d. The lack of medical decision-making capacity and court determined incompetence are equivalent medico-legal terms.

21. The best class of drugs to treat increased secretions at EOL is:

a. Anti-cholinergic/anti-muscarinic (e.g. scopolamine)
b. Benzodiazepine (e.g. lorazepam (Ativan))
c. Butyrophenone (e.g. haloperidol (Haldol))
d. Local airway anesthetic (e.g. inhaled lidocaine)
e. Opioid analgesic (e.g. morphine)

22. A person dies an expected death in the hospital, from congestive heart failure. You are called to “pronounce the person”; the family is at the bedside. Which of the following is not appropriate:

a. Ask the family to leave the room while you perform your examination.
b. Offer to remove medical paraphernalia (e.g. oxygen mask, IV line).
c. Stand quietly for a moment and offer consolation to the family
d. Volunteer to contact a chaplain
e. Volunteer to contact family members not present.

23. You happen to see the husband of a person you cared for who died from metastatic cancer. His wife has now been deceased for 3 months. He says that he sometimes thinks that his wife is in the house talking with him, that he imagines he hears her voice; he has lost 10 pounds since her death, but otherwise feels well. He is concerned that he is “going crazy”. These symptoms are most consistent with a:

a. Complicated grief reaction
b. Major depression
c. Minor depression
d. Normal grief reaction
e. Psychotic disorder
24. Rick is a 45-year-old man who had a sudden, unexpected cardiac arrest during cosmetic surgery. Resuscitation efforts succeeded in restoring Rick's heartbeat, and he was placed on a ventilator. Brain studies show that due to the anoxic event, only brain stem functions remain; Rick is in a persistent (permanent) vegetative state. Rick's wife asserts that she clearly knows that her husband would not want to be kept alive by machines when there is no hope he can regain consciousness. She is able to recount his past statements of wanting “the plug to be pulled” if he wasn’t going to recover. Which statement best characterizes the obligations of Rick's doctors:

a. They should require Rick's wife to get a court order authorizing the removal of the ventilator, in order to prevent a lawsuit
b. They should continue Rick's ventilator and other treatments because the surgery was elective
c. They should discontinue Rick's ventilator and other treatments because the surgery was elective
d. They should discontinue Rick's ventilator and other treatments because Rick's wife (and SDM) presents clear information that Rick's previously expressed wishes are guiding the decision she is making as his SDM
e. They should continue Rick's ventilator and other treatments because Rick did not put his wishes in writing

25. Number the list of SDM(s) found within the HCCA from highest to lowest ranked person(s). (1 to 9)

- Office of the Public Guardian and Trustee
- Spouse or partner
- Brother or sister
- Child or parent or CAS
- Parent with right of access only
- Any other relative by blood marriage or adoption
- Guardian of person with authority for treatment
- Representative appointed by Consent and Capacity Board
- Attorney named in Power of Attorney for Personal Care

26. The best drug to palliate the sensation of dyspnea, in a person with advanced pulmonary fibrosis who is on maximal medical management is?

a. Acetaminophen
b. Diazepam
c. Haloperidol
d. Ibuprofen
e. Morphine

27. An anxious person with pancreatic cancer, metastatic to liver, cachexia with a PPS of 20% asks you for artificial nutrition (feeding by tube or through an IV), as he has lost a lot of weight and is concerned that he is “starving” to death. Which one of the following best describes your response to his request for artificial feeding?

a. Suggest he try an appetite supplement such as megesterol acetate, or a steroid or cannabinoid derivative in the hope it would increase his weight
b. Refer him to a dietitian
c. Refer him for placement of a gastrostomy tube and initiate enteral feeding
d. Sensitively explain to him that artificial feeding would not improve his quality of life or life expectancy
e. Offer what he has asked in the hope that it would give him some hope and decrease his anxiety
28. Withdrawal of artificial feeding through a feeding tube, from a person dying of end-stage heart disease, who is comatose with death expected within a few days, is an example of:

a. Acceptable medical practice  
b. Assisted suicide  
c. Euthanasia  
d. Murder  
e. Unprofessional practice

29. Spirituality is best defined as a person's understanding of:

a. Heaven and hell in the context of imminent death  
b. How a higher being values life accomplishments  
c. The origins of life and the universe  
d. Their relationship between one's self, others, nature and the transcendent  
e. Their religious traditions and rituals

30. A 44-year-old woman with advanced gastric cancer and a PPS of 20% is being cared for at home. She develops agitated delirium and starts to vomit. Her wish is to die at home. On examination she is dehydrated and has generalized myoclonus. She is taking hydromorphone 6 mg po q4h and 4 mg po prn. With respect to artificial hydration which of the following statements best describes the role of artificial hydration:

a. Artificial hydration is a futile treatment and should not be offered  
b. Artificial hydration constitutes a basic standard of care and should be offered  
c. Artificial hydration may improve this person's delirium and opioid toxicity and should be offered  
d. She should have artificial hydration but be admitted to the hospital because the volumes cannot be given in the home setting  
e. The adverse effects of hydration namely increased airway secretions and edema far outweigh the potential benefits and should
The Case: Barb is a 63-year-old woman diagnosed with ovarian cancer. She has no indication of metastases. Barb is divorced and lives alone in an apartment. She has a supportive son, daughter-in-law, and grandchildren living in the same town. Barb has smoked a pack of cigarettes a day for 35 years; she has COPD. Her family physician has cared for her and her family for the past decade.

Barb’s PPS is 50% and her ESAS-r scores are:

- Pain: 8/10
- Nausea/Vomiting: 6/10
- Appetite: 4/10
- Tired: 6/10
- Depressed: 6/10
- Anxiety: 7/10
- Sense of Well-being: 6/10
- Drowsiness: 0/10
- Shortness of Breath: 2/10
- Constipation: 6/10

You have completed a pain assessment using the OPQRSTUV (Fraser Health) Symptom Assessment tool and prepared a report with the following information to discuss with the physician:

Region: Lower abdomen

Severity: 8/10 – 10/10 at its worst when standing or walking; 4-6/10 when lying down

Quality: pressure with diffuse, constant, sharp pain when mobilizing; constant dull ache throughout the lower abdomen

Other symptoms: constipation, vomiting, a sense of feeling full, depression, and anxiety

Findings of Physical Assessment:

- No evidence of thrush
- Bowel sounds faint; last bowel movement 3 days ago – small hard stool
- Digital check of rectum not done due to increased pain
Her current regime for pain management is:

- Percocet 2 tablets po q4h
- Statex 5 mg po q4h prn - has taken 8 doses in the last 24 hours

1. What type of pain is Barb experiencing?

2. What could be causing Barb’s nausea and pain?

3. What orders would you expect from the physician?

4. What are some potential medication choices to manage nausea?

The Case: When you call the family physician, you provide the pertinent assessment information and ask about an opioid rotation. His response is, “Let’s give her Dilaudid 1 mg SC q6h.”

5. Is this an appropriate rotation order? Why or why not?

6. Using the Opioid Rotation Worksheet provided, calculate an appropriate dose of SC hydromorphone with an appropriate BT dose. Select an appropriate reduction for cross-tolerance, and provide rationale for your choice.
**Formula**

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<th><strong>Total in 24h of each opioid</strong></th>
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<tr>
<td>Using DRUG conversion ratio (i.e., morphine 10 mg po = hydromorphone 2 mg po), rotate to one drug. Choose the medication you plan to use for regular dosing, rotate and add together for a new 24h total.</td>
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</tbody>
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* clinical judgment may indicate the need to lower the calculated dose
The Case: X-Rays reveal that Barb is severely constipated.

7. What are some potential treatment options to manage her constipation?

The Case: Barb feels better with management of symptoms; however, 2 weeks later she presents in the ED with diffuse abdominal pain, and is vomiting to the point that in the last 24-48 hours, she has been unable to keep anything down. She has not had a BM in the past 5 days. On examination she is dehydrated and has tachycardia. Abdominal sounds reveal high-pitched, tympanic bowel sounds. Her abdomen is tender to palpation. Rectum is empty, and she is passing no flatus.

8. What is the most likely cause of Barbs symptoms?

9. What are the treatment options?
Section 3: Mateo

Read the following case and answer the associated questions in your Program Guide. Be prepared to discuss your answers with the CAPCE Coach during your last Coaching Session.

Be prepared to discuss your answers including assessment findings, critical thinking, and rationale.

The Case: Mateo is a 36-year-old male with a diagnosis of Stage III testicular cancer, with metastases to lymph nodes, lung, and very recently, brain. His PPS is 40%. Mateo’s wife, Lindsay, works full time as a schoolteacher, and they have two sons, ages 9 and 5.

Mateo has just been admitted to your acute medicine unit from the ED. As you begin the admission process for him, Lindsay tells you that she awoke during the night to find the front door open and Mateo missing from the home. After searching the house and yard, she called 911 and reported him missing. Local police found him wandering in the neighborhood; he was disoriented, belligerent, and severely dyspneic. He knew his name, but could not tell the police his address. Police brought him to the ED, and after assessment, he was admitted.

Mateo is currently taking the following medications:

- MS Contin 60 mg po q12h (recently increased)
- Statex 10 mg po q1h prn (has taken 6 doses in past 24 hours)
- Ativan 1 mg SL prn for anxiety
- Gabapentin 600 mg po bid
- Decadron 4 mg po bid (started 1 week ago)
- Mateo uses marijuana recreationally and drinks 2-3 beers a day

1.a Identify the possible causes of Mateo’s confusion and aggression.

1.b What is your next step?
The Case: Your assessment reveals the following:

- Myoclonic jerking in upper extremities
- Hyperalgesia when touched during physical assessment
- Tachycardia
- Respirations 26-28/minute
- Bowel sounds in all 4 quadrants, and abdomen soft to touch
- Decreased A/E in left lung, lower lobe
- Hand grips weak bilaterally
- Nausea, with vomiting three times since admission
- Complains of pain in feet; “feels like needles”

2. After you complete your assessment, you consider that Mateo is experiencing a delirium. Using the Confusion Assessment Method (CAM) tool, what specific symptoms would confirm your suspicions?

3. What would be the potential approaches to manage Mateo’s delirium, including non-pharmacological and pharmacological interventions?

The Case: Mateo remains in hospital for investigation and treatment of the delirium. Lindsay comes to visit with the children; Mateo is still confused and aggressive, and does not recognize the boys. This is frightening for Lindsay. When she tells Mateo she is taking the boys home, he says he is going with her and becomes verbally abusive when she explains he has to stay at the hospital. Lindsay goes to the nursing station, and crying, tells you that she wants arrangements made for Mateo to stay in the hospital; she says she can’t have him at home like this.

4. How would you respond to Lindsay? What supports are available for this family in your community?
**The Case:** With an opioid rotation to Dilaudid and the addition of Haldol, Mateo's delirium is managed, and within 5 days, he is ready for discharge. Lindsay has reluctantly agreed to take him home, but the boys have been sent to live with her parents in a neighboring town. Mateo manages well at home for the next few weeks; the development of significant left-sided weakness and changes in cognition lead to a fall in the bathroom at home. Lindsay thinks he had a seizure, calls 911, and Mateo is admitted to the hospital. PPS is 20%.

After admission, Mateo develops symptoms of delirium once again, including visual hallucinations and extreme agitation. He continues to experience grand mal seizures. Despite pharmacological measures to manage, Mateo’s delirium increases, and he falls out of bed twice, once hitting his head. You speak with Lindsay about Mateo’s goals of care, and she expresses that his wish would be to not live like this. She says, “He always told me if he couldn’t be independent, he wouldn’t want to be kept alive.” Mateo’s delirium is intractable.

5. What are the options to manage intractable symptoms at end of life?

6.a What is Palliative Sedation Therapy (PST)?

6.b What are the indications?

6.c What are the guidelines for initiation, according to Pallium?

6.d What are the recommended pharmacological agents?
The Case: Mateo is sedated, but before deep sedation takes effect, Lindsay’s parents bring the children to the hospital to say goodbye to their Dad. Mateo remains sedated for 3 days and dies peacefully with Lindsay at the bedside.

7. Mateo’s journey was challenging for both his family, and the care team. As a change agent, your next steps are critical in assisting Lindsay to move forward. In a paragraph, identify the following:

• How will you support Lindsay?

• What would you say?

• What specific supports are available within your organization and your community to support Lindsay and her children in their bereavement?

• What supports are available for the care team?
**REQUIRED READING**

This is the preparation that is required in advance of each Case Based Learning (CBL) or Coaching Session (CS).

Please note that the required reading is listed below in an ‘anticipated’ order of sessions in CAPCE. There may be local adjustments to the order of coaching sessions and CBL's based on coach and local needs. Adapt your expected session preparation accordingly.

**Case Based Learning Session 1 (CBL1)**
*Full Class session*

**Required**

- **CAPCE Program Guide**: read Chapters 1, 2
- **Pallium Pocketbook**: read Chapters 1, 3, 4, 16
- The National Model to Guide Hospice Palliative Care
- Domains of Issues Laminate and Therapeutic Encounter: review
- PPS/ESAS-r laminate: review
- Early Identification & Prognostic Indicator Guide: review
- CCO Algorithms: read Mucositis and Intra-oral infections
- SBAR communication tool: review

**Coaching Session 1 (CS1)**
*(email your 3 goals to coach by the end of week 2)*

**Required**

- **e-Learning**: Modules A
- **RNAO Pamphlets**: review
- **CNO Smart Goals**: review

**Coaching Session 2 (CS2)**
*Small Group session*

**Required**

- **CAPCE Program Guide**: Chapter 4
- **Pallium Pocketbook**: read/review - Chapters 2 and 5
- **CCO Algorithm**: Pain
- **Equianalgesic Laminate, Opioid analgesics used frequently in Palliative Care**: review and bring to session

**Case Base Learning Session 2 (CBL2)**
*Full Class session*

**Required**

- **CAPCE Program Guide**: read Chapters 3 and 4, review and answer questions for CS 2
- **Pallium Pocketbook**: read/review Chapters 5, 6, 7, 9, 13, 14, 15, and 16
- **e-Learning**: Module B
- **Heart Failure Card**
- **CCO Algorithms**: Dyspnea, Delirium, Anxiety
- The Three D’s Comparison Chart: [http://ltctoolkit.rnao.ca/sites/default/files/resources/DDD_BPG_AppD.pdf](http://ltctoolkit.rnao.ca/sites/default/files/resources/DDD_BPG_AppD.pdf)
- **Equianalgesic Card**
- **Dignity in Care Card**
- **Opioid analgesics used frequently in Palliative Care**
- **PPS/ESAS-r laminate**
- **SBAR communication tool**
- **OPQRSTUV tool** - in Pallium Guide
- **FICA tool** - in Program Guide
- **Early Indication to Prognostic Indicator Guide**: review

**Coaching Session 3 (CS3)**
*Small Group session*

**Required**

- **CAPCE Program Guide**: Chapter 8
- **Pallium Pocketbook**: read/review Chapter 5, 10, 18, 20 and Appendix A
- **CAPCE Program Guide**: review and answer questions for Coaching Session 3, bring completed PA #1 Group A (bring SBAR to the session)
- **CCO Algorithm**: Depression
- **The Three D’s Comparison Chart**: review
- **Equianalgesic Laminate, Opioid analgesics used frequently in Palliative Care**: bring to session
- **SBAR communication tool**
- **RNAO Practice Guideline on Delirium, Depression and Dementia**: link in additional resources listed below
Coaching Session 4 (CS4)
Small Group session

Required

- CAPCE Program Guide: Chapter 5
- Pallium Pocketbook: read/review Chapter 8, 11, 12, 17, 19
- e-Learning: Module C
- CAPCE Program Guide: review and answer questions for Coaching Session 4
- Heart Failure Card
- CCO Algorithms: review Depressions

Coaching Session 5 (CS5)
Small Group session

Required

- CAPCE Program Guide: Review Chapters 4, 5 and 8
- CAPCE Program Guide: Review and answer questions for Coaching Session 5, bring completed PA#1 Group B
- Equianalgesic Laminate, Opioid analgesics used frequently in Palliative Care: bring to session

Case Base Learning Session 3 (CBL3)
Full Class session

Required

- CAPCE Program Guide: review Chapter 5
- Pallium Pocketbook: read/review Chapters 2, 3, 13, 18, 19 and 20
- e-Learning: Module D
- CCO Algorithm: Nausea/Vomiting, Constipation/Bowel Care, Loss of appetite

Recommended

- CNO Guide on Nurses’ Roles in Medical Assistance in Dying: CNO website

Coaching Session 6 (CS6)
Phone contact

Note: This session is identified as Session 6 but may take place at any point between the 6 or 12 week mark in the course. This coaching session timing is at the discretion of the coach and learner.

Required

- Review: progress on your learner goals as established at coaching session 1 email to your coach

Coaching Session 7 (CS7)
Small Group session

Required

- CAPCE Program Guide: review Chapters 6 and 7
- Pallium Pocketbook: read/review Chapters 2, 5, 8, and 14
- e-Learning: Modules E & F
- CCO Algorithms: Loss of Appetite
- CAPCE Program Guide: Review and answer questions for Coaching Session 7
- Plan of treatment for CPR algorithm: review

Coaching Session 8 (CS8)
final Coaching session (individual or small group as determined by CAPCE coach)

Required

- No additional reading
- Bring completed PA #2 (multiple choice and case studies)
ADDITIONAL AND RECOMMENDED WEB BASED RESOURCES

- Advocacy Centre for the Elderly: Tip sheets on Health Care Consent and Advance Care Planning and Substitute Decision Makers  
  http://www.advocacycentreelderly.org/advance_care_planning_-_publications.php

- Canadian Problem Checklist:  

- Canadian Virtual Hospice: Taking a Wound Management Approach  

- Cancer Care Ontario: link to tools, care plans, symptom algorithms:  
  https://www.cancercare.on.ca

- Champlain Region Palliative Sedation Guideline:  

- Dignity In Care website with articles and dignity tool kit:  

- Fraser Health Refractory Symptoms and Palliative Sedation Guidelines:  
  http://www.fraserhealth.ca/media/RefractorySymptomsandPalliativeSedationTherapyRevised_Sep09.pdf

- OPQRSTUV symptom assessment tool:  
  http://www.fraserhealth.ca/media/SymptomAssessmentRevised_Sep09.pdf

- RNAO End of Life Care During Last Days and Hours Guideline:  
  http://mao.ca/bpg/guidelines/endoflife-care-during-last-days-and-hours

- RNAO – Best Practice Resources for nurses:  
  http://ltctoolkit.rnao.ca/sites/default/files/resources/eol

- RNAO Best Practice Guideline on Delirium, Dementia, Depression:  
  http://mao.ca/bpg/guidelines/screening-delirium-dementia-and-depression-older-adult

- RNAO Recognizing Delirium, Depression and Dementia (3D’s) comparison chart:  
  http://ltctoolkit.rnao.ca/sites/default/files/resources/DDD_BPG_AppD.pdf

- Sample Palliative Sedation Protocol from Waterloo Wellington:  

- Speak Up Ontario: resource of information on Advance Care Planning, Health Care Consent for health care professionals and public  
  http://www.speakupontario.ca

- Virtual Hospice: excellent Canadian resource - tools, articles, videos for health care providers, patients and families:  
  http://www.virtualhospice.ca
CAPCE Program Guide
### WORKSHEETS: OPIOID ROTATION CALCULATION WORKSHEET (COPY)

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WORKSHEETS: OPIOID ROTATION CALCULATION WORKSHEET (COPY)

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