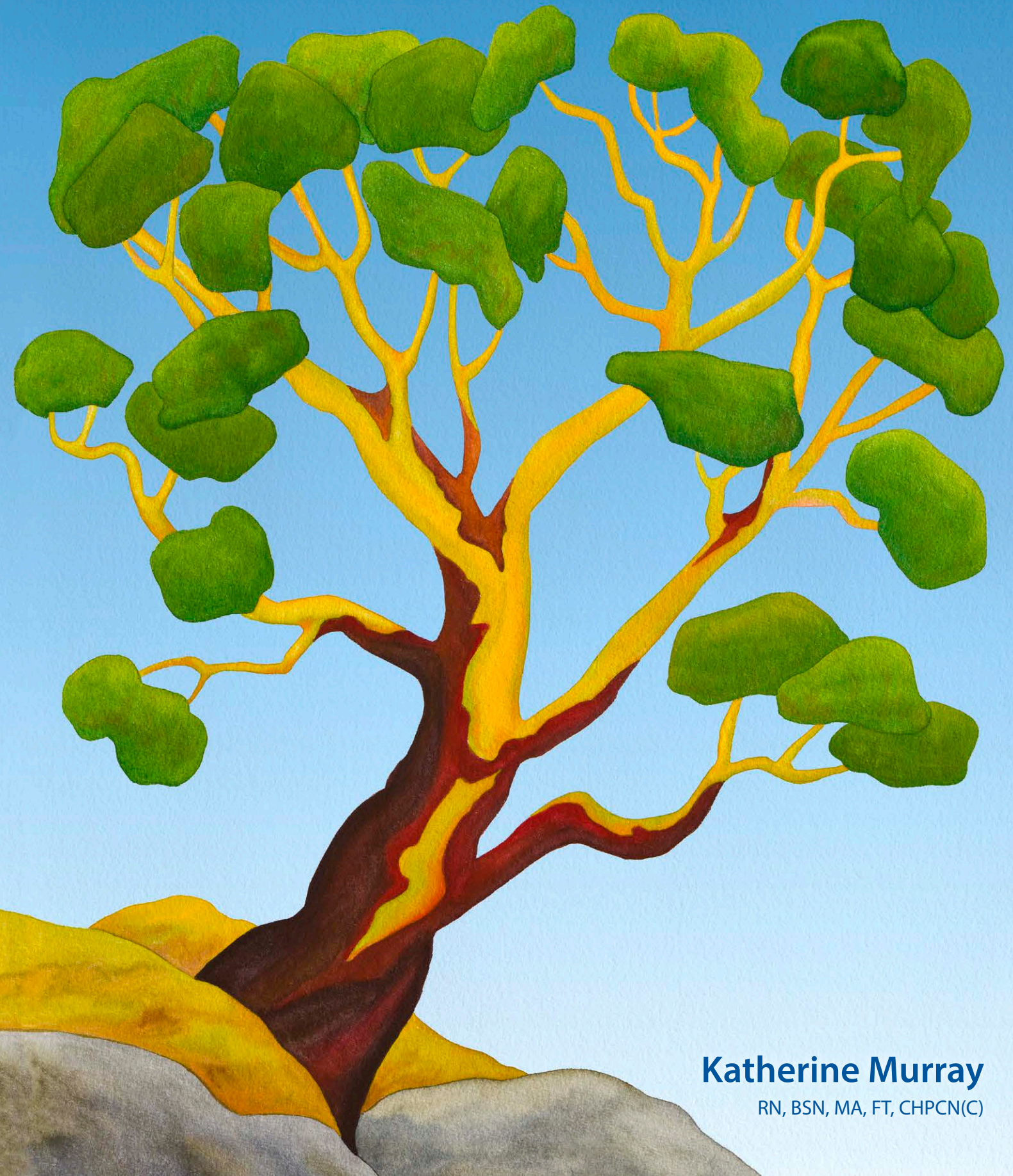


Essentials in Hospice and Palliative Care:

A PRACTICAL RESOURCE FOR EVERY NURSE



Katherine Murray

RN, BSN, MA, FT, CHPCN(C)

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Life and Death Matters

Victoria, BC



Life & Death Matters

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Disclaimer

This book is intended only as a resource of general education on the subject matter. Every effort has been made to ensure the accuracy of the information it contains; however, there is no guarantee that the information will remain current beyond the date of publication. The information and techniques provided in this book should be used in consultation with qualified medical health professionals and should not be considered a replacement, substitute, or alternative for their guidance, assessment, or treatment. The author and publisher accept no responsibility or liability with respect to any person or entity for loss or damage or any other problem caused or alleged to be caused directly or indirectly by information contained in this book.

DEDICATION



About the Cover

The arbutus tree shown on the cover of this book is native to southeastern Vancouver Island, the nearby Gulf Islands, the adjacent coast of mainland British Columbia, and some areas along the west coast of the United States. Often rooted in the crevices of rock faces along the shore, this tree, with its gnarled and twisted branches, hangs over the edge and is blown about by the wind. The smooth, papery bark peels off as new bark grows. Each arbutus is unique.

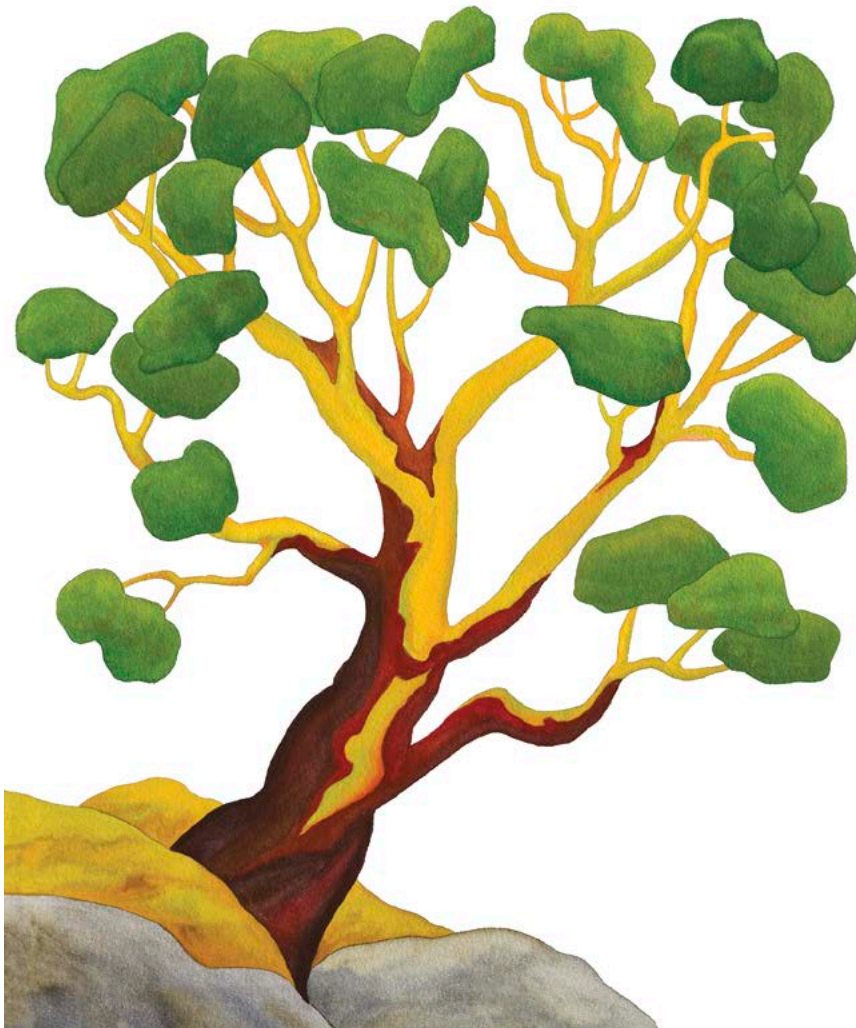
The arbutus inspires me with its ability to grow, survive, and even thrive in such rough and rocky areas. This tree graces the cover of my book because to me the arbutus symbolizes the strength of the human spirit, the amazing ability of human beings to survive, grow, and even thrive in difficult, harsh, and even traumatic situations. Like the

tree, we too get gnarled as we age. And like the tree, we are all unique.

The arbutus reminds me of those I care for, those who grew in the midst of dying, who grew as they cared for their loved ones or in the years following.

The arbutus reminds me of you, the many nurses I have worked with over the years. You also struggle with personal and work challenges, you provide excellent care, and you inspire me with your stories.

I wish you well as you continue on your path of caring for others. I hope that you will find great satisfaction and growth in doing this work.



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Kath

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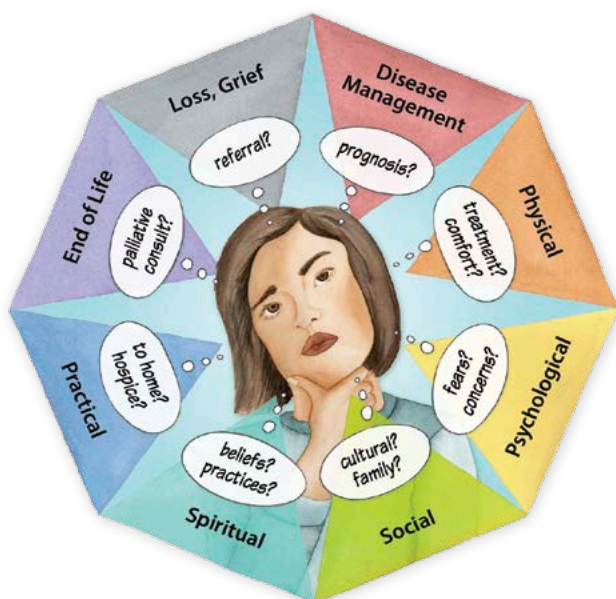
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PREFACE

A Text for Every Nurse

Every nurse cares for dying people. Whether you nurse in a hospice, palliative care, medical, intensive or long-term care unit, you care for people who are dying, you care for their family members, and you care for people experiencing loss and grief. You care in your professional and your personal life, and you care as a member of the larger community. This text will help every nurse to integrate a palliative approach into care by incorporating the principles and practices of hospice and palliative care across all care settings, early in the disease process, for people with any life-limiting illness.

This text was created to be “delicious and digestible.” The colorful, evocative illustrations make it delicious for the eyes, helping you envision the concepts of hospice and palliative care in practice. The stories bring flavor and depth to the concepts and principles, and build your appetite to turn the page and see what is next. The text is digestible, because current best practice, principles, and practical care strategies are provided in bite-sized pieces that you can easily absorb and use in your practice. The ultimate goals are for nurses to learn how to provide excellent physical and psychosocial care for the dying person and their family, and to feel more confident, competent, and compassionate in doing so.



The illustration with the nurse within the star is used in this text as an icon to prompt reflections on what best practice might be for a given situation. The icon will be your cue to consider the care issues presented and reflect on how best to provide care.

I hope that this text will both be an educational tool and inspire you to claim or to reclaim and to celebrate the art and science of hospice and palliative care nursing.

Essential Reading for Every Nurse

Every nurse provides hospice and palliative care. This text provides knowledge, skills and strategies for providing excellent hospice and palliative care and as such, is an essential resource for every nurse.

Use these chapter summaries to decide how you want to approach the book in a way that will best meet your needs.

Chapter 1—The Dying Process

Causes of death have changed in the past 100 years. Read this chapter to learn about the common patterns of dying for people in the 21st century and the impact of these patterns on the dying person, their family, and the health care system.

Chapter 2—Integrating a Palliative Approach

Learn about the first hospice that Dame Cicely Saunders created, the philosophy, principles, and practices of hospice and palliative care and how they have been shaped, woven together, and reformed into the current practices of integrating a palliative approach.

Chapter 3—Preparing to Care

Strategies for best practice, including compassion and providing love in professional practice, are explained in this chapter. Learn to reflect on how you provide care, and to consider how you can integrate best practice interactions.

Chapter 4—Using Standardized Tools

The screening, assessing and communication tools referenced in the text are gathered together in this chapter – a hospice and palliative care toolbox. When a tool is mentioned in the text, refer to this chapter to view the full size tool and read the instructions for use.

Chapter 5—Enhancing Physical Comfort

In Part 1, read the principles and practices for enhancing physical comfort—the heart of providing care—in hospice and palliative care. In Part 2, learn to recognize and assess common symptoms dying people experience and to incorporate strategies for managing symptoms using non-pharmacological and pharmacological comfort measures.

Chapter 6—Providing Psychosocial Care

Explore common psychosocial needs of the dying person and their family and learn strategies for supporting them. Examine and reflect on medical assistance in dying, and physician-assisted dying and the impact on HCPs. Consider the importance of strengthening the “social” in psychosocial.

Chapter 7—Last Days and Hours

Learn the common changes that a dying person might experience in their last days and hours, and ways to provide comfort and support for the person and family. Understand the importance of preparation in planning for care at the time of death, following death and the use of rituals.

Chapter 8—Caring for You!

Develop your understanding of compassion fatigue and your ability to self-evaluate for early signs of compassion fatigue. Learn ways to minimize your risk for developing compassion fatigue by caring for yourself even as you strive to provide excellent care for others.

Addressing Ethical Issues

The text addresses ethical principles and issue through ethics touchstones. The term “touchstone” is commonly used to mean a standard against which to evaluate quality or genuineness. In this text, the ethics touchstones draw upon the codes of ethics of the International Council of Nurses (ICN), the American Nurses Association (ANA), and the Canadian Council for Practical Nurse Regulators (CCPNR) and the College of Licensed Practical Nurses of Alberta (CLPNA).

The ethics touchstones also include thought providing reflective questions, designed to unearth previously unnoticed or overlooked ethical dimensions of practice. As you read, use the ethics touchstones to assess the value of your new understandings in terms of relationships, responsibilities, behaviors, and decision making, as well as for self-reflection and peer feedback. Return to these touchstones as your nursing practice develops and reconsider your earlier responses to the reflective questions.

The icon for the ethics touchstones consists of a box to represent the framework in which every nurse provides care, a heart to remind you to provide care from the heart, and an “e” signifying ethical questions for reflection.

The 2012 code of ethics of the ICN states, very simply, that nurses have four fundamental responsibilities: to promote health, to prevent illness, to restore health, and to alleviate suffering (International Council of Nurses, 2012). This text will help you to fulfill the responsibilities the ICN has identified as you work to prevent or manage common symptoms, support healthy grieving, prevent or respond to complicated grief, and decrease suffering associated with dying, death, loss, and grief.

Developing Cultural Competence and Cultural Humility

The text incorporates stories to help nurses develop cultural competence and cultural humility. The stories provide the nurse with the opportunity to reflect on their ethnocentric view, to develop awareness of other cultural beliefs and values, to develop cultural skills for communicating and interpreting and engaging with people of different cultures. With these practices the nurse can mindfully respect and support the person and family and their cultural wishes.

Incorporating Leadership and Advocacy

As a nurse you are in a unique position to lead and advocate for the dying person and the family. You witness suffering, and you assess physical and psychosocial issues. Through the text you will be encouraged to consider your role as a leader and advocate through your day to day work as you share information and help prepare and support people to make informed decisions. When you open the door to conversations and as you involve the person and the family in care planning. You are invited to consider and reflect on your role as a leader as you help to evaluate and confirm whether the person's goals are being met, and as you strive to integrate hospice and palliative care across the continuum of care.

I wish you well, and mostly I wish that this text helps you increase your competence, confidence, and compassion in caring for the dying person and their family.





Understanding the Dying Process

Common Patterns of Dying

When I studied thanatology (the study of death, dying, and bereavement), one of the questions students considered was, "When does dying begin?" The answers, of course, ranged from birth to the visible onset of illness, to last days and hours. The answer I always liked best was, "At 40, when the dog dies and the kids leave home!" (At this point I am 60ish and still hoping to get a dog. The kids have come back home!) In fact, dying begins differently for each person, depending on the illness and the person's own health.

What does dying look like? To answer this question, you might observe the physical changes the person experiences in their last days and hours. However, understanding what dying looks like in this century requires that you

look further back than the last days, back to the weeks, months, and perhaps years prior to death.

To answer the question "What does dying look like?" you need to understand the changes in the way people are dying in the 21st century.

This chapter explores common patterns of dying and discusses the reality that a dying person is still very much a living person.

Palliative care is now seen as a valuable service from time of diagnosis. Why? Because the dying person may have many needs for holistic care early on.



Defining People Referred to in This Text

Dying person: I use this term (or simply “person”) because I cannot bear to use the word “client” to describe someone who is so vulnerable and so unable to be a “consumer.” I also cannot use the word “patient” to describe someone who probably feels anything but patient, and I cannot use the word “resident,” as it is not applicable in all settings.

Family: This term means anyone that the person defines as family, as well as anyone significant to the person. For simplicity, I use “family” rather than using “family and significant others” repeatedly.

Health care provider (HCP): This term means trained people who are paid to provide care (e.g., nurses, physicians, nursing assistants, personal support workers, medical assistants, counselors, and spiritual care providers), including health care workers.

Health care worker: This term means any paid frontline worker. In Canada they may be called personal support workers or health care assistants, as well as other titles, while in the United States, they may be called nursing assistants, nurse’s aides, medical assistants, patient care technicians, or a variety of other titles.

Caregiver: This term means any unpaid caregiver, such as a friend or family member, who provides care for the dying person.

Nurse: This term means “every nurse,” that is, anyone trained in the nursing profession, including, but not limited to, practical nurses, vocational nurses, registered nurses, psychiatric nurses, and retired nurses.

Physician/nurse practitioner: This term is used to identify a person responsible for diagnosing, treating, and managing the dying person’s symptoms.



Common Trajectories of Dying

Dying is a unique process for each person but usually occurs in one of four patterns: sudden death, steady decline, stuttering decline (the “roller coaster”), and slow decline. Each decline reflects changes in the person’s function and abilities, specifically changes in:

- Ambulation—the ability to move around
- Participation in activities
- Personal care
- Eating and drinking
- Cognitive functioning

A person’s decline in function over time can be illustrated as a line on a graph. The line—the progression of the decline—is known as the “trajectory” or pattern. Each trajectory has different challenges for the dying person, their family, and HCPs. HCPs can observe changes in a dying person’s abilities as a way to understand their declining condition. This section defines the parameters of these trajectories, the illnesses that are often involved, and the challenges for the person and family.

Sudden Death

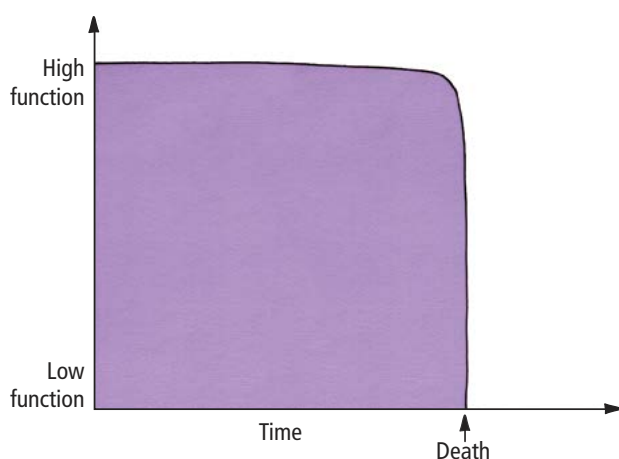


Figure 1. The sudden death trajectory

Approximately 10% of people in developed nations will die suddenly. A heart attack, major stroke, or car accident are common causes of sudden death. In most cases of sudden death (Figure 1), the dying person and the family do not know that death is imminent.

When I ask people how they want to die, there are always some who say they would prefer a sudden death. They often state that they do not want to be a burden on their loved ones. However, grieving people whose loved one has died suddenly often express regret that they did not have time to say good-bye or to prepare for or anticipate the death, and may say that they wish they could have provided care. These people may say,

Well it might have been a good death for her, but it was not a good death for me.

As a nurse you may witness a sudden death or arrive just after a sudden death. Chapter 7, “Providing Psychosocial Care,” includes information on what to do after a sudden, unexpected death has occurred in the home setting.

Sudden Death

I was playing baseball when my brother called to tell me that our mom had had a heart attack. I went straight to the hospital but was too late. It is hard to believe. I wish we had been prepared. It would have been easier if she had been sick for a while so that I could have said good-bye and told her that I loved her. I feel like I was hit by a truck!



Ethics Touchstone

Have you, or anyone you know, been affected by the sudden death of a loved one? Were there advantages? Were there disadvantages?



Integrating a Palliative Approach

A Dream of Better Care for the Dying

Historically, care of the dying was the responsibility of the family and the community. People died in their own homes. In the mid-1900s, with medical advances and the building of acute care hospitals, care of the dying was moved to the hospitals. People lived their last months, weeks, or days under the care of physicians, nurses, and other health care providers (HCPs).

It was in a busy acute care hospital that Cicely Saunders, a social worker and former nurse, met David Tasma. Tasma was living alone in London, England. He was dying. They talked for hours about the challenges that dying in an acute care hospital presented, and envisioned a place and philosophy of care designed specifically to address the needs of the dying person and family—care that would relieve suffering and improve quality of life.

Following Tasma's death, Saunders spoke with a surgeon colleague about her dream. He suggested that she would be better able to make changes to care of the dying if she was a physician. Saunders then returned to study and earned a medical degree. With the holistic perspective of a nurse, a social worker, and now a medical doctor, she saw and understood the "total pain" that people experienced. In fact, she coined that term to describe the various types

of pain—emotional, spiritual, physical, bureaucratic, and so on—that people might experience in the dying process.

In 1967, Saunders opened St Christopher's Hospice outside of London, England. In 1979, Queen Elizabeth II honored her with the title "Dame Commander of the Order of the British Empire" for her contributions to hospice and palliative care. Thereafter she was known as Dame Cicely Saunders.



Ethics Touchstone

Provision 6

The nurse, through individual and collective effort, establishes, maintains, and improves the ethical environment of the work setting and conditions of employment that are conducive to safe, quality health care.

Code of Ethics for Nurses (ANA, 2015a)

PALLIATIVE
CONSULT

Care
Conference

Respite
Ahead

Once upon a time I thought that hospice and palliative care meant “doing nothing.” When my dad died, I found out that the palliative care team did everything possible to help my dad live a full life right up to the day he died.

Dad had access to a team of people, depending on his needs. When he was in severe pain, he was seen by a palliative care physician and an oncologist. He was offered radiation therapy, not to treat his disease, but to decrease his pain. It was hard for him to get to the treatments, but they decreased his pain and he was able to attend and enjoy my sister’s graduation, which meant so much to him.

When he was no longer able to get out of bed, the counselor and nurse talked with him and offered home

support help. The health care workers provided daily personal care. Their care helped him to preserve his energy for the things that mattered to him the most.

When Dad’s breathing became uncomfortable, the doctor ordered medications to help him breathe easier. The nurses taught us how to give him the medications. They supported us when we realized that he would not get better, and helped to prepare us for when he died. They told us what to expect, what he might do, and what we could do. They gave us phone numbers to call if we needed anything in the middle of the night. They changed what could have been an awful experience into a positive time of being together.

Common Issues in the Process of Providing Care

The person and family face uncertainty, multiple losses, and changes in their physical, psychological, and social spheres. Hospice and palliative care seeks to identify and address all these complex and often interconnected issues. The CHPCA identifies eight “Common Issues,” and the National Consensus Project for Quality Palliative Care in the United States identifies eight “Domains of Care” (Figure 2) (CHPCA, 2013; Dahlin, 2013; Ferrell et al., 2007). By considering the Common Issues or the Domains of Care, HCPs can ensure that they address the holistic needs of the person and family. In this text, the term “Common Issues” rather than “Domains of Care” is used because it may be more easily understood by the dying person and their family. The CHPCA Common Issues and the US Domains of Care are provided in full in Appendices 4 and 7, respectively.

CHPCA Process of Providing Care

The CHPCA developed a national model of hospice palliative care—the “Square of Care”—to help ensure a consistent, quality approach to care that addressed all needs. Figure 3 shows two sides of the Square of Care, with the steps in the process of providing care appearing horizontally across the top (CHPCA, 2013). While the traditional nursing process has four steps—assessment, care planning, care implementation, and evaluation—the CHPCA process of providing care has two additional steps: information sharing and decision making.

Figure 2. Congruence of Common Issues in Canada and Domains of Care in the United States

CHPCA Common Issues	US Domains of Care
Disease Management	Structure and Processes of Care
Physical	Physical Aspects of Care
Psychological	Psychological and Psychiatric Aspects of Care
Social	Social Aspects of Care Cultural Aspects of Care Ethical and Legal Aspects of Care
Spiritual	Spiritual, Religious, and Existential Aspects of Care
Practical	Social Aspects of Care
End-of-Life Care / Death Management	Care of the Imminently Dying Patient
Loss and Grief	Psychological and Psychiatric Aspects of Care

When the answer to the Surprise Question is “No,” it triggers nurses and the health care team to begin the GSF process of identifying, assessing, and planning care. When the answer to the Surprise Question is “Yes,” the health care team assesses the person for general and specific indicators of decline. Answering “Yes” for any indicators of decline will also trigger the GSF process. Tools to help answer the Surprise Question and to assess general and specific decline are available in Chapter 4, “Using Standardized Tools.”

For nurses beginning to integrate a palliative approach, it will be essential to educate the public about the benefits to the person and family of integrating a palliative approach early in the disease process, including how such an approach may more effectively support the needs of people living with a progressive life-limiting illness.

When to Consult with a Hospice and Palliative Care Specialist

Sometimes, despite the excellent care provided by the primary care team, symptoms may persist and remain unrelieved, or the dying person’s goals are unmet. Hospice and palliative care consult teams are specialist teams, often consisting of a physician, a nurse, a social worker, and others such as a pharmacist and spiritual counselor, who can assist primary care teams as needed with:

- Complex pain and symptom management issues
- Complex psychosocial or spiritual needs of the person or family
- End-of-life discussions that the primary care team does not feel able to address or for which the person and family need more support

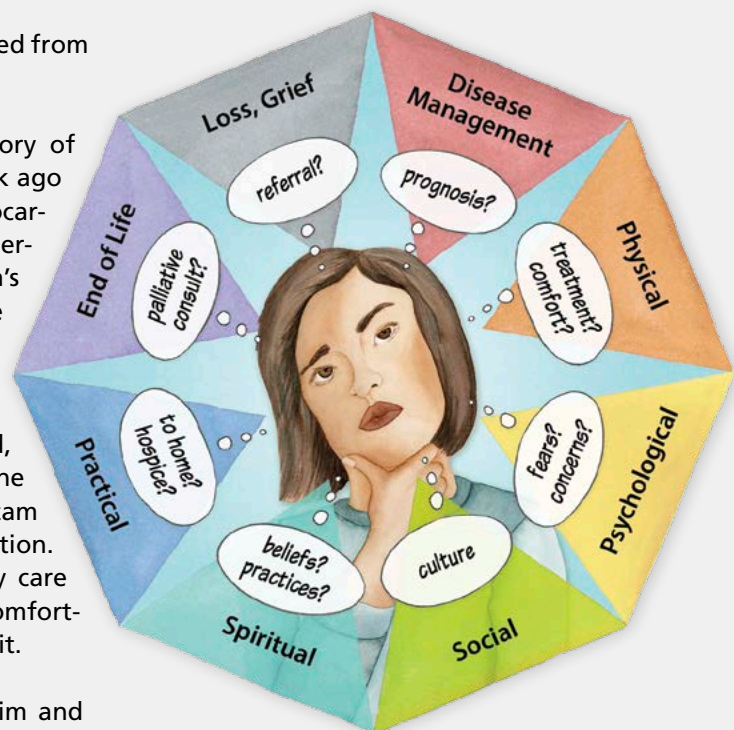
If the dying person’s symptoms are not being managed and/or their goals are not being met, then consider a referral to a hospice or palliative care team.

Case Study: Integrating a Palliative Approach on a Medical Unit

In this case study, Pritam has been transferred from the coronary care unit to the medical unit.

Pritam is a 73-year-old male with a history of cardiac disease. He was admitted one week ago to the coronary care unit following a myocardial infarction while shopping. CPR was performed immediately by a bystander. Pritam’s PPS (score on the Palliative Performance Scale) is 20%, he is sleeping most of the time, and he can answer questions but has periods of delirium. He has pulmonary and peripheral edema, his breathing is labored, and he is receiving oxygen at 5 L/min. The urinary catheter is draining clear urine. Pritam is not a candidate for surgery or rehabilitation. At a family meeting held in the coronary care unit, the decision was made to keep him comfortable. He was transferred to the medical unit.

The nurse on the medical unit receives him and considers the Common Issues that Pritam and his family may be experiencing, and how she might best assess and address their needs. The illustration indicates a few of her thoughts.





Preparing to Care

Preparing to Care—a Personal Journey

I came to hospice and palliative care nursing as a curious child. My earliest recollections of death include a dead rat and a lovely transparent leaf. I tried to nurse both back to life, with no success. When my siblings and I found a dead bird, we opted for burial. As a teenager I lived with my Aunt Frankie. Frankie, a nurse, was the master family caregiver. She cared for many family members and friends through aging, illness, and dying. I learned that death is part of life.

During high school and university, I encountered death and learned that even the young die. I learned that people die from cancer, accidents, and suicide. When I was in my 20s my father, uncle, and a few dear friends died. I saw severe pain that went untreated and respiratory congestion that led to distress and anguish. My compassion for the dying grew.

While the hospice movement spread globally, I completed my nursing degree. In 1988 I began working at Victoria Hospice, on the west coast of Canada. As a nurse working on the inpatient unit and then as a member of the Palliative Response Team, I worked with health care providers who showed me their incredible skills and compassion. I cared for people who died in the hospice and palliative care unit and those who died at home. I learned to prepare to care as I also learn-

ed more about diseases, disease progression, symptom management, and the dying process.

I also learned from the dying and their families. They taught me how to be more comfortable talking about death, as well as the importance of sharing information, responding to questions, and having difficult conversations. And in walking with dying people on their journey, I learned to put aside my agenda and to try instead to address their concerns and their needs. I learned that I could not fix, but I could companion and I could “be with” suffering. They taught me how to prepare for dying.

From my colleagues, in particular the nurses, counselors, and physicians, I learned about best practices in symptom management, ways of being, communication skills, and humor. I was fortunate to have colleagues who debriefed after visits and were happy to reflect together to fine-tune and improve care. These interactions continue to help me as I prepare to provide care.

From early childhood and on through my nursing years, I have been passionate about learning and curious about people, and yearn to provide excellent and compassionate care—in particular, excellent care for the dying person and family. Through my practice I have learned the importance of preparing to care.

Preparing to Care—an Essential Practice

The “journey of the dying” is a metaphor frequently used to describe the path a person follows as they die. Nurses are often companions for people on their journey of dying. As the companion, nurses need to prepare for the journey—to prepare to care.

Consider what you need to know, to be, and to have for this particular journey, with this particular person. You might ask yourself, “What will be supportive? Helpful? Needed?” You might wonder, “How do I need to be within myself so that I am able to support this person in their journey and do not try to take them on my journey?”

To be a companion on someone’s journey you will need to gather information, acquire skills, and learn ways of being that together will develop into best practice. This chapter will help prepare you to be a companion on someone else’s journey, by providing the knowledge to develop these skills and ways of being.

While this preparation may feel simple, it can profoundly enhance your capacity to provide hospice and palliative care with compassion, confidence, and competence. When health care providers (HCPs) prepare to provide hospice and palliative care, the dying person and family receive excellent care, and the professional minimizes stress and avoids burnout (Causton, 2016; Davies et al., 2016).

Striving for Best Practice

Preparing to care is, in part, about developing knowledge and skills for providing the best care possible. Over the past 20 years, hospice and palliative care has improved the quality of life of the dying, as HCPs have learned about best practice. Research by Dr. Betty Davies and Dr. Rose Steele identifies beliefs and attitudes of health care professionals¹ that provide the best care possible for parents and their dying child (Davies et al. 2016). Their research is similar to themes found in compassionate caregiving and the principles of “incorporating love in professional practice.” Discussed below are three aspects to consider when developing your best practice in providing hospice and palliative care.

Best Practice Is What You Bring

Davies and Steele asked the question, “What makes for excellence [defined as best practice] in health care professional/parent interactions?” They asked parents to identify health care professionals who provided the best care, and then observed their practices. Their analysis identified common behaviors that these health care professionals demonstrated at all times and in all interactions. The researchers suggest best practice and best practice interactions that they believe all health care professionals can adopt when providing care (Davies et al., 2016).

As you strive to increase your competencies, consider the following behaviors and how you might integrate them into your practice.

At the core of best practice was honoring and valuing the intrinsic worth of people from all cultural groups and providing the person with autonomy and control, clearly echoing the Code of Ethics for Nurses, Provision 1: “The nurse practices with compassion and respect for the inherent dignity, worth, and unique attributes of every person” (American Nursing Association, 2015a). Davies and Steele’s research also identified that best practice health care professionals:

- Are curious about the world and, in particular, desire to understand the experiences of the dying person and family
- Are committed to learning about their field of work
- Withhold judgment and refrain from labeling people
- Understand that the person, family, disease, and health care professionals are all connected



Ethics Touchstone

Ethical practice is the underpinning of best practice health care professionals. Integral to weaving a palliative approach into nursing practice and your way of being with the dying person and family is the examination of your beliefs and values regarding how people experience chronic illness, dying, and death. To provide best care, it is essential to reflect on what you believe excellent care is, and challenge yourself to discover what constitutes excellence. The goal of hospice and palliative care is to provide care that honors the person and family. The context in which care is provided changes constantly as do the needs, experiences, beliefs, and values of the person receiving care. The many changes in the setting, the situation, and the people involved will require changes in how care is provided. In order to provide best care, it will be essential to consider the ethical dimensions of nursing practice.

1. The term “health care professionals” is used in this book to refer to Davies and Steele’s research subjects. That term should not be confused with the more general term “health care providers (HCPs).”

Personal Strategies for Preparing to Care

This section discusses the following strategies for preparing yourself to provide care for the dying and their family:

- Developing a reflective practice
- Establishing and maintaining therapeutic boundaries
- Establishing and maintaining self-care practice

These preparations can enhance your capacity to provide hospice and palliative care with compassion, confidence, and competence. When health care professionals provided care following best practice, the dying person and their family reported receiving excellent care, and the health care professionals minimized their personal stress and avoided burnout (Davies et al., 2016).

Developing a Reflective Practice

Developing a reflective practice can help prepare you to provide care (Barnard, Hollingum, and Hartfiel, 2006; Causton, 2016; Davies et al., 2016). The term “reflective practice” is commonly used to refer to the process of considering your values, judgments, beliefs, opinions, culture, stereotypes, experiences, and so on—informally called “your baggage”—and learning to understand their influence on your behavior. All people have baggage. It is neither good nor bad—it is a part of being human.

Reflecting on the Baggage You Bring

The “journey of the dying” has already been mentioned as being a common metaphor for the path a person follows as they die. Nurses are often companions for people on their journey. When companioning someone, it is im-

portant to be clear that it is *their* journey, not your journey. When you consider what to bring on this journey, it is important to reflect on what would help make this the best possible journey for the dying person, rather than taking what you would want if the journey were yours. There are benefits to traveling light and bringing only what you will need.

Nurses can prepare to care for the dying by developing a reflective practice and making conscious decisions about what to bring with them in terms of their beliefs, values, and biases. In the series of images below, a nurse is carrying all the baggage from her life. Next, she sorts her baggage to decide what is appropriate to take with her when providing care. She does not want her baggage to hinder her or weigh her down when caregiving. In the final image, she has much less baggage. She knows what is in the bag and how to work with it, and is not burdened by the weight of carrying too much.

Engaging in a reflective practice and becoming aware of your baggage allows you to decide what to take with you when providing care and what to leave behind. With this self-awareness, you are wholly available to support and assist the dying person and family in their journey. With your excess baggage identified and placed to the side, the path forward is clear, and you will be less likely to trip on your baggage and confuse your personal issues with what is happening professionally.

Davies and Steele’s definition of a reflective practice included health care professionals’ thinking about their





Using Standardized Tools

The Rationale for Using Standardized Tools

The focus of this chapter is to provide health care providers (HCPs) with standardized tools for gathering information and for screening and assessing symptoms as you strive to provide excellent hospice and palliative care. Standardized tools have been validated by multiple researchers and are known to gather consistent information.

The standardized tools presented here are widely used across Canada and the United States; however, this collection of tools is not exhaustive. In your practice, you might encounter other standardized tools commonly used in your location, community, hospital, or hospice. Follow your employer's policies and procedures when determining which tool to use.

It will be helpful to familiarize yourself with these tools so that when the need for a tool arises you know where to find it. As with any tool kit, you will want to choose when and how to use the tools.

Do not feel that you need to read this chapter from beginning to end. Rather, become familiar with the tools, and refer to them as they are mentioned throughout the text.

Note the following:

- Certain assessment tools, such as the Palliative Performance Scale (PPS), can be completed on the basis of observation; others require input from the dying person and/or the family.
- People may experience “assessment fatigue” when presented with too many questions. It may be helpful to clarify with the person and the family when and how to best complete the assessment.
- You can obtain copies of the original forms by using the links available on the Life and Death Matters site (lifeanddeathmatters.ca/tools).

Tools Described in This Chapter

Screening Tools for Identifying When to Integrate a Palliative Approach	51
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Enhancing Physical Comfort

Part 1: Principles and Practices

Death is inevitable. Pain, distress and other symptoms do not have to be.

A nurse

The principles for managing symptoms, using medications, and using opioids are key to increasing the physical comfort of the dying person. Physical comfort and symptom management are essential to the person's improving quality of life. When symptoms are not controlled, the dying person and family may experience increased suffering and anxiety. The principles for symptom management can be integrated into care in any setting. Globally, the medications and guidelines for symptom management vary, but the principles remain the same.

Understanding the person's place in their illness trajectory will help guide investigations and treatments. Consider

using the Gold Standards Framework Prognostic Indicator Guidance tool, the SPICT, and tools for assessing frailty and one-year mortality (see Chapter 4, "Using Standardized Tools") to help inform goals-of-care conversations and determine whether investigations are appropriate.

Remember that physical symptoms are not managed in isolation. In order to manage symptoms in a way that meets the needs of the dying person and is appropriate for their decline, it is essential to address psychosocial issues. Using the Psychosocial Assessment Form (see Chapter 4, "Using Standardized Tools") will help the health care team to understand the dying person, in terms of who they are, what is important to them and their family, and their community support.

Principles of Symptom Management

Physical symptoms are managed by addressing the underlying disease causing the symptoms, by using medications and treatments to diminish or mask the symptoms, by using nonpharmacological measures to enhance physical comfort, and by addressing psychosocial needs. Apply these principles for symptom management:

- Focus on the person's goals of care.
- Educate the person and family.
- Prevent symptoms that can be prevented.
- Manage symptoms before they escalate.
- Use nonpharmacological comfort measures when possible.
- Support the family to participate in planning and providing care.
- Follow the care plan and administer medications as ordered.
- Evaluate, record, and report the person's responses to medications and comfort measures.

(Pallium Canada, 2013; WHO, 2012; ELNEC, 2015)



Ethics Touchstone

Principle 2

Licensed Practical Nurses provide safe and competent care for their clients.

Reflect on how nurses provide safe and competent care by integrating the principles of symptom management to help prevent and manage symptoms.

Code of Ethics for Nurses (CCPNR, 2013).

Principles for Using Medications to Manage Symptoms

These principles guide the practice of health care providers (HCPs) who administer medications for managing symptoms in hospice and palliative care:

- Use the oral route when possible. Use an alternative route when necessary.
- Remember that a combination of medications may be more effective than a single one.

Part 2: Common Symptoms

Part 2 of this chapter describes the most common symptoms a dying person might experience and strategies for enhancing the person's physical comfort. Symptom-specific assessment tools are identified. Consider also using the GSF Prognostic Indicator Guidance, the SPICT, a one-year mortality prognostic tool, and/or the CSHA Clinical Frailty

Scale to help inform goals-of-care conversations and determine needs for investigations.

Psychosocial factors are integral to enhancing a person's physical comfort and may change as symptoms progress. Use the Psychosocial Assessment Form to help address changes in the person's psychosocial needs.

Anorexia and Cachexia

Jack, 84 years old, was admitted a month ago. His condition is declining, and he has repeated chest infections, frequent falls, progressive dementia, and lung cancer. Since admission Jack is sleeping more, is withdrawn and refusing food, and is having some difficulty swallowing.

Megan, Jack's wife, visits daily, brings homemade custard, and encourages Jack to eat. Megan is concerned that if Jack does not eat, he will die.

Jack's daughter Mary arrived today from out of town. Alarmed by his weight loss, Mary promptly declared, "He is starving!" She believes that decreased nutritional intake is responsible for his declining condition.

Food is a basic need and a fundamental preoccupation of human beings. Many social gatherings and cultural rituals involve food and eating as a way of "being together." Preparing and serving food is one way to communicate love.

The nutritional needs and therefore the dietary intake of a person change from birth to adulthood to the senior years and through the dying process as a normal function of living and dying. The type of food a 2-year-old eats would cause a newborn to choke, and the quantity of food required to nourish and satisfy a 25-year-old male would cause an older adult to feel bloated or nauseated.

Regardless of changing nutritional needs, and regardless of whether decreasing intake is normal when a person is living with a life-limiting illness, their declining interest in food and decreasing dietary intake may become the primary concern for family. Different understandings of

what is happening and how to respond may cause conflict within families and within the health care team, as well as between the family and the health care team, in the last months, weeks, or days of a person's life.

What Are Anorexia, Cachexia, and Anorexia-Cachexia Syndrome?

Anorexia in the context of this text for a person living with a life-limiting illness is defined as decreased appetite or lack of interest in food and eating. Cachexia is defined as substantial weight loss comprising muscle (skeletal) and fat tissue losses that do not respond to increased intake or supplementation, bone mineral losses, overall weakness and inflammatory processes (Wholihan, 2015). In this context, anorexia or cachexia can occur in the absence of the other. Primary anorexia-cachexia syndrome (ACS), in which both anorexia and cachexia are present, is caused by multiple endogenous abnormalities, possibly related to the perceived threat of increasing chronic progressive illness. The presence of primary ACS indicates a poorer prognosis than if either anorexia or cachexia is absent. Secondary anorexia or cachexia result from factors that reduce intake or absorption of nutrients (e.g., nausea, diarrhea, pain).

Prevalence

Primary ACS has been reported in up to 86% of people with cancer-related illnesses. Among people with COPD, 30%–70% experience ACS, as do 30%–60% of people with end-stage renal disease. HIV and CHF are also associated with anorexia and cachexia, affecting 10%–35% of people with those conditions (Wholihan, 2015).

Pain

I cared for her over 30 years ago in a small-town hospital. Lying at the far end of the hall in a two-bed room, she would call out, "Nurse ... Nurse ... help me ... Nurse ..." and after a while, she would call out, "God, God, God ... help me God." When I look back all these years later, I can still recall her name, and can remember walking into her room, not knowing what to do or how to help. In retrospect, I think that she received two tabs of acetaminophen twice a day ... She was not assessed regularly for pain, she did not receive any additional acetaminophen when she called out. My memory of her still haunts me, and I regret not having known how to assess her pain and how to advocate for her.

What Is Pain?

Pain is the unpleasant sensory and emotional experiences of physical suffering and distress due to injury or illness. Pain can originate from a variety of diseases, for example, cancer, COPD, or arthritis, and for a variety of reasons, including physical and psychosocial issues (Pallium Canada, 2013). The way that people express their pain varies with different cultures (Carteret, 2011).

Margo McCaffery provides a straightforward way to look at pain that has become a classic in the field of pain management (McCaffery, 1968):

Pain is what the experiencing person says it is, and exists whenever the experiencing person says it does.

Dame Saunders and the Concept of Total Pain

Remember that pain, like death, is always experienced by the whole person, not just the physical body. Dame Cicely Saunders developed the concept of "total pain," which she defined as pain that includes physical, emotional, spiritual, and social dimensions of distress. The concept

of total pain can remind you to look beyond the physical causes and see other factors that may affect and potentially increase a person's pain. The experience of physical pain may be greater when a person is afraid or concerned, such as when they are experiencing existential suffering, interpersonal conflict, financial challenges, family issues, and so on. Being aware that pain is experienced by the whole body and that issues affecting the body will affect the experience of pain will help you when providing care to increase physical comfort.

Prevalence

More than 80% of people with advanced cancer experience pain; 66% of these people will experience moderate to severe pain, and 60% will experience pain at more than one site. The prevalence of pain evaluated one month before death did not differ greatly by diagnosis: cancer—45%, heart disease—48%, frailty—50%, other diagnoses—47% (Smith et al., 2010). The actual prevalence of pain is probably higher, because some people do not report their pain.

The level and intensity of pain fluctuate as diseases progress and conditions decline. Regularly assessing pain and developing a plan of care focused on maintaining quality of life are essential steps to managing pain. Applying the basic principles of pain management will help manage pain in 85% of people experiencing pain due to advanced cancer (Pallium Canada, 2013).

These populations are at risk for undertreatment of pain:

- Children and the elderly
- People who are nonverbal or cognitively impaired
- People who deny pain, for personal reasons
- People who are unable to communicate their pain or have difficulty doing so due to a language barrier
- People who, because of their culture or traditions, are discouraged from talking about, expressing, or managing pain
- People with a history of addiction



Providing Psychosocial Care

What Is Psychosocial Care?

The word “psychosocial” refers to the emotional, intellectual, spiritual, interpersonal, and cultural aspects of a person. Simply said, it means “everything except the physical.” In this text, physical symptoms and psychosocial issues are addressed in separate chapters. However, it is important to remember that people do not experience life in an unconnected or compartmentalized way. Human beings are whole persons and are holistic. Care that is holistic recognizes that a person’s whole being is involved in their care. It involves how they are emotionally, spiritually, cognitively, socially, and physically. It is recognized that physical symptoms can have emotional effects, and that emotions can have physical effects. Hospice and palliative care includes a holistic approach that sees the person as more than their illness, more than the sum of their body

parts, and more than their emotional reactions to death, dying, loss, and grief.

This chapter focuses on ways to provide psychosocial support for the person and family experiencing transitions, uncertainty, loss, and grief. Having difficult conversations about advance care planning, for example, is discussed as a way to help people identify their priorities, concerns, hopes, and fears so that their wishes can be honored when they are unable to speak for themselves.

Use the Psychosocial Assessment Form (see pages 83 to 88 in Chapter 4, “Using Standardized Tools”) to help understand the person, their goals of care, their family and their support needs and inform goals of care conversations.

Common Psychosocial Responses to the Diagnosis of Life-Limiting Illness

Advances in disease diagnostics and treatments have increased the length of life for most people. However, the combined effects of multiple diagnoses that the majority of dying people now experience severely affects their quality of life. While the diagnosis of diseases and the integration of hospice and palliative care are currently moving upstream, management of psychosocial issues must now also move upstream to support people and their families through multiple changes in their health and psychosocial transitions (Pasacrete et al., 2015).

People vary in their responses to a diagnosis, depending on the illness, their personal experiences, and the ways that they process information (Pallium Canada, 2013). Emotional responses may include feelings of shock, disbelief, anxiety, depression, denial, irritability, and turmoil. These responses may present as physical symptoms, such as sleep loss and changes in appetite, as well as difficulties with concentrating and performing normal tasks (Pasacrete et al., 2015). Responses may last only days for some people and may extend into weeks or months for others. Ideally, reactions diminish when the person knows the treatment plan and comes to terms with the expected outcomes. Some people may require medication to help settle their reactions.

Of particular concern is the assessment and support of people experiencing anxiety and depression in response to an initial diagnosis and during transitions. Anxiety and depression are natural reactions in people with chronic illness. However, physicians/nurse practitioners may not treat these reactions, considering them to be organic, appropriate to the situation, or not severe enough to warrant treatment. Sometimes this can lead to extended unhappiness, increased family conflict and worry, non-compliance with treatment, and suicidal thoughts (Pasacrete et al., 2015). HCPs can support ill people and their families who are coping with anxiety and depression by offering cognitive behavioral therapy and, for some people, medications. Cognitive behavioral therapy has been successful in helping people cope with their anxiety and depression and is more desirable in some cases because it does not involve medication.

HCPs, specifically nurses, can help by being aware of the signs and symptoms of depression and anxiety that may occur alongside, but independent of, the progressing disease. When distress is noticed, HCPs need to review all potential sources, including unmanaged symptoms. Nurses can support a person experiencing anxiety and depression by providing a caring presence, referring for counseling and alternative therapies, and, for some people, suggesting treatment through medications.

Developing Awareness of the Advance Care Planning Process

Nurses who develop their understanding of the ACP process will be better prepared to help others. Experiencing the process is one way to develop understanding. Use this exercise as a starting point.

Reflective Activity

1. Reflect on what is important to you as a person today, tomorrow, in a year, in 10 years.

What gives your life meaning? What gives you joy, strength, and support?

2. Talk with a friend or colleague and share your thoughts on what is important to you now and in the future.
3. Record on paper what values or ideas you want your SM to consider if you were to become unable to speak for yourself.
4. Who would you like to ask to be your SDM?

Understanding Physician Assisted Dying and Medical Assistance in Dying

Requesting and receiving medical assistance in dying/physician assisted dying (see definitions in the next section) raise complex issues for the dying person, the family, and HCPs, and for hospice and palliative care communities. (For the purpose of this text, unless otherwise indicated the term “assisted dying” encompasses both medical assistance in dying and physician assisted dying.) This section of the book is not intended to be a discussion of whether assisted dying should be legalized. Laws in Canada and in certain jurisdictions in the United States have clearly established that assisted dying is a health care service that is or will be available to certain people at the end of life—people who meet specific criteria and who want to choose their time of death. The focus of this section is first to clarify terminology and identify hospice and palliative care principles that pertain to assisted dying, and second, to provide stimulation that encourages you to consider your beliefs and identify challenges you may face when engaging with the dying person, the family, and you colleagues when assisted dying is being contemplated or pursued as an end-of-life care practice.

It is timely and appropriate to address assisted dying in this text because integrating a palliative approach includes relieving suffering, responding to difficult questions, and helping people explore care options. HCPs can apply their skills learned when responding to other difficult end-of-life questions to respond to requests for information about assisted dying. Nurses, as a community and as individuals, need to learn to engage in reflection, dialogue, and exploration to support the dying person and family in their process of considering assisted dying.

Terms Relating to Assisted Dying

In Canada and in the United States, laws are evolving in response to the requested death movement, a global social movement that is “concerned with the ultimate control of one’s body at life’s end” (McInerney, 2000). This movement seeks to empower people to choose the timing and manner of their own death. Terms relating to assisted dying vary by location and legislation, causing confusion for the dying person and the family, as well as for nurses and other members of the health care team.

In the United States, the term “physician assisted dying” refers to the legal practice of deliberately ending a dying person’s life at their request; in Canada, the parallel term is “medical assistance in dying.” As mentioned above, in this text the term “assisted dying” encompasses both medical assistance in dying and physician assisted dying.

Physician Assisted Dying

In the United States, “physician assisted dying” means:

A physician provides, at the patient’s request, a lethal dose of medication that the patient can take by his own hand to end ... intolerable suffering.

(AAHPM, 2016)

In cases of physician assisted dying, the physician provides the prescription and the dying person receives it and self-administers the medication when and where and if

Supporting Children Whose Loved One Is Dying

Many people find it challenging to support a child when a person close to the child is dying or has died. The separation of dying and death from ordinary life has raised more issues than it has solved. When the dying process happens behind closed doors, adults may separate children from their dying loved one, often with the unintended effect of interfering with children's ability to say good-bye to the person. In addition, the separation denies children the opportunity to learn about death, one of life's greatest teachers. Current research-based principles on supporting children whose loved one is dying suggest that children should be included and communication with them should be open and honest.

Applying the principles discussed below can help nurses and families feel more confident when supporting children whose loved one is dying, as well as help children in their grieving process.

Principles for Supporting Children Whose Loved One Is Dying

Include Children

People often ask questions such as "Should my daughter visit her grandfather who is dying?" Children benefit by having the choice to visit dying friends and family members. Children of all ages can be asked whether they want to visit and should be allowed to participate to the extent that they are comfortable doing so. Children must also have the option not to visit. If they choose not to visit, they can be asked if they would like to draw a picture or write a story as ways to participate. What is most important regarding children is that they are asked and given choice.

Prepare Children

Some parents are hesitant to let a child visit a dying person due to concerns that the person's appearance or the equipment in the person's room may frighten the child. Andrea Warnick, a social worker and child and youth counselor, states that preparing a child to visit their dying loved one will help make the experience a positive one (Warnick, 2015a). Before the visit, set the stage for the child:

- Describe how the person's room will look—the equipment in the room, the lights on the equipment, and the sounds that may be present in the room.

- Describe how their loved one looks now compared with when the child last saw the person, including any dramatic changes such as weight loss, hair loss, or pallor (a child could be shocked by seeing a person who customarily wears dentures without them).
- Explain:
 - Where the child is allowed to go and what the child may touch when visiting someone in a hospital or hospice setting.
 - What the child is allowed to do in the presence of, say to, or talk about with the dying person
 - What will happen during the visit (e.g., both laughter and tears may occur).

Be Honest

Adults may try to protect children from the news that a family member is dying. However, most children sense when something is wrong in the family, and if they are not told the truth, they invent a story to explain what is wrong. Quite often their imaginations create scenarios that are worse than reality. This means that withholding the news that a family member is dying tends to be more frightening than the truth and denies children access to accurate information and appropriate emotional support. When children sense they have not been told the truth or they learn the truth after the fact, their sense of security and ability to trust the adults around them may be damaged.

Invite Participation in Caregiving

Children may want to participate in caregiving but probably will not know what to do or how to help. They can be included in caregiving by inviting them to:

- Assist with personal care, such as mouth care and applying nail polish or skin moisturizer
- Help create a comfortable atmosphere by means of music, decorations, storytelling, or reminiscing
- Share daily events, do homework, or do other quiet activities at the bedside
- Sit quietly at the bedside and hold hands with their loved one.

Update
Care
Plan

PSW
24-7 ➡



Nursing
Care

Caring in the Last Days and Hours

Preparing the Person and the Family for the Last Days and Hours

Some people will want to know what dying will look like and how to care for the dying person before death is imminent, and others will not want to know until the person is actively dying. The authors of *Transitions in Dying and Bereavement: A Psychosocial Guide for Hospice and Palliative Care* suggest that the family is often ready to discuss the changes that may occur in the last days and hours when the dying person's score on the Palliative Performance Scale (PPS) has decreased to 30% to 20% (Victoria Hospice Society, Wainwright, W., Thompson, M. (2016)). The person's condition will change in the last days and hours, and in some cases changes are rapid. Health care providers (HCPs) will need to anticipate changes in medications and needs for support, develop a plan for the time of death, and identify rites and rituals that are relevant to the person and family.

Assessing, sharing information, and responding to questions and concerns are part of preparing the person and family for the last days and hours. In some cases, HCPs may need to consider how to offer support if the family or the person is *not* interested in talking about death.

Assessing and Sharing Information

Assessing what the family knows about the dying process, the last days and hours in particular, what they want to know, and what they may need to know if they are providing care will facilitate excellent care for the person and family.



In her research, Davidson found that family members want information (Davidson, 2011). They want to understand what to expect. As death draws near, the person and the family may have questions, and they may be concerned

but not know what questions to ask. Forbes Hospice developed a Question Prompt Sheet (QPS) (Table 1) based on actual questions caregivers asked, to help the family identify and ask questions (Hebert et al., 2008).

Table 1. Question Prompt Sheet

Medical	<ul style="list-style-type: none"> • How long does my loved one have? • Will my loved one recover? • What should I expect to happen over the course of the illness? • What caused the illness? • What are the common side effects of my loved one's medications? • What can I expect when my loved one is dying? • What does dying look like? • Will my loved one be in pain? • Is my loved one in pain? • Can the pain medicine make my loved one's heart stop or cause him/her to stop breathing? • What if my loved one stops eating—will they starve? • Will my loved one need a feeding tube? • Will my loved one need IV fluids? • What are the risks of the treatment my loved one is receiving? • Will the pain medicines stop working if used too often? • Will the pain medicines cause addiction? • Can my loved one hear me? • What do I do if my loved one seems depressed?
Practical	<ul style="list-style-type: none"> • Who can I talk to about insurance? • Who can I talk to about financial concerns? • How do I get information about home health services, assisted living or nursing homes? • Who can I call if I have questions or need help? • How can I get in touch with the doctor? • How do I get information about hospice? • How do I get information about living wills? • How and when should I make funeral arrangements?
Psychosocial	<ul style="list-style-type: none"> • What do I do if family members disagree about treatment or disagree about what should be done for my loved one? • Should I discuss death and dying with the my family? With the person? • How can I help the children understand what is happening?
Religious or spiritual	<ul style="list-style-type: none"> • Who can I speak to about religious and spiritual concerns? • Why is this happening? Why is God allowing this?

(Adapted from Hebert et al., 2008)

When you provide the family member with the QPS, you are communicating that it is normal to have questions and that questions are welcomed. The QPS can be adapted to address the unique needs of any community. Sharing information about what to expect in the last days and hours can validate what family members are seeing, help them anticipate what might come next, and help them participate in providing care.



Ethics Touchstone

Do any of these questions surprise you? How would you answer these questions if your loved one was dying?

Another woman told me of how she sat at her mother's bedside and was thinking that death was a number of hours or days away. When the health care worker said, "If

you need to go to the bathroom, let me know and I can come and sit with her," the woman realized that death would be soon.

Preparing to Meet the Person's Needs in the Last Days and Hours

When a person is dying, their needs for personal care, medications, and support will change. When a person's score on the PPS declines from 30% to 20% to 10%, you can anticipate the changes in care needs and help prepare the team to respond. When preparing to respond, knowing the preferences of the person and the family is helpful.

Developing a Plan

When I was pregnant with my first child, I was keen to develop a birth care plan. I wanted to be sure that the care team knew what I wanted and would respond to the needs that arose during the birthing process as discussed in our prior conversations and noted in my care plan.

And so it is with dying. When the time comes, I want my caregivers to know what is important to me. I want my caregivers to know my hopes and preferences for my dying and the care of my body after I die. And I expect that, just as my birthing plan was adjusted to meet my and my baby's needs during the birthing process, my family and care team will honor my preferences when I am dying and will adjust to meet needs as they arise. Whether I die at home or in a hospital, hospice, or residential care setting, the essence of who I am, what I am, and what I hope for can be honored.

As death approaches, the more hypothetical discussions that may have occurred in the preceding years and months, and the care plans that were developed weeks or days ago, will need to be adapted and fine-tuned to best meet the current needs of the person. The Psychosocial Assessment Form (see pages 83 to 88 in Chapter 4, "Using Standardized Tools") provides guidance for discussing practical, financial, and spiritual topics with the person and family to help you prepare for the last days and hours, when death occurs, and after death. Keep

this tool with the person's chart, and update the plan as necessary.

Psychosocial Assessment Form Page 6 of 6

Forms, Facilitators, and Funeral

FORMS	Signed	Date	Document location	Notes
Advanced Directive form				
Do Not Resuscitate form				
Representation Agreement				
Will				

FACILITATORS			
Power of Attorney	Person(s) appointed	Relationship to dying person	Contact phone numbers
• Enduring			
• Bank/financial			
• Other			
Substitute Decision Maker			

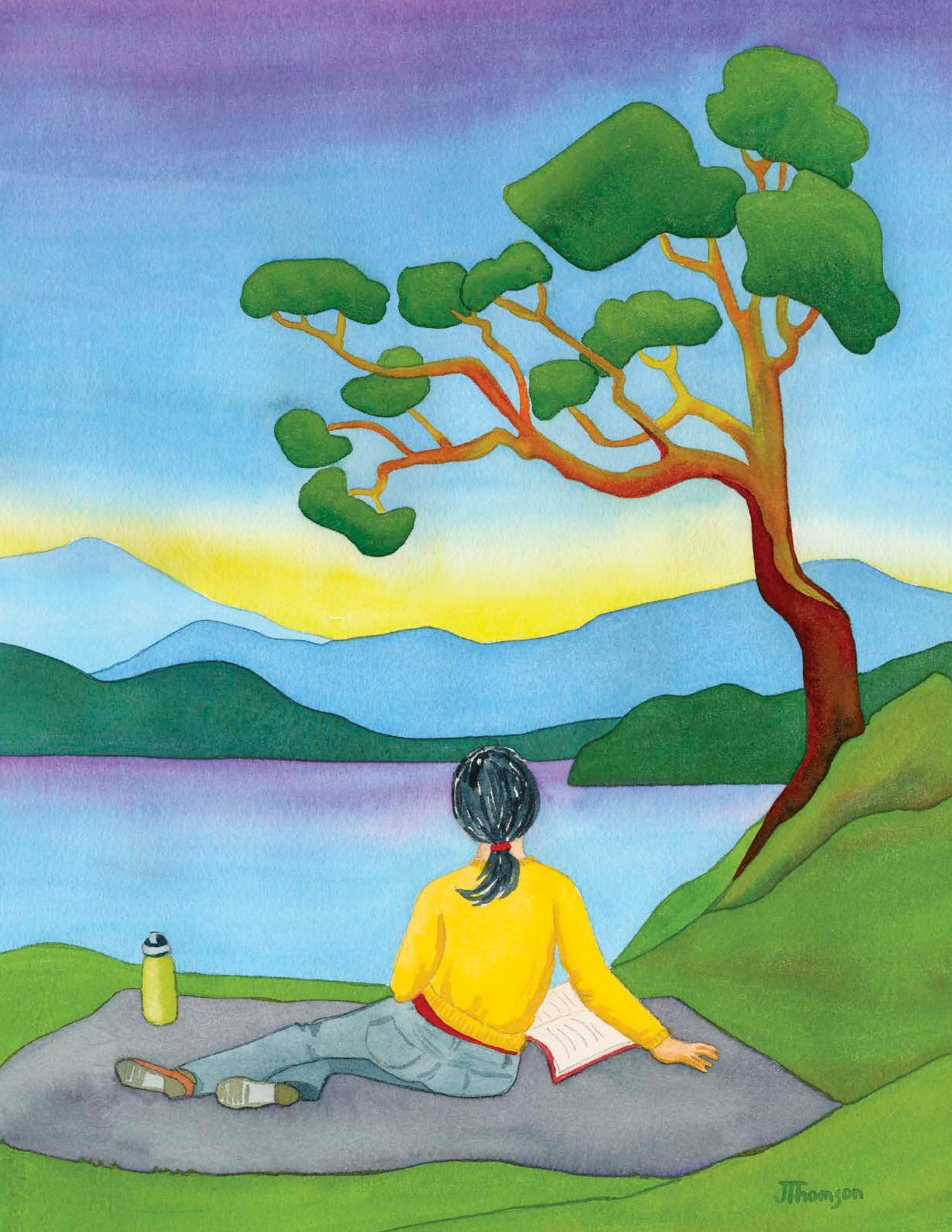
FUNERAL			
Funeral planning	yes	no	Notes
Funeral home			Phone number

Requests to be called or present		Call to be present for time of death		Call when death is imminent	
Times available to be called		Anytime	Day or evening only	Anytime	Day or evening only
Name	Phone number				
Name	Phone number				

Request for religious or spiritual contact to be present when death is imminent, at the time of, or following death			
Person requesting	Phone number	Religious/spiritual contact requested	Phone number

Notes

Psychosocial Assessment Form



Caring for You!

Providing Care for the Dying Will Change You

Caring for the dying will touch you and change you. In her book *Kitchen Table Wisdom: Stories That Heal*, Rachel Naomi Remen says,

The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet.

(Remen, 1997)

There are both positive and negative consequences to providing hospice and palliative care. On the positive side, being with people during their dying process may enhance your enjoyment of living, increase your appreciation of simple things, strengthen your ability to empathize, and increase your awareness of the challenges that people experience. These benefits may increase your capacity to care and may inspire you to face your own challenges with renewed strength and determination.

On the negative side, there may be times when your work and the sorrow you witness leave you grieving, sad, and feeling exhausted. You may find yourself grieving the dying person's losses as though they were your own. You may feel guilty that you are mobile while the person you care for is immobile, and that you are living while they are dying.

The purpose of this chapter is to stress the importance of caring for you! You do invaluable work, and you need to care for yourself as well as you care for others. Activities that may nurture and strengthen you include developing strong social support networks; learning and growing through education; and seeking out supervision, counseling, and coaching. In addition, activities that may help you to refuel include stepping back, reflecting, shaking things up, and practicing mindfulness strategies. If your compassion is in alignment with your intentions and the work that you do, then your work can energize you rather than deplete your energy.

Considering Compassion Fatigue

Françoise Mathieu, a mental health counselor and compassion fatigue specialist, and author of *The Compassion Fatigue Workbook* (Mathieu, 2012), encourages health care providers (HCPs) to care for themselves as well as they care for others. She works with organizations to help them develop ways to better support their staff. I am honored by Mathieu's significant contribution to this chapter and thank her for it.

Nurses require self-care in order to prevent burnout and compassion fatigue. The term "compassion fatigue" encompasses the emotional and physical exhaustion that can occur when a nurse (or any other HCP) is unable to refuel and regenerate quickly enough to meet the emotional and physical demands of her or his work. Nurses doing this work—providing care for the dying person and family, and

witnessing suffering day after day and year after year—are at high risk for developing compassion fatigue. In addition to the demands of the work itself, challenges such as high workloads, insufficient staffing, and policies and procedures contribute to compassion fatigue. Self-care can help you withstand the negative effects and benefit from the positive effects of caring for the dying. Without the buffer provided by self-care, you may lose your capacity to provide excellent care for the dying. For example, nurses with compassion fatigue may be impatient, cynical, and irritable, be less sensitive to or less able to empathize with people, and be neglectful or dismissive of the suffering of the dying person and family.

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About the Author

Kath is a hospice palliative care nurse, a thanatologist (which means that she specializes in death, dying, and bereavement), an educator, a mom, and a nana.

She has a love for education that is engaging, delicious, and digestible. Her passion is to develop and provide excellent resources (based on current research and best practice) to help nurses and health care workers provide excellent care for the dying and their family.

Kath appreciates hearing about your experiences and receiving feedback. You can email Kath from the Life and Death Matters website, www.lifeanddeathmatters.ca.

Essentials in Hospice and Palliative Care:

A PRACTICAL RESOURCE FOR EVERY NURSE

Whether working in a facility for long-term care, acute care, emergency care, or intensive care, a hospice, a palliative care unit, or the home or community, every nurse cares for the dying person and that person's family.

Integrating a palliative approach into care can improve quality of life for people with any life-threatening illness, early in the disease process, and across all care settings.

This text will enhance your caregiving by helping you:

- Understand the dying process and common issues that arise
- Understand principles of hospice and palliative care
- Integrate principles of palliative care in all care settings
- Learn about and develop best practice interactions
- Develop assessment, communication, and care planning skills
- Learn about physician assisted dying
- Become more comfortable and confident in having difficult conversations
- Develop confidence and skills for collaborating and communicating with the health care team
- Develop skills for responding in difficult situations

"Kath has taken the theory and principles of palliative care, her experience as an excellent bedside nurse, and her compassion for both those receiving and giving care, and merged them into this amazing book."

Kath presents complex issues in practical and clear ways. Through stories and illustrations she reminds us that care includes the person, the family, and ourselves. She shares all the necessary tools, knowledge, and skills, while emphasizing that it is our presence and human connection with people that create truly meaningful moments for all those who are involved."

— **Wendy Wainwright, MSW, MEd,**
Co-author, *Transitions in Dying and Bereavement*,
Co-editor, *Medical Care of the Dying*



Kath Murray, RN, MA, CHPCN(C), FT has a love for hospice and palliative care and a love for engaging education and resources. Her passion is to provide exceptional resources to help nurses, health care workers and personal support workers, to provide excellent care for the dying and their family, and to find meaning and value in doing so.

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Life & Death Matters

www.lifeanddeathmatters.ca



1.888.788.6781



info@lifeanddeathmatters.ca



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