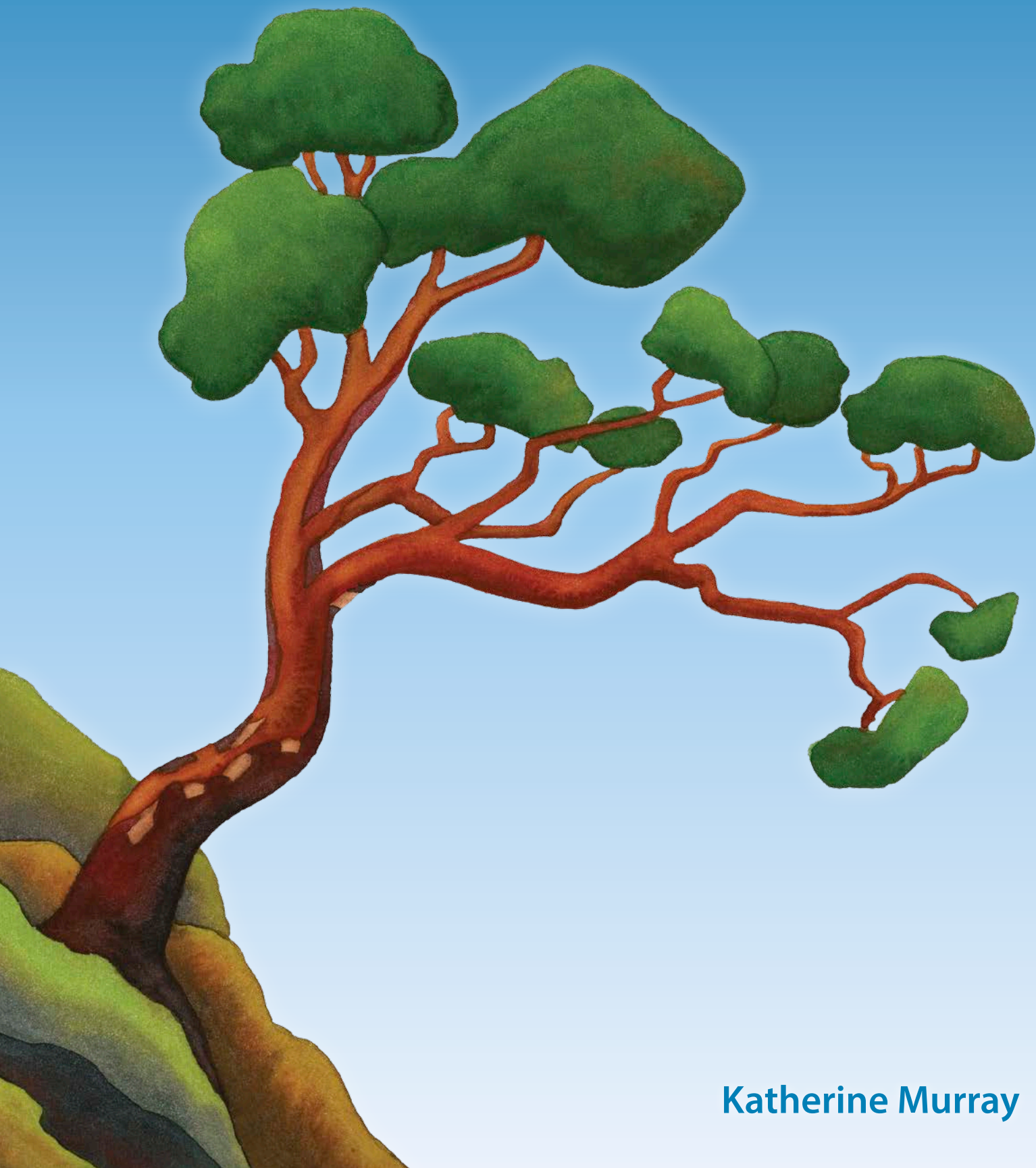


# Integrating a Palliative Approach:

ESSENTIALS FOR PERSONAL SUPPORT WORKERS



Katherine Murray

# CONTENTS

Dedication .....	v
About the Cover .....	.vi
Acknowledgements .....	vii
Preface .....	xiii
How to Use This Book .....	xv
<b>Chapter 1: Preparing to Care .....</b>	<b>1</b>
<b>Life Is a Journey .....</b>	<b>1</b>
<b>Using Reflection to Develop Self-Awareness .....</b>	<b>4</b>
Why Self-awareness Is Important .....	4
Enhancing Self-awareness with Reflective Activities .....	6
<b>Maintaining Therapeutic Boundaries .....</b>	<b>6</b>
How Do You Know If Boundaries Are Not Clear? .....	7
How Do You Know If Boundaries Are Clear? .....	8
How Can You Get Better at Maintaining Therapeutic Boundaries? .....	8
<b>Chapter 2: Understanding the Dying Process .....</b>	<b>13</b>
<b>People Have Never Died Like This .....</b>	<b>13</b>
<b>Patterns of Dying .....</b>	<b>14</b>
Sudden Death .....	15
Steady Decline .....	16
Stuttering Decline—the Roller Coaster .....	18
Slow Decline .....	20
<b>The Dying Process .....</b>	<b>23</b>
<b>Chapter 3: Integrating a Palliative Approach into Caregiving .....</b>	<b>25</b>
<b>The Beginning of Better Care for the Dying .....</b>	<b>25</b>
Hospice Palliative Care .....	25
Principles of Hospice Palliative Care .....	27
A Palliative Approach .....	28
End of Life Care .....	29
Terms Used in Hospice Palliative Care .....	30
<b>The Health Care Team .....</b>	<b>32</b>
<b>What Is a Good, Bad, or Appropriate Death? .....</b>	<b>35</b>
<b>Providing Support .....</b>	<b>36</b>
Creating a Nurturing Place .....	36
<b>The Team at Base Camp .....</b>	<b>46</b>

<b>Chapter 4: Increasing Physical Comfort</b> .....	<b>49</b>
<b>Part 1: Tools, Communication, and Palliation</b> .....	<b>49</b>
<b>Tools for Gathering Information</b> .....	<b>49</b>
The Victoria Hospice Palliative Performance Scale.....	50
The List of Sample Questions.....	52
<b>Communicating with the Team</b> .....	<b>54</b>
Recording and Reporting.....	54
Advocating.....	56
<b>Palliation</b> .....	<b>58</b>
Principles of Palliation.....	58
Principles of Using Medications to Manage Symptoms.....	58
Using Opioids to Manage Symptoms.....	59
<b>Basket of Comfort Measures—Creativity in Caregiving</b> .....	<b>61</b>
Guidelines for Using the Comfort Basket.....	61
Music Care.....	63
<b>Part 2: Common Symptoms</b> .....	<b>65</b>
<b>Changes in Bowel and Bladder Function</b> .....	<b>65</b>
<b>Decreased Appetite and Weight Loss</b> .....	<b>68</b>
<b>Dehydration</b> .....	<b>74</b>
<b>Delirium</b> .....	<b>77</b>
<b>Difficult Breathing</b> .....	<b>85</b>
<b>Fatigue</b> .....	<b>90</b>
<b>Mouth Discomfort</b> .....	<b>93</b>
<b>Nausea and Vomiting</b> .....	<b>97</b>
<b>Pain</b> .....	<b>101</b>
<b>Chapter 5: Providing Psychosocial Care</b> .....	<b>119</b>
<b>Transitions</b> .....	<b>119</b>
Supporting through Periods of Decline.....	119
Sharing Information.....	122
Supporting Choice, Control, and Independence.....	126
Supporting Hope.....	127
Maintaining Family Relationships.....	128
<b>Advance Care Planning—Having a Say through to Death</b> .....	<b>129</b>
What Is Advance Care Planning?.....	129
Supporting the Advance Care Planning Process.....	130
<b>Loss and Grief</b> .....	<b>134</b>
Basic Truths about Loss and Grief.....	134
Understanding Grief.....	138
Supporting a Grieving Person.....	143

**Chapter 6: Caring in the Last Days and Hours . . . . . 151**

**Preparing to Care. . . . . 152**

- Sharing Information . . . . . 152
- Responding to Questions . . . . . 153
- Arranging for Support and Resources. . . . . 155
- Developing a Plan for the Time of Death. . . . . 156
- Identifying Rituals and Preferences for Care Following Death. . . . . 157
- Providing Compassion: It’s hard to Be Family. . . . . 158

**Physical Changes and Psychosocial Implications . . . . . 160**

- Decreased Physical Strength and Increased Drowsiness. . . . . 161
- Reduced Intake and Difficult Swallowing . . . . . 162
- Delirium or Confusion. . . . . 163
- Agitation and/or Restlessness . . . . . 166
- Unresponsiveness. . . . . 167
- Irregular Breathing . . . . . 168
- Congested Breathing. . . . . 169
- Changes in Skin Colour and Temperature. . . . . 171
- Other Changes As Death Nears. . . . . 172
- Last Breaths . . . . . 173

**When Death Occurs . . . . . 174**

- What You Will See . . . . . 174
- What You Can Do . . . . . 175
- Caring for the Body after Death. . . . . 176
- Creating a Special Space . . . . . 177
- Supporting. . . . . 181
- Debriefing with Staff . . . . . 184
- Preparing to Transfer the Body. . . . . 185

**When Death Is Sudden and Unexpected . . . . . 187**

- The Role of the Coroner When Death Is Sudden . . . . . 187

**The Home Funeral Movement. . . . . 188**

**Chapter 7: Caring for You! . . . . . 191**

**Providing Care for the Dying Will Change You . . . . . 191**

- Self-Care—Buffering the Effects of Caregiving . . . . . 192
- Checking In: Signs of Compassion Fatigue. . . . . 193

**Self-Care Strategies for Caregivers. . . . . 196**

- Developing Self-Awareness . . . . . 196
- Remembering Your Boundaries. . . . . 196
- Developing a Strong Social Support Network. . . . . 198
- Learning . . . . . 199
- Refuelling . . . . . 199

**Closing Thoughts. . . . . 203**

<b>Appendix A: Medications for Managing Symptoms</b> .....	<b>205</b>
Non-Opioid Analgesics .....	205
Adjuvant Analgesics .....	205
Opioid Analgesics .....	206
Principles for Using Opioids to Manage Pain .....	206
Fears and Misconceptions about Opioids .....	207
Common Side Effects of Opioids .....	208
<b>Appendix B: Supporting Children Whose Loved One Is Dying</b> ....	<b>211</b>
Principles for Supporting Children Whose Loved One Is Dying .....	211
Including Children .....	211
Preparing Children .....	211
Being Honest .....	212
Inviting Participation in Caregiving .....	212
Inviting Questions .....	212
Using Correct Language .....	213
Understanding Children’s Concerns: The Three C’s .....	213
Recognizing Children’s Grief .....	214
Grieving Together .....	214
<b>Appendix C: Palliative Performance Scale</b> .....	<b>217</b>
Instructions for Use of PPS .....	217
Definition of Terms for PPS .....	218
<b>Appendix D: Resources</b> .....	<b>221</b>
References .....	221
Recommended Reading for Personal Support Workers .....	223
<b>Index</b> .....	<b>225</b>
<b>About the Author</b> .....	<b>231</b>

# Preparing to Care

## Life Is a Journey

Life is often referred to as a journey. I will use the metaphor of the journey throughout this book to refer to the journey of the dying person and their family.<sup>1</sup>

Journey of the dying

As a personal support worker (PSW), you are not the travel guide, the ticket agent, or the pilot for this journey. (Your journey, and the need to attend to your own needs, is discussed in Chapter 7. Self-care, including taking time for reflection, is good for those you care for and good for you.)

I start and end this book with a focus on you, the PSW. Why? Because this book is for you! It is a tool to help you feel more confident and be more competent in providing excellent, compassionate care for the dying and their family. The care you provide for them and your ability to continue to do this work begins and ends with you.



*You are invited on a journey.  
You are invited to journey  
with people who are dying  
and their families.*

---

<sup>1</sup> I use the term “dying person” because I cannot bear to use the word “client” to describe someone who is so vulnerable, I 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 care settings.

In this book, “family” means not only people who are related biologically to the dying person, but also chosen family and, for the sake of simplicity, significant others.

# Integrating a Palliative Approach into Caregiving

## The Beginning of Better Care for the Dying

It was the 1960s, and David Tasma was dying in an acute care hospital in London, England. The focus of acute care was not on providing individualized care for the dying person. David talked for hours with his social worker, Cicely Saunders (a former nurse, honoured by Queen Elizabeth II in 1979 with the title Dame Commander of the Order of the British Empire), about a better way to care for the dying. After he died, Cicely completed a medical degree. She built on those early discussions with David to establish a new way of caring for the dying. In 1967, Cicely Saunders opened St. Christopher's Hospice, a facility providing care specifically for dying people, and simultaneously started the hospice movement. This movement has expanded to address the needs of the dying throughout the world.

Cicely Saunders founded St Christopher's Hospice in London, England

### Hospice Palliative Care

Dr. Balfour Mount, a Quebec physician, studied in England with Cicely Saunders so that he could better understand the needs of people in his hospital who were dying. He created the term "palliative care" because the word "hospice" did not translate well into French. He opened the palliative care unit in 1974 at the Royal Victoria Hospital in Montreal. In Canada, the terms "hospice" and "palliative" are often used together.

Dr Balfour Mount created the term "Palliative Care"

One goal of hospice palliative care (HPC) is to improve a person's quality of life. Two recent studies support the role of HPC in reaching this goal. A study reported by the Canadian Hospice Palliative Care Association (CHPCA) states that people receiving HPC reported better quality of life, fewer symptoms, and greater satisfaction with care. They also had fewer emergency room visits and fewer hospitalizations.<sup>1</sup> Another study indicated that people receiving palliative care in addition to oncological treatments reported better quality of life.<sup>2</sup> Although HPC is not aimed at helping

Hospice palliative care seeks to improve a person's quality of life

1 Paraphrased from Canadian Hospice Palliative Care Association, *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*, revised and condensed ed. (CHPCA, 2013), 6.

2 J.S. Temel et al., "Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer," *New England Journal of Medicine* 363, no. 8 (2010): 733–742.



people live longer, this study found that people who also received palliative care also lived a few months longer than those who did not receive HPC.

HPC helps people manage symptoms caused by any life-threatening disease.

Life-threatening diseases include end-stage kidney, cardiac, respiratory, and neurological illnesses, as well as dementias, and congenital and metabolic illnesses that occur mostly in children.

People benefit from HPC early in their disease process, sometimes as early as the time of diagnosis. Early in the disease, HPC can help a person by providing information about the disease process, advance care planning, current care options, and support for psychosocial issues.

A person can receive palliative care while still receiving acute curative treatments.

These two approaches, curative and palliative, can work together to provide better quality of life for people with life-threatening diseases.

In hospice palliative care, curative and palliative approaches can work together





## Principles of Hospice Palliative Care

HPC is care that

- Affirms life
- Regards dying as a normal process
- Considers the dying person and their family to be the unit of care and continues through death and bereavement

HPC principles promote care that

- Does not speed or delay dying or death
- Improves the dying person's quality of life
- Provides pain relief and manages distressing symptoms
- Attends to the person's needs in a holistic way

HPC is best when provided by an interprofessional team. The diverse perspectives and abilities of the members of the team enable it to provide holistic care.

### Hospice Is about Living Well Until Death

Around the world, HPC is based on the common philosophy of improving the quality of life for dying people, wherever they are—at home, in a care facility or hospital, or in a palliative care unit. People often say, "Hospice is all about living and living well until you die."

HPC is holistic care that addresses the needs of the entire person—the physical, emotional, spiritual, and psychosocial needs. HPC includes care for whomever the person who is dying defines as "family." The illustration at the beginning of this chapter depicts person- and family-centred care: the caregivers and the health care team are holding the person and family gently, supporting them with compassion and respect for their unique personal experience. Ideally, an interprofessional team that includes PSWs, volunteers, nurses, physicians, social workers, and spiritual care personnel provides HPC.

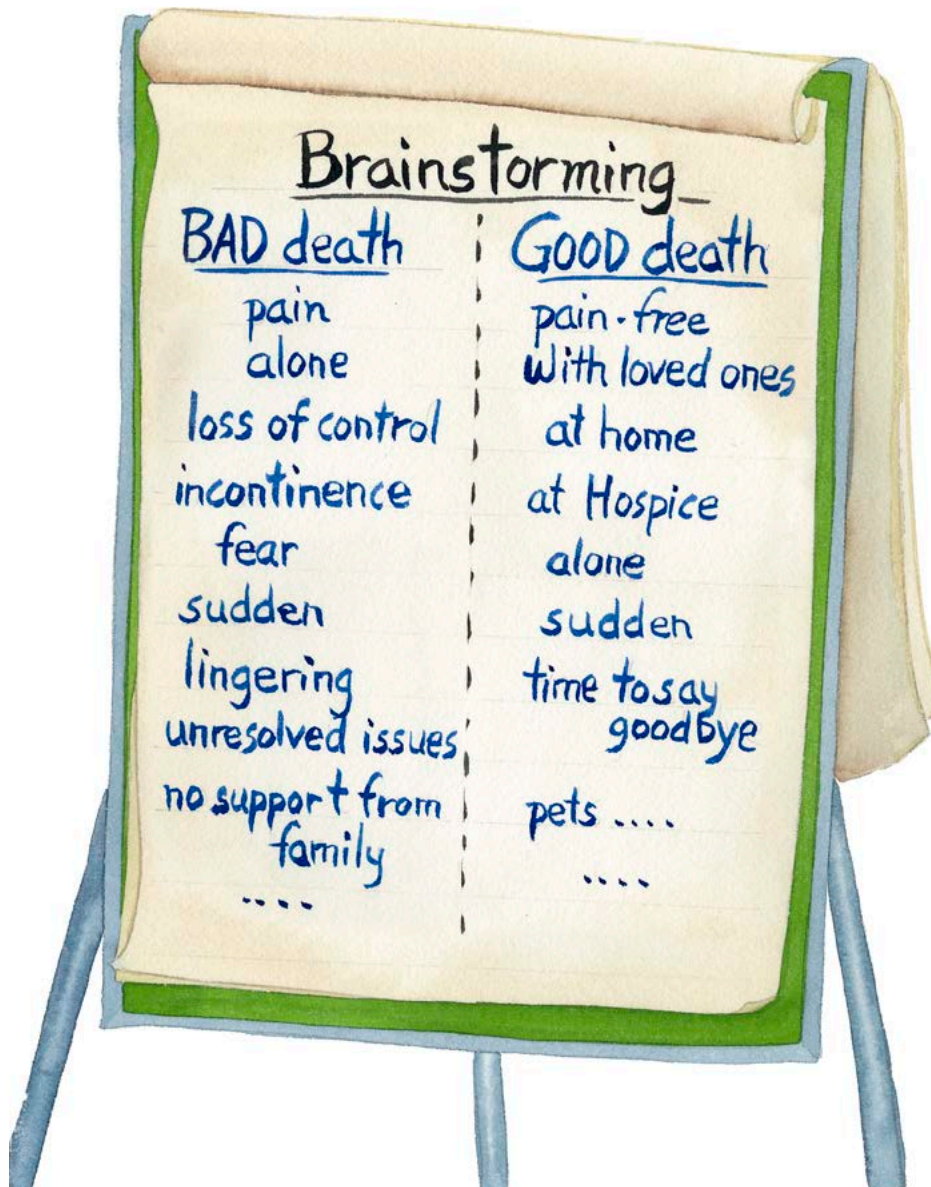
HPC acknowledges that dying is a normal process and that people often need support to cope with feelings of loss and grief. HPC may include medical tests and interventions to provide comfort, and therefore is appropriate early in an advancing chronic or terminal disease process. People do not need to wait until death is imminent to benefit from HPC.



## What Is a Good, Bad, or Appropriate Death?

As you look at ways to integrate a palliative approach into caregiving, it is important to know what the dying person wants, and how that person defines “a good death” or “a bad death.” The lists in the illustration below show PSWs’ responses to the question, “What would be a bad death/good death for you?”

Good death,  
Bad death  
Appropriate death



It is interesting to note that some items are on only one list while other items are on both lists, which indicates that what makes a good death for one person might be a bad death for someone else.

## Defining an appropriate death

Rather than use the words “good” or “bad” to describe a death, you may want to think about the phrase “an appropriate death.” An appropriate death is one with dignity, where the needs of the dying person are addressed by the team. The term “appropriate death” is not intended to be a judgment. In the following story, a daughter talks about how badly she felt about her mother’s death, until she learned the concept of an appropriate death.

*For years, I felt badly that Mom had died before I got back to the hospital. The staff had phoned me to tell me that Mom was declining, and I asked them to tell her that I was on my way. She died just before I got there. For years, I felt guilty that I was not with her when she died.*

*When I heard about an “appropriate death,” I remembered that she was a very private person and had always protected us from seeing or experiencing difficult things. When I remembered that, I thought, “Wasn’t that just like her to die when I wasn’t there!” With this new understanding, I felt at peace with her death.*

As she turned her focus to the person her mother was, the daughter realized that the death was what her mother would have wanted. Knowing the dying person—their beliefs, hopes, and concerns—will help you provide support that addresses and respects their specific needs and wishes.

## Providing Support

### PSWs provide physical and psychosocial support

In the previous pages, I have presented HPC as a resource designed to more fully meet the needs of the dying person and their family. The goal of HPC is to improve the quality of life—the quality of the living and of the dying—for the dying person and the family. PSWs provide physical and psychosocial supports.<sup>7</sup> What can you do to provide support?

### Creating a Nurturing Place

Someone once asked me where I wanted to die. Perhaps they were wondering if I wanted to die at home or in the hospital. Immediately I responded, “I want to die in a bed of roses without the thorns.” That sounds good to me! A few years later I purchased an outdoor wicker bed with a bright lime green mattress. I told my kids that I had found the bed that I would die on—outside under the stars. I failed to mention that wherever I die, I hope that I get wrapped in lovely warm flannel sheets on a regular basis!

---

<sup>7</sup> According to the Canadian Educational Standards for Personal Care Providers related to caring for people with palliative and end of life needs, the PSW “provides emotional support for the client and his/her family.”

# Increasing Physical Comfort

## Part 1: Tools, Communication, and Palliation

I have heard people say, “It is not being dead but the dying I fear.” People often fear the physical suffering associated with dying. The focus of Part 1 of this chapter is to provide PSWs with a few key tools—the Palliative Performance Scale and the List of Sample Questions—and tips on recording (documenting), reporting, and advocating that will help you gather information about the person and communicate it to the health care team. The chapter also reviews the principles of palliation and the use of medications to help manage common symptoms. The dying person, their family, and formal caregivers often have concerns about the use of opioids, so that topic is addressed in detail. A discussion of nonpharmacological measures to provide comfort follows. Finally, in Part 2, the chapter elaborates on each of nine common symptoms you may observe in the dying person.

People often fear the physical suffering associated with dying

## Mouth Discomfort

*Most of the people I care for have dementia. They can't tell me when something is wrong. They can't tell me that they have a sore mouth. So I listen like I am a detective. I observe really carefully, I "listen to behaviours." Then I try to figure out what could be wrong.*

*I remember one lady who was upset, but she couldn't tell me what was wrong. She hit me and resisted care. Finally I started singing with her, and she relaxed a bit, I sat next to her.*

*Then I thought, "I need to see her mouth. She has not been letting me give her mouth care for the last few days. Sure enough, her mouth was ugly with red patches and creamy white spots sloughing off. She had a thrush infection. That had to be the cause of the pain.*

Mouth discomfort develops when the normal tissues of the oral cavity become dry, irritated, and/or infected. There are many causes of mouth discomfort (e.g., medication side effects, poorly fitting dentures, a weakened immune system); therefore, preventive mouth care is important. Because PSWs provide the majority of personal care, they will be the first to notice changes in a person's mouth or their behaviour that may signal mouth pain.

PSWs are likely to notice signs of mouth discomfort first

### Gathering Information

#### Observing

Some people may tell you their mouth is sore, but most people manage their sore mouth by avoiding activities that cause mouth pain. PSWs need to watch for behaviours that may signal mouth pain. A person who suddenly does not want anything in their mouth (e.g., refuses food, drinks less than usual, doesn't want their teeth cleaned) may have a sore mouth. If talking causes pain, the person may stop talking or moan instead of using words. If you see these behaviours, look further for symptoms of mouth discomfort.

Decreased eating may indicate mouth discomfort

The person with mouth discomfort may have

- Visibly dry lips, gums, or tongue
- Swollen mucosa, lips, or tongue
- Fresh or dried blood in their mouth or on their lips
- A coloured discharge on their toothbrush after use
- An unpleasant smell in the mouth
- Colour changes with or without red or white sores in their mouth
- Difficulty swallowing



## Asking questions

You can adapt the questions in the List of Sample Questions to create your own questions to use in exploring and developing an understanding of the person's mouth discomfort and to individualize comfort measures.

## Comfort Measures

Providing mouth care regularly will help prevent mouth dryness and sores. The preventive mouth care strategies discussed below are useful for all people receiving supportive care and are especially important for those at high risk for developing thrush infections (e.g., during and after radiation or chemotherapy). Focus on hydrating and lubricating the mouth in people at risk for dry mouth, such as those with limited intake or in who are in their last days and hours.

### Preventive

It is important to use these mouth care strategies:

- Provide mouth care before and after the person eats.
- Remove the person's dentures before providing mouth care.
- Brush gently or wipe the mucosa to remove plaque and debris.
- For people resisting mouth care, use creative strategies to complete the task (e.g., distract them with singing, talking, gently touching).
- If the person has a thrush infection, soak their dentures and toothbrushes in a vinegar or disinfectant solution to prevent spreading the infection.
- Use a soft toothbrush and, if necessary, a specialized toothpaste.

Good mouth care can prevent mouth discomfort



### In the moment

In addition to using the mouth care strategies listed above, if the person's mouth is dry, use these strategies to hydrate and lubricate:

- Offer water or other drinks frequently.
- Spray the inside of the person's mouth with cold water.
- Offer them ice cubes wrapped in a clean washcloth to moisten the mouth.
- Offer them slightly thawed Popsicles, pineapple chunks, sour candies, or chewing gum.

Hydrate and lubricate to manage sore mouth

# Providing 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, people do not experience life in an unconnected or compartmentalized way. Human beings are holistic. All physical symptoms have emotional implications, and emotions, such as grief, can actually change a person physically at the cellular level. It is important to remember the holistic approach. The person is more than their illness, more than the sum of their body parts, and more than their emotional reaction to death, dying, loss, and grief.

Transitions at any time of life can be complex. Transitions that include illness, discomfort, decline in functioning and health, uncertainty, and lack of control are challenging. The focus of this chapter is on providing psychosocial support for the person and family experiencing transitions, uncertainty, loss, and grief. Advance care planning is discussed as a way to help people direct their future care now in case they become unable to later.

I acknowledge that the strategies provided here focus more on providing emotional support than on providing social, intellectual, interpersonal, or spiritual support. And yet, the emotional support PSWs provide by its very nature influences and affects those other types of support. I hope that I can offer you ideas and inspiration for being with and responding to those you care for in a way that creates a nurturing, safe place that will help the person and the family grow, even as the person is dying.

The next section discusses what can be expected for people who are dying with dementia. Relatively little is known about dying with dementia, so talking about what is known is helpful.

### Common questions about dying with dementia

#### **The Dementia Difference: Integrating a Palliative Approach in Caring for People with Dementia<sup>1</sup>**

Caring for someone dying with dementia has a few unique challenges: the person is unable to participate in decision making, there are many uncertainties, and the family may be exhausted after extended periods of caregiving.

These are some of the questions frequently asked about the uncertainties that relate to people dying with dementia:

- When will death occur?

*I don't know how long he has. Do I need to keep up my energy for months or years?*

- What will the trajectory look like?

*What can I anticipate? What is going to happen?*

- What will death will look like?

*Will he be peaceful? Will he die suddenly? Will I know when death is going to happen?*

- What other illnesses will contribute to dying?

*Does it matter that he also has diabetes and kidney failure?*

- What is going to happen next?

*When she eats her dinner, I wonder if she is getting better. When she has a bad day, I wonder if she is dying. Tonight she ate her dinner. Is she getting better?*

---

<sup>1</sup> Thanks to Broadmead Care Society in Victoria, BC, for the opportunity to develop a staff-education workshop titled "The Dementia Difference: Integrating a Palliative Approach in Caring for People with Dementia, in 2007, revised in 2013.

It is important to not get stuck in the uncertainties and to remember the certainties that are known about people dying with dementia:

- The overall trajectory will be a decline.
  - There may be ups and downs, but overall, there is a decline.
  - A person with Alzheimer's type dementia will first lose skills associated with higher-level functioning, such as balancing a chequebook or following a recipe. Eventually the person will lose more basic skills, including doing self-care, dressing, and walking. Eventually people with this type of dementia will not be able to feed themselves, and if they live long enough, they will lose the ability to swallow, one of the most basic reflexive behaviours.
- Death is certain to occur.
  - It is easy to forget this reality when a person has declined slowly over so many years, when the person has improved in the past when they seemed to be dying, and when the person seems relatively stable now. Death is certain to occur.
- Comorbidities will affect the trajectory.
  - If a person is healthy other than having whatever is causing the dementia, they might live longer than a person who has a history of strokes, diabetes, cancer of a vital organ, and so on.
- Certain interventions, such as those below, are not effective in late-stage dementia:
  - Attempts at cardiopulmonary resuscitation
  - Gastric tubes, which *do not*
    - Increase survival
    - Reduce the risk of infection
    - Prevent aspiration
    - Improve functional status
    - Improve comfort
  - Transfers to hospital for intravenous antibiotics
    - IV antibiotics are no more effective than oral antibiotics for repeat infections in late-stage dementia. The body requires a functioning immune system for antibiotics to be effective.
    - Antibiotics are not essential for comfort in the last days.
- Several indicators often precede the actively dying phase for people dying with dementia. In the period before death, the person may
  - Have repeated infections
  - Have skin ulcers that do not heal
  - Have a significant decline in intake
  - Be unable to swallow
  - Increasingly sleep and withdraw from others

Certainties about dying with dementia

Indicators that precede active dying with dementia

See Chapter 6 for more information on last days and hours.

# Caring in the Last Days and Hours

Chapter 1 of *Integrating a Palliative Approach: Essentials for Personal Support Workers* is about preparing yourself to provide care. In Chapter 2, four common patterns, or trajectories, of dying and some of the challenges associated with each of those patterns are described. Chapter 3 is about the principles of hospice palliative care (HPC) and the concept of integrating a palliative approach into care as a way to address the needs of the dying person and their family. Chapter 4 discusses a few tools to help you provide excellent physical care, describes the common symptoms that dying people experience, identifies questions that you can adapt to help you gather information to use in assessing how best to care, and provides information about many measures you can use to provide comfort to dying people. Psychosocial issues and strategies for providing support are discussed in Chapter 5.

This chapter is the last in this book that discusses care of the dying person and their family, specifically in the last days and hours of the person's life. The focus in this chapter is on preparing the family to provide care (depending on their ability and willingness to do so), the physical changes that occur in the dying person, ways to support the person and their family, and care of the body after death and care of the family. What to do when death is sudden, and the emerging home funeral movement, are also discussed briefly.





# Physical Changes and Psychosocial Implications

Dying people experience some or all of these changes, in their own unique order and timing

Physical changes often occur during the last days and hours when a person is actively dying. Not all dying people experience every change, nor do they experience the changes in the order listed below. Anticipating the changes will validate what the family is seeing and will help the family participate in providing care.

It is helpful if you, as a PSW, understand the physical changes the dying person undergoes, as well as the emotional consequences for the family.

The following sections about these common changes during the last days and hours suggest ways that, together with those discussed in Chapter 4, will help you support the person and their family.

## **Common Physical Changes during the Last Days and Hours**

Decreased physical strength and increased drowsiness

Reduced intake and difficulty swallowing

Delirium or confusion

Agitation and/or restlessness

Unresponsiveness

Irregular breathing

Congested breathing

Changes in skin colour and temperature

Muscle twitching

Dry eyes

Lack of urinary output and/or bowel and bladder incontinence

# 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.<sup>1</sup>*

There are consequences, both positive and negative, to providing palliative care. 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, 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, but you need to care for yourself as well as you care for others. You need to develop strong social support networks, and learn and grow through education, supervision, counselling, and coaching. Simple self-care strategies will help you refuel. When you are fatigued (and you will be), step back, reflect, shake things up a bit, and get some extra support.

Care for yourself so that you can provide care for the dying

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1 N.R. Remen, *Kitchen Table Wisdom: Stories That Heal* (New York: Putnam, 1997), 52.