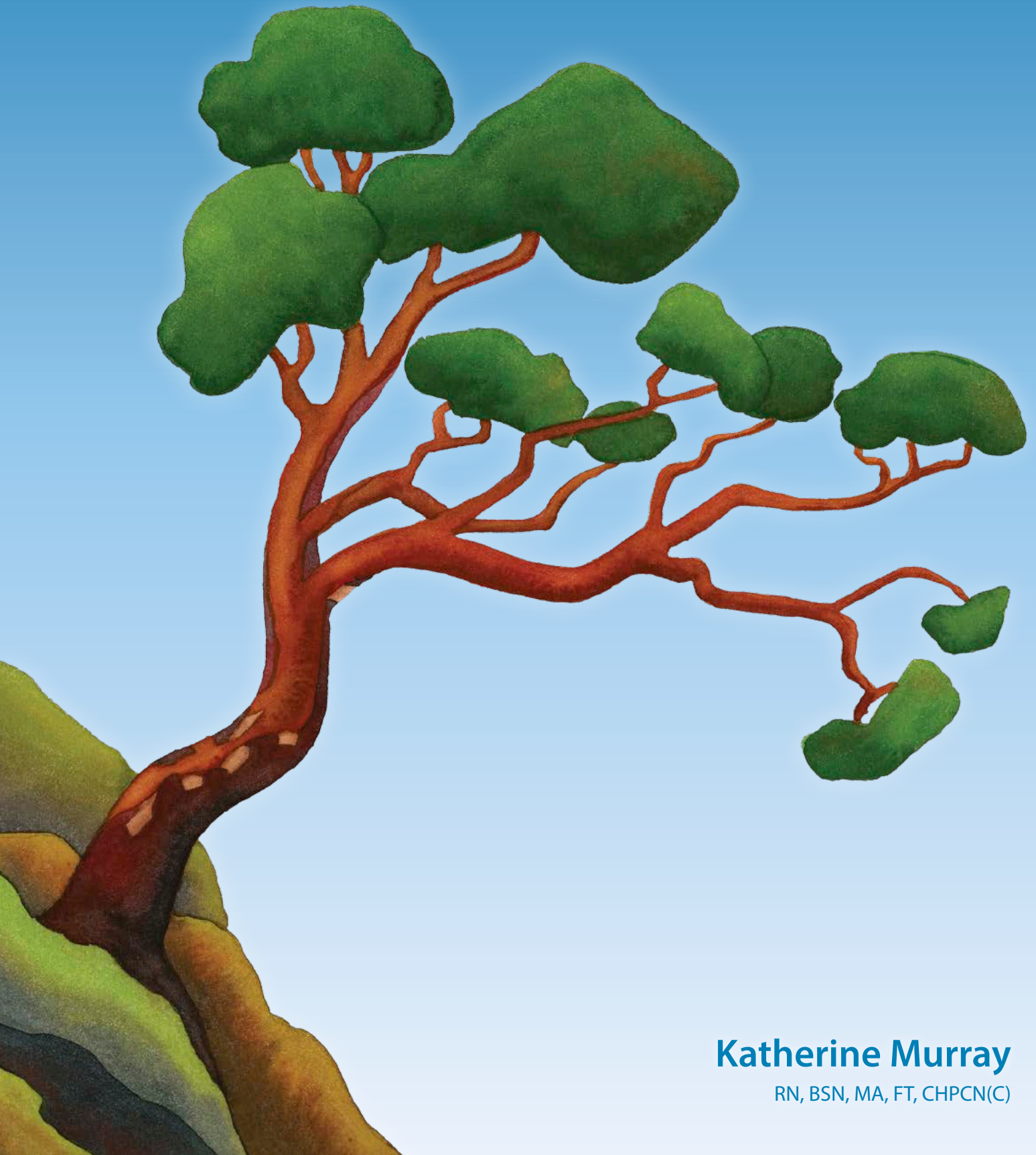


Essentials in Hospice and Palliative Care: A RESOURCE FOR NURSING ASSISTANTS



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Preparing to Care

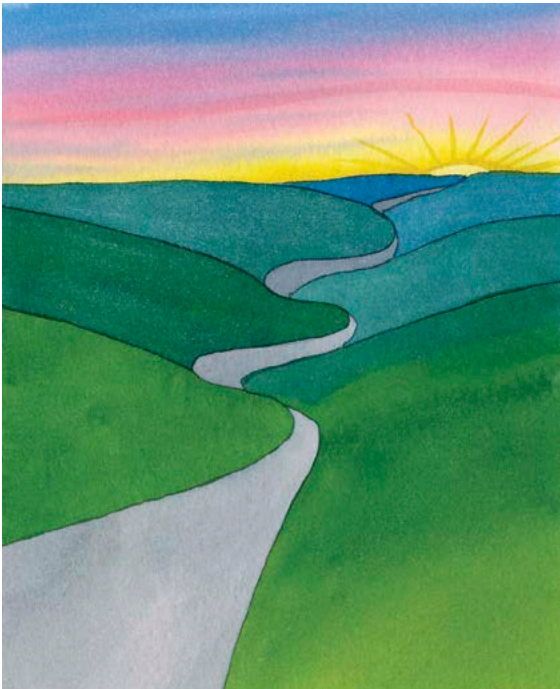
Life Is a Journey

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.¹

Journey of the dying

As a nursing assistant (NA), 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 NA. 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.*

¹ 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, honored 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 and Palliative Care

Dr. Balfour Mount, a Canadian physician from Quebec, studied in England with Cicely Saunders so that he could better understand the needs of dying people in his hospital. 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"

Saunders introduced the idea of specialized care for the dying to the United States during a 1963 visit to Yale University. Her lecture, given to medical students, nurses, social workers, and chaplains about the concept of holistic hospice care, included photos of terminally ill cancer patients and their families, showing the dramatic differences before and after the symptom control care. This lecture launched the following chain of events, which resulted in the development of hospice care as we know it today.¹

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

¹ National Hospice and Palliative Care Organization website content reproduced here on pages 25 to 31, with permission, John Mastrojohn, chief operating officer, NHPCO, <http://www.nhpco.org>.

In the United States, both the terms “hospice” and “palliative care” describe types of care available for people with serious, advanced illnesses.

Palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering that occurs with dying. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice.

The following features characterize palliative care philosophy and delivery:

- Care is provided and services are coordinated by an interdisciplinary team.
- Patients, families, palliative and non-palliative health care providers collaborate and communicate about care needs.
- Services are available concurrently with or independent of curative or life-prolonging care.
- Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death.

Community-based palliative care includes a variety of models of care designed to meet the needs of seriously ill individuals and their families, is differentiated by the setting of care which is typically delivered outside of the hospital setting.



Hospice care is considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury. Hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well. At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.

Hospice focuses on caring, not curing and in most cases care is provided in the patient's home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.

Typically, a family member serves as the primary caregiver and, when appropriate, helps make decisions for the terminally ill individual. Members of the hospice staff make regular visits to assess the patient and provide additional care or other services. Hospice staff is on-call 24 hours a day, seven days a week.

The hospice team develops a care plan that meets each patient's individual needs for pain management and symptom control. This interdisciplinary team usually consists of the patient's personal physician, hospice physician (or medical director), nurses, home health aides, social workers, clergy or other counselors, trained volunteers; and speech, physical, and occupational therapists, as needed. The interdisciplinary hospice team meets many needs, specifically:

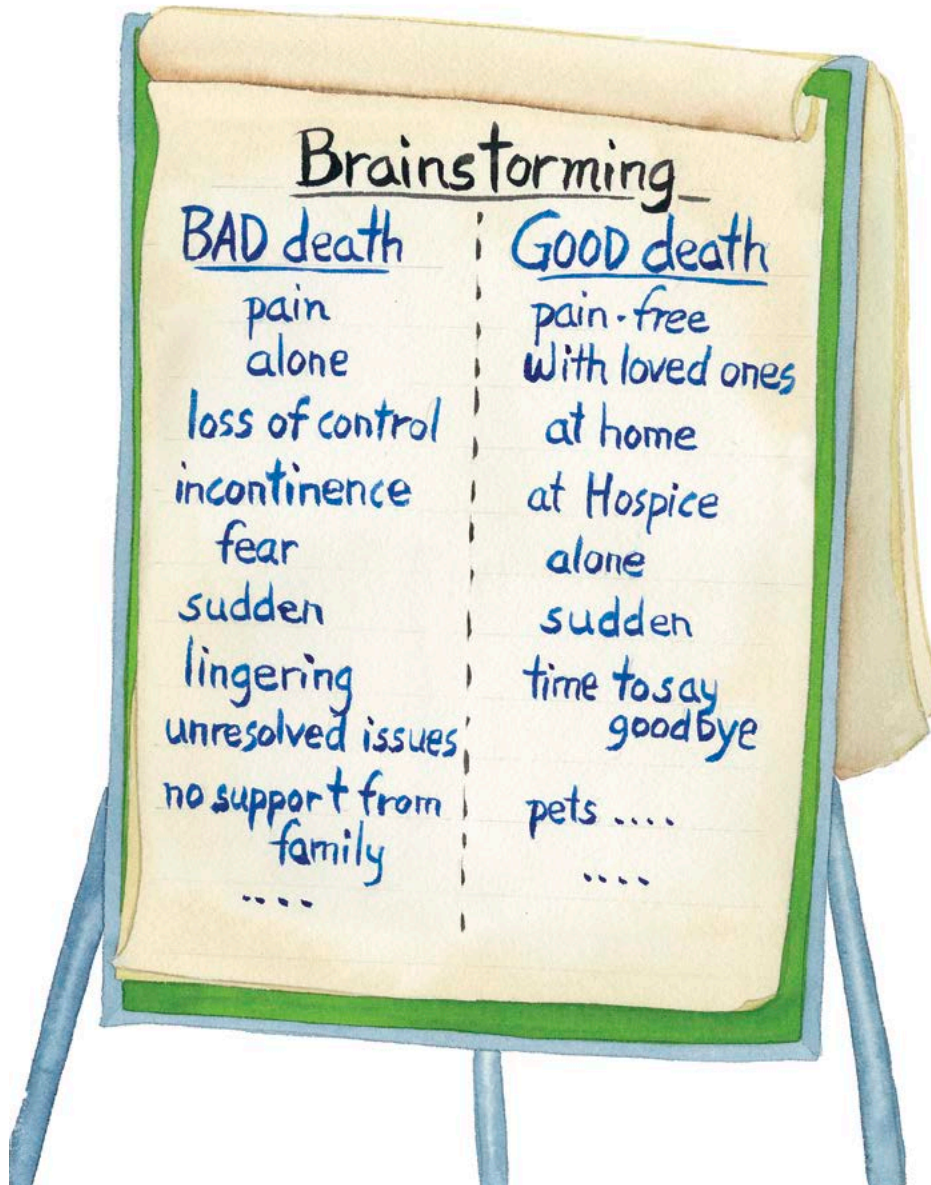
- Managing the patient's pain and symptoms
- Assisting the patient with the emotional, psychosocial and spiritual aspects of dying
- Providing necessary medications, medical supplies, and equipment
- Coaching the family on how to care for the patient
- Delivering special services when needed, e.g. speech therapy, physical therapy
- Providing short-term inpatient care when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time, and
- Providing bereavement care and counseling to surviving family and friends



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 NAs’ 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

NAs provide physical and psychosocial support

In the previous pages, I have presented hospice and palliative care as a resource designed to more fully meet the needs of the dying person and their family. The goal of hospice and palliative care is to improve the quality of life—the quality of the living and of the dying—for the dying person and the family. NAs provide physical and psychosocial supports. 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!

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 NAs 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

Tools for Gathering Information

Can you look after Mr. K.? He was 60% last week, 40% yesterday, and is 20% today. The family is blown away and needs support.

You may not understand what this statement means ... unless you speak the language of the Victoria Hospice Palliative Performance Scale (PPS).¹ You will be using the PPS and the List of Sample Questions² to gather and share information about the dying person’s needs. The List of Sample Questions is adapted from a tool specifically designed to support the gathering of information required for effective symptom management. Understanding the terminology and tools used in hospice and palliative care will help you communicate more clearly and easily. As you become more comfortable with the List of Sample Questions, you will be able to adapt the questions to gather important information about any symptom. When you provide

Gather information with the PPS and List of Sample Questions

1 Victoria Hospice, Palliative Performance Scale, see Appendix C.

2 The List of Sample Questions is adapted from Fraser Health’s Symptom Assessment Acronym—OPQRSTUV—which prompts the user to ask comprehensive questions that will help the user to complete a thorough assessment and thus improve symptom management. To simplify the list of questions and make it more accessible for NAs, the acronym is not provided in this text but is available from http://www.fraserhealth.ca/media/SymptomAssessmentRevised_Sept09.pdf.

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



When a person cannot manage their own mouth care, you can use these strategies:

- Moisten their mouth mucosa gently using packaged or homemade mouth swabs.
- Offer these liquids to rinse their mouth:
 - Water
 - Salt water (1 teaspoon table salt mixed into 2 cups boiled and cooled water)
 - Alcohol-free germicidal mouthwash diluted to half strength with water
 - Club soda to loosen materials on mucosa and teeth
- Apply lubricant to the oral mucosa using a swab, after the mouth has been cleaned and rinsed.
- Apply lip balm after applying the lubricant (use water-based products if the person is receiving oxygen).
- Use a humidifier in the room to moisten the person's dry airways.

Individualize care

For the family

Invite the family to participate in mouth care as one way to support their loved one. Remind them to use gloves if the person has a thrush infection.

Medications and Treatments

Medications may be necessary for pain relief, to prevent or treat infections, and to encourage healing. Topical treatments may be “swish and swallow” or “swish and spit” depending on the medication. Report to the nurse when a person is not able to swallow or spit. Depending on your scope of practice, you may be directed to “paint” medication on with mouth swabs or to squirt medication onto the inner cheeks using a syringe.



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 NAs 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.

Transitions

Supporting through Periods of Decline

Three Victoria Hospice counselors, Moira Cairns, Marnie Thompson, and Wendy Wainwright, wrote a book titled *Transitions in Dying and Bereavement: A Psychosocial Guide for Hospice and Palliative Care*. In it they identify psychosocial issues that commonly occur as a person’s level of functioning decreases, as indicated by a score on the Palliative Performance Scale (PPS) (see page 51). Key times of transition include those of the initial diagnosis and the recurrence or progression of disease, the time when illness dominates, the time when the person becomes totally bed bound, and the period of watching and waiting as death becomes imminent.

- Work with the health care team to identify other people who can provide support to the person and family if they have no one to call at night.

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 Dementia¹

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?

¹ 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 checkbook 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 behaviors.
- 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 *Essentials in Hospice and Palliative Care: A Resource for Nursing Assistants* 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 and palliative care 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

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 an NA, 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.

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

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 color 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.¹

There are consequences, both positive and negative, to providing hospice and 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, counseling, 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

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