

HOSPICE FOUNDATION OF AMERICA

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# A CAREGIVER'S GUIDE to the Dying Process



*“Dying is not primarily a medical condition,  
but a personally experienced, lived condition.”*

— WILLIAM BARTHOLME, M. D. 1997, Kansas City  
*Died of Cancer of the esophagus, 2001*

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## INTRODUCTION



## A Caregiver's Guide to the Dying Process

*A Caregiver's Guide to the Dying Process* is intended for anyone who is caring for a person near the end of life. Our goal is to help make your experience as meaningful and manageable as possible. Many who are caring for a terminally ill person have never done so before. You may feel frightened, confused, and overwhelmed. It is hard to know and accept that someone we care for is near the end of life. Caregiving is difficult, but it can also be rewarding. Caregivers tell us that they are both exhausted and uplifted by the task of caring for someone near the end of life, and when it is over, most of them say they are grateful they could do it.

### Topics Covered in This Booklet

- ▶ Descriptions of the physical, emotional and spiritual changes occurring near the end of life, to help you understand what is happening;
- ▶ Suggestions for what you, as the caregiver, can do to ease physical and emotional distress and make the dying person as comfortable as possible;
- ▶ Information to help you, as the caregiver, communicate effectively with doctors, nurses and other healthcare professionals; and
- ▶ Reflections on how you might feel as the caregiver for someone who is dying and ideas for how to care for yourself.

For each person and each caregiver, the path through end of life to death is different. With this booklet, Hospice Foundation of America hopes to provide you, the caregiver, with knowledge and understanding to guide you through caring for your terminally ill loved one.

The booklet is divided into 6 sections. In the first section, we provide an overview of the physical, emotional, psychological and spiritual changes that are often seen in the last months or year of life. We also describe common changes in the final days and hours prior to death.

In the second section, we discuss what you, the caregiver, can do to ease physical and emotional discomfort. In addition, we offer suggestions for how you can communicate effectively with health care professionals.

In the third section, we introduce ideas about the changing goals of care as a person approaches the end of life. We also discuss some of the difficult health care decisions that arise and offer information that may help you think through these issues.

In the fourth section, we provide more detail on specific symptoms — physical and emotional — common near the end of life. We describe each symptom and common treatments, and suggest when you may want to call on professionals to help.

The fifth section is about you, the caregiver. We discuss what you may experience as your loved one approaches death, and suggest ways to take care of yourself.

In the sixth and last section, we list resources such as books and websites where you can find additional information.

## SECTION 1:



## What to Expect When Someone is Dying

As you care for a dying loved one, understanding the physical and emotional changes that occur during illness and death will help you provide meaningful and effective support. In this section, we present a general description of what you might expect to happen physically and emotionally. For more detailed information about specific symptoms and how they can be managed, turn to Section 4.

### The last months of life

In the last 6 to 12 months before death, people with a progressive, debilitating disease commonly experience certain physical symptoms. Many people, as they approach the end of life, will become less active and experience chronic fatigue or weakness. Weight loss and diminished appetite are also common. Many people experience increasing pain which may be diffuse or in specific areas. Other common physical symptoms include shortness of breath, even though they are moving little, or tingling in the hands and feet usually due to disordered nerve function. All of these together generate increasing physical discomfort.

If your loved one has an advanced disease, these and other physical symptoms specific to the illness may be pronounced. In addition, skin may become thin and begin to break down, causing irritation or open sores. “Bed sores” may form when the person sits or lies down most of the day without changing position. As time goes by, many people lose the ability to control their bladder or bowels. This is often distressing for both the dying person and the caregiver.

In the final 6 to 12 months of life, people often go through emotional changes as well. Caregivers who understand this can help relieve the worries and stresses of the person who is dying.

As the reality of approaching death sets in, people tend to experience a variety of emotions ranging from anger, anxiety,

or depression to feelings of acceptance and contentment. They may become less interested in the world around them and withdraw into themselves. Sometimes this is due to sadness and a sense of loss, but it may also be a healthy way of preparing to leave their world. Many people fear becoming a burden on loved ones and may feel guilty or resentful. While it is common for people nearing the end of life to be moody, dying may be a time of revelation and profound change.

In addition to physical and emotional changes, many people near the end of life begin thinking about the meaning and purpose of life in general, and of their life in particular. They often think about how they have lived and who they are, resulting in feelings of either contentment or discomfort. For many, there is sense of heightened spirituality. They may feel closer than ever to a “supreme being” or “spiritual power,” or they may feel rejected by this entity. Some people find religious meaning in the physical suffering that can accompany dying and may feel that suffering on earth is rewarded in the afterlife.

### The final days and hours

All dying experiences are unique and influenced by many factors, such as the particular illness and the types of medications being taken, but there are some physical changes that are fairly common. For some, this process may take weeks; for others, only a few days or hours.

For most dying persons, activity decreases significantly in the final days and hours of life. They speak and move less and may not respond to questions or show little interest in their surroundings. They have little, if any, desire to eat or drink.

As you hold their hand, you may notice that they feel cold. When a person is dying his or her body temperature can go down by a degree or more. Blood pressure will also gradually lower and blood flow to the hands and feet will decrease.

When a person is just hours from death, breathing often changes from a normal rate and rhythm to a new pattern of several rapid breaths followed by a period of no breathing. This is known as “Cheyne-Stokes” breathing — named for the person who first described it. Coughing can also be common as the body’s fluids begin to build up in the pharynx. Fluid that accumulates in the pharynx also causes “rales” and “rattles.” This breathing sound is often distressing to caregivers, but it is not an indication of pain or suffering. The secretions that cause these sounds can be dried up with a medication called atropine, typically administered orally, or with a small dose of liquid morphine. The oral administration of a small amount of a common eye drop solution usually prescribed to reduce the amount of tears can also help reduce the amount of fluid buildup. On the other hand, when secretions are thick or dry, running a vaporizer in the room can ease breathing.

As death approaches, skin color is likely to change from its normal tone to a duller, darker hue. The fingernail beds may also become bluish rather than their normal hue.

Because the central nervous system is directly impacted by the dying process, your loved one may sometimes be fully awake and other times not responsive. Often before death, people will lapse into a coma. A coma is a deep state of unconsciousness from which a person cannot be aroused. Persons in a coma may still hear what is said even when they no longer respond. They may also feel something that could cause them pain, but not respond outwardly. Caregivers, family, and physicians should always act as if the dying person is aware of what is going on and is able to hear and understand voices. In fact, hearing is one of the last senses to lapse before death.

It is not unusual for dying persons to experience sensory changes. Sometimes they misperceive a sound or get confused about some physical object in the room. They might hear the wind blow but think someone is crying or see a lamp in the corner and think that someone is standing there. These types of misperceptions are called illusions. They are misunderstandings about something that is actually in their surroundings.

Another type of misperception is hallucination. Dying persons may hear voices that you cannot hear, see things that you cannot see, or feel things that you are unable to touch or feel. They may also have visions of deceased relatives, which may be haunting to the dying person or to you the caregiver, but it is a common occurrence.

Some dying persons confuse reality and might think that others are trying to hurt them or cause them harm. Or, they can come to believe that they are much more powerful than they really are and think that they can accomplish things that are not possible. These types of misconceptions are called delusions of persecution and delusions of grandeur.

If you want more information about the sequence of events leading up to the moment of death, we suggest the book *How We Die* by Sherwin Nuland, M.D. (New York: Knopf, 1993.)

## SECTION 2:



## What Can You Do?

Because family members and other caregivers may not feel prepared to handle the events and changes that occur near life’s end, we offer the following suggestions from hospice physicians, nurses, social workers, chaplains and aides with many years of experience caring for dying people. In most cases, health care professionals will be responsible for treating the physical symptoms associated with serious illness toward the end of life. (In Section 4, we will explain the treatments for common symptoms.) But you, the caregiver, will be complementing the care of professionals with personal attention and support.

### General types of support provided by caregivers

- ▶ Talking and listening
- ▶ Assistance with eating and drinking
- ▶ Communicating with physicians and other health care professionals

In this section, we focus not on specific symptoms, but rather on general types of support that tend to fall on you, the non-professional caregiver. We are not suggesting that this is all that can be done, or that all of our suggestions are appropriate in your particular case. Every situation is different and we can only offer advice based on collective experience. We hope the ideas presented here from experienced caregivers will help you think about how you can best care for your loved one.

### Talking and listening

As the end of life approaches, you can assure your loved one that they will be cared for and will not be abandoned. You can provide them with the opportunity to talk about their wishes and concerns or their reflections on the illness

and what it means to have only a short time to live. Just talking about what they are thinking, feeling, and needing can be very comforting. Dying people oftentimes want to tell their story, to remind themselves and others of who they are and what they value in their life. They may need time to reflect on and to grieve past and present losses as well as explore their mortality and spirituality.

You can talk with them about how they want to be cared for when the end is near. Some people will want to stay at home and “die in their own bed;” others will want to be in a hospital or other health care facility where health care professionals are at hand. They may want to have all the family close by, or they may prefer to be with just one or two people. They may want to hear soothing music or have favorite photos or mementos close by. Or, they may not have any specific preferences.

You can make sure that documents like a power of attorney for health care, a health care surrogate designation, and/or a living will are completed and available to health care providers. Perhaps one of the most meaningful advance directives is called “5 Wishes,” which is completed by the dying person and then given to the physician or team of health care providers. Additionally, something known as a POLST or Physicians Orders for Life Sustaining Treatment is a growing trend. This document is typically discussed and signed by both the patient and physician; however it is not yet legally binding in all 50 states. These procedures assure that end-of-life wishes are documented so they can be carried out.

You can offer to contact people they care about so that they can say goodbye. Spending time with selected family and friends may be some of the most valued moments as death approaches. Ira Byock, MD, in his book *The Four Things that Matter Most* (New York: Free Press, 2004) offers stories about the role of interpersonal relationships

near the end of life. In his work with the dying, he has learned that most people want the chance to say one or more of four things to people who have been important to them: “Please forgive me,” “I forgive you,” “Thank you,” and “I love you.” In some cases, people near the end of life also need to express dissatisfaction, anger, or resentment in order to feel at peace.

As death approaches, you can help your loved one to attend to unfinished business and take care of financial responsibilities. It is important to many dying persons to decide who will receive their personal possessions, and they may want to create or update their will. You can ask them about their preferences for funeral arrangements and talk to them about their concerns regarding the loved ones they are leaving behind. When young children are surviving the dying person, they need particular attention. It may be best to speak with a professional, such as a social worker, psychologist, child life specialist or art therapist, who knows how to talk with children at different ages about death and dying. And, you may want to speak with financial consultants who can help set up trusts to assure that young children are protected financially.

## Eating and drinking

You may be wondering why there is a section on food and drink in this booklet. Eating and drinking are important parts of most cultures and are a way we relate to each other, particularly within families. One of the most important ways we care for each other is through offering food and drink.

As mentioned earlier, people who are in the last year of life often lose their appetite; food stops tasting good and they do not want to eat. Sometimes they can be tempted with favorite foods, or what we call “comfort foods.” But at some point they will simply not be able to eat. This is hard on caregivers who want to provide nourishment, and who may feel that their loved one would live longer if only they would eat more.

When appetite begins to fail, you as the caregiver can and should offer a variety of foods. Talk to your loved one about what they think would taste good and let them

know it is acceptable not to have a full meal. They may not want “usual foods” at “usual times.” Ask the doctor if there are any foods that should be avoided. For those who have been on restricted diets, ask the doctor if they can now have favorite foods. Foods previously avoided for health reasons may now be acceptable and could improve an otherwise declining outlook. Offer small portions and do not force them to eat. Make sure water or other drinks are available and remind them to drink, as they may not feel thirsty. Dry mouth is uncomfortable but can be counteracted by applying sponges dipped in the patient’s favorite liquid. Remember that there are many ways to show you care that do not involve food and drink.

Sometimes, people with serious life-threatening illness will make a specific choice to stop eating or drinking; this is different from the natural decrease in appetite discussed above. If this happens, you will want to consult a physician who may suggest counseling. It is important to be sure that any decisions made are well-considered and not the result of treatable depression or anxiety. (More information on these symptoms appears in Section 4.)

## Communicating with doctors, nurses and other professionals

In your role as caregiver, you may be dealing with physicians and nurses on behalf of another adult for the first time. And you may be the only person, other than your loved one, who knows all of the different health care professionals who are providing care. You can help by making sure that all of the doctors and nurses know what your loved one wants and that they know which other health care providers are involved.

Different people want and need different levels of information from health care professionals and everyone deserves to receive information in ways they can understand. Tell the doctors and nurses how much you want to know and ask for further information if you do not understand what they tell you. Take notes or ask them to write things down for you so you can remember them and review them at any time.

Make sure that the doctors and nurses know how involved you and your loved one want to be in making treatment

decisions. Most people want to discuss all the options with the doctor or nurse and then make a decision that all can agree on; but some people want the doctor to decide what is best.

Although doctors and nurses have medical knowledge that you as a non-professional do not have, you and your loved

one are the experts on your needs and preferences. You can work as an effective team with health care professionals to assure that your loved one receives treatment that relieves symptoms, helps maintain dignity and quality of life, and honors his or her goals of care.

## SECTION 3:



## Goals of Care and Facing Tough Decisions

### Difficult decisions near the end of life

- ▶ Artificial nutrition and hydration – Whether or not to have tube feeding and/or intravenous fluids
- ▶ Cardiopulmonary resuscitation – Whether or not to restart the heart if it stops beating
- ▶ Mechanical ventilation (Intubation) – Whether or not to use machine to breathe for a person whose lungs have stopped working
- ▶ Stopping treatment aimed at curing the disease

### Goals of care

When health first begins to fail, because of a specific illness or generalized decline, most people hope for a cure. They hope to be returned to better health and freedom from illness. But even as that hope fades, there is much to hope for. People can hope and expect to have their pain and discomfort acknowledged and treated effectively. They can hope for and expect to be involved in activities they enjoy, though perhaps in different ways. And people have the right to hope for a miracle and to seek aggressive treatment that others may think is futile.

For most people, the goals of care will shift as patients decline or as illness progresses and cure seems less likely. Although efforts to modify and treat the disease may continue, the primary focus will be on maintaining comfort, supporting as much physical functioning as possible, and maintaining quality of life.

### Health Care decision making

Four of the most common but distressing health care decisions near the end of life are: whether to provide tube feeding; whether to use electric shock and/or CPR (cardiopulmonary resuscitation) to restart a heart that has stopped working; whether to use a machine to breathe for someone whose lungs have stopped working; and whether to stop treatments aimed at curing disease.

The decision to forego life support is a very personal one. It is frequently influenced by cultural and religious beliefs. Hopefully, you and your loved one can talk about these issues in advance of the need for any of these types of artificial support. In this section, we will describe these procedures and some of the pros and cons of each, to help you make informed decisions.

### Tube feeding and intravenous or subcutaneous fluids

One difficult decision you may confront as a caregiver is whether to provide your loved one with artificial nutrition (tube feeding), or liquids delivered via a needle into the bloodstream (intravenous or subcutaneous fluids.) Artificial nutrition and hydration may supplement or replace ordinary eating and drinking by giving a chemically balanced mix of nutrients and fluids through a tube placed directly into the stomach, the upper intestine, or a vein. Short-term artificial nutrition and hydration can save lives in cases where a person has a curable illness, has suffered an accident, or is recovering from surgery and needs help to take in nutrition until the body heals. Long-term artificial nutrition and hydration may be given to people with serious intestinal disorders that impair their ability to digest food, thereby helping them to enjoy a quality of life that is important to them.

The use of tube feeding has pros and cons, however, when used for people with end-stage conditions. Nutritional treatment may help to keep up energy levels if the person otherwise is feeling well or wants to be able to participate in a specific event — like a wedding or a holiday celebration. But nutritional treatment will not reverse the course of the disease itself. For individuals who have trouble swallowing, as often happens with Alzheimer’s disease or other dementias, tube feeding may increase the risk of pneumonia because the liquid food may unintentionally get into the lungs.

Similarly, artificial hydration has pros and cons. For people who cannot swallow or who cannot “keep anything down,” but have otherwise good organ function, intravenous delivery of fluids can be essential to maintaining the function of the brain and other critical organs. But for people whose organs are not functioning well, particularly those who are having heart, lung and/or kidney problems, delivery of intravenous liquids can put more strain on these organs causing even more difficulty.

You may be worried that not eating or drinking would cause discomfort, but studies show that for persons in the final phase of illness, going without food and fluids is not painful. The fact is that people at the end of life who have

stopped eating and drinking naturally, or by choice, do not complain of thirst or hunger. In fact, there is a side effect of going without food and fluids in which metabolism changes produce a mild sense of euphoria and calm.

For people who are not eating or drinking, it is standard care to apply moisture in some form to the lips and mouth regardless of whether or not the dying person is ever able to swallow again. You can use a moistened cloth or swab. In fact, application of moisture to the lips is comforting even for people who are able to drink fluids.

Some religious traditions require that people not be denied food and drink, so artificial nutrition and hydration may be important from a religious perspective for your loved one or for you. A decision to start or stop tube feeding or intravenous fluids should be discussed with your loved one whenever possible, so that their wishes can be expressed and honored. The decision should also be discussed with family and health care professionals so that you can be as comfortable as possible with the decision. The patient’s goals of care should come first in all discussions on the benefits and burdens of tube feeding.

### Cardiopulmonary resuscitation

Cardiopulmonary resuscitation (CPR) is a group of treatments used when someone’s heart and/or breathing stops. CPR is used in an attempt to restart the heart and breathing. It may consist only of mouth-to-mouth breathing or it can include pressing hard on the chest to massage the heart muscle and cause blood to circulate. Electric shock and drugs are also used frequently to stimulate the heart. Most people have seen some form of cardiopulmonary resuscitation acted out on television or in movies.

The fact is that CPR can be successful for healthy people whose heart and lungs have stopped due to a severe injury or other trauma. These are people whose heart and lungs are not damaged by illness or old age. But the success rate for CPR when used for people who are at the end of a terminal disease is extremely low. In these cases, the heart and lungs usually stop because of irreversible progression of the disease. Even though the heart can possibly be restarted, it is likely to fail again soon. Another thing to consider is that the CPR process, which includes strong

compression of the chest, can be painful and may damage fragile bones and internal organs.

The decision to allow CPR should follow a thorough discussion of the patient’s goals. If you and your loved one decide that you do not want CPR, it is important to let the doctor and other health care professionals know about this choice. This information is usually included in a living will or other advance directive document, but even if the documents are completed, it is important to talk to health care providers about this and other decisions and choices.

If your loved one is in the hospital and does not wish to receive CPR, the doctor must write a “do-not-resuscitate order,” called a DNR. In many states, the doctor can also write this order for a person being cared for at home or in a nursing home, and it will be honored by paramedics or other emergency medical personnel. Ask your doctor how to be sure that your loved one’s wishes will be honored.

### Mechanical ventilation

Mechanical ventilation is used to support or replace the function of the lungs. A machine called a ventilator (or respirator) forces air into the lungs. The ventilator is attached to a tube inserted in the nose or mouth and down into the windpipe (or trachea). For many people, mechanical ventilation can be life restoring. It is very successful when used to assist a person through a short-term health problem. It is also useful for prolonged periods for people with irreversible respiratory failure due to a progressive neurological disease or injuries to the upper spinal cord.

For the dying person, however, mechanical ventilation often merely prolongs the dying process until some other body system fails. It may supply oxygen, but it cannot improve the underlying condition. Important questions to ask if mechanical ventilation is suggested include:

- ▶ How long will your loved one be connected to the ventilator?
- ▶ Is this a temporary measure to allow the lungs or other organs to heal?
- ▶ What is this experience like?

- ▶ How likely is it that your loved one will ever regain the ability to breathe on his or her own and return to an acceptable quality of life?

If possible, you and your loved one will want to talk about your preferences for or against mechanical ventilation before the decision has to be made. As with CPR, if you and your loved one decide not to have mechanical ventilation, you can ask the doctor to write a “do not intubate” order. Whatever you decide, be sure to share the information with all of the health care providers serving your loved one.

### Stopping treatment aimed at curing the disease

It is always hard to accept the idea that someone we love will die, or that we ourselves will die. For people with advanced, progressive illness, there often comes a time when physicians will say that a cure is not possible and that there is no more curative treatment they can provide. This is usually the point at which both the sick person and the family begin to understand that the end of life is inevitable. But for many illnesses, the point at which further curative treatment becomes futile is harder to identify. There may be experimental treatments available, which cannot promise to cure, but provide hope of some positive effect. And for many people, there is always hope for a miracle that will allow life to continue.

There may come a point when you and your loved one question whether it is worth continuing treatments that are aimed at curing the disease. Aggressive curative treatment can have distressing side effects, and may come to feel like a burden rather than a gift. The decision to stop potentially curative treatment is very personal, and it is important to have clear information about the potential benefits and burdens of continued treatment. The decision will likely be influenced by personal values as well as cultural and religious factors, but one should also consider the existing burdens of the illness.

If the decision is made to discontinue efforts to modify and treat the disease, you and your loved one may want to consider hospice care, a philosophy and system of care that uses a team of health and social service professionals to care for individuals. Hospice defines the patient and

## Palliative Care and Hospice

- ▶ Aim to help your loved one live as well as possible for as long as possible
- ▶ Involves a team of professionals to address physical, psychosocial and spiritual distress
- ▶ Experts address symptom management, coordination of care, communication and decision-making, clarification of goals of care, and quality of life
- ▶ Focuses on both the dying person and their entire family

family as the “care unit” and has the goal of relieving a patient’s pain and symptoms through palliative care. The word palliate comes from a Latin word meaning to cloak or conceal — and palliative care aims to lessen pain, discomfort and suffering. Hospice care embraces the goals of palliative care and can be provided in a variety of settings. Given the choice, the majority of people would prefer to spend their last weeks and months at home. Hospice is one form of palliative care that is provided across multiple settings. A hospice team can care for you and your loved one at home, the hospital, a nursing home, or another long term care facility. In some cases, hospice care is provided at a freestanding inpatient hospice facility. Hospice staffers are experts in palliative care, and the goal of hospice care is to support the dying person and their family to maintain the highest possible quality of life, however the dying person defines it throughout the course of the illness. Hospice care does not seek to lengthen life or hasten death. If possible, your loved one should be involved in the decision whether or not to seek hospice care.

The patient, family and/or physician can initiate an information/referral call to a hospice provider as soon as a terminal disease is diagnosed, or at the same time a patient decides to move from a treatment plan focused on curing the disease to a plan focused solely on providing comfort and pain relief. A hospice will develop a “plan of care” for each individual patient. The plan of care provides

the hospice staff, the patient, and the family with details about what services and support visits (physician, nurse, social worker, aide, counselor, spiritual care, and volunteer) to expect, in addition to what medications, therapies, supplies and equipment will be used. It also outlines what training the patient and family can expect from hospice staff and how the family will participate in care. Following a death, hospices provide bereavement support to families for 13 months.

Medicare has a hospice benefit for patients with a prognosis of 6 months or less if the disease runs its normal course. The Medicare benefit is covered for longer than 6 months if the patient is re-certified by a physician as being terminally ill. The benefit covers services, medications, and equipment related to the terminal illness. Most private insurers also provide a hospice benefit, and Medicaid covers hospice care for eligible persons in most states. Hospices must be certified to provide services under the Medicare or Medicaid benefit.

Whether or not you and your loved one decide to continue curative treatment, you will want to consider seeking some form of palliative care, which can be provided without forgoing curative treatment or electing hospice care. The goal of palliative care is to help your loved one live as well as possible for as long as possible. More and more hospitals and home care providers have palliative care professionals on staff who are experts at pain and symptom management, coordination of care, discussion of treatment options and choices, as well as patient and family support. Some hospices also provide bridge programs, providing palliative care to patients who are still receiving treatment for their disease. Some of these patients will choose hospice care later, and some will not. Each person and family knows what is best for them. No matter what illness your loved one suffers from, you will want to have the right specialists treating him or her; that includes the right cardiologist (heart problems), oncologist (cancer), pulmonologist (lung problems) or other curative specialist AND a good palliative care team.

## SECTION 4:



## Spiritual and Existential Concerns

Although every dying experience is unique, there are several common physical, spiritual, and emotional symptoms. In this section, we will describe these symptoms and provide suggestions for managing them.

The most important thing to be said about end-of-life symptoms is that almost all of them can be managed. This does not mean that they can be eliminated, but skillful use of medications and alternative treatments like hot or cold compresses, massage, and complementary therapies usually provide considerable comfort. The key is to make sure that health care providers know what symptoms are causing discomfort. Do not assume that nothing can be done if initial treatments are not working. There is always something that can be done. Ask professionals to try something else.

For some people, suffering is expected and some may feel it is deserved. For others, it is an important feature of their culture or religion. It is important to respect these beliefs while offering assurance that help is available if they want it.

### Common symptoms at the end of life

- ▶ Pain
- ▶ Shortness of breath (dyspnea)
- ▶ Nausea and vomiting
- ▶ Bowel and bladder problems
- ▶ Anxiety
- ▶ Depression
- ▶ Anger
- ▶ Spiritual/existential concerns

Below we discuss 8 of the most common symptoms. But there are many other symptoms experienced at end of life, and all of them can be managed in one way or another.

### Pain

**Definition and description:** Many dying people experience chronic pain as a result of their disease or as a side effect of their treatment. Chronic pain is very different from acute pain.

Acute pain is due to a temporary condition, like cuts and bruises, surgery, or a broken bone. Once the condition heals, the pain will lessen and go away. It is effective to treat acute pain when it occurs, and when the pain goes away, the pain treatment can stop. Medications for acute pain may be prescribed “prn” meaning that they are to be taken as needed, when a person feels some pain.

Chronic pain is caused by physical changes such as bone, nerve and muscle degeneration. The changes may occur because of disease or as a side effect of some treatments for the disease. Because the changes are irreversible, the pain will not go away and it must be aggressively managed all the time so that your loved one feels as little discomfort as possible. Medications for chronic pain should be taken on a regular schedule, and the dose is usually timed to be taken before any pain is felt. Once the pain is under control, it is important to keep taking the pain medication on time so that the pain does not get of control.

Pain can have both physical and emotional components and can be complicated to manage. There are many ways to treat chronic pain and often it will take a mixture of these techniques to effectively manage the pain.

The experience of pain is different for each person. An important lesson is: “Pain is what the person who has it says it is.” The same disease or treatment might cause



severe pain for one person and only mild pain for another. Factors that affect the personal experience of pain include the location of the pain, the severity of the pain, whether it is constant or comes and goes, and whether it is a stabbing, burning, or aching sensation. A good way to begin to understand someone's pain is to ask them to rate the severity of the pain from 0, meaning no pain at all, to 10, meaning the worst pain imaginable. You may want to keep a "pain diary" where you record the pain rating for your loved one at different times of the day. This information can be very helpful to the doctor who is prescribing pain treatments.

#### PAIN SEVERITY SCALE

0	1 2 3	4 5 6	7 8 9 10
No Pain	Mild Pain	Moderate Pain	Severe Pain

Too often, pain is accepted as a consequence of serious illness so it often goes untreated or under-treated. Another problem is that both healthcare professionals and patients are sometimes afraid of pain medications, therefore the dying person does not take enough medication to relieve the pain. Many health care professionals have not been trained well in the use of pain medications. Skillful physicians and nurses can prescribe medications so that the person in pain remains alert, while their pain remains under control. It takes time and it may be necessary to try different types or combinations of medications to manage the pain.

Unmanaged severe pain never occurs alone. It is accompanied by anxiety, fear, difficulty sleeping, reduced appetite, frustration, depression, memories of past pain, anticipation of pain yet to come and, in some instances, thoughts of suicide. When the pain is relieved, these strong emotional reactions go away.

Chronic, unrelieved pain can become the focus of the dying person's experience, making it impossible for them to address important issues of family relationships and life closure. Once pain and other physical symptoms (see below) are effectively managed, dying people can turn to the emotional, interpersonal, religious and spiritual elements of dying.

**Common treatments for pain:** Chronic pain is almost always treated with medications that can be taken orally as long as the person can swallow. All medications that relieve pain are called "analgesics." For mild pain, described as 1 to 3 on the 0 to 10 scale, the doctor may prescribe common over-the-counter analgesics in slightly higher doses. These include ibuprofen (Advil), aspirin, naproxen (Aleve), and acetaminophen (Tylenol). If the pain is not relieved by these medications, or if it is described as moderate (4 to 6), then the doctor may prescribe a medication that includes one of the above plus a stronger medication like codeine. For severe pain (7 to 10), or moderate pain that does not respond to the milder medication, the doctor will probably prescribe a form of an "opioid" analgesic such as morphine.

Opioids are also called narcotic analgesics, although opioid is the more correct name, and many people are scared of taking these drugs. But these fears are unnecessary because opioids are safe and effective when used by trained professionals to treat chronic pain.

Here are some important facts about opioid analgesics used for treating both acute and chronic pain:

- ▶ Opioid analgesics, most commonly morphine, are not used exclusively at the end of life and their use does not signal that the end is near. Many people with chronic pain who are not terminally ill also take opioids to manage pain and live an otherwise normal life — driving, working, shopping, etc. In fact, when used for people with terminal illness, opioids can make them comfortable enough to live more fully and may even prolong life since untreated chronic pain can drain limited energy. Unmanaged (or inadequately managed) severe, chronic pain is a complex problem that needlessly aggravates the symptoms of the underlying disease.
- ▶ It takes a few days for people to get used to opioid medications. Common side effects such as nausea, sleepiness, slower breathing and slight confusion diminish over the first two to three days of taking the medication.
- ▶ Opioids often have a calming, relaxing effect in addition to pain relief. People often sleep after receiving pain relief because they have been sleep-deprived for days or weeks with recurrent episodes of pain. (Such sleeping

people can be roused by calling their name or touching them.) This initial, sleepy side-effect lessens as the body becomes used to the medication, and people on even large doses of narcotics can be clear-headed, aware of all that is happening, and be involved in decisions affecting their care.

- ▶ Opioid analgesics can cause constipation and this side effect does not disappear over time. Anyone taking opioids should also be taking a bowel stimulant and a stool softener. Make sure to ask the doctor about a "bowel regimen" and report any changes in bowel habits to the nurse or doctor.
- ▶ People who need opioids to relieve chronic pain do not become addicted to the medication. They do not experience euphoria or become anti-social. They do experience "tolerance" meaning that their bodies get used to the effects of the drug and after some time, they may need a higher dose of opioid to relieve their pain. If the person is not getting enough medication to manage the pain, he or she is likely to ask for higher doses, or take more than the prescription suggests. This is not a sign of addiction. Once the pain is properly managed, these behaviors stop.
- ▶ Opioids are available in both long-acting and short-acting pills. Usually the doctor will prescribe medication to be taken every 4 to 6 hours. Once the pain is under good

control, the doctor may switch to a longer acting pill taken every 8 to 12 hours, so that doses do not have to be given during the night.

- ▶ In addition to the routine dose of opioid analgesic, the doctor may also prescribe a smaller dose to be taken if the pain recurs before the next regular dose is due. This smaller dose is called the "breakthrough" dose since it is used if the pain "breaks through" the routine dosing. Increased frequent use (greater than 3 times per day) of breakthrough medication is a sign that the routine dose probably needs to be changed.
- ▶ Once the pain is well-controlled, the dose of medication may be reduced as long as the person remains comfortable. Many patients who receive opioids for severe pain have had their dose adjusted down without experiencing any discomfort.

Some types of pain require a combination of medications and treatments before they are relieved. The doctor may prescribe "adjuvant medications," particularly if the pain is due to disordered nerve function (called "neuropathic pain.") Other treatments for pain include chemotherapy, acupuncture, radiation therapy, nerve block, and physical therapies.

Some classic comforting treatments can also help with chronic pain. These include application of cold or heat, gentle massage, and distraction (listening to music, watching a movie, or reading out loud.)

**How you can help with pain management:** The most important thing for you as a caregiver is to listen to your loved one and help them to describe their experience of pain to their doctors and nurses. If he or she cannot speak, there are other ways to recognize pain. For instance, moving away when being touched, moaning, or making faces that clearly show discomfort are signs of pain and should be discussed with health care providers. Talk with the doctor and nurse and ask them to help you put together a combination of treatments best suited for your loved one.

#### When to call for help with pain:

- ▶ a new pain occurs – not the one the person usually has
- ▶ pain continues after you have given three breakthrough doses (see text) in 24 hours or there is a rapid increase in the intensity of the pain
- ▶ there is a sudden acute pain
- ▶ you notice sudden and deep confusion

*This list was adapted from [A Caregiver's Guide](#) by K. Macmillan, J. Peden, J. Hopkinson, and D. Hycha; Canadian Hospice Palliative Care Association; ISBN: 0-9686700-1-6.*

- ▶ Try to understand your loved one's pain. Use the 0 to 10 scale to determine the intensity of the pain. Ask where the pain is and when it is at its worst. Ask your loved one about their desired comfort level.
- ▶ Encourage your loved one to take pain medications as they are prescribed — at the times specified — in order to keep the chronic pain under control. This will usually mean taking some medication in the middle of the night, especially in the beginning, because if any dose is skipped, your loved one is likely to awake in pain.
- ▶ If your loved one always seems to want more or less medication, try to find out why and then discuss this with the nurse or doctor. This usually means they are not getting enough medication to relieve their pain.
- ▶ Be an advocate for your loved one, making sure that the doctor and nurses know what your loved one wants. If the doctor and nurse cannot seem to help, ask to see a pain specialist.
- ▶ If your loved one has a new pain, different from their usual chronic pain, contact the doctor or nurse.

## Shortness of Breath (Dyspnea)

**Definition and description:** Another common symptom that dying persons experience is shortness of breath (also called dyspnea, pronounced “disp-knee-uh”). Dyspnea occurs when the body's tissues cannot get enough oxygen. It may happen because a person cannot take deep breaths or because the lungs and circulation cannot deliver enough oxygen to the body.

People experience dyspnea as a sensation of not being able to catch their breath or not being able to breathe deeply enough. It is frightening for you, the caregiver, and also for your loved one. When the body does not get enough oxygen, the skin around the mouth and fingernails may become blue, and it may become difficult to talk and still take breaths.

**Treatments for dyspnea:** There are 2 basic kinds of treatment for dyspnea. The first is to use oxygen therapy to deliver more oxygen to the body. The doctor will write a prescription that indicates how much oxygen is to be used and how often. The oxygen is typically delivered from a pressurized canister either through a tube inserted into

the nose or via face mask that covers the nose and mouth. If oxygen is used in your home, remember that it is very flammable. Do not allow anyone to smoke or use an open flame near the oxygen.

The other therapy is to use an opioid like morphine. As with pain, the doses of opioid are adjusted carefully to match the patient's symptoms. This treatment is used to reduce the sensation of shortness of breath and to reduce anxiety which may allow for deeper breathing.

Sometimes dyspnea is accompanied by an excess of thick mucus that cannot be coughed up. There are medications that can dry up the mucus. Ask your health care providers what they recommend or would prescribe.

**What you can do about dyspnea:** There are a number of things you can do to ease your loved one's discomfort if they experience shortness of breath. Help them to sit up by using extra pillows or a recliner chair, but make sure they are in a comfortable and relaxed position. Calm surroundings will help reduce anxiety and naturally slow breathing. Make sure that your loved one rests between eating, bathing, dressing and any other activity.

Humidifiers, fans or fresh air can also make breathing easier. Use lightweight blankets and loose clothing so that the person does not feel “smothered.”

If oxygen is prescribed, make sure you know how to use it as prescribed and that there is a back-up supply for weekends or holidays. In many cases, special arrangements can be made with your local power company to add your house to a first-serve list for restoring power.

## Nausea and Vomiting

**Definition and description:** Many illnesses and medications can cause people to feel sick to their stomach or to vomit. Constipation can also cause nausea or vomiting. Dying persons can be particularly challenged by nausea and vomiting because they get weaker as the end of life approaches.

**Common treatments for nausea and vomiting:** There are several very effective medications that can help with nausea and vomiting. Talk to your health care providers about

what would be best for your loved one. Nausea can often be relieved by placing a cool, damp cloth on the forehead or back of the neck.

**What you can do about nausea and vomiting:** To help relieve nausea, eliminate strong smells from the home or area where your loved one is living. Make sure that the temperature is not too warm, and that the room is not stuffy. Let in fresh air or use a fan to move the air around.

If your loved one tends to vomit, make sure they are lying on their side so vomit is less likely to be inhaled and cause choking. Keep a record of how often the person throws up and, if it is frequent (more than twice a day), alert the nurse or doctor. Offer liquids after vomiting has subsided. These may relieve a bad taste in the mouth and also help to avoid dehydration which may occur with frequent vomiting.

Vomiting can be very serious if it is frequent and continuous, if there is blood in the vomited liquid, and/or if the person is not able to drink fluids or eat solid food. If this type of vomiting happens to your loved one, seek professional help immediately.

## Bowel and bladder problems

**Definition and description:** The most common bowel and bladder problems are incontinence, constipation, and diarrhea. Incontinence is a lack of control over the bowels or bladder. Constipation is difficulty in passing feces (stool) and diarrhea is the passage of frequent, loose or watery stools. Constipation itself can cause severe abdominal pain. As unpleasant as these problems are, it is critical that they be discussed and treated because they can cause significant discomfort for someone near the end of life.

**Common treatments for bowel and bladder problems:** The common treatments for bladder incontinence are the use of adult diapers or the use of a catheter. A catheter is a tube inserted into the bladder that collects the urine and drains it into a bag outside the body. These catheters must be inserted by healthcare professionals. Men can also use an external catheter that looks like a condom with a tube that drains from the tip into a collection bag.

The common treatments for constipation are stool softeners and laxatives. Although these are available over the counter, it is important to discuss the use of these medicines with the doctor or nurse. People near the end of life may not be eating or drinking enough to generate typical volumes of feces and the use of strong stimulant laxatives can cause considerable discomfort. In addition, the hard stool may become “impacted” meaning that it is too hard to be passed normally and must be mechanically removed. In that situation, adequate medication is given for comfort prior to removal.

There are many treatments for diarrhea and the right one depends on the cause of the diarrhea. Diarrhea can be caused by an infection, as a side effect of chemotherapy or other medications, or as a consequence of disease. It is important to note that loose, watery feces may flow around an impaction. Treatments include medications prescribed or recommended by the doctor, and changes in food.

**What you can do about bowel and bladder problems:** If your loved one is experiencing incontinence you will want to help them with cleaning and skin care. Just as babies

### Important points about bowel problems:

- ▶ If there is no bowel movement in 2 days, contact the nurse or doctor.
- ▶ Avoid “bulk” laxatives like Metamucil™. They need to be taken with large amounts of fluid or they make the problem worse.
- ▶ Call for help if:
  - there is blood in or around the anal area or stool;
  - no bowel movement occurs within one day of taking a laxative; or
  - there are persistent cramps or vomiting.

*This list was adapted from A Caregiver's Guide by K. Macmillan, J. Peden, J. Hopkinson, and D. Hycha; Canadian Hospice Palliative Care Association; ISBN: 0-9686700-1-6.*

experience diaper rash, adults using diapers can experience skin rashes. They need to be kept clean and as dry as possible. You can treat reddened skin with gentle creams. You can also keep an eye on the volume and color of urine. If the volume decreases or the color becomes very dark, you should alert the nurse or doctor immediately.

If your loved one is experiencing constipation, you can try offering high-fiber foods including whole grains, prunes or other dried fruits. Make sure that your loved one takes any stool softeners or laxatives as prescribed or recommended by the doctor. You should encourage your loved one to drink plenty of liquids as these ease constipation and allow the laxatives to work well.

If your loved one is experiencing diarrhea, remember that this can be dehydrating, like frequent vomiting. Try to shift away from foods that simulate the bowel — whole grains, dried fruits, caffeine, or fried foods. If you notice any blood in the stool or if bowel movements are more frequent than 6 a day for 2 days, contact the doctor or nurse.

## Anxiety

**Definition and description:** Temporary anxiety is a normal reaction to stress and most people have experienced anxiety at some time in their lives. End-of-life patients may feel jittery or fearful, and have trouble concentrating or sleeping. When the stress or fearful event is over, the anxiety subsides.

Many people who are dying experience anxiety caused by the awareness that they have only a limited time to live. The anxiety may be caused by concerns about the dying process, about “unfinished business,” the care of dependent survivors, what will happen during the dying process, or about what happens after death.

The passage from a healthy or ‘non-dying’ person to one who knows that he or she is reaching the end of life usually occurs in stages. At each stage, new fears and anxieties may appear and need to be addressed. When dying persons are given honest answers and choices for care are provided, much of the anxiety can be relieved.

**Common treatments for anxiety:** Most anxiety seen in dying persons can be relieved if they know they have trusted people to answer their questions and they will be cared for and not abandoned. Calming music, herbal teas (if the person can swallow), and quiet surroundings can help to relieve anxiety that occurs from time to time.

Talking about fears also helps to relieve anxiety. Often as people near the end of life, they can sense disturbing changes within. They may say “I just don’t feel like myself.” Clear communication is very important. It is important for both you, as the caregiver, and all the health care providers to give the dying person honest answers to their questions. Typically, if there is something they do not want to know, they will not ask about it.

Your loved one has the right to know about the illness, how long to expect to live, the treatment alternatives, the side effects of the proposed treatments, and where they will be while being cared for. They also have the right to say that they do not want this information, and this preference should be respected by caregivers and health care professionals.

Anxiety that is more severe than the ‘normal’ anxiety described above may require prescription medication. Anti-anxiety medications come in a variety of forms. Some cause sleepiness more than others. These types of anti-anxiety medications are usually reserved for persons with persistent, disabling anxiety. If you are concerned that your loved one’s anxiety is severe, you need to talk to his or her health care providers.

**What you can do about anxiety:** Perhaps the most important thing you can do is to acknowledge their fears and reassure them that you will not abandon them. Do not dismiss their fears as “silly” and instead, let them know that it is normal to sometimes feel anxious or fearful.

As noted above, you can also try to create a calm environment and offer soothing music. Sometimes just offering a hand to hold or a gentle touch can be reassuring. Provide a calm presence and listen empathetically.

If your loved one is chronically anxious and cannot be calmed, or if they cannot sleep or eat because of anxiety, contact the doctor or nurse. In these cases, medication may be helpful.

## Depression

**Definition and description:** True clinical depression is a mood disorder lasting at least several weeks in which there is depressed mood and loss of interest in nearly all activities, plus several of the following: change in appetite, weight loss, decreased energy, feelings of guilt, worthlessness, hopelessness, and difficulty concentrating or making decisions. In severe cases, there may be thoughts of suicide.

Depression is not normal in dying persons, nor is it universally present. However, if the condition exists it needs to be treated. Depression can be either “primary” (the person is pre-disposed to depression in response to stress) or “secondary” (depression is a result of the disease or treatment). Sustained fear and anxiety may also result in depression. It is also possible that your loved one may feel depressed because he or she is in pain. Unmanaged pain is the most common source of depression in dying persons.

Sadness in anticipation of one’s own death is a normal and expected response called anticipatory grieving. It may be difficult to separate this normal sadness from true clinical depression, but depression is typically more profound and a depressed person rarely shows any happiness.

### Important Points on Depression:

- ▶ Unmanaged pain is the most common source of depression in dying persons
- ▶ Clergy, other spiritual leaders, or counselors may also be helpful in dealing with depression
- ▶ Combinations of medications can sometimes cause depressed mood.

Many of the above symptoms of depression, such as weight loss, loss of interest in surroundings, and decreased talking and activity are also common features of a natural dying process so it can be difficult to tell if depression or the dying

process is the cause. Your knowledge and experience of your loved one is your best guide to deciding whether they are suffering from depression, and sometimes they will tell you they feel depressed. If you think your loved one is experiencing clinical depression, you should tell the doctor or nurse.

**Common treatments for depression:** When depression occurs near the end of life, it can be successfully treated with medication. There are a variety of anti-depressants that are quite successful in elevating mood. Some, but not all, of these medications require weeks or months to take effect so the doctor will need to consider the best ways to elevate your loved one’s mood as quickly as possible. As noted above, depression may also be a result of unrelieved pain or fear and anxiety, therefore addressing these other symptoms may help reduce depression.

Clergy, other spiritual leaders, or counselors may also be helpful in dealing with depression. Ask your loved one if he or she would like to talk to a professional. Family members may also need professional counseling to help them deal with the dying person’s low mood. Additionally, be sure you have your health care providers or pharmacist review the dying person’s medications. Combinations of medications can sometimes cause depressed mood.

**What you can do about depression:** If you suspect primary depression and your loved one has suffered from depression in the past, it is best to seek professional help. Whether the depression is mild or severe, primary or secondary, you can help by talking with your loved one about why they feel depressed. Dying persons grieve multiple losses and often need to talk about the losses they are experiencing. They grieve not only their own death, but the loss of all that they leave behind. Talking may relieve many of the depressed feelings. The greatest fear for many dying persons is the fear of abandonment. Reassure your loved one that you will not abandon her or him.

Ask your loved one what is bothering her or him. Is there some unfinished financial business? Is there some unsettled conflict or disagreement with another member of the family? Are spiritual needs not being met? What worries and fears have not been addressed? You can even ask, “Are you feeling sad or depressed?”

Encouraging your loved one to develop an overview of her or his life for the benefit of others is a positive way to deal with depression. Oftentimes, people receive a renewed appreciation for what they have done and they are reminded of happier times. Life review self-help books are available, including *A Guide to Recalling and Telling Your Life Story* from the Hospice Foundation of America. (Details about the Guide can be found at <http://www.hospicefoundation.org> or by calling 1-800-854-3402.)

When dying persons talk about suicide, it may mean that something is seriously wrong. They have a problem that has been bothering them for some time or they may be clinically depressed. If your loved one brings up suicide, it is best if you do not act surprised, afraid, or angry. Thoughts of suicide are not uncommon in persons facing the end of life, especially in those who feel they may be a needless burden on their family, feel unworthy, have unrelieved chronic pain, or feel that they are exhausting the financial resources they had hoped to pass on to survivors. Many persons with advanced illness see no future and the present is filled with discomfort. They may feel that suicide is a way of taking control. Reassure your loved one that these types of thoughts are not uncommon in people who are dying, and beware of people who say they have a plan to hurt themselves. If this is the case, contact the physician immediately.

If you feel that you are not able to help with your loved one's depressed feelings, then you need to contact a counselor or the doctor to make sure that your loved one receives professional assistance.

## Anger

**Definition and description:** We need not define anger, but we should try to describe its occurrence among those who are dying. Dying persons commonly experience anger, often from a sense of unfairness or powerlessness in the face of their illness and debility. Sometimes fear of pain and death is expressed as anger. This anger may find focus on you, as the caregiver, or on some other family member or person, or on the disease itself. Sometimes those who are dying are angry at God or the universe.

You may find that your loved one is generally short-tempered. They may feel frustrated and angry that they cannot do

things they used to be able to do; this loss of function is only one of many losses suffered by people near the end of life. They may also feel that they are becoming a burden on others, and feel angry about their own helplessness. Some dying persons look for reasons to express anger.

### **Common treatments and what you can do about anger:**

There are no specific “treatments” for anger — but in some cases, professional counseling may be helpful. As with other forms of emotional distress, talking about the cause of the anger is helpful. As with anxiety and depression, just giving your loved one the opportunity to tell you what they are feeling can be very healing.

You may be able to help them find other ways of expressing their feelings to minimize angry outbursts. Anger is often the result of feeling powerless. If you can help your loved one identify things they can control, or help them accept the fact that now is the time to let go of control, it may calm the feelings of anger. If you feel that you cannot help your loved one with her or his anger, then professional assistance may be necessary. Contact your health care providers, clergy or spiritual leaders, or professional counselors to be sure that your loved one receives the help they need.

## Spiritual/Existential Concerns

**Description:** Dying persons commonly have a strong desire to understand the meaning and purpose of their life, why they are ill, and why they are dying. For many people, the end of life is the first time they have thought about these things. This search for meaning often comes in the form of spiritual or religious questioning. For each individual, this search is very personal and unique. It is typically influenced by whether they have been part of an organized religion or the type of spiritual practices they have engaged in.

It is not uncommon for dying persons to feel that they have failed in some way and that they do not deserve to go on living. They may feel they are being punished for things that they have done or not done in their lives, or that they have been abandoned by whatever higher power they believe in. They may feel angry that their higher power does not heal them. It is equally common for people near the end of life to feel closer than ever to their spiritual power, for the first time, or as a consequence of a lifelong relationship with a higher power. Some will be

anxious about what will happen to them after they die, while others may look forward to being with their higher power and loved ones who have died.

### **What you can do about spiritual/existential concerns:**

Again, as caregiver, it is important for you to give your loved one the opportunity to talk about what they are feeling. He or she may just want to talk to you, or they may want to spend time with faith community leaders or others they see as spiritual guides. Dying persons may request that you pray for them or with them. If you cannot do this, perhaps you can offer to find others who can be comforting in this way.

If organized religion has been part of your loved one's life, then asking the clergyperson to call or visit may be very helpful. Too often, dying persons lose contact with their faith community because they can no longer attend

services. You can help by making sure that the people who have been part of your loved one's religious or spiritual community know that your loved one is ill. Let them know how they can help your loved one and you, depending on your preferences. Tell them if your loved one would like to receive visits, cards, or other tokens of connection and concern. It is a tremendous gift and source of comfort to be present and listen empathetically.

If your loved one has not belonged to a particular religious group, most hospitals and hospice teams have chaplains who have been trained to help people of all backgrounds with spiritual concerns. These professionals can offer spiritual support to people of all religions or belief systems, as well as those who choose no religious practice. They can be helpful in contacting community faith leaders as well.

## SECTION 5:



## What About You – the Caregiver?

Make no mistake, caring for a person who is dying is hard work, but it can also be very rewarding. It is perhaps one of the most loving acts of support that one human being can do for another. At the same time, it is physically, mentally, and emotionally exhausting. Your experience as a caregiver will be unique, but in this section we will share what we have learned from other caregivers in hopes this information will help you realize that what you are feeling is normal, and that you are not alone.

## Emotional Reactions

Be prepared for a confusing mix of emotions, both positive and negative. Caregivers are often overwhelmed by the intensity and mixture of emotions they feel. These may include:

- ▶ Sadness that your loved one is dying mixed with relief that they soon will not suffer anymore;
- ▶ Fear that you do not know the right thing to do and that you are failing as a caregiver mixed with moments of realization that you are doing the best you can and amazement that you can do as much as you are doing;

- ▶ Anger at your loved one for leaving you, or at your higher power for taking your loved one away, mixed with gratefulness that you have this precious time with them; and
- ▶ Fulfillment because you are giving a gift of love mixed with guilt that you are never doing enough.

As the length of time as a caregiver increases, you may begin to long for it to end and also wonder what you will do and how you will handle the sense of loss when your loved one dies.

Not everyone is “called” to be a caregiver and sometimes people have to care for someone who has been unkind to them and may continue to be unkind. In these cases, caregivers are likely to feel burdened and angry and will need to find an outlet for these feelings.

Some caregivers will experience chronic anxiety or depression similar to the symptoms described previously for the dying person. If these problems begin to interfere with your daily life or with your role as the caregiver, you will need to seek professional help.

## Physical Reactions

Caregivers experience a variety of physical reactions, most of which are related to the emotional and practical stress of caregiving. You may have a hard time sleeping or find yourself sleeping more. You may find it difficult to eat, or you may eat more than usual. You may lose or gain weight. You may feel sick to your stomach or light headed. Exhaustion and fatigue are common for people caring for someone who is dying. You may experience headaches or other pain in your body. You may find that you forget things or that you cannot concentrate. Most of the time, these will come and go depending on the fluctuating demands of caregiving. If they become constant, this may signal chronic anxiety or depression.

You can lessen both the physical and mental effects of caregiving by taking care of yourself. Sometimes this will feel like “one more thing I just don’t have time for,” but caring for yourself must be a priority or you may “burn-out” and be unable to care for your loved one. Keep up with, or start, a regular routine. Eat regularly and, if you are having difficulty eating, take nutritional supplements. Ask your health care providers for assistance regarding sleep issues or other physical discomforts. You may also

### Signs of Caregiver Burnout

- ▶ A strong urge to run and hide from responsibility.
- ▶ Feeling scattered and frantic.
- ▶ Major changes in your sleeping or eating patterns.
- ▶ Forgetting important details or an inability to concentrate.
- ▶ Increased use of alcohol, drugs, or tobacco.
- ▶ Significant weight loss, sleeping less than 3 hours a night, or inability to read more than a few sentences without losing concentration.

*This list was adapted from [A Caregiver's Guide](#) by K. Macmillan, J. Peden, J. Hopkinson, and D. Hycha; Canadian Hospice Palliative Care Association; ISBN: 0-9686700-1-6.*

benefit from physical exercise, massage therapy, listening to special music, or relaxation techniques.

Sometimes you just need a few hours or a day to yourself. Try to take some time away from caregiving so that you can return refreshed. You may consider taking advantage of respite services offered by your local hospice. Hospices can provide volunteers so that you can leave the home for a few hours and attend to your own needs.

## Support networks

Perhaps you are thinking that you barely have time for all the things you have to do for others and cannot possibly find time to exercise or get a massage. The answer is to do one of the hardest things for most caregivers to do — ask for help. Create a support network and rely on the support of others.

You already have a formal support network made up of the health care professionals caring for your loved one and you. It is important to call on them whenever you need information and professional support.

You will also want to develop your informal network of support. This will include other family, friends, neighbors, members of social or religious organizations, and local volunteer organizations. (See Section VI for suggestions on finding these.) Think about how you would feel if a friend or neighbor was caring for a loved one; you would want to help, but you might not know what to do. As a caregiver, you can develop a list of ways that others can help you and when they ask, give them a specific assignment. Here are some ideas:

- ▶ Grocery shopping
- ▶ Picking up prescriptions or doing other errands
- ▶ Cooking a meal
- ▶ Sitting with your loved one while you take a break (for a walk, or other self-care)
- ▶ Reading, writing letters, playing cards, etc. with your loved one
- ▶ Housework, laundry, or yard work
- ▶ Caring for pets

- ▶ Listening to your story — you need people who can just listen to you and provide moral support

Using support networks can help you avoid caregiver burnout.

## Spiritual or “Existential” Reactions

Your own spiritual reactions to caring for a dying loved one may be very similar to those of the person who is dying. You may rely totally on your faith to help you with your loss. Or, you may become angry at God and feel that it is unfair to have to sacrifice so much of your own life and lose the one you love. You may come to a new place in your faith, or be filled with faith even if you previously were not. You may question your faith or lose it altogether.

If you answer yes to any of these questions more than a year after the death, consult a healthcare professional

Since the death are you:

- ▶ Bad tempered and angry most of the time?
- ▶ Busy all the time, restless, unable to concentrate?
- ▶ Afraid of getting close to anyone for fear of another loss?
- ▶ Going over and over the same things in your mind?
- ▶ Unable to get rid of guilt about the death?
- ▶ Always feeling numb and alone?
- ▶ Often thinking about your own death?
- ▶ Drinking too much, taking too many medications, or driving unsafely?
- ▶ Thinking about suicide?
- ▶ Feeling fearful or anxious for no reason?

*This list was adapted from [A Caregiver's Guide](#) by K. Macmillan, J. Peden, J. Hopkinson, and D. Hycha; Canadian Hospice Palliative Care Association; ISBN: 0-9686700-1-6.*

If you are part of an organized religion, and have previously attended services regularly, you may feel cut off from those with whom you worshiped. You may also feel cut off from your spiritual power. The dying process can be a very spiritual journey for both your loved one and for you. If you are struggling with your faith, talk to someone: a friend, a family member, or someone you have worshiped with. Your own clergyperson or a hospice chaplain could be helpful to you.

## Grief

Grief is a universal response to loss and is part of the process of healing. Many of the common responses to grief are well understood and we will describe some of them here. Although your reactions to grief may feel very strange to you, particularly if this is your first significant loss, it is likely that others have shared these feelings and that they are completely normal.

Often, feelings of grief come in waves, feeling all consuming at times, especially when something triggers a memory of your loved one, and then receding into the background at other times. Your period of grief may last weeks, months or even years, but your feelings of sadness, loneliness and loss should diminish over time. Sometimes feelings of grief are delayed, coming up months later when the activity and attention surrounding the death have subsided, or at the time of the first holiday spent without your loved one.

Even if you have been caring for your loved one for a while and expect to be prepared for the fact that they will die, you are likely to experience a sense of shock when the death occurs. Oftentimes, shock is accompanied by numbness. Time may seem to slow way down, and you may find yourself lost in thought and unaware of your surroundings. Forgetting conversations or what you were about to do is very common. It may take you much longer to get things done and you may find that you can only manage a few responsibilities, or even one a day at first.

As some of the numbness wears off, you may experience times of uncontrollable crying and sadness that feels unbearable. You may also feel anger toward the person

who died or toward others who could have done more. Guilt and regret for not having done more yourself are also common. Some people engage in denial or in magical thinking — choosing to act as if the person has just gone away for a time.

You may also experience physical symptoms like trouble sleeping, sleeping too much, feelings of restlessness, or like you just do not want to do anything. Lack of energy, loss of appetite, decreased sex drive, shortness of breath, or tight chest and irregular heartbeat have also been reported by people who are grieving. You may worry that something is very wrong with you. If you feel that you are experiencing serious physical symptoms, you may want to contact your doctor or nurse.

On the other hand, you may not have any of these reactions to grief. Many people have done their grieving while their loved one was dying. They may have grieved each loss — like loss of health, independence, companionship — as they occurred. If your loved one has been very sick, your grief may be less than your relief that they will not suffer anymore.

No matter what your grief reaction, you must try to accept and express your feelings. Be patient and try to take care of yourself in the best way you can. Try to engage in regular physical activity and eat healthy meals. Talking with family members and friends, sharing your feelings, and asking for help are all ways that you can take care of yourself.

Many people find it helpful to contact a grief counselor, or join a grief support group. If your loved one is enrolled in hospice care, inquire about ongoing grief counseling that is provided as a hospice service. Because the death of a loved one often sparks spiritual questioning, you may also find it helpful to talk with the leader of your faith community, whether you have ever been religious or not. (See Section 6 for resources to help you deal with grief.)

Although you may begin to return to work and other activities you enjoyed before you became a caregiver, it may be a long time before you really feel that you have a good life without your loved one. If your grief reactions remain intense for more than a year after the death (see inset), you may be experiencing a clinical depression, and you should consult a health care professional for help.

## SECTION 6:



## Resources

### Local Resources

**Hospice:** Depending on where you live, there is probably at least one hospice in your community. Hospices provide a team of health care professionals — physician, nurse, nursing assistant (to help with bathing and other personal care), and counselors — who come to your loved wherever he or she is (home, hospital, nursing home, etc.) This team helps you as the caregiver and provides support to other family members as well. Even if you think you are not ready to have hospice care, they can help you with decision-making and practical concerns. We suggest you contact them as soon as you realize that your loved one is gravely ill. They can help you decide when their services will be most helpful. Note that most people do not pay for hospice care because it is paid for by Medicare, Medicaid (in most states), private insurance, or charity funds.

Many hospices also provide palliative care, or pain management, for patients with advanced illness who are not yet ready for hospice. Ask them about this form of palliative care. However, not all insurance will pay for this care.

Most hospices also provide grief support to the community, whether your loved one becomes a patient or not. Contact them for information about bereavement support for you and other family members.

*Contact information:* Look in the Yellow Pages under “Hospice” or visit <http://hospicedirectory.org>. You may also want to contact the state organization for hospice care. Although enrollment in hospice requires a referral from a physician, you can call the hospice on your own to get more information. You will also want to talk with the doctor about palliative care and hospice care.

**Home Health Agencies:** Home Health agencies provide a variety of services depending on your loved one’s needs. They have nurses, social workers, physical therapists, and aids who can bath your loved one, change bedding, and provide respite care. These services are only covered by Medicare and other insurance in special circumstances so be sure to ask about costs and payment.

*Contact information:* Look in the Yellow Pages under “Home Health Care” or search the Internet.

**Pain Centers or Pain Management Specialists:** There may be a pain center at one of your local hospitals. It is more likely if there is a medical school in your town, although some pain centers are independent. Pain specialists use an interdisciplinary approach. In addition to doctors who prescribe medications, the team may include physical therapists, psychologists, and massage therapists.

*Contact information:* Your doctor should know if there is a pain center nearby. You can also look in the Yellow Pages or search the Internet.

**Geriatric Care Managers:** Geriatric care management is a growing profession that may be helpful if your loved one is aging. Managers help older people and their families with everything from food preparation to moving to obtaining healthcare. Typically, they do not provide healthcare, but they help link you and your loved one with the services you need. Geriatric care managers may be trained in any number of fields related to long-term care, including, but not limited to, nursing, gerontology, social work, or psychology, with a specialized focus on issues related to aging and elder care. The manager acts as a guide and advocate by helping you find ways to improve the quality of life for you and your loved one. Look for a manager who is certified and a member of the national professional organization.

*Contact information:* You can learn more about geriatric care management and search for a certified professional in your community at the website for the National Association of Professional Geriatric Care Managers, <http://www.caremanager.org>.

**Community End-of-Life Coalition:** In the last ten years, more and more communities have developed coalitions of healthcare professionals, consumers, social service agencies and others who are working together to improve end of life. Often these groups publish a resource guide to help local caregivers. To see if there is a coalition in your community, type “community end of life coalition” into your preferred Internet search engine.

**Volunteer Services:** Community volunteers can provide a variety of services. While there are usually volunteer services available in every community, it is sometimes hard to find them. We suggest you start with two agencies found in most communities — the United Way and the Area Agency on Aging. If neither of these has branches in your community, try looking at the state level and see if someone can help you find services in your locale. Another good source of information about volunteer services is a local church.

*Contact information:* United Way: Search for the local office in the Yellow Pages or on the Internet at <http://www.unitedway.org/myuw/>. Area Agency on Aging: Search for the local office in the Yellow Pages, or type the words “area agency on aging” plus the name of your state or community into your preferred Internet search engine.

## National Resources

The National Family Caregivers Association provides education and information to caregivers, as well as state and federal agencies, intended to improve the quality of life of those who are caring for an ill, elderly, or disabled person. The Association has many resources for you to use, and can connect you with other caregivers. It focuses on removing barriers to caregiver health and well being. You can become a member and receive their newsletter and other useful materials.

*Contact information:* Phone: 1-800-896-3650  
Website: <http://www.nfcacares.org/>

**The Hospice Foundation of America** is a non-profit educational foundation and informational resource dedicated to disseminating free and low-cost education via live and recorded video programs, webcasts, webinars, and books. In addition, HFA provides free materials to the public about the dying process, grief and caregiving, and provides the opportunity to ask questions of hospice professionals to those who are coping with issues of caregiving, terminal illness, and grief. (See the “Ask HFA” and “Hospice Information Center” pages on the HFA website for more information) The Foundation also publishes a grief and bereavement newsletter entitled *Journeys*, available for subscription on the website or by calling HFA headquarters.

*Contact information:* Phone: 1-800-854-3402  
Website: <http://hospicefoundation.org/>

**The National Hospice and Palliative Care Organization** works to advance the care of people at the end of their life through research, community, professional and governmental engagement, and education. It provides resources for both professional and family caregivers, as well as dying persons. Caring Connections is an NHPCO program focused on caregivers and others facing terminal illness.

*Contact information:* NHPCO/Caring Connections  
HelpLine – 1-800-658-8898;  
Spanish HelpLine – 1-877-658-8896  
Email: [caringinfo@nhpco.org](mailto:caringinfo@nhpco.org)  
Website: [www.caringinfo.org](http://www.caringinfo.org)

**Disease-specific organizations:** There are many associations that focus on specific diseases, such as diabetes, arthritis, cancer, or heart disease to name a few. These associations are national, but will often have local chapters. They provide resources, education, and information related to the particular disease they focus on. Support groups may also be organized to help you or your loved cope with the disease process.

*Contact information:* Look in your local phone book yellow pages or search the Internet.

## Other Useful Websites

<http://www.aoa.gov/>

US Government Agency on Aging (AoA) is the official Federal agency dedicated to policy development, planning and the delivery of supportive home and community-based services to older persons and their caregivers.

<http://www.aging-parents-and-elder-care.com/>

Aging Parents and Elder Care: A website provided by Senior Solutions of America, Inc. The site offers online support, resources, and connections to elder care services.

<http://www.painfoundation.org/>

American Pain Foundation: An independent nonprofit 501(c)3 organization whose mission is to improve the quality of life of people with pain by raising public awareness, providing practical information, promoting research, and advocating to remove barriers and increase access to effective pain management.

<http://www.childrenshospice.org/>

Children’s Hospice and Palliative Care Coalition: a social movement led by children’s hospitals, hospices, home health agencies, and individuals to improve care for children with life-threatening conditions and their families.

<http://www.dyingwell.org/>

Dying Well: Resources for people facing life-limiting illness, their families, and their professional caregivers.

<http://www.caregiver.org/>

Family Caregivers Alliance: the first community-based nonprofit organization in the country to address the needs of families and friends providing long-term care at home. FCA offers programs at national, state and local levels to support and sustain caregivers.

<http://www.growthhouse.org/>

Growth House, Inc.: provides links to resources for life-threatening illness and end-of-life care. Their mission is to improve the quality of compassionate care for people who are dying through public education and global professional collaboration. The organization’s search engine gives you access to the Internet’s most comprehensive collection of reviewed resources for end-of-life care.

<http://www.agingwithdignity.org/>

Aging with Dignity is a non-profit resource founded in the Spirit of Mother Teresa of Calcutta. Its goal is to maintain the dignity of individuals at the end of life and is the primary source for the 5 Wishes advance directive mentioned on page 5.

<http://www.cancer.net/>

Cancer.net is a resource for individuals, families, and caregivers that is maintained by the American Society of Clinical Oncology. It provides resources and tips for coping, caregiving, end-of-life care, and palliative and hospice care options.

## Books

How We Die by Sherwin B. Nuland, MD (New York: Alfred Knopf, 1994. ISBN: 0-679-41461-4)

Dying Well by Ira Byock, MD (New York: Riverhead Books, 1997. ISBN:1-57322-051-5)

The Four Things that Matter Most by Ira Byock, MD (New York: Free Press, 2004. ISBN: 0-7432-4909-7)

Handbook for Mortals by Joanne Lynn, MD and Joan Harrold, MD (New York: Oxford University Press, 1999. ISBN: 0-19-511662-3)

Choices at the End of Life by Linda Nordlander, RN and Kerstin McSteen, RN (Minneapolis: Fairview Press, 2001. ISBN: 1-57748-103-3)

A Caregiver’s Guide by K. Macmillan, J. Peden, J. Hopkinson, and D. Hycha (Ottawa: The Military and Hospitaller Order of St. Lazarus of Jerusalem, 2004. Co-published by the Canadian Hospice Palliative Care Association. ISBN: 0-9686700-1-6)

## Conclusion

Caring for a dying person creates feelings and situations that can be experienced very differently depending on the caregiver, the dying person, and the relationship that the caregiver has with the dying person.

The Hospice Foundation of America hopes that this booklet will serve to inform you, the caregiver, about the dying process, so that you are able to provide the best care possible to your loved one. While many people consider death a frightening event, knowing the physical signs and symptoms, and having an understanding of the psychological and spiritual issues can provide comfort.

Understanding what will occur during the dying process is an important step in providing excellent care. Thank you for taking that step and for all you do as a caregiver.

## About this Booklet

This booklet draws upon the Hospice Foundation of America curriculum developed for the clergy training program on care at the end of life, conducted on behalf of the Florida Department of Elder Affairs. The program was funded by the Florida Legislature and enacted by Florida Governor Jeb Bush.

The Advisory Committee to the project provided valuable insight in developing the curriculum, and included members of the clergy, physicians, hospice experts, and grief experts.

William Lamers, M.D., Medical Consultant, Hospice Foundation of America, and Kenneth J. Doka, Ph.D., Senior Consultant to HFA and Professor of Gerontology at the Graduate School of the College of New Rochelle, and a grief expert, were instrumental in the effort. Dr. Lamers provided medical expertise, information and review, and Dr. Doka provided guidance regarding spiritual and psycho-social issues. Hank Willner, M.D., Medical Consultant, Hospice Foundation of America, provided essential knowledge on the accuracy and clarity of medical and practical concepts.

Melanie P. Merriman, PhD, MBA and Kaye Norris, PhD. Contributed to the 2007 revision of the booklet.



Hospice Foundation of America exists to help those who cope personally or professionally with terminal illness, death, and the process of grief and bereavement.



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