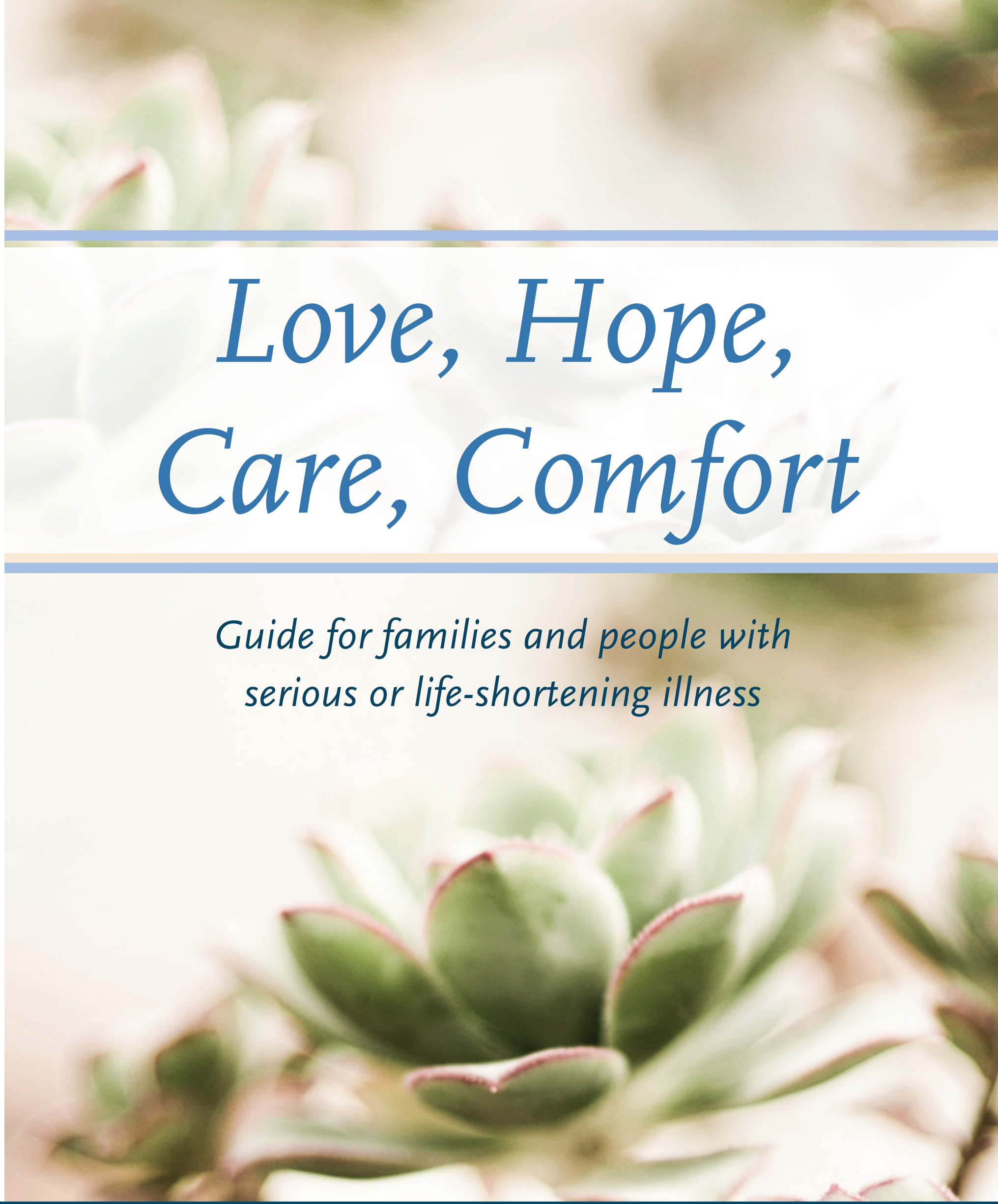

Love, Hope, Care, Comfort

Guide for families and people with serious or life-shortening illness

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> “It’s important to realize we can never
> cure everything. But we can care for everyone,
> and in that caring, true healing will occur.
> The healing of the spirit and of lives.”
>
> **—Bernie Siegel, MD**

Introduction

Advances in medicine allow people to survive many illnesses that before would have ended in death. Sometimes, treatments can cure or fix a health problem. More often, medication or treatments manage a chronic disease. While treatments may improve the condition, they do not fix the disease.

This guide is a resource for people who have a serious, chronic or life-limiting disease and their families. We hope it will ease the burden of suffering that often goes with disease and help with decisions about care.

Healthcare Providers' Purpose

Healthcare providers strive to work together to give the best possible care to patients and their families. We work to manage disease and reduce its impact. However, despite our best efforts, disease and disability often still progress.

Each person and their family deals with a serious illness, and approaches the end of life in their own way. As much as possible, we will:

- Understand each person's perspective.
- Develop a coordinated approach to each person's care.
- Listen to patients' and families' needs.
- Inform them what to expect in the course of their illness.
- Help our patients manage symptoms and maintain as much control as they are able.

Healthcare providers provide supportive care to patients and their families. By "Supportive Care" or "Palliative Care" we mean:

- *We will assess patients' and their family members' needs, strive to minimize physical suffering and provide support for emotional, existential, spiritual, social and psychological concerns.*
- *We will assess the effectiveness of our efforts with you*
- *We will respect the preferences and ensure the dignity of our patients and their families.*
- *When medical interventions are not able to prolong life, or when the burdens of life-prolonging treatments exceed the benefits for the person, we will support people and their families with the best possible quality of life as the person approaches death.*

The Question "Why"

Some patients ask themselves Why? Why me? or Why a family member? Why now, or ever? Why this illness?

Sometimes there is an answer to these questions, but other times an illness, injury or death is just bad luck.

The reality is that all of us will die at some time. Some will die suddenly, unexpectedly, or accidentally. Many die more slowly from chronic disease like cancer, lung disease, kidney or liver failure, heart failure, dementia or AIDS.

At times treatments can "save" a patient from dying at the moment, and some treatments improve health. Treatments may provide the patient with a good quality of life for a while. For some, better health can continue for many years, but for others the time is weeks or months. Some people spend long periods of time in hospitals receiving treatments, hoping to improve, and they might or might not get better.

Doctors can help you know what length of time to expect, within a range. Some people live longer than we expect and others die more quickly, so we cannot predict exact length of life. We will try to tell you how long others with similar conditions have lived. Extra time before the patient becomes sicker or closer to death is very valuable to many.

Things to Consider

Knowing what to expect in the course of an illness can relieve anxiety. Knowledge also gives more control over your life.

Doctors and nurses can help patients and their families learn what problems may arise in their illness or when approaching death, and plan for how to manage them. They are a resource to clarify concerns about the illness and its symptoms.

We Have Choices

You, your family and your doctors have choices about what care you receive and where you receive it, as long as you understand the pros and cons of each choice. When someone becomes ill:

- Care can be given in the Emergency Room and Hospital
- At home with Home Health Care or Hospice
- In the Intensive Care Unit or in the medical or surgical unit
- We can *Allow Natural Death* or *Try to Revive* you when your heart or breathing stops

"Death with Dignity"

Dignity is an idea that means different things to people. Dignity can come from telling your story or making sure others know how you are important as a person. For some people dignity comes from doing as much on their own as possible. For some people dignity comes from having a sense of control over what happens to them in the last part of life. You can tell your doctors what control you want.

In the United States eight states have laws to allow physician aid in dying or "assisted suicide". The laws are different in each state. The person must not be depressed; they must find a physician who will prescribe medication to end their life, and often they must wait for some time before they can fill a life-ending prescription. This booklet does not endorse assisted suicide. It gives people some other ways to have control when they have a serious or life-ending illness.

How to Understand What You Hear

Sometimes families and patients hear "there is nothing more that we can do." What we really mean is that when treatments don't cure or fix a patient's disease we <u>will</u> do everything possible to improve their quality of life for as long as they live. We will focus on managing symptoms and on improving the life and function of the patient and their loved ones.

It is important that doctors and nurses hear what matters most to patients and their families. Most people would choose to live as long as they can if they are feeling well. It is helpful to stop at least once and talk with your family and doctors about what is most important to you in life, and on what things you would want to focus at the point when you might learn that time is short.

Sometimes the person with a serious illness improves and lives for several more years. Other times the disease progresses and the person dies over a short time. Sometimes death comes as a surprise when the person is doing well.

Many people fear that a lingering illness will be filled with pain, suffering, and misery for both the person and their family. People worry about becoming dependent on others for basic care. Being aware of those worries will help your health care team plan with you to meet your future care needs.

During times of life-shortening illnesses, some people choose to settle issues in their life. They want to say things to loved ones that have been unsaid. They want to "heal" wounds that have affected a family or a relationship. For some, death is not expected and they do not have this chance.

People to help you explore these issues include spiritual or religious leaders, or chaplains and social workers, or psychologists.

Planning Your Care is Important

Most people do not like to talk about dying or getting sick, but having a general plan in advance will help both the person and their family. Make the time to discuss these things with your family and your doctor before you are in crisis.

The COVID-19 pandemic made us more aware of the need to think what care you want and plan for options if you become sicker. People with chronic illnesses can have serious complications or die from COVID-19. People who are hospitalized might not be allowed to have family and friends stay with them during the pandemic. Some people choose to stay out of the hospital to be able to spend time with family and friends.

How to Talk With Your Doctor

Your doctor can help you know what to expect in the course of your illness. If your doctor does not begin this conversation, you should do so. Tell the doctor you want to plan your care.

- Ask for information you can read, or have a friend or family member present to help you ask questions or help you remember, or ask to record the conversation so you can listen again later.
- Ask your doctor for information about your medical illness.
- Ask your doctor to tell what different treatments can be used and what your life would be with each treatment.
- Make a list of questions you have.
- Make a plan in advance to manage problems your doctor thinks might occur for someone with your medical illness.
- Know what to do in an emergency:
    - what medications or treatments to use while you are waiting for help
    - whom to call or where to go in an emergency

Planning With Your Doctor

Your doctor should understand what has been important to you in the past and what you hope for now.

Some issues to discuss are:

- What you want done when your heart stops beating or breathing stops

  > *You can allow natural death or you can ask that someone try to revive you.*

- What treatments you might want for problems your doctor says you might have, for example if your breathing is short

  > *You can have medicine to help you feel less short of breath,*

  > *You can have oxygen or a breathing mask to help breathing.*

  > *Or you can ask doctors to put a tube in your lungs and connect you to a ventilator (a machine to breathe for you).*

- Are you willing to go to the hospital when you are very ill, or do you want care where you live? Are you willing to live in a nursing home?

  > *We will always try to provide comfort.*

  > *You can choose care to let you live out your life, or care that tries to extend your life.*

Advance Directives

Advance Directives are legal documents in each state. Standard forms can be used. One tool to help you and your family think about decisions you may make is called "Five Wishes". This is a legal advance directive in many states, but can also help you work through what is important and guide your doctor, or someone you appoint, to make decisions if you are not able to do so.

All adults should have an advance directive to ease decision-making for their medical care if ever they cannot speak for themselves. It is important to make sure your doctor or health system has a copy of your Advance Directive.

The most common Advance Directives are:

Durable Power of Attorney for Health Care:
Also called "Special Power of Attorney" or "Healthcare Surrogate". This is the most important advance directive. It appoints someone to make health care decisions for you if you are not able to speak for yourself. The durable power of attorney for health care can plan treatments a patient will or will not receive and make decisions about current treatments.

Living Will: A Living Will is a directive that states when life-sustaining treatments are not to be used. It is usually written and must be witnessed by two people not related to you or members of your health care team. The Living Will usually applies if the person is "Terminally ill", or "Permanently unconscious", or "If there is no hope of recovery".

In most states, Living Wills need two doctors to state that the patient is terminally ill. Living Wills often may not apply to a patient's situation if the heart or breathing stops unexpectedly, or if a slow decline from chronic disease is not recognized as a "terminal illness."

Medical Treatment Plan: This can be a separate document or part of the Advance Directive forms. In some states it documents a plan and identifies treatments that will or will not be given. The patient's or surrogate's signatures are usually witnessed by someone who is not family, doctors or nurses.

POLST (or MOLST): Physician (or Medical) Order for Life Sustaining Treatments: this is a bright colored form with orders to be followed by emergency workers, doctors or nurses. It states whether or not to try to revive a person when their heart or breathing stop, whether to have them go to the hospital or remain where they are for "comfort care" when they are very ill. The form is signed by a doctor, nurse-practitioner or physician assistant. In some states the patient also signs the form.

There are limits to Advance Directives. Living Wills don't always protect people from treatments they do not want. The Durable Power of Attorney for Health Care is a better tool for this because the person you appoint makes decisions for situations based on what they know you would have wanted.

Other Plans

Plan for Life

- Finances: if needed, find someone to help you manage them.
- A Will: this legal document says who gets what after you die. Having a will makes things easier for your family and friends.
- Where you live and how to get help when you need it.

Plan Hope and Joy

- Find hope: think about things that are important to you and explore ways to do them.
- Plan ways to spend time with people who make you happy.
- Plan to do things that you enjoy.
- Be creative.
- Write letters or record messages about important future events, so you can be "present" for others if you die before birthdays, graduations, weddings and other important things happen.

Plan to Stay Safe

- Exercise and build strength.
- Work with therapists and use a cane or walker to prevent falls.
- Learn what foods to eat for your health. Keep up your nutrition.
- Learn to monitor your blood pressure, weight and other things to work with your doctors and nurses.
- Plan who will care for you when you need help or you are not able to care for yourself.

Where You Receive Care

Serious Illness or Death in the Hospital

When you have conditions that benefit from hospital treatment you can be admitted to the hospital. Your healthcare team will work together to respect the treatment options you prefer. They strive to best meet your needs and those of your family. As possible, when death is near they will plan with you in order for you to die as you prefer. They might help you plan for another care setting, such as a nursing home, if you are not able to go home after hospital treatment ends.

Your healthcare team will use medications and other treatments to help manage symptoms. The social work staff will also be available to provide support, to help you contact family and plan with them. Social workers or chaplains help those facing sadness or coping with loss whether or not they have a spiritual belief, other faith, or no religious tradition.

Illness or Death at Home

You can organize care at home with assistance from paid caregivers, family or friends. Professional teams can help you. Sometimes a new “home” setting, such as assisted living, a nursing home or adult foster home is the best way to receive care.

Home Health

Home Health companies are paid for by most insurance when the skill of a nurse, a physical therapist, occupational therapist, social worker or speech therapist is needed. These professionals visit one to three times per week to provide treatments or teach the person and family.

Caregivers can help the patient do things on their own as much as possible. They address self-care including:

- Bathing
- Walking Safely
- Using the toilet
- Other aspects of physical care

Equipment including walkers, canes or other tools are often helpful. Physical or occupational therapists can help a person get equipment to keep them safe.

Hospice

Hospice is an insurance benefit that offers a team to help care for those facing the end of their life. You must "enroll in" or sign up for hospice care. Hospice is paid for by most insurance when your doctor says it would not be surprising if you died in about 6 months. Hospice companies are either nonprofit or for-profit. Some nonprofit hospices offer services regardless of the patient's ability to pay.

Usually when a person enrolls in hospice they do not go back to the hospital. You may continue to receive care from other doctors in addition to hospice care.

Some hospice companies offer more than the required services listed below. Talk to several companies to learn what they will provide for you and your family. The person and their family can choose the hospice company, and decide what care they want. When other care providers are involved, the hospice should work with them.

All hospice companies must provide:

- Medical supervision
- Medications to manage symptoms and for your hospice-related illness
- Nursing care at least every 2 weeks, usually for a few hours each visit
- Home health aides for personal care, usually 1 to 2 times per week

- Counseling and social work support
- Chaplain or religious support
- Bereavement (grief) support for the patient and family before death, and for the family for a year after death
- Volunteers for companionship, errands, chores or activities

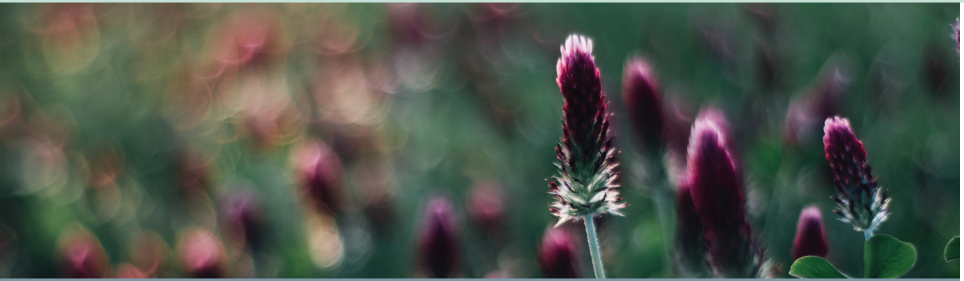
Levels of care under the Medicare Hospice Benefit include:

1) Routine Home Care: Almost all people receive care where they live, including visits as needed, at least once every 2 weeks from nurses, therapists, or other hospice staff. Family, paid help or friends must help with care.

2) General Inpatient Care: this is care in a hospital or nursing home for a short time (2–7 days) to control urgent problems or symptoms not well managed at home.

3) Inpatient Respite Care: Respite care provides a break from giving care for family or friends. Respite is limited to 5 days or less. It is provided on an occasional basis. A nursing home, hospital, or inpatient hospice staff provide the care under contract with the hospice company.

4) Continuous Home Care: This is reserved for times of crisis or increased need. It allows 8 to 24 hours of professional care to keep the person at home. Medicare hospice provides Continuous Care in most cases for a few days. When caregivers can again manage the person's needs, Routine Home Care takes over.



Management of Symptoms

Healthcare providers will work with you to manage "symptoms", the things the person feels, to promote comfort. Many people worry about pain or shortness of breath. Medication and other treatments can help get these to the level you prefer.

Patients need to know that they need only endure physical symptoms as much as they choose. Tell your health care team about your symptoms and ask for a plan to manage them.

Family, caregivers and healthcare providers may overestimate or underestimate the patient's symptoms. Care providers should rely on the patient's rating of their symptoms and ask the person to rate them as mild, moderate or severe, or give the symptom a score 0–5 where 0 = no pain or shortness of breath and 5 = the worst imaginable pain or shortness of breath they can imagine.

Non-Medical Treatments

Your doctors, nurses and others can help you find non-medication treatments for symptoms:

- Massage therapy or physical therapy can reduce pain or anxiety.
- Braces or other equipment can reduce pain in muscles or joints.
- Exercise can:
  - reduce pain
  - improve shortness of breath
  - improve sleep
  - reduce anxiety
  - improve mood
  - improve general well-being
- Acupuncture helps some pain, anxiety and other symptoms.
- Ice reduces pain and swelling.
- Heat or over the counter muscle rub medications reduce muscle aching.
- Aromatic oils decrease anxiety and aromas can be calming.
- Counseling can help low mood or depression.
- Relaxation and Guided Imagery (thinking of a positive experience or place) can help many symptoms.
- A fan blowing on the face reduces shortness of breath.

Other treatments can be helpful. Your healthcare providers can help you think about therapies you can try.

Medications

Medications that treat the disease may improve quality of life. In so doing, they can reduce the uncomfortable symptoms of the disease. On your doctor's advice, continue medications for your illness that help you feel as good as possible.

Pain, anxiety, and shortness of breath are common in those who are seriously ill or facing the end of their lives. The following are the most common medications used to treat the symptoms of pain, anxiety, and shortness of breath. (We refer to medications here by their generic names. Many medications have several brand names. Your pharmacist or other healthcare providers can identify the generic names of your medications.)

Opioid Analgesics: (o'pe-oid an"ə l-je'zik)

These medications treat pain or shortness of breath. They include:

- Morphine (MOR-feen)
- Fentanyl (fen'tah-nil)
- Methadone (meth'ah-dōn)
- Oxycodone (ok''se-ko'dōn)
- Hydromorphone (hi''dro-mor'fōn)
- Hydrocodone (hi''dro-ko'dōn)
- Other medications

These medications can be given:

- By mouth
- Under the tongue
- Through a catheter into a vein
- Under the skin
- Through a catheter into the nervous system or other organs
- As a patch on the skin
- By a suppository in the rectum

The dose required by a particular person will depend on the way their body handles the medication. There is no standard dose and there is no maximum dose. The medication needs to be adjusted to the patient response.

Some people have less side effects with one opioid than another. It may be necessary to change opioids to manage side effects. Most side effects from opioid medications can be managed.

- *Opioids always cause constipation. You must take laxatives to keep regular bowel movements.*
- *Opioids often cause drowsiness or confusion.*
- *Opioids may cause urinary retention (trouble emptying the bladder).*
- *Opioids may also cause nausea or itching.*

Telling your doctor or nurse how the medication affects you or about side effects is important. Changing the medication can relieve some side effects.

When opioids are used over time the person develops physical dependence. This is not addiction. It is important to always work with your doctor or nurse to adjust doses or stop an opioid.

Sedative-hypnotics: (sed’∂-tiv hip-not’ iks)

These medications are used for anxiety, restlessness or sleep. They include:

- Lorazepam (lor-ah’zĕ-pam)
- Oxazepam (oxs-az’ĕ-pam)
- Midazolam (mī-DAH-zō-lam)

These medications can be given:

- By mouth or under the tongue
- Through a vein or under the skin
- In the rectum

- *The dose of the medication can be adjusted to the patient response, although we try to use the lowest effective dose.*
- *These medications may cause confusion or agitation.*
- *They always increase the chance of falling, and slow reactions. Driving and other activities might not be safe.*

Tell your doctor or nurse how the medication is affecting you.

Non-steroidal Anti-Inflammatory Drugs (NSAIDs):

NSAIDs treat pain and inflammation. They are useful in treating pain from bones and joints. They include:

- Ibuprofen (i”bu-pro’ f∂n)
- Naproxen (n∂-prok’s∂n)
- Diclofenac (di-klo’fen-āk)

Most of these drugs are given by mouth. Diclofenac is given as a gel, absorbed through the skin, so does not have the side effects of medications by mouth. NSAIDs taken by mouth have many possible side effects including:

- Ulcers in the upper intestinal tract
- Worsened kidney function
- Fluid retention and swelling

NSAIDs should be monitored closely, and you should ask your doctor if they are safe for you.

Other Medications for Pain

Some drugs used to treat other disorders also treat pain well. Some treat pain from nerve irritation and other processes. Examples are:

- Gabapentin (GA-ba-pen-tin)
- Amitriptylene (a-mee-TRIP-ti-leen)
- Nortriptylene (nor TRIP-ti-leen)

Your doctor or nurse can review the medication effects with you.

Antidepressant Medications

Antidepressant medicines can safely relieve:

- Fatigue
- Anxiety
- Sleep disturbance
- Depression
- Some types of pain

Antidepressants are given by mouth. Your doctors and nurses can talk with you about the benefits and how the medicines might affect you.

Other Medications

You might have other symptoms not listed here. Doctors and nurses can answer questions about medications for other symptoms and their side effects.

Grief and Anticipating Loss

People with progressive illnesses anticipate and grieve many losses as their diseases advance.

Initially, they may grieve loss of ability to do things as they did before. Serious illness can change ways people relate to each other. Some people grieve a loss of strength or independence when they must accept care from someone else. Recognizing these losses can help people cope with their new situation.

When they know death is near, patients and their loved ones may mourn their deaths in advance. They may anticipate “not being there” for events and missing out on more time with loved ones.

These are normal grief responses. Recognizing and accepting grief about loss is important. Often, this acceptance allows people to move on to positive things that they want to do while they can.

Writing or recording messages are one way people can be present for loved ones in the future. Designating gifts or putting together photographs are other ways to help the people you care for remember you after you die.

What to Expect As Death Approaches

Understanding what might happen as death approaches may help you prepare for it, and reduce your fears and worries. Death comes in its own time for most people. Each person dies in their own way, yet some things are common in the dying process. Often people die the same way they live. As they approach death people use many of the same coping mechanisms, strengths and weaknesses they used throughout life.

In some diseases there is a predictable course toward death. In others, death occurs abruptly during chronic illness.

When death occurs slowly, all, a few, or none of the signs described below may appear. They do not always happen in a specific order, and their time frame may range from minutes to a year, or more, for different individuals.

Withdrawal

As a person becomes more ill or realizes that death is approaching, they withdraw from the world around them. They may be unresponsive, reserved or, late in the illness, in a coma-like state. Sleep increases. Sometimes they spend more time resting or inactive than awake. With this withdrawal comes less need to communicate with others. At this point, try touching them, and being with them, playing favorite music or reading to them.

Although they do not talk to you, they can listen to you. Tell the person you are present. Now is a good time to tell them whatever you wish them to know. You can tell them about good memories. Share your feelings with them. It is best to speak in normal tone of voice.

Food/Fluid Decrease

Food energizes our body. It keeps our body going, moving, alive. We eat to live. When a body is preparing to die, it is natural that eating and drinking will decline or stop. This is one of the hardest concepts for family members to accept. Appetite and thirst decrease as the illness advances and as death approaches. Forcing food or drink is not helpful and can cause frustration.

On the other hand, food can be a source of pleasure. If the person wants to eat, then offering favorite foods and helping them eat is fine. Sitting up helps people swallow. Ice chips or small amounts of fluids may feel refreshing. The person's mouth should be kept clean, and when they stop eating and drinking their mouth and lips should be moistened regularly.

Disorientation and Confusion

Confusion about time and place may develop as a result of the illness itself, other medical problems, chemical changes in the body or medications. The doctor or nurse will look for causes of confusion that can be treated. If a medication is causing confusion it can be changed. Oxygen to help breathing can reduce confusion at times. Doctors can try to correct blood chemical levels, like sodium and calcium, to reduce confusion. Additional medication may be prescribed when confusion frightens or upsets the patient.

The ill person may not recognize people in the room. This may happen even though people are close and familiar. The person might speak to those who have already died. They may see places not visible to the rest of us. Trying to correct the person or arguing about these things is not helpful. It is fine to tell the person you do not see the things they see. Some believe that there is meaning behind the things people hear or see as they move closer to death. These beliefs should be honored.

Visions or hallucinations that are frightening should be treated by managing the cause of the confusion or using medications to suppress the frightening visions.

There may be restless and repetitive motions such as pulling at bed linen or clothing, or agitated arm or leg movements. Loved ones should not interfere or attempt to restrain the person. Instead, speak in a calming voice, quietly and naturally. Lightly massage their forehead, arms, or feet. Read something comforting. Play soothing music. It may also help to recall a favorite experience and to reassure.

Changes Prior to Death

Coolness

Hands, arms, feet, and legs may be increasingly cool to the touch. At the same time, the color of the skin as well as nail beds can appear blue or purple. The underside of the body may become darker and the skin blotchy. This indicates that circulation is decreasing to the arms and legs. The body reserves blood for the most vital organs, like the brain, the heart and lungs. Using a blanket for warmth (not an electric blanket) is fine, but no treatment is needed.

Breathing Changes

The breathing rate can decrease to five or six breaths per minute. It may cycle between rapid breathing to nearly stopping. This is called “periodic respiration” and is common in people with heart and lung disease, and in some neurological disease. There can be puffing, blowing the lips on exhaling, or an actual stop in rhythmic breathing. Then breathing may resume. These breathing patterns mostly take place when the patient is not awake or responsive. These patterns are common. They are not usually associated with the sensation of being short of breath, and do not need to be treated. Elevating the head or turning patients on their side may bring comfort in some instances.

Sometimes rapid breathing is a sign of air hunger, anxiety, or shortness of breath, although usually the person is awake if they are having these symptoms. Nurses and doctors can help sort out what a change in breathing pattern means. Medications can provide comfort when the person is short of breath.

Congestion

Gurgling in the chest, making a rattle-like sound, may become frequent. This is due to the decrease in the ability to cough up normal secretions, or from changes in the airways. The person usually does not feel anything. Suctioning can increase the amount of secretions the person produces and it may be uncomfortable for the person. Instead, one can turn the head to the side to drain the secretions by gravity or gently wipe their mouth with a moist cloth. In some cases, medication can be used to decrease secretions.

Urine Decrease

Urine output decreases. Urine may become “tea” colored. Urine becomes concentrated because of decreased fluid intake as well as slower circulation through the kidneys.

Other Signs

Blood pressure or heart rate can lower, though we do not usually check blood pressure or heart rate when someone is dying.

Skin can be mottled with spots of purple and white areas. This is not uncomfortable but happens when circulation shifts to the heart, lungs and brain and away from the skin.

The body temperature may fluctuate. Sometimes people are sweaty and clammy, or cold. It is fine to wipe their body with a cloth.

The Moment of Death

Although loved ones may feel they are prepared for the dying process, they may not be prepared for the actual moment of death. It may be helpful for all involved to discuss what they will do if they are present at that moment. It is not an emergency. Nothing must be done right away.

For some, a time of death may be a time to say a final goodbye or to openly mourn. Others may not want to remain with the body, feeling that the “person” or “soul” is gone. Religious and cultural beliefs may guide how you respond.

Death occurs when breathing ends, the heart stops beating, or the brain no longer functions. One or two long-spaced breaths often follow what appears to be the last breath. Then the body dies. There will be no breathing or heartbeat and no response to touch or sound. The eyelids may also be slightly open with the eyes fixed on a certain spot. The jaw is relaxed and the mouth is slightly open. Bowel or bladder control may be lost.

If the person is in the hospital at that time, a nurse or doctor will pronounce death. The nurse will ask whom to contact and ask about funeral arrangements. If you wish, the nurse can contact other important family members for you. The nurse will make sure that loved ones have private time with the body. Afterwards the nurse will prepare the body for transport to a funeral home. Hospital staff will allow family and friends as much time with the body as they need. Then they will arrange for the funeral home to take the body.

If the person dies at home, note the approximate time of death. Call the doctor, hospice agency or mortuary. Since this is not an emergency, there is no need to call 911. The mortuary will get signatures on the death certificate from the doctor.

It is our desire that this time be as free from fear and as peaceful as possible for each person and their family.

Spirituality at the End of Life

Concerns about meaning and value in life are generally present for those near the end of their lives. Many people have a need to address spiritual concerns. Family and loved ones also have these needs.

For some, being a part of a specific religion is a central focus. They receive support from the faith leaders they know. Some people are not a part of any religious community. They respect and honor their personal beliefs. There is no "right way" to reconcile and integrate one's life and death.

Those who are seriously ill, or approaching the end of life, share some common thoughts. They summarize life's experience and try to make sense of it. Other thoughts include:

- Saying goodbye
- Offering or seeking forgiveness
- Wondering about meaning and purpose
- Pondering what may be "on the other side" of death

Rituals, practices, and customs can provide comfort and meaning in a way that may provide more peace than words.

Often, we ask questions such as:

1. What have I accomplished with my life?
2. Is there something beyond this life?
3. If there is, will it be a place of joy and happiness or misery and suffering?
4. What can I "hope" for?
5. Do I have value that transcends my span of living?
6. Is my illness a form of punishment for what I have done or not done?
7. Who will look after the people I love when I die?
8. Does anyone understand what it's like to be me now?
9. How have I done?
10. Will I die alone or will someone who cares be there with me?

This list suggests ways in which we look at our lives and our relationships as we face letting go. Each person is on their own journey. For many, facing death involves seeking to integrate, make sense of and find meaning, in their life.

The task of caregivers, family and friends, is to listen, to hear, and to support the process.

Spiritual or religious leaders may provide additional support. Family and friends can help to identify a specific religious leader if the person identifies with someone, or with a given religion.

A chaplain, through a hospital or a hospice company, can provide support for the decisions a person faces and for the spiritual questions they confront. Chaplains can also support family and friends, or can reach out to specific religious leaders on behalf of the ill person and their family.

Planning Funerals, Memorials, Burial or Cremation

Making plans for funeral services in advance can reduce stress for your family and friends. These plans include your wishes for the care of your body after death. Some people do not want to think about their death, but it is important to appoint someone to do this. Other people have ideas about what they want and it is important to tell someone or to organize those things.

Organizing legal affairs is an important step, and it is helpful to complete a will, and to designate someone to manage affairs after death.

We can help people plan for others after they die. These plans can be for care or finances, or they can be remembrances at special events in the future.

For some people it is important to leave written or recorded messages. Family and friends can help create the messages by taking dictation, assembling pictures or other things, or making recordings.

Caregiver and Family Issues

Family and other caregivers also face a range of issues. These issues may differ from those faced by the ill person.

Grief and Sadness

You will cope with your own grief as you watch the person decline. People grieve:

- The loss of life as it was
- Changes in relationships
- Losses they expect in the future

Often people grieve while providing care or helping the person be as independent as possible. Being aware of your sadness and other emotions is important. A plan for coping with your own sadness will make watching the person's decline less difficult.

Recognizing the ill person's grief and loss will help you acknowledge their emotion.

Worry About the Patient's Well-Being

As a caregiver, you may see suffering. But often, what you see may not be what the person feels. Check how the person says they feel. It will help you, the person and their doctors or nurses better manage symptoms. Hearing what they say can also lessen your worry.

How to Talk With the Patient

Some people feel awkward talking to a person who is very ill or who may die soon. Remember that you do not need to talk about "dying" if the person does not open the subject. You can help the person reflect on how their life has mattered to others. Some ways to do this are:

- Talk about good times
- Talk about significant events and accomplishments
- Talk about people you both know and care about

Impact on One's Own Health and Other Aspects of Life

Caregivers often change their lives to help ill family or friends. They take time out of their own life's activities. The illness can affect the caregiver's finances, their ability to complete tasks and their work. Often helping others comes at the cost of their social activities.

Caregivers must remember to attend to their own lives. You need to eat and sleep. You need to exercise. Maintain social contacts and activities. Keep in contact with friends to reduce your isolation. It is important to have breaks in caregiving to do things that are important to you. Sometimes friends or family will provide scheduled breaks. Other times you may need to arrange paid care. A break or "respite" should be scheduled into care you provide.

Many resources are available to help caregivers. You can get help with financial planning to arrange care. The Area Agency on Aging or social workers can refer you to resources.

Additional Resources

Handbook for Mortals: Guidance for People Facing Serious Illness. Joanne Lynn, Oxford University Press, 1999

The Complete Bedside Companion: No-Nonsense Guide to Caring for the Seriously Ill. Rodger MacFarland and Philip Bashe, Fireside, 1995

Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill. Cappy Capossela and Sheila Warnock, Fireside, 1995

Facing Death and Finding Hope: A Guide to the Emotional and Spiritual Care of the Dying. Christine Longaker, Doubleday, 1998

A Year to Live: How to Live This Year As If It Were Your Last. Stephen Levine, Three Rivers Press, 1998

Beyond Grief: A Guide for Recovering from the Death of a Loved One. Carol Staudacher, New Harbinger Publications, Inc., 1987

Present Through the End: A Caring Companion's Guide for Accompanying the Dying. Kirsten DeLeo, Penguin/RandomHouse

Books Specifically for Children

Part of Me Died, Too: Stories of Creative Survival Among Bereaved Children and Teenagers. Virginia Lynn Fry, Dutton Children's Books, 1995

The Next Place (ages 4-8) Warren Hanson, Waldman House Press, 1997

Organizations and Web Sites

The Conversation Project:

Online resource for planning and talking about the end of life

https://theconversationproject.org

Growth House:

Contains comprehensive links to end-of-life care, including many that focus on diversity

www.growthhouse.org

The National Family Caregivers Association

Kensington, MD
1-800-896-3650

www.nfcacares.org

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I am grateful for critical input from friends and from a special group of people at Terwilliger Plaza who have experienced serious illness.

—Sarah J. Goodlin

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