

PREPARING TO SAY GOOD-BYE



Care for the Dying



THE COMPLETE LIFE SERIES

Preparing to Say Good-bye: Care for the Dying is the third in a series of five booklets on end-of-life planning and care. The booklets in the Complete Life series are:

Booklet 1 - Advance Care Planning: Making Choices Known. *A workbook to document the kind of care you want if you are unable to make decisions for yourself. Includes web addresses to find your state's forms.*

Booklet 2 - Planning Ahead: Funeral and Memorial Services. *A workbook to document your funeral or memorial service preferences ahead of time. Includes tips for consumers.*

Booklet 3 - Preparing to Say Good-bye: Care for the Dying. *Learn about common symptoms experienced by dying people and what you can do to make the dying person more comfortable.*

Booklet 4 - When Death Occurs: What to Do When a Loved One Dies. *A guide to help you get through the hours, days, and weeks following a loved one's death.*

Booklet 5 - Help for the Bereaved: The Healing Journey. *Learn about the common expressions of grief, the healing process, and when to get help.*

All five booklets can be downloaded from www.hawaii.edu/aging

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*At heart, hospitality is
a helping across a threshold.*

—Ivan Illich



CARE FOR THE DYING

Many physical changes occur during the process of dying that affect the emotional, social, and spiritual aspects of a person's life. There are some signs and symptoms of dying that are observable, although not everyone follows a predictable sequence of events or stages.

Sometimes, the last stages of life can be very stressful for the dying person and those caring for him or her. You may observe changes that are unfamiliar to you. You may have concerns and questions. Learning about the dying process will help.

Health professionals speak of "dying trajectories" that suggest how persons with specific diseases will die. For example, those with a terminal illness, such as advanced cancer, will show a steady decline toward death. Those with serious chronic illnesses, however, may have peaks and valleys that sometimes give the impression of recovery. Remember that each person's dying process is unique.

In this booklet, you will learn about the common symptoms experienced in people who are dying. You may observe none, some, or all of these symptoms in the dying person's last days and hours on earth. You will also learn to anticipate and manage the changes that may occur to help promote the comfort of your loved one.



Work of sight is done.

*Now do heart work
on the pictures within you.*

—Rainer Maria Rilke

QUESTIONS TO ASK YOUR DOCTOR

Like most people, doctors may be hesitant to talk about the inevitability of death. Should your loved one become seriously ill, here are some useful questions to ask the doctor.

1. How long do others in this condition live?
2. Are there any treatments that will make him or her well again?
3. Are there any treatments that will help him or her to live longer?
4. What are the benefits and the burdens of the recommended treatment options?
5. Tell me about hospice and palliative care. Are either of these appropriate at this time?
6. What is meant by Comfort Care Only?

HOSPICE AND PALLIATIVE CARE

 **What is Hospice Care?** Hospice is a philosophy of care that focuses on improving the quality of life for individuals with life-limiting illness. Hospice care can be provided in the home, hospital or nursing home setting. In the U.S., insurance currently only pays for hospice services if the doctor certifies that the person is expected to live for six months or less. Hospice services are covered by Medicare, Medicaid, private insurance with hospice benefits, and/or private pay.



What is Palliative Care? Like hospice care, palliative care can be provided in the home, hospital, or nursing home. Unlike hospice, however, palliative care can be provided to persons with a life expectancy beyond six months, and persons may still continue to pursue curative treatment for their condition.

Hospice and palliative care utilize a team approach to improve the quality of life by controlling pain and other symptoms, as well as providing emotional, social, and spiritual support for patients and their families.

Achieving the best possible quality of life is a cornerstone of both hospice and palliative care. For more information, visit www.nhpc.org and www.hospice.net/.



What is Comfort Care? Many states have a “Comfort Care - Do Not Resuscitate” (CC/DNR or CCO/DNR) program. When death is the expected outcome of a serious or life-limiting illness and a person does not want to be resuscitated, a CC/DNR bracelet may be ordered through a doctor. When worn, this alerts emergency first-responder personnel to provide comfort measures only should the heart or breathing stop. Ask your doctor more about this option in your state.

COMMON SYMPTOMS AND WHAT YOU CAN DO



Loss of Appetite. As death nears, a person may lose interest in food and drink. The ability to swallow becomes impaired. Loss of appetite and reduced intake are normal parts of dying.

In the early stages of dying, the person may prefer only soft foods and liquids. In the very last stages of life, however, he or she may not want any food or drink. The person may want to suck on ice chips or take a small amount of liquid to wet and freshen the mouth, which can become very dry.

In the last stages of dying, forcing food when the body says “no” may be harmful or painful to the person. Many dying persons will exhibit the clenched jaw sign as a way of saying “no.” Forcing fluid may cause choking, or the person may draw liquid into the lungs, making matters worse.

It is hard for most people to respect the person’s lack of appetite. That’s because many of us equate food with caring. Family members may feel that withholding nutrition is cruel or neglectful. They may worry that they are “killing” their loved one.

For the raindrop,

joy is entering the river.

—Galib



Remember that your loved one is dying from his or her disease, not from starvation. As the physical body dies, the vital organs shut down and nourishment is no longer required to keep them functioning. This is the wisdom of dying, and the body knows exactly what to do.

What you can do:

- Talk to the doctor or nurse about the advantages of reducing food and fluid in the last stages of dying.
- Refrain from giving liquids or food unless requested.
- Wet the lips and mouth with a small amount of water, ice chips, or a sponge-tipped applicator dipped in water.
- Protect lips from dryness with a protective lip balm.
- Consider removing dentures and bridges, as they may become loose.
- Continue to be a caring and loving presence.





Change in Bowel and Bladder Functions. The two major concerns are constipation and incontinence (loss of control over bowel and bladder functions).

Constipation may be caused by lack of mobility, pain medication, and decreased fluid intake. If left untreated, fecal impaction may occur and can become uncomfortable. Laxatives generally are needed to keep the bowels moving, particularly if the dying person is still eating or receiving nutritional supplements. Regulating bowel movements may be difficult at first, and the dying person may alternate between constipation and diarrhea.

Incontinence is likely to be distressing to the dying person and those in attendance. In the early stages, accidents can occur. Urine may be sparse, highly concentrated, and may look tea-colored. Sometimes a urinary catheter is inserted, or the dying person may wear diapers or briefs. This will help keep the bedding clean. Keep in mind that changing the bedding may be more disturbing to the dying person than the catheter or the diapers. As death nears, the muscles in these areas relax further and contents are released. This is normal.

What you can do:

- Watch for signs of constipation and incontinence, and help loved ones report this to the doctor or nurse.
- Keep affected areas clean and dry. After cleansing, apply a protective barrier cream to prevent skin rashes and bedsores.



Withdrawal from the External World. As the end of life approaches, there is a feeling of detachment from the physical world and a loss of interest in things formerly found pleasurable. There is a tendency to sleep more. There is less desire to talk. This is the beginning of letting go of life and preparing for death.

Days or hours before death, the dying person becomes less and less responsive to voice and touch and may not awaken. Sometimes, quite unexpectedly, the person may appear well and even look as if he or she is going to recover. The person may be alert and talkative. This is temporary and does not mean that there will be recovery; the person is still dying. Use this as an opportunity to say what you need to say and have closure.

What you can do:

- Always speak gently, and identify yourself before speaking. Hearing is normally preserved throughout the dying process.
- Use gentle touch, and provide reassurance. The dying person can feel your touch up until the end.
- Let relatives and close friends know what is happening.
- Dying requires energy and focus. Try not to distract the dying person from this necessary preparation.
- Allow time for silence. Remember that you are supporting the person to “let go.”



Visions and Hallucinations. Visual or auditory hallucinations often are part of the dying experience. The appearance of family members or loved ones who have died is common. These visions are considered normal. The dying may turn their focus to “another world” and talk to people or see things that others do not see. This can be unsettling, and loved ones may not know how to respond.

What you can do:

- Do not judge what is happening. Just be as supportive as possible. Or be silent.
- Refrain from discounting the experience and orienting the person to “reality.” Most often, these visions are reassuring, and they comfort the person.
- It is important to differentiate visions from hallucinations or bad dreams that may be caused by medications or metabolic changes. Visions of loved ones generally are comforting, but bad dreams may frighten the dying person. Alert the doctor or nurse about bad dreams. An adjustment in medication may correct this.

*Now, I have no choice but to see with your eyes,
so I am not alone, so you are not alone.*

—Yannis Ritsos



Confusion, Restlessness, and Agitation.

Restlessness and agitation are common. You may see the person "reaching out" with arms extended. You may also see picking, pulling, and fidgeting behaviors. These symptoms may be caused by reduced oxygen to the brain, metabolic changes, dehydration, pain medications, or a combination of these. "Terminal delirium" is a condition that may occur when the person is very close to death, and is marked by extreme restlessness and agitation. Although it may look distressing, the delirium is not considered to be painful. Medications are available to control symptoms.

What you can do:

- Never startle the dying with bright lights, harsh tones, or abrupt movement.
- Always identify yourself. Even if the dying person knows you well, he or she might not recognize you at this time.
- Use a gentle voice and reassuring touch.
- With mindful awareness, be sensitive to any cues that might signal that there is something the person wants to resolve before he or she can let go. Offer support.
- Consider the use of light massage and soothing music.
- If the dying person is agitated, ask the doctor if medications might help to reduce the agitation. Emotional and spiritual interventions may also be helpful at this time.



Changes in Breathing, Congestion in Lungs or

Throat. You may observe that breathing is shallow and quickened, or slow and labored. As death nears, the person may make gurgling sounds, sometimes referred to as the “death rattle.” These sounds are due to the pooling of secretions and an inability to cough them up. The air passing through the mucus causes this sound.

The breathing pattern most disturbing to witnesses is marked by periods of no breathing at all (typically 10-45 seconds), followed by deeper and more frequent respirations. These respirations, known as Cheyne-Stokes breathing, are common in dying persons and result from a decreased oxygen supply to the vital organs and a build-up of waste products in the body. This irregular breathing pattern is not uncomfortable or distressing to the dying person, although it may be unsettling to observe. The "death rattle" and very irregular breathing indicate that death is near.

What you can do:

- Do not panic. This can increase any fear that may already be present for the dying person.
- Raise the head of the bed (mechanically or with pillows) to aid breathing.
- If secretions are pooling in the mouth, turn the head and position the body so that gravity can drain them. Deep suctioning rarely helps and is not recommended.
- If appropriate, wipe out the mouth with a soft, moist cloth to cleanse excess secretions.
- Using a fan to circulate air may make your loved one more comfortable.

- Speak lovingly, and use gentle reassuring touch to ease fear.
- Alert the doctor or nurse of increased chest congestion, if breathing is especially labored, or if you notice the “death rattle” or very irregular breathing.



Change in Skin Temperature and Color.

As the body dies, the blood moves away from the extremities toward the vital organs. You may notice that while the extremities are cool, the abdomen is warm. You may notice changes in body temperature. The dying person may feel hot one minute and cold the next. As death approaches, there may be fever. You also may see purplish-bluish blotches and mottling on the legs, arms, or on the underside of the body where blood may be collecting. As death nears, the skin may appear yellowish or waxy in color.

What you can do:

- Try to keep the person as comfortable as possible.
- Be alert to signs (such as kicking off blankets) that the person is too hot. Use a damp, cool washcloth to ease the discomfort.
- Use a blanket to cover the person who feels cold. Don't use electric blankets or heating pads, as these may burn the skin.
- Alert the doctor or nurse if you notice changes in skin color. This may be a sign that death is near.

MANAGING PHYSICAL PAIN

Physical pain can be controlled. No one should die in pain when the means to alleviate it are available. All persons have the right to have their pain controlled.

Pain is real. Always believe a person who says he or she has pain. Remember that each person is an individual and that perceptions of pain differ.

Talking to the doctor. People should expect their doctors and nurses to ask these questions about pain:

- Do you have pain?
- Where is it? What does it feel like: dull, stabbing, throbbing, etc.?
- How intense is the pain? Please rate it on a scale from zero to 10, with zero being no pain and 10 being the worst pain imaginable.
- What makes the pain better or worse?

The answers to these questions will help the doctor prescribe the right medicine in the right amount. Make sure you and your loved one understand:

- What may be causing the pain
- The recommended treatment
- The possible side effects
- What to do if there are questions or concerns

For more information about pain, visit www.stoppain.org/.



TIPS FOR CAREGIVERS

You can be a caring presence throughout the dying process. Your presence for the dying person indicates your loving kindness, compassion, and your willingness to help.

Learn. Learn what you can about the dying person's illness and the dying process so that you can provide comfort and assurance. Do not hesitate to ask questions of the medical professionals involved in your loved one's care.

Realize your limitations. No one is perfect. No one can do everything. Take a break when you need one. Get help when you need it.

*True love is not a feeling
by which we are overwhelmed.
It is a committed, thoughtful decision.*

– M. Scott Peck

SAYING GOOD-BYE

People who are dying often want “permission” to die from those they love. They may need to be assured, quite literally, of five things:

- Things they were once responsible for will be taken care of
- The survivors will survive without them
- All is forgiven
- Their life had meaning
- They will be remembered

Saying good-bye is not easy. Yet, it is important for you and the dying person to do so. Take advantage of opportunities when the person is awake and communicative to facilitate the “saying good-bye” process.

If the dying person is not lucid or is in a coma, remember that hearing is the last sense to leave. Assume everything you say can be heard and understood, even if the person is not responsive. Never speak about the dying person as if he or she was not in the room.

Some people feel comfortable lying in bed next to their loved one as they say their parting words. Others may want to simply hold hands. If music, chanting, or prayer is used to assist the dying, let it be comforting and familiar, making way for gentle passage. The dying person’s body language will let you know if these sounds are welcome and soothing.



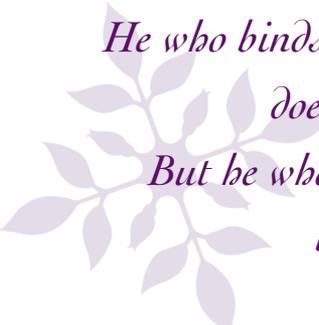
BEING PRESENT AT THE MOMENT OF DEATH

Even with all the preparation in the world, it is not comfortable watching someone you love die. Your decision to be present at the moment of death depends on many things. It is OK to choose to be present, and it is OK to be absent.

It is not uncommon, however, for the dying person to wait to die until loved ones have left the room. Make sure you allow for this, even if it is your wish to be present at death. Sometimes, if your loved one seems to be holding on, your kindest gesture may be to simply say, “I’m going to leave the room for awhile. I love you.”

In some cultures, specific prayers, sutras, or other rituals, may ease the passage to death. These may be comforting to you as well as to the dying person. You may ask your clergy person for assistance.

Booklets in the Complete Life series were developed under grant #90-CG-2548 from the National Family Caregiver Support Program, U.S. Administration on Aging.



*He who binds to himself a joy
does the winged life destroy.
But he who kisses the joy as it flies,
lives in eternity's sun rise.*

—William Blake

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