

As Death Draws Near

When a Loved One is Dying



Allina Health

Introduction

Dying is a sacred passage in life. As intimate and earthy as birth, each individual experiences dying in his or her own way.

Death is an event, while dying is a process. Dying can be sudden and unexpected, or drawn out over weeks and months. It is a journey everyone must take. The destination is known, but there are choices about paths, people, sites, and experiences along the way.

This is time of laboring not unlike childbirth. Many signs and symptoms are recognizable, but there is no prescribed way to die. Just as with life, dying comes easily for some, and less naturally for others. And like living, it is not a precise process, but sometimes is filled with uneventful days and quickening hours.

This booklet is offered as a guide on your journey. May these pages lighten your way with knowledge, reassurance, inspiration and hope as your loved one travels down this sacred passage.

Physiological Aspects

Physical aspects are changes in the body that occur near death. The body's needs shift from the work to develop and maintain strength to a process of shutting down and preparing to let go.

Food

In a variety of traditions, people gather around food (such as potlucks, wedding, banquets and funerals). Sharing meals is a source of nutrition, comfort and community during life.

As death approaches, the body naturally decreases its need for food to lessen the demands on the body. Appetite lessens and eventually disappears. Swallowing can become difficult.

While cravings may come and go for different foods, eating more than is needed can become physically uncomfortable.

While the desire for food lessens, your loved one's need for comfort and community remains and increases.

Nourishment also comes in the form of touch, conversation, story, music, laughter and caring presence.

- Listen closely to your loved one's requests and follow his or her lead.
- Offer food. Do not feel badly if it is refused.
- Eat a balanced diet yourself so you can help maintain your strength and coping abilities. Eat plenty of fruits and vegetables and drink plenty of water.

Fluids

The healthy body is more than 60 percent water. Many people begin the day with coffee or juice, and end it with tea or water. That is what a body needs to maintain health.

People struggling with illness and disease also need fluids to keep their systems working properly. But as your loved one moves toward death and the kidneys begin to weaken and shut down, excess fluids (including intravenous fluids) can cause discomfort and even place demands on the body.

- Talk with your care team about the amount of fluids your loved one needs for hydration and comfort. Health care team members can also provide special rinses that can help with dryness and thirst.
- Swab the mouth or give small ice chips or water from a straw to wet the tongue. These will provide comfort without giving your loved one too much fluid.
- Use a water-based (nonpetroleum) lubricant on the lips and lotion on the skin. This will express care as well as meet physical needs.

Pain and discomfort

Everyone feels pain differently. The dying person is the only person who can accurately describe his or her pain.

With increased knowledge and options for pain control, pain can be managed without inducing sleep in most cases. There is no need for anyone to suffer from uncontrolled pain, shortness of breath, agitation, nausea (upset stomach), vomiting (throwing up) or anxiety.

- Have a discussion with the dying person (if alert) and the health care provider about your loved one's views, wishes and values about pain management.

- Ask health care providers to discuss a plan for managing pain so you know it is in place.
- Keep a notebook with questions and information about pain.
- Ask questions.

Suffering can also be emotional or spiritual. Emotional, psychological and spiritual pain can make the physical pain worse. Physical pain can also worsen suffering that is caused by other sources. Relief for this kind of suffering may involve reconciling broken relationships or long-lost dreams, or addressing fears.

A palliative care consult can help assess sources of pain and suffering and suggest a plan. Ask the doctor or nurse about talking with a palliative care representative.

Alertness

It is common to feel an increasing desire to rest or sleep. Sometimes the desire to be alert for visiting with family and friends is a drain on energy.

Becoming overly tired or overly stimulated can cause fatigue or confusion. Sometimes this may be part of the disease process and may not be related to activity or stimulation. As the sleep cycle changes and naps occur more often, it is easy to become uncertain about the day or time.

- It is sometimes helpful to use reminders — using a daily calendar, talking about routine daily tasks or placing clocks where they can easily be checked — to support your loved one's orientation.
- Speak with your health care team if you see dramatic decreases in your loved one's consciousness or ability to communicate in a short period of time.

Sleep

Babies can be awake and alert and then suddenly asleep. Often, people go through a similar shift in sleep patterns as they move toward the end of life.

Your loved one may take several naps during the day and be awake several times during the night. This is natural. The need for rest and sleep allows your loved one's mind to do subconscious work in preparation for death.

- Sleeping is a way of coping for both the physical fatigue and the emotional and spiritual work of preparing for death.
- Sleeping more than half the day is not unusual.

Restlessness or agitation

Restlessness comes and goes. Some days are peaceful, others less calm. It is all part of the normal process as the body makes the transition between the work of living and the process of dying.

Agitation is a symptom with many causes. It is common during the last few hours of life.

If restlessness seems extreme, talk about it with the nurse or doctor. While there may be physical causes that are easily corrected, anxiety or fear can cause restlessness. It may be helpful to talk with a chaplain, social worker, or friend to share thoughts and address anxieties.

- Talking it through may help you find comfort and peace.
- There are medicines for your loved one that can help him or her rest.

Rally

Your loved one may have a time when his or her symptoms may decrease. He or she may appear to be stronger and become more alert or even talkative. This is known as a “rally.” It can be a wonderful time to share memories or wisdom, say prayers, or say goodbye.

As death nears

Remember that each person is unique and experiences may vary. These are some signs you may see in the last days and hours:

- Your loved one may withdraw and “move inward.”
- Blood circulation slows. This causes the skin to change color to gray or blue in hands, feet and around the mouth.
- His or her skin may feel clammy (cold and damp), even if the temperature shows a slight fever.
- Alertness varies. Some people remain aware of others, some become drowsy, others go into a coma.
- Blood pressure is lower.
- The pulse is faster than normal, then later slows and is weak with an uneven beat.
- There is little or no urine production.
- Breathing is fast, shallow and uneven. Later, breathing slows and becomes uneven, even with long pauses between breaths. Mucus may stay in the back of the throat and might cause a rattling sound. The rattle does not cause physical discomfort. (It may be helpful to raise your loved one’s head or have him or her lie on one side.)
- The muscles in your loved one’s jaw and face relax. The mouth stays open.

When death has occurred

- There is no breathing, pulse or blood pressure for several minutes.
- The pupils of the eyes are dilated and do not change.

Health care providers can guide you through the physical signs and symptoms of dying.

Psychological and Emotional Aspect

Emotional responses

This is an emotional time. Often people feel many things, sometimes in a random, chaotic order. Some people withdraw, not knowing how they are “supposed to feel” or what is the “right” thing to say.

When facing the death of someone you love, there are no rules about how to feel or how to act. Whatever you feel is normal — expressing it in safe ways with certain people may be particularly helpful.

Solo journey

Withdrawing is a part of preparing for separation, both for the person dying and for family and friends. It is one of the ways people grieve and prepare for the transition. To an outsider it might seem like a lack of desire for life has set in.

It is normal for both the one who is dying and the loved ones to have a variety of feelings and ways of expressing them. This may include feeling thankful for life and relationships or finding a sense of peace. Other reactions may include becoming quiet, feeling sad or angry, having regrets, or wishing for a different reality. These feelings (sometimes called hopelessness, despair or situational depression) can be a part of the grieving/reconciling process.

Talk with your health care team if you are concerned about how long or severe these feelings are for you or another. Remember:

- Withdrawal is common.
- Sullen, depressed, quiet behavior may be part of the process.
- Medicine and therapy may lessen the effects of severe depression.

Grieving as you go

The inner process of dying might involve feeling helpless against physical illness. Both you and your loved one may feel the emotions of grief (disbelief, anger, despair, blame, sadness, peace). There are many losses that contribute to grieving.

The work of moving toward peace can include:

- facing and accepting mortality
- grieving the loss of one's own independence, relationships, and goals and dream not fulfilled
- changing identities within the family as members shift roles and learn new patterns out of necessity.

This is hard work. Many people can find it emotionally challenging when they are already physically tired from care giving. A social worker, nurse or chaplain can help in finding a support group for those living with terminal illness and for their survivors.

Individual needs

It is helpful to be aware that individual needs might change near the end of life. What is important at one time may no longer be in need of attention.

As a family member, you want to protect your loved ones and provide for them. But it is easy to make incorrect assumptions based on what you think others would want.

It is difficult (but important) to ask your loved one about what he or she needs — and then wait patiently for the answer. You may be surprised to learn that your loved one wants something you didn't anticipate. This can be a time of learning and giving.

Hearing and touch

Hearing is the sense that usually stays with each person the longest. Favorite music can be refreshing. Even while sleeping without stirring, the tender voice of a loved one can be heard.

When speaking becomes too difficult or mumbled, a gentle hand brings relaxation and assurance of presence. If restlessness occurs, use gentle ways, such as telling stories in a calm voice, to assure your loved one of your presence.

Sometimes people need a rest from touch, particularly as they withdraw. Talking and being present is a powerful way to support each other. Allow your own comfort level to guide you in caring for and talking to your loved one.

- Speak normally. Avoid whispering, as it can be thought of as telling secrets.
- Carry on conversations.
- Laugh and tell stories that complete the circle and bring the past and future together into the present moment.

- Know that a peaceful presence or reassurance may be enough without long conversations.

No one expression of love meets all needs. Do your best, and allow family and others significant to your loved one to offer their best.

Social Aspects

Environment

No two people make the same choices about what they want or hope for while living out their last months or days. Some choose to go home, surrounded by family and friends, or to be wrapped in the quiet of a still room without nurses and attendants. Some choose a residential hospice or nursing home where professionals attend to the daily tasks.

It is an individual choice influenced by the desires of the individual, the family, personal finances, and circumstance. Care giving at home can be exhausting, even for the kindest of people.

- Do the best you can.
- Reassess how care is done on a regular basis and decide if more or less help might be needed.
- Don't be afraid to ask for help. Living, loving and letting go is hard work for everyone involved.
- Remember your relationship. Sometimes you might need to just "be family" while letting others (such as nursing home or hospice staff or private pay staff) care for your loved one.

Space

The way the room is arranged can help transform it into a place of passage. One or two objects which are well-loved (such as a painting, a treasured book, quilt or pictures) can make clinical space feel more homelike. For some people, the presence of spiritual, religious or cultural items can bring great comfort.

Material needs fall away with time, and your loved one may want simplicity. Small gifts of affection can keep people connected and living each day fully, even when it is only a few hours of awake time.

You might:

- Use music, soft lighting, candles or other sensory objects as reminders of your care. (Never leave lit candles unattended.) In health care facilities, check with your nurse.
- Place chairs that can easily be moved within hand-holding distance for short visits from friends.
- Move a bed or chair near a window so your loved one can see outside.
- Offer gentle massage or light touch to stay connected.

Roles

Each family decides, on purpose or not, who will carry out which roles. The roles might include: main contact person, advocate, financial adviser, secretary, social coordinator, care giver, maid, friend, confidant, minister/spiritual adviser, nurse, doctor, family member.

Often, one person takes on many roles in the care team. When this happens, others may need to watch for the effects of added stress that come with each job. All people have needs and limits, and need to receive support in order to keep giving.

If more support is needed, it may be helpful to speak with friends, extended family, or the chaplain, social worker or nurse who is part of the health care team.

- Take care of yourself to avoid emotional and physical exhaustion.
- Rearrange your family time to take care of your physical or emotional rest.
- Accept offers of help from volunteers or friends, or ask a social worker about respite care. This is care that offers care givers a needed break.

Helping children cope

The following are suggestions on how to help children while a loved one is dying.

- Be honest about what is happening.
 - Children may be uncomfortable about asking questions, but they still have a need for honest, straightforward information about what is happening.
 - If you are not sure what to say, ask your health care team to contact a social worker or chaplain to talk with you.
- Give children the opportunity to visit their dying loved one.
 - Children deserve the opportunity to say goodbye. If a child doesn't want to visit, this should not be forced. It is important to ask about what frightens him or her about visiting so that you can alleviate any fears.

Often, children who are worried about visiting may change their minds if they know what to expect.

- If children choose not to visit, encourage them to send a picture, poem, letter, e-mail, audio or videotape, or other expression of their love with someone who is planning a visit. Be sure to let the children know how much their efforts meant to the loved one.
- If children choose to visit, prepare them for what they will see.
 - Describe any changes in the dying person's behavior or level of awareness. You can say, "The medicine that helps grandma not feel any pain makes her very sleepy. Even though she can't talk back to you, she can hear what you're saying and loves you very much."
 - Describe any changes in the way the person looks and may feel if the children choose to touch him or her.
 - Describe any tubes or machines the children can see.
 - Take a photo of the dying person in the hospital and share it with the child in advance. This is a helpful way to prepare them for what they will see and gives an opportunity for discussion before the visit.
 - Make a plan for what children will do during the visit, such as talk to the dying person, touch him or her, read something they've written or share a memory. This may also be an appropriate time to help children begin the memory-making process.

With help, they may choose to start a memory box or photo album, make a book about special times with the loved one, or make a family hand print poster.

- Reassure children that another adult will be with them and they can choose when the visit is over. It is common for visits to be brief, sometimes less than 5 minutes.

- Death can be confusing for children. Be alert for any misunderstandings and reassure the children.
 - Three questions are common for children when a loved one is dying, whether they can say them or not:
 - “Did I cause it?”
 - “Will it happen to me?”
 - “Who will take care of me?”
(If the dying person is an immediate caregiver.)

It is important to answer each of these questions as soon as possible.

- Sometimes children believe they may catch the same disease their dying loved one has by touching them. Reassure them that this is not possible.
- When talking about death use the words “dead” or “dying” or words that are culturally appropriate. Words such as “sleeping” or “taken by God” can be confusing, especially for younger children.
- Children may have a wide range of emotions when a loved one is dying.
 - Let children know that there may be times when they feel happy or sad and that both are OK. Because children grieve differently than adults, they may ask permission to play and want to resume their routine activities.
 - Sometimes children can’t express their feelings and fears so they react by changing their behavior. A child who was toilet trained may have accidents or an independent child may be more clingy. He or she may have more trouble concentrating in school.
 - Give children chances to share their thoughts and feelings. Some children may like to draw, write or just talk.

■ Teenagers can have a difficult time when a parent is dying.

- They are capable of greater empathy than younger children. As a result, they may be more troubled by the pain and physical discomfort of their parents.
- When a parent is dying, the teen is challenged deeply, not only by grief but also by trying to figure out what role he or she is now being asked to play in the family.
- Like many loved ones, teens feel deeply the “loss of dreams” that goes with the death of someone who close.
- Some teens — although they feel emotional pain deeply — have trouble expressing it, especially at home.
- When a parent is dying, a teen may cope by stepping away or becoming overly responsible. The teen may take on adult roles he or she is not ready for developmentally.
 - As a teen changes physically, mentally and emotionally, conflict with parents is common. If a troubled relationship is with the sick parent, a teen may have a hard time dealing with the loss due to unresolved issues.
 - Anger, guilt and regret are powerful emotions that teens may not easily share. As a result, teens may feel these emotions intensely, “stuff” the emotions, or act them out.

Good communication between parents and teenagers has been shown to help reduce anxiety and help teens cope better. Support groups and the support of teachers, school counselors, youth leaders, and other significant adults can also be a great help.

- The following are general guidelines about how children understand death.
 - Infants and toddlers do not understand death but they are sensitive to their surroundings.
 - Children ages 3 to 6 view death as reversible and temporary. They believe that people who die will come back.
 - Children ages 6 to 9 begin to view death as final.
 - Children ages 9 to 12 are more aware of the finality of death and their own mortality.
 - Adolescents have an adult understanding of death as inevitable, universal and irreversible.

For more information about how you can help children understand death and things you can do to help, ask a member of your health care team.

Outside support

Living with a terminal illness or condition as part of daily life affects family relationships and friendships. Some people don't know what to do or say. Others have grace and humor. Relationships shift — some become deeper, some become strained. Remember, people are doing the best they can.

Communities, hospitals, faith congregations and cultural communities may offer support resources for those living with illness, as well as for their family and friends. A friend may allow you to reflect on the changes, struggles and strains of daily life.

- You may find seeking support challenging, but reaching out can strengthen and deepen your spirit and bring perspective.

- Hospice can provide nursing care and help, chaplain and social work support, and volunteers who specialize in hospice care.
- Palliative care doctors and nurses have specific training in the care of dying people that focuses on comfort with dignity and peace.

If you have a large support group, you might consider a few tips:

- Create a phone tree. You do not need to call everyone to update them about changes. Create a system where you make one call.
- Allow your voice mail/answering machine to pick up messages.
- If there is a family member who is skilled with computers, ask him or her to create a website or email group to update people. These can also bring messages of support, encouragement and love to you. This is also a good way to actively involve children and grandchildren. A free online service for helping families keep their friends and communities informed is available at caringbridge.com.
- If there are several care givers, create an everyday log of activities and care. A simple notebook placed for everyone to see helps to keep track of activities and care.

Spiritual Aspects

Closing the circle

The physical completion of life can feel sudden. But the spiritual process of living and dying is around you each day. You are familiar (though often unaware) with the pattern of birth and death.

Some people feel the rhythm of seasons deeply, gladdened by the cycle and the promise that it will come again next year. For many, dying is another season.

- Many people, religious or not, believe in an afterlife. This may be a source of hope and encouragement.
- Some people may refer to death as the final phase, returning to the dust of the ground from which they came. It is a completion of their earthly journey.
- For some people, it is meaningful to participate in the religious, spiritual or cultural rituals of their tradition.
- Others may wish to create something new that will affirm the life of their loved one and prepare the family for the “letting go” of death.

Hospital spiritual care providers or chaplains can help you make connections with community elders and religious/spiritual care givers. They can also provide spiritual comfort or care as desired by you or your loved one.

Talking about life and death

It is common for people who are nearing death to want to talk about the experience, their hopes and fears, their beliefs and their needs. Sometimes they may choose not to talk about these things with family or friends because they think it will be too hard for themselves and/or their loved ones.

These are conversations that are not normally practiced ahead of time. You may feel unskilled to talk about these things. Maybe all that’s needed is for you to listen to your loved one.

- Ask your loved one if there is anything he or she wants to talk about.
- Be open. It is not necessary to have answers.
- Invite people to tell stories from all times of life. This can allow your loved one to reflect on history, wisdom and values.

Reconciliation

The desire to make amends and heal old wounds can be an important part of this journey. Making peace with the past, future, family, and God happens in many ways. A few helpful hints for finding the difficult words:

- **“Forgive me.”** Relationships often involve hurt.
- **“I forgive you.”** Seize the moment. It is unhealthy to hold on to old wounds or past mistakes.
- **“Thank you.”** It is a wonderful gift to offer thanks for people and things that hold meaning in your life. It is a legacy to have loved and been loved.
- **“I love you.”** Expressing love with words and touch is a powerful affirmation of life.
- **“I/We will be alright.”** Releasing another and assuring them can bring peace.
- **“Goodbye.”** Saying goodbye is difficult. You may want to hold on forever in fear of closing the circle. Goodbye is a shortening of “God be with ye” — a blessing. You can offer that affirmation and blessing of life with love.

Moving on

As they grow near death, people sometimes see visions or talk with people who have died before. This may be experienced as the lifting of the veil between this world and the next. It is not unusual and does not need to be frightening.

If your family finds spiritual or cultural tradition or ritual to be a source of strength and hope, it may be appropriate to have a prayer service, ceremony or blessing. These are sacred places, filled with mystery and wonder.

For More Information

Booklets

- Financial and logistical information is found in the Allina Health booklet “When a Loved One Dies.”
- Grieving information is found in the Allina Health booklet “Grieving the Death of a Loved One.”
- “A Guide Book for Adults Helping Children and Teens Cope Through Serious Illness, Grief and Loss.” (Call 1-888-815-HOPE or visit HopingSkillsCompany.com.)

Websites

- allinahealth.org/hospice
Allina Health Hospice
- lastacts.org
Last Acts, a national coalition to improve the care and caring at the end of life
- hospicemn.org
Hospice Minnesota
- nhpco.org (includes information for children)
National Hospice and Palliative Care Organization

- HopingSkillsCompany.com (for families with children)
This is a commercial site. You will be asked to pay for some information.

Phone numbers

- Allina Health Home Care Services
651-635-9173
- Allina Health Grief Resources Line
651-628-1752

Professional references

- *"Peace and Possibilities at the End of Life,"* Byock, Ira, Riverhead Books, 1997
- *"To Comfort Always: A Nurse's Guide to End of Life Care,"* Norlander, Linda, American Nurses Association, 2002
- *"End of Life Care: Clinical Practice Guidelines,"* Kuebler, Kim K.; Berry, Patricia H.; Heidrich, Debra E., The Saunders Company, 2002
- *"How to Help Children Through a Parent's Serious Illness: Supportive, Practical Advice from a Leading Child Life Specialist,"* McCue, K., St. Martin's Griffin, 1994
- *"The Oxford Textbook of Palliative Medicine,"* Doyle, Derek; Hanks, Geoffrey W.C.; and MacDonald, Neil, Oxford Press, 1993
- *"Palliative Care Nursing: Quality Care to the End of Life,"* Springer Publishing Company, Inc., 2001



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grief-ah-22925 (5/09)