



Understanding end-of-life transitions





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Gone from my sight

I am standing upon the seashore. A ship, at my side, spreads her white sails to the moving breeze and starts for the blue ocean. She is an object of beauty and strength. I stand and watch her until, at length, she hangs like a speck of white cloud just where the sea and sky come to mingle with each other.

Then, someone at my side says, "There, she is gone."

Gone where? Gone from my sight. That is all. She is just as large in mast, hull and spar as she was when she left my side. And, she is just as able to bear her load of living freight to her destined port.

Her diminished size is in me — not in her.

And, just at the moment when someone says, "There, she is gone," there are other eyes watching her coming, and other voices ready to take up the glad shout, "Here she comes!"

And that is dying...

— Henry Van Dyke

Our place is by your side. You are not alone.

Hospice care offers physical, emotional and spiritual comfort for patients who are making the transition to end-of-life. We care for the person, instead of the disease. Hospice care do not hurry death or prevent it; instead it reaffirms life, focuses on dignity, and brings comfort and quality to a person's remaining months, weeks and days.

We are here to answer your questions and guide you through the process. Our hospice support team helps patients and families with personal care needs along with social and emotional issues, as well as grief. We have grief counselors available to meet with you at your request before and after the death of your loved one.

Everyone experiences losses throughout life, but the death of a loved one is unequalled in its sadness. It can reshape our existence with a slowness and surreal feeling that is hard to overcome.

We emerge into a different world; one in which our loved one will no longer be physically present. For many, strange and unexpected feelings also emerge including feelings of relief in the midst of the pervading sadness.

A relief that our loved ones are no longer suffering, mingled with the grief of their physical loss.

We are here for you

There is hope and possible growth in the wake of death and separation. Our bereavement counselors and staff offer support services to those who are grieving. Talk with your hospice care team to learn about services available to you.

Through our professional team of bereavement counselors, social workers, and volunteers we offer support to you and your family members as requested.

For more information about our support services and bereavement care program, ask any member of your care team or contact our office any time.

Part of understanding end-of-life transitions is knowing that it is a personal journey for your loved one. There may be emotional, spiritual, and physical changes through the transition. There is no precise order for any of the processes, but the following is a guide to what you may experience with your loved one and what you can do for them.

Preparations

Your loved one may want to compile “to do” lists. This may be as simple as going outside, looking out the window, going to the table for a meal, or finishing a book. It may also be as complex as taking a planned trip, finishing a home project, or personally taking care of some practical business. Some of these may be achievable and some may not.

Help your loved one compile their list and achieve them. Alternatives may need to be substituted for complex items. A travel movie may be watched as opposed to making that planned trip. Enlist others to help accomplish the list when necessary. This provides closure to the person and helps them through the “letting go” process.

Another “to do” list may be directed at personal and business affairs. It is very helpful to those left behind if your loved one has a chance to complete any personal business, including financial arrangements, creating a will, or planning their funeral.

Your loved one may want to give away some personal belongings. While this can be a very emotional time for you, remember this is another way your loved one may feel closure. Make a list of people they want contacted now or at the time of death, including friends, family, business associates, community, and church groups. Including addresses and phone numbers may prevent any confusion later.

Emotional changes

Withdrawal

Your loved one may appear to be withdrawn or unresponsive. This is a preparation for “letting go.” A detaching from relationships and surroundings is a normal part of the dying process. Since hearing is the last sense to go, speak to your loved one in a normal tone and identify yourself. Say whatever you need to say that will help them “let go.” Withdrawing may be one of the first things you notice occurring as your loved one is accepting that they have a terminal diagnosis.

Decreased socialization

This may be one of the hardest parts of the dying process for family and loved ones to accept. Your loved one may only want to be with one person or a few select people. This is an affirmation of who they are and who they need the most to help them make the transition from life. It does not mean that others are unwanted or unloved. It simply means that you have fulfilled your job of helping them and it is time for you to say “good-bye.” If you are one of the ones they want to keep close, you need to give your support, affirmation, and permission for your loved one to let go.

Anxiety and nervousness

Your loved one may have some unfinished business or tasks that may cause them to be anxious, nervous, or to do repetitive tasks.

Try reading some comforting words or talk about favorite people or experiences to help calm them. Play some soothing music and reassure them that it is ok to let go.

Unusual communication

Your loved one may make comments or gestures that are out of their normal character. This is their way of testing to see if you are ready to let them go. This is your time to kiss, hug, hold, cry, and say whatever it is you most want to. This moment should be seen as a beautiful final gift.

Vision-like experiences

Your loved one may speak to people who are not visible to you, including others who have already died. This is not a hallucination or reaction to a drug. They are detaching from life as we know it and making the transition less frightening. Do not contradict or argue with what they claim to have heard or seen. Explain that these feelings are normal and natural. This type of behavior is often seen in the later weeks or days of life.

Emotional changes for the family & caregiver

Saying goodbye

Saying “goodbye” gives closure and is a final gift you give your loved one. It may be helpful to both of you to lie in bed and hold them close or simply hold their hand while you say whatever you need to. This may be as simple as an “I love you” or it may be a remembrance of favorite memories you share. It may be the words “I’m sorry” or “thank you.” — whatever you feel from the heart. Tears are a normal and natural part of this process and do not need to be apologized for. Crying is a way we express our love and it will help you let go.

Giving permission

This can be a very difficult thing to do. Your loved one may hold on, even though it may be very difficult or uncomfortable, waiting to know that those who are left behind will be alright. One of the greatest gifts that you can give the dying person is permission for them to let go whenever they are ready and not to feel guilty for leaving you behind. You need to release them from this concern so they can make this journey. Simply telling them “it’s ok” or letting them know that you understand they are ready to go can bring relief to them.

Spiritual changes

Forgiveness

Your loved one may have a need to ask for and receive forgiveness for whatever they have done in their life. They may want to talk to people they have not seen in years. They may want to reconcile differences with those whom they feel estranged from. They may simply want to say “I’m sorry” or hear those words from someone else. It is helpful if this can be achieved, but it is not always possible. Reassure the person that all is forgiven or help them write their needs for forgiveness.

Confession

Depending on the individual’s religious affiliation, they may have a desire to make a final confession of their sins, misdeeds, or perceived wrongdoings. Seek the help of your spiritual or religious leader to accomplish this. They may have a need to release themselves of the burden of guilt for past actions. This is a normal part of the “letting go” process. Often people want to tell these feelings to someone outside of their “inner circle,” which is normal, natural, and alright.

Speaking of the afterlife

We all have our own perceptions of an “afterlife.” The dying person may see visions of people or places that we cannot see. They may talk about heaven and what it will be like. They may see or talk to people who are already dead or call the names of loved ones who are not there. Your loved one may be aware of dimensions that we cannot experience. These are all very real to them and giving them reassurance can be very helpful.

Suggestions

We all have questions of what will happen to us when we die. For someone in the active dying process, this may be more pronounced. They may have questions about where they will go or wonder, “What has been the meaning of my life?” “What is my purpose for being here?” or “Why is this happening to me?”

Listen to what is being asked, answer when you can, and seek the help of the hospice chaplain or spiritual leader when needed. Do not be offended if your loved one does not want to discuss these issues with you. They may be far too personal to discuss with those we are close and connected to. Tears are very common in discussing spiritual issues. Presence is of utmost importance and the simple act of holding someone’s hand and letting them know they are loved and cared about is often the best thing you can do.

Physical changes

Sleeping

The person may spend an increasing amount of time sleeping and appear unresponsive. This is a normal change in which the body is conserving energy and is due in part to a decrease in the metabolism. Sit with your loved one and speak to them as you would naturally do. Plan to spend more time with them when they are awake. Hearing is the last sense to go, so never assume that the person cannot hear you. Speak directly to them, even when there is no response.

Restlessness

Your loved one may appear restless, picking at covers or the air for no apparent reason. This is also due, in part, to the changes in metabolism or decreasing oxygen in their blood. They may also become confused. Speak softly to create a calming effect. Try playing some soothing music or massage their forehead. Talk with your hospice nurse about medications which might help with this if it becomes pronounced.

Fluid and food decrease

Your loved one may want little food or fluids. The body naturally decreases the amount of energy required for this as a way to conserve it for more vital functions. Do not force food or fluids as it may make the person more uncomfortable. Try giving them ice chips or frozen juices or Gatorade which can feel very refreshing in the mouth. Mouth swabs or a moist cloth will help keep the area moist and more comfortable.

Your loved one may experience a decrease urine output or it may become dark or tea colored. This is due to a decrease in the circulation in the kidneys as well as a decrease in fluid intake. Talk with your

hospice nurse about this to determine if there are alternative solutions which will make them more comfortable.

Confusion/disorientation

Your loved one may be confused or disoriented at times as to where they are, the time, or who is around them. This is also due to changes in their metabolism and is a natural and normal part of the dying process. It can be very disheartening when your loved one does not recognize who you are. Identify yourself when talking to them, and never have them try to guess who is around them. Speak softly and in a clear voice. Give specific instructions and reasons when giving medicines or providing treatments.

Loss of bowel and bladder control

As the muscles begin to relax, the person may experience loss of control of their bowels or bladder. This is called incontinence and can be a very difficult adjustment for the patient and family. Talk with your hospice nurse for help in keeping your loved one comfortable and clean, as well as to protect bedding.

Coolness

As the blood circulation decreases to the arms, hands, legs and feet, they may feel cool to the touch and become bluish, splotchy or mottled in appearance. This is a normal accommodation of the body to keep blood supplied to the most vital organs. Keep the person warm with a blanket, but do not use an electric blanket. Sometimes the person may feel cool, but does not want added covers. All of this is normal.

Congestion

Gurgling or rattling sounds are due to the decrease in fluid intake and the inability to cough up normal secretions. It may sound like there are marbles rolling around inside, and it may become very loud. Try gently turning their head or body to the side to allow gravity to drain the secretions or gently wipe the mouth with a moist cloth. These sounds do not indicate the presence of pneumonia or an increase in pain.

Changes in breathing patterns

Changes in breathing patterns are normal and natural. These may be a consistently irregular pattern with periods of no breaths for 5 to 30 seconds or up to a minute. This is called Cheyne-Stokes breathing. A decrease in circulation to internal organs may result in a rapid shallow pattern or a panting-like breathing. Try elevating the head or turning the person on their side. Holding their hand and speaking gently will also help the person know that you are there. The simple act of holding someone's hand is often the best thing you can do.



Understanding end-of-life transitions

Below is an overview of some emotional, spiritual, and physical changes that occur near the end of life to help you understand the transition. Your loved one may experience some or all of these changes, which are all normal and natural in the dying process. We are here for you and to answer your questions. Any time you have a concern about changes, ask your hospice care team.

Emotional & spiritual changes	
What you may see	What you can do
<p>Preparations Wanting to complete a task or make arrangements; may be simple, financial, or complex; Giving away possessions</p>	<p>Help your loved one make their lists and complete them as possible; honor their wishes</p>
<p>Restlessness Appears agitated or does repetitive tasks</p>	<p>Give words of comfort, be calming, and talk about favorite experiences</p>
<p>Visions/unusual communication Comments made out of character; speaking to people not visible to you</p>	<p>Do not argue with their claims, but assure that the feelings are normal and natural</p>
<p>Withdrawal Unresponsiveness, or detaching from people and surroundings</p>	<p>Continue to talk with them in normal volume as they may still be listening to you as they begin to “let go”</p>
<p>Forgiveness May seek forgiveness, be asked for forgiveness, or need to reconcile differences</p>	<p>Help your loved one achieve this if possible, and reassure them of forgiveness</p>
<p>Giving permission/saying goodbye Your loved one may hold on to make sure those left behind will be alright</p>	<p>Release them from their concern and let them know they may let go whenever they are ready; saying goodbye or simply “I love you”</p>

Physical changes	
What you may see	What you can do
<p>Coolness Circulation decreases and skin may feel cool and appear blotchy or blueish</p>	Keep them covered with a blanket, though they may not want to be covered
<p>Sleeping or confusion/restlessness Increased sleeping and unresponsiveness; when awake may not know where they are or time; increased confusion may make them appear restless</p>	Keep your loved one company and speak in a normal volume; identify yourself and speak calmly to reassure them
<p>Fluid or Food Decrease Decreased desire to eat or drink is normal</p>	Do not argue with their claims but assure that the feelings are normal and natural
<p>Loss of bladder or bowel control Urine will decrease and may be tea colored; as muscles begin to relax, your loved one may have loss of control of their bladder or bowels</p>	Continue to talk with them in normal volume as they may still be listening to you as they begin to “let go”
<p>Congestion in the lungs or throat Gurgling sounds or inability to cough up secretions; May sound like marbles rolling around, possibly loud</p>	Help your loved one achieve this if possible, and reassure them of forgiveness
<p>Breathing patterns Irregular patterns with periods of no breaths for 5-30 seconds, up to a minute called Cheyne-Stokes breathing; also rapid, shallow breaths or panting</p>	Release them from their concern and let them know they may let go whenever they are ready; saying “goodbye” or simply “I love you”

As death approaches

As death becomes imminent, some or all of the physical and emotional changes become more evident and pronounced until death occurs. Although you may have done everything you can to prepare for the death, you may not be prepared for the actual moment. This is ok, normal, and natural. You may want to talk with your family about what to do if you are the one present at the time.

Signs of death include no breathing, no heartbeat, no response, pupils enlarged and the eyelids slightly open, no blinking and eyes fixed on a certain spot, release of bowel or bladder, and jaw relaxed with the mouth slightly open.

Contact your hospice nurse when you think death has occurred. They will come to the home and contact the doctor and funeral home. The body does not have to be moved until you are ready, and you can assist in preparation, such as bathing or dressing, if you want to.

Bereavement care

Whether a death is expected or not, grief is a natural response. Anxiety, fear, depression, sorrow, and anger are often present at the time of death and for months to come.

Through bereavement care we will continue to support your family for up to 13 months following the death of your loved one.

Please talk with your hospice care team or agency to learn about what is available to you in your area.* We provide bereavement care in some or all of the following ways:

Individual support

This may include personal visits, phone calls, or a series of letters sent to provide words of encouragement and support through your journey of grief.

Support groups

Groups provide an understanding environment in which to share the experience of loss with others.

Memorial services

Services focus on the spiritual aspects of loss. The service is a special time to honor and remember lost loved ones.

In-services

Bereavement training and education seminars are available to families and the community upon request.

Grief is a natural process that we experience before and after we suffer the loss of a loved one.

Understanding grief

There are seven recognized stages of grieving any loss. You may go through all seven stages or only a few. You may go forward and then go backward before moving forward again.

Since we all are individuals, each of us progresses through these stages on our own schedule. It can be difficult to deal with the dying loved one when we are at different stages, but recognizing our differences can help.

7 Stages of grief

Shock and denial

Every individual reacts differently to the loss of a loved one. You may deny the reality of the loss at some level in order to avoid the pain. Shock provides emotional protection from being overwhelmed all at once. This may last for weeks.

Pain and guilt

Life feels very scary and chaotic during this phase as you realize the loss that has happened is true. Although almost unbearable, it is important that you experience the pain fully and not hide it, avoid it, or escape from it with alcohol or drugs. You may have guilty feelings or remorse over things you did or didn't do with your loved one.

Anger and bargaining

Frustration gives way to anger and you may lash out and lay unwarranted blame for the death on someone else. Permanent damage to your relationships may result if you don't control your anger. This is a time for the release of bottled up emotion. You may question, "Why me?"

Depression, reflections and loneliness

Just when your friends may think you should be getting on with your life, a long period of sad reflection may overtake you. This is a normal stage of grief, so do not be talked out of it by well-meaning outsiders. During this time, you finally realize the true magnitude of your loss and it depresses you. You may isolate yourself on purpose, reflect on things you did with your lost one, and focus on memories of the past.

The upward turn

As you start to adjust to life without your loved one, your life becomes a little calmer and more organized. Your physical symptoms lessen and your "depression" begins to lift slightly.

Reconstruction and working through

As you become more functional, your mind starts working again and you will find yourself seeking realistic solutions to problems posed by life without your loved one. You will start to work on practical matters and begin reconstructing yourself and your life without them.

Acceptance and hope

During this last stage, you learn to accept and deal with the reality of your situation. Acceptance does not necessarily mean instant happiness, but there is a ray of hope. Given the pain and turmoil you have experienced, you may never return to the carefree, untroubled you, but you will find a way forward.

While there is no set timeframe for how long any of the stages of grief may last, if you find yourself to be still overwhelmed and having difficulty functioning after the first year, it may be helpful to seek additional individual counseling.

Resources

We will answer your questions and provide support however you request. Some find it helpful to read and gather information on their own, as well. Below is a list of additional resources you may find helpful.

Books

When Death Touches Your Life by Mervin Thompson

Stay Close Do Nothing by Merrill Collett

Dying Well by Ira Byock, MD

A Caregiver's Guide by K. Macmillan, J. Peden, J. Hopkinson, and D. Hycha

The Grace in Dying by Kathleen Dowling Singh

How We Die by Sherwin B. Nuland, MD

The Four Things that Matter Most by Ira Byock, MD

Choices at the End of Life by Linda Nordlander, RN and Kerstin McSteen, RN

Websites

National Hospice & Palliative Care Organization: www.nhpco.org

Family Caregivers Alliance: www.caregiver.org

Hospice Foundation of America: www.hospicefoundation.org

Aging With Dignity: www.agingwithdignity.org



For most people, caring for someone at the end-of-life is a new experience. We understand this can be a very confusing time. This booklet provides some information on questions you may find difficult to ask.

We are here to care for our patient, and we are here for you. You may be going through a very emotional experience. We are here to support you.

The end-of-life process is as unique as the person experiencing it. This booklet is a basic guide to answer questions you may have and offer suggestions designed to help you.

Our place is by your side. Any time you have questions or concerns, call us first. We are here for you 24/7/365.



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