

When the Time Comes



A CAREGIVER'S GUIDE


Serenity First
HOSPICE CARE

Your Comfort, Your Legacy

“The things that matter most
in our lives are not fantastic or grand.
They are the moments when we touch one
another, when we are there in the most
attentive or caring way.”

— Jack Kornfield

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Introduction

Dying is a natural part of life. Yet many of us do not know how to care for someone at the end of life. It's normal to have a wide range of feelings or to be unsure of what to do.

At times it may seem as if you're on a roller coaster. You may not know what will come next. This booklet will help you know what to expect when caring for someone in the final days of life.

Family, friends, and caregivers can all play an important role. At the end of life, it is not so much what you say or do. Just being there can provide a sense of support and comfort.

Each person's death is unique. No one can guess what it will be like or when it will happen. We hope this booklet helps to guide the way.

Please contact us if you have questions. It is our goal to respect the dignity of each person by providing quality comfort care.

"Death is not extinguishing the light;
it is only putting out the lamp
because the dawn has come."

— Rabindranath Tagore

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Thoughts at the End of Life

Source: Dr. Ira Byock

Dr. Ira Byock is a well-known leader in end-of-life care. Below is his list of things people may think about as they near death. These thoughts put us in touch with the emotional and spiritual side of the dying process.

- Feeling love for one's self and for others.
- Having a sense of meaning about life.
- Being at peace about the finality of life.
- Having a sense of completion with life tasks.
- Having a sense of completion in relationships with others.
- Having a sense of a new "self" beyond personal loss.
- Giving in to the unknown — being able to "let go."

The journey at the end of life may not be easy. But it can often be a time of growth and healing. We are here to help you and your loved ones along the way.

"One person caring about another represents life's greatest value."

— Jim Rohn

Withdrawal

It is normal for people who are dying to begin to withdraw, or pull away, from the world around them. This might start as early as weeks before the death. They may stay in bed all day and spend more time asleep than awake.

With withdrawal comes less of a need to talk. Touch and silence take on more meaning. At this point, the person may not respond or may look like they are in a coma.

Some people might think pain medicine is causing the person to not respond. But detaching from surroundings and relationships is a normal part of the dying process. It may be the person's way of preparing to let go.

What you can do:

- Plan tasks and visits for the times of day when the person seems most alert.
- Say your name when you speak. Tell the person what you are going to do before you do it. For example: "Bob, this is Karen. I'm going to adjust your pillow now."
- If you are worried medicine could be causing the person to sleep too much, talk with the care team. They will check to make sure the person is getting the right dose. Be aware reducing or stopping pain medication for people who are in extreme pain or who are near the end of life is not recommended. In these cases, a focus on comfort is most important.
- Be aware the person may be able to hear until the end. So even if the person is not awake, you can still talk to them. Speak in your normal tone of voice. Avoid saying anything you would not say if they were awake.

Changes in Eating

Many people may no longer want food or drink at the end of life. Seeing a loved one who is not eating can be very hard for families to accept. Meals are how we spend time with family and feed our bodies.

Often nothing tastes good to the person. Cravings will come and go. As the body slows down, it will no longer use food in the same way. Weight loss is normal. It does not mean that the person is hungry or being starved.

What you can do:

- Do not force food or drink. Let the person be the guide.
- There may be times when the smell or a small taste of familiar foods is comforting. If the person asks for food or drink, check with the nurse to be sure it is safe.
- Liquids may be better than solid foods. Some people find thicker liquids easier to swallow.
- Small chips of ice or frozen juice may help if the person feels thirsty. Liquids may be given in small amounts by dropper. Ask the nurse for advice.
- Look for signs the person does not want to eat. Signs could be coughing, biting the spoon, clamping teeth closed, turning the head, or spitting food out.
- A person near death may appear thirsty but won't be able to drink water. Frequent mouth care can help. Use swabs to keep the mouth and lips moist.

Changes in Toileting

The loss of bladder and bowel control (incontinence) can happen at the end of life. When the body weakens, muscles in the lower body will relax. These changes can be embarrassing. Make sure the person is kept clean, dry, and comfortable to protect their dignity.

The amount of urine may lessen at this stage. The color may be darker than normal. It may also be cloudy or have a strong smell. This is a sign that the kidneys are slowing down. It is the normal response to drinking less liquids.

Bowel movements that are hard, painful, or not regular (constipation) are also common. Pain medicine can slow the bowels even more. This can cause major discomfort at the end of life.

What can help:

- The person must be checked often to be sure they are clean. Give privacy during personal care.
- Disposable briefs and bed pads may help. The nurse or home health aide can show you how to change these for someone who is in bed.
- The nurse may suggest certain creams to protect the skin.
- The nurse may place a tube (a catheter) into the bladder. This will keep the skin dry. There may be a little discomfort as the tube is placed. After that the person should not know it is there.
- Contact the nurse if the person has less than 3 stools per week or has trouble passing stools. Care teams will give laxatives or stool softeners with pain medicine to help. Only give treatments that are approved by the nurse.

Changes in Breathing

Breathing patterns often change at the end of life. Breathing may slow down. There may be fast, shallow breaths with periods of no breathing. These periods can last from 5 seconds up to a full minute. This is not uncomfortable for the person. It is another normal response as the body weakens.

People who are very near the end of life (within days or hours) may get so weak that they cannot swallow. Saliva will sit in the back of their throat and make a “rattling” sound.

At this late stage, suctioning is not recommended. Most times suctioning only creates more saliva and may cause a dying patient more discomfort. The sound may be troubling to hear, but it does not mean the person is suffering.

What you can do:

- Let the care team know if there are changes in breathing. They will check to see if oxygen might provide comfort.
- The person may breathe with their mouth open, making the mouth very dry. Lightly moisten the mouth and lips often with swabs. Use lip balm to prevent chapping.
- If saliva gathers in the throat:
 - Remember, the noise may be much more distressing for you than it is for the patient.
 - Gently turn the person on their side or raise the head of the bed to help drain the saliva. Check with the nurse to see if medicine can be used to dry the saliva.
- Let the care team know if you think the person is truly struggling to breathe. They may order medicine (such as morphine) or have other recommendations to make the person comfortable.

Changes in Body Temperature

The brain will start to lose control of body temperature as the body weakens. This can cause a fever or cause the body to become cool. Sometimes the person may get sweaty. These changes are a natural part of the dying process.

Blood flow will slow down. Feet, legs, hands, and arms might feel cool to the touch. Skin color may change. The person may look very pale. Hands and feet may turn slightly purple. Knees, ankles, and elbows may look blotchy. Lips and the skin under the fingernails may turn bluish. These changes to the skin do not cause any discomfort for the person.

What can help if the person has a fever:

- Let the nurse know if the person has a fever. Put a cool washcloth on the forehead or remove blankets. The nurse may suggest pain medicine (like Tylenol) if the fever is high.
- The person might sweat a lot as the fever drops. Change the gown/pajamas and sheets as needed to provide comfort.
- Gently rearrange the person in bed. Consider using a fan or opening a window.
- If the person throws the covers off, remember that they may be warm even if you feel cool.

What can help if the person becomes cold:

- Use a warm blanket, but not an electric blanket.
- Gentle massage may help increase blood flow. Check with the nurse before giving a massage. Some people may have skin that is too sensitive for massage.

Confusion

People nearing the end of life may seem confused at times. They may not know what time it is or where they are. They may not recognize family or friends. They may say that they see things no one else can see. They may talk to people who are not there, or who have already died.

People near the end of life will sometimes talk about travel. They may say things such as: "I want to get my keys," "I need to find my suitcase," or "Where is the train/bus?"

This is known as "symbolic language." It may be one of the ways people let us know that they are ready for death. They could be trying to tell us goodbye. As with withdrawal, some people may think pain medicine could be causing confusion. Again, this is a normal part of the dying process.

What you can do:

- Let the care team know if the person is confused. They will show you how to best support the person at this time.
- The care team will check to make sure the right medicine is being given at the right dose.
- Gently try to reorient the person. Remind them of who you are. Tell them what you are doing. Point out familiar things in the room.
- Provide comfort. Tell the person that you are there to take care of them. Let them know that they are safe.
- Limit visitors to help lessen confusion.

- Let the person tell you what they are seeing, feeling, or hearing. Do not argue with them. These things are real to the person, even though they may not seem real to you.
- Listen carefully. There may be meaningful messages being shared in symbolic language.
- Consider writing down important things that happen. A journal may be a source of comfort to share with other loved ones later.

"We do not remember
days, we remember
moments."

— Cesare Pavese



Restlessness and Anxiety

At times, the person may seem restless. They may pick at the sheets or make the same motions over and over again. This is common. Restlessness can be caused in part by a slowing of blood flow. This causes less oxygen to flow to the brain.

Sometimes restlessness and anxiety can be a sign of discomfort or pain. Emotional or spiritual concerns may also cause anxiety. Having unfinished affairs may make the person feel uneasy or restless.

What you can do:

- Let the nurse know if the person is restless or tense. They will check for pain or discomfort. Keep giving medicines as prescribed by the doctor.
- Ask the social worker or chaplain to talk with the person about emotional or spiritual matters. They can provide support if there are concerns.
- Try to help the person resolve issues. Offer to take over tasks that need to be finished. See if others can help complete tasks.
- Restraints, such as straps or belts, may cause more anxiety. Do not strap the person to the bed or hold them down. Instead, use bed rails or have someone sit with the person to keep them safe. Use a baby monitor when out of the room.
- Be calm and give comfort. Speak to the person in a slow and soothing tone of voice. Read something the person enjoys or play soft music.

- Sharing memories can be comforting. Some people talk about special holidays, good times with loved ones, or favorite places.
- Keep the person's space quiet. Turn radios, TVs, and phone ringers down or off. It also may help to limit visitors.
- Bring comfort with a gentle touch or by holding hands.



"Among the best things we can give each other are good memories."

— Henri J.M. Nouwen

Wave of Energy

Dying loved ones may show sudden, short-lived waves of energy. The person may become surprisingly alert and clear. They may ask to eat when they haven't had food for days. They may want to get up to visit when they haven't been out of bed for weeks.

Waves of energy don't always happen in such dramatic ways. They can be more subtle, like the person being awake more often. It is easy to see how this might give false hope that the person is getting better. Sadly, this is not likely. It may be that the person is building up strength for their last full-body moments in this life.

What you can do:

- Enjoy this special time for what it is.
- Use the time to share memories and say goodbye.
- Be together holding hands.

"In this life we cannot do great things. We can only do small things with great love."

— Mother Teresa

Saying Goodbye

Family and friends may not be sure whether to say goodbye. Some worry that it might cause death sooner. Others may want to say goodbye, but do not know what to say. Some people wonder if they should say it is okay to let go.

When and how to say goodbye is a personal choice. There is no right or wrong way to do it. Some people have a hard time saying goodbye. Many find that once it is done, it can be a gift.

What you can do:

- Take time while the person is awake to say or do what you need to. Follow your heart. This time with your loved one is precious.
- Some people start with:
 - *"What I love most about you..."*
 - *"What I will always remember..."*
 - *"What I will miss most about you..."*
 - *"What I learned from you..."*
 - *"What I hold close to my heart is..."*
- Some people may take this time to say, "I am sorry," to forgive, or to let go of past anger.
- Some people use this time to give thanks.
- It may be helpful to hold your loved one, if possible. Or take their hand and say everything you need to say.
- Tears are a normal part of saying goodbye. Crying can be a healthy way to show how much you love the person.

When Death Is Near

Below is a list of signs that may mean death will take place soon. Each person's dying process is unique. This is only a guide. Some people may not show all of these signs. Some may show signs at different times.

1 to 3 months:

- Withdraws from people and activities
- Talks less
- Eats and drinks less
- Sleeps more

1 to 2 weeks:

- Confused about place, time, or people
- Uses symbolic language ("Where is the train/bus?")
- Talks to others who are not in the room
- Physical changes:
 - Pulse speeds up or slows down
 - Blood pressure drops
 - Skin color changes
 - Breathing is weak or uneven
 - Body temperature turns hot or cold
 - Does not eat, drinks little or no fluids

Days to hours:

- Sleeps most of the time
- Wave of energy
- Is restless
- Has a hard time swallowing
- Weak pulse
- Bigger drop in blood pressure
- More changes in skin color
- More changes in breathing (long pauses between breaths)
- Rattling sounds while breathing
- Less urine or no urine
- Eyelids do not close all the way

Minutes:

- Short breaths with longer pauses
- Mouth open
- Does not respond

Moment of Death

No one can tell when death will take place. Some people die when others are there. Some take their last breaths when they are alone. Talk to family, caregivers, and friends about what to do if they are there at the time of death.

When the person has died, there will be no breathing or heartbeat. There will be no response to voice or touch. The eyes may be partly open. The pupils will not respond to light. The jaw will relax, and the mouth will open. There may be loss of bowel and bladder control.

Death can feel like a shock even if it was expected. At the time of death, nothing needs to be done right away other than calling hospice. There is no need to call 911 or the police.

What you can do:

- Please contact hospice. A nurse will visit. Other care team members may help as needed.
- You may want to call a friend or a family member to be with you at this time.
- When a nurse or care team member visits, they may:
 - Confirm the death
 - Remove any tubes
 - Offer to bathe and prepare the body
 - Give you guidance on what should be done with unused medicine
 - Call the funeral home, if you wish
 - Contact the doctor and the rest of the hospice team
 - Arrange to have equipment removed
 - Provide support

- Some people want the funeral home to come right away. Others wait before calling.
- Some honor their loved ones by:
 - Bathing and dressing the person in special clothes
 - Telling stories
 - Lighting a candle or putting flowers in the room
 - Sharing a ritual from the person's spiritual beliefs
 - Playing special music
- Let the funeral home know when you are ready for them to come. You can be there when they take the body or wait in another part of the house. The funeral home will help you make memorial plans, if you wish.



“Death ends a life,
not a relationship.”

— Mitch Albom,
Tuesdays with Morrie

Care for the Caregiver

Caring for someone who is at the end of life can be draining. It can leave caregivers weary in body, mind, and spirit. Caregivers often juggle other duties like work, caring for a family, or their own health concerns. Balancing another's care with your own needs can be a big challenge.

What you can do:

- Find balance between your loved one's care and your own needs. It is important to take care of yourself too.
- Take a deep breath many times a day. Deep breathing can refresh body and mind. Rest when you can. Lie down or sit with your feet up in a quiet place for 20 minutes.
- Try an exercise routine. Take a walk outside. This can help lessen stress and boost energy.
- Drink plenty of water. Eat healthy meals at regular times.
- Decide if calls or visits will help. Limit visits if you need to. Give yourself time alone when you need it.
- Ask for help. People often want to help but don't know what you need. Keep a list of tasks to be done, such as shopping or walking the dog.
- Contact hospice. Trained volunteers can help with errands or sit with the person while you take a break.
- Share your feelings with a trusted friend, your spiritual counselor, or someone from the care team.
- Please be gentle with yourself. Take life one moment, one step at a time. **Contact us if you need help. We are here for you.**



Questions and Notes: