



When the Time Comes

A CAREGIVER'S GUIDE

HOSPICE
& COMMUNITY CARE

*May the longtime sun shine upon you,
All love surround you,
And the pure light within you
Guide you on your way.*

Introduction

Dying is a natural part of life. Even so, many do not know how to care for someone at the end of life. This can be a new and scary experience. It's normal to have a wide range of feelings.

You may feel unsure of yourself. At times you may feel as if you're on a roller coaster, like you don't know what to expect next. This booklet will help you know what to expect. It will tell you what you can do to care for someone in the final days of life.

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

Each person's dying experience 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 hospice for more information and support. It is our goal to respect the dignity – the sense of honor or self-esteem – of each person by providing quality comfort care.

Table of Contents

Introduction	1
Goals at the End of Life	3
Withdrawal	4
Changes in Eating	5
Changes in Toileting	6
Changes in Breathing	7
Changes in Body Temperature	8
Confusion	9
Restlessness and Anxiety	11
Wave of Energy	13
Saying Goodbye	14
When Death Is Near	15
Moment of Death	17
Care for the Caregiver	19

Goals at the End of Life

Source: Dr. Ira Byock

Dr. Ira Byock is a leader in comfort care. He is well-known for teaching others about quality end-of-life care. Below is his outline of some issues many people may face as they near death.

The journey toward death may not be easy. But it can often be a time of major personal growth and inner healing. Dr. Byock puts us in touch with the emotional and spiritual side of the dying process.

At the end of life, many people want to:

- Have a sense of completion with worldly affairs.
- Have a sense of completion in relationships in their community.
- Have a sense of meaning about one's life.
- Experience love of self.
- Experience love of others.
- Have a sense of completion in relationships with family and friends.
- Be at peace about the finality of life.
- Have a sense of a new self beyond personal loss.
- Have a sense of meaning about life in general.
- Give in to the unknown – to be able to “let go.”

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. Or they may spend more time asleep than awake.

With withdrawal comes less of a need to talk. Touch and silence take on more meaning. People at this point may not respond to you or may look like they're in a coma. This may be their way of getting ready to let go.

What you can do:

- Plan visits for times of day when the person seems most alert.
- Speak to the person in your normal tone of voice. People can hear until the end.
- Call yourself by 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 clean your mouth now."
- Remember not to say anything in front of the person that you would not say if he or she were awake.

Changes in Eating

It is natural for a person to no longer want food at the end of life. Often nothing tastes good. Cravings will come and go. Changes in eating can be one of the hardest things for caregivers to accept. Food is the way we feed the body. It is how we share time together with loved ones.

As the body begins to slow down, it no longer digests food in the same way. Weight loss is common. Keep in mind, this does not mean that the person is hungry or being starved.

What you can do:

- Let the person be the guide. He or she will let you know if food or drinks (liquids) are needed or wanted.
- Liquids are better than solid foods. Some people find thicker liquids easier to swallow.
- Small chips of ice or frozen juice may be refreshing.
- If the person can swallow, liquids may be given in small amounts by dropper (ask the hospice nurse for help).
- Familiar foods can be given in small amounts. There may be times when the taste or smell is comforting.
- People who can't speak will let you know they don't want to eat in other ways. They may cough, bite the spoon, clamp their teeth closed, turn their heads, or spit food out.
- Respect the person's wishes by trying not to force food or drink.
- Often a person near death may appear thirsty but won't be able to drink water. Use swabs to keep the mouth and lips moist.

Changes in Toileting

“Incontinence” is the loss of bladder and bowel control. This can happen as muscles in the lower body start to relax. However, the amount of urine will lessen as people get weaker.

The color of urine may be darker than normal. It may be cloudy or have a strong smell. This is the normal reaction to drinking less liquids. The kidneys are no longer working as much as they used to.

Weakening of the body can also lead to constipation (infrequent or difficult bowel movements). It is a serious issue that causes cramping and discomfort for many people at the end of life. Pain medicine can make it worse. Care teams often give laxatives or stool softeners alongside pain medicine.

These kinds of changes in toileting can be embarrassing for many people. Always keep the person clean, dry, and comfortable. The overall goal is to protect the person’s dignity.

What can help:

- Adult diapers and bed pads may help. The nurse or home health aide can show you how to change these for someone in bed.
- The nurse might suggest placing a tube (called a “catheter”) into the bladder. This will keep the person’s skin from being wet all the time. There may be a few seconds of discomfort as the tube is put in. After that the person is usually not aware of it.
- Allow for privacy during personal care. Check the person often to make sure that he or she is kept dry and comfortable. The nurse may suggest using certain lotions or creams.
- Contact the nurse if the person has less than three stools per week or has difficulty passing stools. If pain medicine is being given, be sure the person is also being treated for constipation. Only give treatments that are approved by the nurse.

Changes in Breathing

Breathing patterns often change for people at the end of life. Breathing may slow down. Or there may be fast, short breaths followed by periods of no breathing. These periods can last 5 to 30 seconds, or up to a full minute.

Breathing this way is not uncomfortable for the person. It's because the body is getting weaker. Your hospice nurse/doctor will see if oxygen would help at this time.

When people get really weak they can't swallow. Saliva can sit in the back of the throat and make a "rattling" sound. Suctioning it out will produce more saliva. You may be trying to help, but this may only cause more discomfort. The sound may be scary to hear, but it does not mean the person is suffering.

What you can do:

- Gently turn the person on his or her side. This may help to drain the saliva. Raising the head of the bed may also help.
- Your nurse may teach you about medicine used to dry the saliva.
- At this point the person usually breathes with his or her mouth open. This can make the mouth very dry. Frequent mouth care is important.
- The person might struggle to breathe. If so, your doctor can use morphine or a similar medicine to provide comfort.

Changes in Body Temperature

FEVER

The brain loses control of body temperature when the body is weak. This can cause a fever or make the person feel cold. Sometimes he or she may get sweaty with or without a fever.

What can help:

- Let the hospice nurse know if the person has a fever. Put a cool wash cloth on the forehead or remove blankets to help. The nurse may use an over-the-counter pain medicine (like Tylenol) if the fever is high.
- As the fever drops, the person might sweat a lot. Change the gown/pajamas and sheets to provide comfort.
- A fan may be used. Or open a window.
- The person may throw the covers off. Remember that he or she may be warm even if you feel cool.

COOLNESS

As your loved one becomes weaker, blood flow slows down. Legs and arms might feel cool to the touch. Skin color may change. The hands and feet may look a little purple. The knees, ankles, and elbows may look spotty.

Overall, the person may look very pale. The lips and skin under the fingernails may look a little blue. None of this causes any discomfort for the person. These changes are a natural part of the dying process.

What can help:

- 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, where they are, or who you are. 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, as if they are planning a trip. They may say things such as: “I want to go home,” “I want to get my keys,” “I need to find my suitcase,” or “Where is the train/bus?”

This is known as “symbolic language” – when things that are said mean something else. 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.

When this happens, we may think the medicine is causing the confusion. But this is a normal part of dying. At each visit, the hospice nurse/doctor will check the medicine being given. They will make sure the person is getting the correct dose.

What you can do:

- Let the hospice nurse or other care team members know if the person is confused. They will show you how to best support the person at this time.
- If appropriate, try to remind the person of who you are. Remind him or her of what you are going to be doing. Point out familiar things in the room.
- Provide reassurance. Let the person know you are there to take care of him or her. Tell the person that you will keep him or her safe.
- Limit visitors. This can help lessen confusion.

-
- Let the person tell you what he or she is seeing without trying to argue it away. What the person sees is real to him or her, even though it may not seem real to you.
 - Listen carefully. There may be meaningful messages being shared in symbolic language.
 - You may want to write down the important things that happen. A journal may be a source of comfort to share with others later.

*“You don’t have to do
or say anything to make
things better. Just be there
as fully as you can.”*

— Sogyal Rinpoche



Restlessness and Anxiety

At times, the person may appear restless, or unable to be still. They may pick at the sheets. They might make the same motions over and over again.

This is common and could be due to a number of reasons. Restlessness can be caused by a lack of blood flow. This causes less oxygen to flow to the brain. Sometimes anxiety (being worried or tense) can be a sign of physical discomfort or pain. Emotional or spiritual concerns can also make the person worried and tense.

What you can do:

- Let the hospice nurse know if the person is restless or tense. He or she will look for any discomfort or pain.
- Continue giving medicines as prescribed by the doctor.
- Ask the hospice social worker or chaplain to talk with the person about emotional or spiritual matters. The social worker or chaplain can provide support if the person has concerns.
- Keep the person's space calm and reassuring. Speak to the person in a slow and soothing tone of voice.
- Help the person resolve issues. Taking over any tasks that still need to be finished can be a relief. See if others can help complete tasks.
- Read something inspiring or uplifting.
- Play soft music.
- Bring comfort by holding hands or providing a gentle touch.

-
- Use bed rails or have someone sit with the person to keep him or her safe.
 - Consider using a baby monitor when out of the room.
 - Restraints – straps or belts – may cause more anxiety. Do not strap the person to the bed or hold him or her down in any way.
 - It may be useful to limit visitors at this time. Keep the room quiet. Turn radios, TVs, and phone ringers down or off.
 - Sharing memories can be comforting. Some people talk about special holidays, good times with family, or favorite places.



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

— Henry Nouwen

Wave of Energy

Dying loved ones may show sudden waves of energy. These usually do not last long. Sometimes the person may be 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 big ways. They can happen in small ways, like the person being awake more. It is easy to see how this can give false hope that the person is getting better. But it is not likely. The person may be building up strength for the last full-body moments in this life.

What you can do:

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

“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

Saying Goodbye

Many people aren't sure if they should say goodbye. Some worry that it might speed up death or that it will be taken the wrong way. Others may want to say goodbye, but may not know what to say. Some wonder whether they should tell the person it's okay to let go.

What to say and when to say it is a personal choice. There is no right or wrong way to do it. Some people have a hard time saying goodbye. But once they've done it, it can be a gift. This time with your loved one is special.

What you can do:

- Take time while the person is awake to say or do what you need to. Follow your heart.
- 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.” They may take the time to forgive or let go of past anger.
- Some people may use this time to give thanks.
- It may be helpful to hold your loved one, if you can. Or take his or her 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. Keep in mind, this is only a basic guide. People may show some or all of these signs at different times.

ONE TO THREE MONTHS

- Withdrawal from people and activities
- Talking less
- Eating and drinking less
- Sleeping more

ONE TO TWO WEEKS

- Confusion about place, time, or people
- Use of symbolic language ("I want to go home")
- Talking to others who are not in the room
- Physical changes:
 - Heartbeat speeds up or slows down
 - Blood pressure goes down
 - Skin color changes
 - Breathing is weak or uneven
 - Body temperature goes hot/cold
 - Eating/drinking less or not eating/drinking

DAYS TO HOURS

- Sleeping most of the time
- Wave of energy
- Being restless
- Having a hard time swallowing
- More changes in skin color
- More changes in breathing (long breaks between breaths)
- Rattling breath sounds
- Weak heartbeat
- Drop in blood pressure
- Less urine or no urine
- Eyelids don't close all the way

MINUTES

- Short breaths with longer breaks between
- Mouth open
- Does not respond

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

— Mother Teresa

Moment of Death

It is important to plan out what to do at the time of death. Talk with family members, caregivers, and friends who might be there. No one can really tell when death will take place. Some people die when others are there. Some take their last breaths when they are alone.

When the person has died, there will be no breathing or heartbeat. There will be no response to your voice or touch. The eyes may be partly open. The pupils won't react 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 you felt prepared for it. When the person dies, nothing else needs to be done right away other than calling hospice. There is no need to call 911 or the police. You may want to call a good friend or a family member to be with you at this time.

What you can do:

- Please contact hospice. A nurse will visit. Other team members may help as needed.
- When a nurse or other team members visit, they may:
 - Confirm the death
 - Remove any tubes that are present
 - Offer to bathe and prepare the body
 - Give you guidance on how to dispose of any leftover medicine
 - Call the funeral home, if you wish
 - Provide support
 - Contact the doctor and hospice team
 - Make plans to have equipment taken away

-
- People honor the passing of their loved ones in different ways. Some want the funeral home to come right away. Others wait before calling.
 - Some people honor their loved ones by:
 - Bathing the body
 - Dressing the body in special clothes
 - Telling stories
 - Lighting a candle
 - Sharing a ritual from the person’s spiritual beliefs
 - Putting flowers in the room
 - Playing special music
 - Let the funeral home know when you are ready for them to come. You can choose to be there when they remove the body. Or you may want to wait in another part of the house. The funeral home will then help you make plans for services.



“Our life is a faint tracing on the surface of mystery.”

— Annie Dillard

Care for the Caregiver

Caring for someone who is at the end of life can be physically and emotionally draining. It may feel like too much at times. It can leave you tired in body, mind, and spirit.

You might also be juggling other duties. That may be work, caring for a home and other loved ones, or taking care of your own health needs. Balancing another's care with your own needs can be really hard. Be sure you seek that balance. It's important that you take care of yourself, too.

What you can do:

- Take a deep breath many times a day. Deep breathing can refresh both body and mind.
- Go outside for a few minutes. Smell and feel the fresh air. Take a walk or sit in a peaceful area.
- Try to stick to an exercise routine, if you have one. This can help lessen stress and boost energy.
- Lie down for 20 minutes or sit in a chair with your feet up.
- Drink plenty of liquids, especially water.
- Follow a well-balanced diet. Eat at regular times.
- Decide if calls or visits are helpful or not. Limit visits as a way of honoring your own needs. Give yourself time alone when you need it.
- Ask for help. Often family and friends want to help but do not know how. Keep a list of tasks to be done, such as shopping or walking the dog.
- Ask for help from a hospice volunteer. 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 your hospice team.

© 2008 by Hospice of Santa Cruz County. This booklet (published as *When Death is Near* and *When the Time Comes*) was created by Hospice of Santa Cruz County, a community-based, not-for-profit organization in Scotts Valley, California, that serves Santa Cruz and North Monterey counties. Through a generous grant from The California Endowment, Hospice of Santa Cruz County has moved forward in its ultimate goal of improving the delivery of end-of-life education, hospice, Transitions, and grief support services within the Latino community.

All rights reserved. No part of this booklet may be reproduced without prior permission of the publisher.
Printed in the United States of America.



Published by Quality of Life Publishing Co.
Naples, Florida
www.QoLpublishing.com

Quality of Life Publishing Co. is an independent, mission-driven firm specializing in branded publications that help ease the way for those with life-limiting illnesses and their families. HOW TO ORDER BRANDED COPIES: Call Quality of Life Publishing Co. during regular business hours (Eastern Time) toll free at 1-877-513-0099 or email info@QoLpublishing.com.

Provided by



685 Good Drive, PO Box 4125
Lancaster, PA 17604-4125

235 St. Charles Way, Suite 250
York, PA 17402

877-506-0149

hospicecommunity.org