

# When the Time Comes

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A CAREGIVER'S GUIDE

UNITED  
**Hospice**  
of Rockland

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

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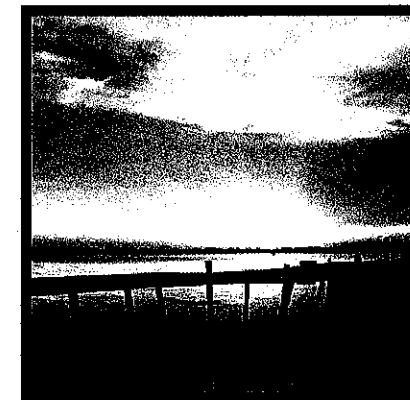
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## Introduction

Dying is a natural part of life, but many people do not have experience caring for someone in their final days and find themselves navigating through new and unfamiliar territory. It is not uncommon to experience a wide range of emotions and a sense of uncertainty. At times you may feel that you are on a roller coaster, not knowing what to expect next. This booklet is designed to help you feel more confident in knowing what to expect and what you can do to care for someone in their final weeks and hours of life.

Family members, friends, and caregivers can play an important role in providing comfort and support to someone entering this final phase of life. Sometimes it is not so much what you say or do, but just being present with another, that can provide a sense of reassurance and comfort.

Each person's dying experience is unique to them, and no one can fully predict what it will be like or when it will occur. However, we hope the information contained in this booklet will provide some landmarks to help guide the way. Please contact hospice at any time for further information and support. It is our goal to respect the dignity of each person by providing quality comfort care.



*"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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## End-of-Life Developmental Milestones and Tasks

Source: Dr. Ira Byock

Dr. Ira Byock is a leader and educator in promoting quality care at the end of life. Below is a framework he developed that outlines some of the issues many people may be contemplating as they approach death. His findings are included here as part of a holistic understanding of the dying process. Although the journey toward death may not be easy, it can often be a time of new insights, personal growth, and inner healing.

- Sense of completion with worldly affairs
  - Sense of completion in relationships with community
  - Sense of meaning about one's individual life
  - Experiencing love of self
  - Experiencing love of others
  - Sense of completion in relationships with family and friends
  - Acceptance of the finality of life – of one's existence as an individual
  - Sense of a new self (personhood) beyond personal loss
  - Sense of meaning about life in general
  - Surrendering to the transcendent, to the unknown – “letting go”
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## Withdrawal

It is common for people to begin to withdraw from friends, family, and the world around them as a normal part of the dying process. This process may begin as early as weeks before the death. The dying person may stay in bed all day and spend more time asleep than awake. With the withdrawal comes less of a need to communicate with others; touch and silence take on more meaning. People at this point may seem unresponsive and difficult to arouse or may appear to be in a coma-like state. This detaching from surroundings and relationships may be preparation for release and letting go.

### **What you can do:**

- Plan activities and visits for times of day when the person seems most alert.
  - Because hearing remains intact to the end, speak to the person in your normal tone of voice.
  - Identify 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 wouldn't say if he or she were awake.
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## Changes in Appetite

When a person is nearing the end of life, it is natural that they are no longer interested in food or are unable to eat or drink. Often nothing tastes good, and cravings come and go. This is often one of the hardest concepts for caregivers to accept because food is the way we nourish the body and share family time together.

As the body naturally begins to slow down, it is no longer able to digest and assimilate food in the same way. Weight loss is expected and does not mean that the person is hungry or that their body is being "starved" by the absence of food.

### **What you can do:**

- Let the person be the guide; they will let you know if food or fluids are needed or wanted.
- Liquids are preferred to solids. Some people find thickened liquids easier to swallow. Small chips of ice or frozen juice may be refreshing in the mouth. If the person is able to swallow, fluids may be given in small amounts by syringe (without a needle) or dropper (ask the hospice nurse for guidance).
- There may be times when the taste or smell of familiar foods in small amounts is comforting.
- People who can't speak will sometimes cough, bite the spoon, clamp their teeth closed, turn their heads, or spit food out to let you know they don't want to eat.
- 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. Their mouth may be dry, and frequent mouth care may provide comfort. Use swabs to keep the mouth and lips moist.

## Changes in Elimination

Incontinence is the loss of control of the bladder and bowels that can sometimes occur as the muscles in the lower body begin to relax. As people decline, the urine output usually diminishes, and the color is usually darker than normal. It may also be cloudy or have a strong odor. This is the normal response to the decreased fluid intake as well as decreased circulation through the kidneys.

Unfortunately, for many people incontinence can be a source of shame and embarrassment. Keeping the person clean, dry, and comfortable, as well as preserving their dignity, is the overall goal.

### **What you can do:**

- Adult disposable briefs and underpads on the bed may solve the problem. The nurse or home health aide can show you how to change these for someone in bed.
- In some situations it may be appropriate for the nurse to suggest placing a catheter (a tube) into the bladder to keep the person's skin from being constantly wet. There may be a few seconds of discomfort as the catheter is inserted, but then there is generally no awareness of it at all.
- The nurse may suggest that certain lotions or creams be applied to the skin periodically.
- To help maintain dignity, provide privacy when changing pads or providing personal care. Check the person frequently to ensure that they are kept dry and comfortable.



## Changes in Breathing

When someone is nearing the end, their breathing patterns often begin to change. Breathing may slow down, or there may be rapid, shallow breaths followed by periods of no breathing. These periods can last 5 to 30 seconds, or even up to a full minute. This kind of breathing is not uncomfortable for the person but is a response to the body's weakening condition. Your hospice nurse, along with your physician, will assess and determine if oxygen would be a comfort measure at this time.

Sometimes when a person is so weak that they can't swallow, saliva gathers in the back of the throat and makes a "rattling" sound. Suctioning usually only increases the secretions and causes discomfort.

This sound may be distressing to hear, but it does not indicate that the person is suffering.

### **What you can do:**

- Gently turning the person on their side may assist gravity to drain the secretions. Raising the head of the bed may also help.
- Your nurse may educate you about prescribed medications that will dry excess secretions.
- At this point the person is usually breathing with their mouth open. This will make the mouth very dry, so frequent mouth care is important.
- If breathing seems labored, your doctor may prescribe morphine or a similar medication to ease the breathing and provide comfort.

## Changes In Body Temperature

### **Fever**

As the body becomes weaker, so does the temperature control mechanism in the brain. This can cause the person to have a fever or cause the temperature to drop and the body to become cool. Sometimes a person may become sweaty and clammy with or without a fever.

### **What you can do:**

- If a fever develops, let your hospice nurse know. Often placing a cool wash cloth on the forehead and removing blankets may be all that is needed. However, your hospice nurse may suggest Tylenol if the fever is high. As the fever lowers, the person may perspire, requiring a change of gown, pajamas, and sheets to provide more comfort.
- Consider using a fan or opening a window.
- If the person throws the covers off, it is important to remember that they may be warm even when you feel cool.

### **Coolness**

As your loved one becomes weaker, their circulation decreases. You may notice that their extremities feel cool to the touch and the color of their skin may change. The hands and feet may become purplish, and the knees, ankles, and elbows may look blotchy. The person may appear pale and have a bluish cast around the lips and under the fingernails. This state doesn't cause any discomfort for the person and is a natural part of the dying process.

### **What you can do:**

- Use a warm blanket, but not an electric blanket.
- Continue to gently reposition the person, or provide gentle massage.

## Confusion and Disorientation

At times, people nearing the end of their life may have confusion about the time, their surroundings, and the identity of those around them. They may report seeing people or things that are not visible to others, and they may engage in conversation with others who are not visibly present or who have already died.

People near the end of their life will sometimes talk about travel, as though they were planning a journey. 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 type of conversation is referred to as symbolic language, and may be one of the ways people let us know that they are preparing for death or are trying to tell us goodbye.

When these symptoms are present, we may wonder if the person is taking too much medicine or not enough. Most often, these symptoms are a normal part of the dying process. The hospice nurse will assess the prescribed medication at each visit and determine along with the physician if it is the correct medicine at the correct dosage.

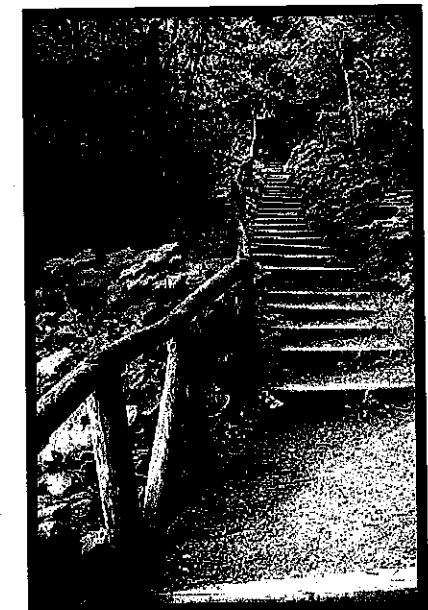
### **What you can do:**

- Report these symptoms to the hospice nurse or other hospice team members; they will assess and provide information on ways you can provide care and support at this time.
- If appropriate, gently try to reorient the person. Remind them of who you are and what you are going to be doing, and point out familiar landmarks in their surroundings.
- Provide reassurance by reminding them of your presence and support, and that you will take care of them and keep them safe.
- Sometimes limiting visitors can decrease the level of confusion or disorientation.

- Allow and acknowledge whatever experience the person may be having, without trying to contradict or argue it away. This experience is real to them, 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 keep a journal to record some of the meaningful things that are shared. This may be a source of inspiration and comfort to share with other family members.

*"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 Agitation

At times, the person you are caring for may appear restless or unable to be still, and may pick at their bed clothes or perform repetitive movements. This is not uncommon and may be due to a variety of physical or emotional reasons.

Restlessness may be caused in part by a slowing down of circulation, causing less oxygen to flow to the brain. Sometimes restlessness or agitation can be a symptom of physical discomfort or pain. Emotional or spiritual concerns, such as an unresolved issue or unfinished task, can be worrisome and also cause feelings of uneasiness or restlessness.

### **What you can do:**

- Let the hospice nurse know if the person is agitated or restless. The nurse will assess for any underlying pain or discomfort.
- Continue with the medication regimen prescribed by the doctor.
- Utilize the hospice social worker and/or chaplain to address underlying concerns and provide emotional or spiritual support.
- Provide a reassuring presence by speaking slowly, calmly, and in a soothing way.
- If appropriate, help the person resolve issues and complete tasks. Sometimes offering to take over a task or suggesting they delegate it to another trusted person can provide relief.
- Try reading something inspirational or playing soft music.
- Holding hands or a light touch may be reassuring.
- Use bed rails or have someone sit with the person to keep them safe.
- Consider use of a baby monitor while out of the room.

- Restraints may cause further agitation and are not encouraged.
- It may be useful to limit visitors at this time and to minimize outside distractions (loud noises, radio or TV, ringing phones).
- Some people find comfort in sharing memories about special occasions or holidays, family experiences, or the memory of a favorite place.

## Surge of Energy

The dying person may exhibit a sudden unexplained surge of energy, which is usually short-lived. They may become unexpectedly alert and clear, ask to eat when they haven't had food for days, or they may want to get up in a chair to visit when they haven't been out of bed for weeks. This doesn't always happen to everyone in such dramatic ways but can be more subtle, such as being awake more when they have been sleeping most of the time. It is easy to see how this could be misunderstood and can give false hope that the person is getting better. It may be that they are marshalling all their physical strength for their last full body experience in this life.

### What you can do:

- Enjoy this time for what it is.
- Use the time to reminisce, say goodbye.
- Be together holding hands.

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

*— Henry Nouwen*



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## Saying Goodbye

Many people have questions about saying goodbye and wonder whether it is appropriate to do so. Some are concerned that it will hasten death or communicate something unintended. Others may want to say goodbye but may not know what to say. In addition, some families have questions about whether they should give permission to let go.

When and how to say goodbye, or giving permission to let go, is a personal decision, and there is no right or wrong way to do it. Some families have difficulty starting the conversation but find that once begun, it can be a gift. This time with your loved one is precious.

### **What you can do:**

- Take this opportunity while the person is alert to say or do what you need to.
  - Listen to the wisdom of your heart, and follow its guidance.
  - Some families begin these conversations 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 will cherish...”*
  - Some people may choose this time to say, “I am sorry,” share forgiveness, or let go of past conflicts.
  - Some people may choose this time to share expressions of gratitude.
  - It may be helpful to lie in bed with your loved one and hold them, or take their hand and say everything you need to say.
  - Tears are a normal and natural part of saying goodbye, and could be a healthy expression of your love.
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## Review of Possible Signs and Symptoms of Approaching Death

Because each person's dying process is unique to them, the outline below is only a general guide. People may exhibit some or all of these signs and symptoms at varying times.

### **ONE TO THREE MONTHS**

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

### **ONE TO TWO WEEKS**

- Disorientation and confusion
- Use of symbolic language ("I want to go home")
- Talking to others not present in the room
- Physical changes:
  - Increase or decrease in pulse
  - Decrease in blood pressure
  - Changes in skin color
  - Irregularities in breathing
  - Changes in body temperature, hot/cold
  - Not eating, taking little or no fluids

#### **DAYS TO HOURS**

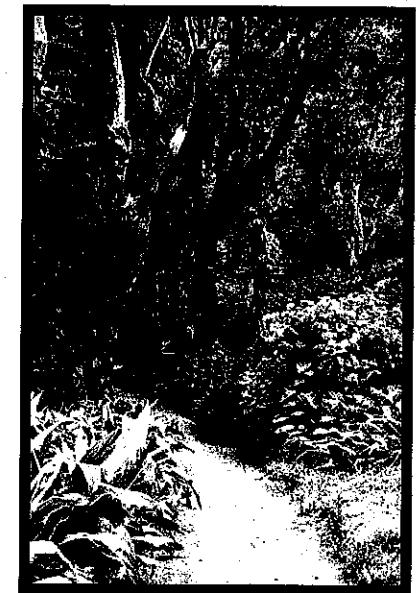
- Sleeping most of the time
- Surge of energy
- Restlessness
- Difficulty swallowing
- Further discoloration of skin
- Ongoing changes in breathing (long pauses between breaths)
- Rattling breath sounds
- Weak pulse
- Further decrease in blood pressure
- Decreased urine output or no urine
- Eyelids no longer able to close completely

#### **MINUTES**

- Shallow breaths with longer pauses
- Mouth open
- Unresponsive

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

*— Mother Teresa*



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## Moment of Death

It is important to discuss with family members, caregivers, and friends what to do if they are present at the time of death. No one can accurately predict when death may occur. Some people die when others are present. Some take their last breath 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, and the pupils will be unresponsive. The jaw will relax, and the mouth will open. Sometimes there will be loss of bowel and bladder control.

No matter how well prepared you are, death can still feel like a shock. At the time of death, nothing needs to be done immediately other than calling hospice. There is no need to call 911 or notify the police. You may want to call a trusted friend or a family member to be with you at this time.

### **What you can do:**

- Please contact hospice. A nurse will visit. Please note that other team members may provide assistance as needed.
- When a nurse or other team members visit, some of the things they may do are:
  - Confirm the death
  - Remove any tubes that are present
  - Offer to bathe and prepare the body
  - Dispose of medications
  - Call the funeral home, if you wish
  - Provide support
  - Notify the physician and your hospice team, and arrange for medical equipment to be removed

- People honor the passing of their loved ones in a variety of ways. Some choose to have the funeral home come right away, while other families may choose to wait for a period of time before calling.
- Some of the ways families honor their loved ones are: bathing and dressing the body in special clothes, telling stories, lighting a candle, sharing a ritual from their spiritual tradition, placing flowers in the room, or playing special music.
- Let the funeral home know when you are ready for them to arrive. When they do come, you can decide whether you want to be present when they remove the body or wait in another part of the house. The funeral home will let you know about making arrangements for services.



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

*—Annie Dillard*

## Care for the Caregiver

Caring for someone in their final weeks and days of life can be physically and emotionally demanding. It may feel overwhelming at times and leave you weary in body, mind, and spirit. In addition, some caregivers are often juggling other responsibilities such as work, household duties, caring for other family members, or have their own health considerations. Trying to balance another's care with your own needs for rest and nourishment is challenging but important for your own wellbeing.

### **What you can do:**

- Take a deep breath several times a day. Deep breathing brings more oxygen to every cell and can refresh both body and mind.
- Go outside for a few minutes; smell and feel the fresh air.
- Take a walk or sit in your garden.
- If you have an exercise routine, try to adhere to it, as this can help decrease stress and boost energy.
- Lie down for 20 minutes or sit in a recliner with your feet up.
- Drink plenty of liquids, especially water.
- Follow a well-balanced diet, eating at regular intervals. Your health and nutrition are just as important as the person you are caring for.
- Determine if calls or visits are helpful or would cause more stress. Limit these as a way of honoring your own needs and private time.
- Ask for help. Often family, friends, or neighbors want to help but do not know how. Keep a list of tasks to be done, such as: shopping, going to the post office, watering the garden, walking the dog, or going to the pharmacy.
- Utilize a hospice volunteer visitor for respite or for help with errands.
- Share your concerns or feelings with a trusted friend, your spiritual counselor, or someone from your hospice team.



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