



WHEN THE TIME COMES: A CAREGIVER'S GUIDE



Community

Hospice & Palliative Care®

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Community Hospice & Palliative Care provides specialized care for adults and children with advanced illnesses, along with support for their loved ones. We emphasize the quality of a person's life by striving to meet his or her needs — physical, emotional, social and spiritual.

Dying is a natural part of life, but many people do not have experience caring for someone during the dying process 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 the 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, 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 Community Hospice & Palliative Care at any time for further information and support. It is our goal to respect the dignity of each person by providing quality comfort care. If you would like more information about Community Hospice & Palliative Care, please call **904.268.5200** or **800.274.6614** toll-free.

END-OF-LIFE DEVELOPMENTAL MILESTONES AND TASKS

— *Source: Dr. Ira Byock*

Although the journey toward death may not be easy, it can often be a time of new insights, personal growth and inner healing.

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:

- *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 unknown — "letting go"*

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 a reduced 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 detachment 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 to be 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.
- Respect the person’s need for minimal interaction at this time.

CHANGES IN APPETITE

Near the end of life, it is natural for a person to no longer be interested in food or to be unable to eat or drink. Often nothing tastes good, and cravings come and go. This is 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 being “starved” by the absence of food.

What you can do:

- Let the person be the guide; he or she 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 your Community Hospice & Palliative Care 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 head 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.
- 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.

Incontinence can be a source of shame and embarrassment for many people. Keeping the person clean, dry and comfortable preserves dignity and 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 who is bedbound.
- 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 he or she is dry and comfortable.

CHANGES IN BREATHING

Breathing patterns often begin to change for those nearing the end of life. Breathing may slow down, or there may be rapid, shallow breaths followed by short periods with 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 Community Hospice & Palliative Care nurse, along with your physician, may assess and determine if oxygen would be a comfort measure at this time.

Sometimes when individuals are 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 his or her side may cause gravity to drain the secretions. Raising the head of the bed may also help.
- Your nurse may educate you about prescription medications that will dry excess secretions.

- At this point the person is usually breathing with his or her 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 body to cool. Sometimes a person may become sweaty or clammy with or without a fever.

What you can do:

- If a fever develops, let your Community Hospice & Palliative Care nurse know.
- Placing a cool wash cloth on the forehead and removing blankets may be all that is needed. Your nurse may suggest an over-the-counter pain reliever if the fever is high.
- As the fever lowers, the person may perspire, requiring a change of clothing and sheets to provide more comfort.
- Consider using a fan or opening a window.
- If the person throws the covers off, remember that he or she may be warm even when you feel cool.

Coolness

Circulation decreases as the body weakens. You may notice that extremities feel cool and skin color changes. Hands and feet may become purplish, and knees, ankles and elbows may look blotchy. The person may appear pale and have a bluish cast to the lips and fingernails. This doesn't cause 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.
- Gentle massage may help increase blood flow. Check with your nurse before giving a massage. Some people may have skin that is too sensitive for 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 life will sometimes talk about travel, as though they are 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 Community Hospice & Palliative Care nurse will assess the prescribed medications 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 nurse or other 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 him or her 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 about it. 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.

RESTLESSNESS AND AGITATION

At times, the person you are caring for may appear restless or unable to stay still, and may pick at 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 your Community Hospice & Palliative Care 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.
- Consult with the Community Hospice & Palliative Care psychosocial specialist 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 it be delegated to another trusted person can provide relief.

- Try reading something inspirational or playing soft music.
- Hold hands or provide a light touch; it may be reassuring.
- Have someone sit with the person to keep him or her safe.
- Consider use of a baby monitor while out of the room.
- Refrain from using restraints; they may cause further agitation.
- It may be helpful 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 a favorite place.
- The Community Hospice & Palliative Care nurse may suggest the use of bed rails.

SURGE OF ENERGY

Dying loved ones may exhibit sudden unexplained surges of energy, which are usually short-lived. They may become unexpectedly alert and clear, asking to eat when they haven't had food for days, or they may want to get up to visit when they haven't been out of bed for weeks.

This doesn't always happen 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 individual is getting better. It may be that they are focusing 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 and say goodbye.
- Be together, holding hands.

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. The Community Hospice & Palliative Care nurse or psychosocial specialist can provide additional resources to help you.

When and how to say goodbye 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.
- It may be helpful to lie in bed with and hold your loved one, or take his or her hand and say everything you need to say.

- 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...”*
- Ira Byock writes in his book, *The Four Things That Matter Most: A Book About Living*, that saying four simple phrases may help improve relationships. They are:
 - *“Please forgive me.”*
 - *“Thank you.”*
 - *“I forgive you.”*
 - *“I love you.”*
- Tears are a normal and natural part of saying goodbye, and could be a healthy expression of your love.

REVIEW OF POSSIBLE SYMPTOMS OF APPROACHING DEATH

Because each person’s dying process is unique to him or her, the following outline 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

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 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, 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 the Community Hospice & Palliative Care Patient Priority Line (904.407.7300 or 877.699.7300 toll-free).

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 Community Hospice & Palliative Care if a team member is not there with you. A Community Hospice & Palliative Care nurse will visit. 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 and notify the patient's physician
 - Remove any tubes that are present
 - Offer to bathe and prepare the body
 - Give guidance on how to dispose of leftover medicine
 - Call the funeral home, if you wish
 - Arrange for medical equipment to be removed
 - Provide support
- 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 before calling.
- Some of the ways you can honor your loved one are: bathing and dressing the body in special clothes, telling stories, lighting a candle, sharing a ritual from his or her spiritual tradition, placing flowers in the room or playing special music.
- Let the funeral home staff know when you are ready for them to arrive. When they 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 and preparing the obituary.

Caring for someone who is in the 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. Additionally, some caregivers are often juggling other responsibilities, such as work, household duties, caring for other family members or addressing their own health concerns. 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 to smell and feel the fresh air. Take a walk or sit in the garden.
- If you have an exercise routine, try to adhere to it. This can help decrease stress and boost energy.
- Lie down for 20 minutes or sit 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 that of the person for whom you are caring.
- 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 and friends want to help but do not know how. Keep a list of tasks to be done, such as shopping, doing yard work, going to the post office, walking the dog or going to the pharmacy.
- Ask for a Community Hospice & Palliative Care volunteer visitor for respite or to help with errands.
- Share your concerns or feelings with a trusted friend, your spiritual counselor or someone from your Community Hospice & Palliative Care team.

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904.268.5200 • 800.274.6614 Toll-Free
4266 Sunbeam Road
Jacksonville, Florida 32257
CommunityHospice.com