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## What to Expect at End of Life

*A Guide for Families of Hospice Patients*



Founded in 1978 as Hospice of the North Shore

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## *The End of Life*

For more than three decades Care Dimensions has been caring for terminally ill patients and their family members. Hospice care has brought hope and compassion into the lives of thousands of area families as they manage the final stages of their loved one's life. As the end of life approaches, it raises many questions.

This booklet will give you information about the end-of-life process so you can help your loved one accomplish the transition with support, understanding and ease. This is a wonderful gift to offer your loved one.

The experience of death occurs when the body completes the physical process of shutting down, and when the spirit releases from the physical body, its immediate surroundings, and all attachments. The physical process is usually comprised of an orderly and undramatic series of changes in the body that do not require emergency medical intervention.

These physical changes are normal and natural, and the most appropriate kinds of responses are those of comfort and compassion. The process of dying is as unique as the life of each person. This is the time to offer acceptance, comfort and support.

Your Care Dimensions nurse is available to answer any questions you might have about your loved one's care.

*“What we have once enjoyed we can never lose.  
All that we love deeply becomes a part of us.”*

Helen Keller

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## *Changing Physical Signs, Symptoms and Responses*

### **Changes in Appetite and Thirst**

The patient may have a decrease in appetite and thirst, wanting little or no food or fluid. This is normal as the body naturally begins to conserve energy. Don't try to force food or drink, or manipulate your loved one into eating or drinking. To do so only increases the patient's discomfort. Honor requests for special food or beverages and provide whatever the patient can eat, when possible. Give only small amounts of food or fluids. Exceeding your loved one's ability to tolerate food can cause eating to be a distressing experience, including increasing her risk of choking, coughing or aspirating.

Small chips of ice or popsicles may be refreshing in the mouth. Sponge toothettes or lip moisturizers may keep the mouth and lips moist and comfortable. A cool, moist washcloth on the forehead may also increase physical comfort.

### **Changes in Sleeping Patterns**

Your loved one may spend more time sleeping or appear to be uncommunicative or unresponsive, and at times be difficult to arouse. This normal change is due in part to changes in the body's metabolism.

Sit with your loved one, hold his hand, but don't shake the person or speak loudly. Speak softly and naturally.

Plan to spend time with your loved one during those times when he is most alert or awake. Speak to him directly as you normally would, even though there may not be a sign of response. Don't talk about him in his presence. Never assume he can't hear you; hearing is the final sense to be lost.

### **Restlessness**

Your loved one may become restless or make repetitive motions such as pulling at bed linen or clothing. This is common and is due in part to the decrease in oxygen circulation to the brain and to changes in metabolism. Don't try to restrain these motions.

To calm your loved one, speak in a quiet, natural voice, lightly massage the forehead or read to the person. Consult your hospice nurse about medication that could help to reduce restlessness.

### **Confusion or Disorientation**

The dying person may seem to be confused about the place, time of day, or the identity of people surrounding her, including close and familiar people. This results from the slowing down of the body's systems.

Identify yourself by name to the patient as you enter the room. Speak softly, clearly and truthfully when you need to communicate something important for the patient's comfort, and explain the reason for your communication. For example, "It is time to take your medication, so you will be comfortable."

### **Decrease in Urine**

Urine output normally decreases because of the decreased fluid intake as well as the slowdown in circulation through the kidneys. The urine itself will become more concentrated and darker in color.

### **Incontinence**

Loss of control of the bladder and/or bowel may occur as the muscles in that area begin to relax. Discuss with your hospice nurse how to protect the bedding and keep your loved one clean and comfortable. Your hospice nurse will also determine whether a urinary catheter may be helpful.

## Congestion

You may hear gurgling sounds coming from your loved one's chest, as if marbles were rolling around inside. This is a normal change caused by the decrease in fluid intake and an inability to cough up normal secretions. This sound may become loud and may be disturbing to family members, but it doesn't indicate the onset of severe or new pain. Suctioning usually only increases the secretions and can cause discomfort.

Elevating the head or turning him onto his side may bring comfort and allow gravity to drain the secretions. You may also gently wipe the mouth with a moist cloth. Talk with your hospice nurse about medication that may reduce the secretions.

## Breathing Pattern Change

Your loved one's regular pattern of breathing may change to a different pace. One common pattern is breathing irregularly, or taking shallow breaths with periods of no breathing (apnea) for several seconds or as long as a minute. She may also experience periods of rapid shallow panting. These patterns indicate a decrease in circulation in the internal organs.

Elevating the head and/or turning her onto her side may bring comfort. Holding your loved one's hand and speaking gently may help to relieve anxiety.

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## Skin Temperature

### Lower Body Temperature

The skin, especially the hands, arms and legs, may become increasingly cool to the touch and may feel damp or clammy. The skin may also become darker or blotchy in appearance. This is normal and indicates that the circulation of the blood is decreasing to the body's extremities.

**Keep your loved one warm with a blanket, but don't use an electric blanket.**

### Higher Body Temperature

It's possible that your loved one may develop a fever. This is mainly due to decreased metabolism. If he has cancer, the tumors themselves produce heat.

Check with your hospice nurse about medication that could reduce the fever. Your loved one may also appreciate a cool sponge bath. The fever may persist despite your efforts because of metabolic changes.

## Emotional, Spiritual and Mental Changes and Responses

### Unusual Communication

The patient may make a seemingly “out of character” statement, gesture, or request. This is usually an indication that she is ready to say good-bye and “testing” to see if you are ready to let her die.

*Accept this moment as a wonderful gift. Say whatever you need most to say and express your affection for your loved one.*

### Decreased Socialization

The patient may want to be with only one or very few persons. This is a sign that he is preparing for the final release and an affirmation of whose support is most needed to complete the final transition. Try not to feel angry if you're not included at the very end of life. You may already have fulfilled your goodbye with your loved one and now he is ready to let go. Those present at the end should offer affirmation, support and permission to their loved one to die.

### Withdrawal

Your loved one may seem unresponsive, withdrawn, or in a comatose-like state. This indicates the preparation for release, a detaching from earthly surroundings and relationships. This is the beginning of the process of letting go.

Since the sense of hearing remains to the end of life, speak to your loved one in your normal tone of voice, identify yourself when you begin to speak, hold her hand, and say whatever you need to say that will help her die peacefully.

### Restlessness

The patient may perform repetitive tasks or seem restless. This may indicate, in part, that something unresolved or unfinished is disturbing him. Your hospice team members can assist you in identifying what may be happening, and help you find ways to relieve your loved one's fear or anxiety.

It may help to calm him by recalling a favorite place he enjoyed, a shared experience, reading something comforting, or playing soothing music.

### Vision-like Experiences

The patient may speak or believe to have spoken to people who have previously died, or to see places not visible to you. This doesn't indicate a hallucination or a drug reaction. More likely, she is beginning to detach from this life and is preparing for the transition so it won't be frightening. Just because you can't see or hear the same experience doesn't mean it isn't real to your loved one.

It will be helpful if you affirm her experiences. If they seem to frighten her, explain to her that these are normal occurrences. Your clergyman or spiritual counselor may also be able to offer comfort.

### Saying Good-bye

**Saying good-bye is your final gift to your loved one; it allows him to make the final release peacefully.**

*Give your loved one permission to let go whenever he is ready. We encourage you to say everything you need to say in your own way. It may be as simple as “I love you” or “I'll miss you.” Remember that you are heard, even if your loved one can't respond.*



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## *How to Know When Death Has Occurred*

As a caregiver, it may not be obvious to you when death has occurred. The two main signs of death are no breathing and no heartbeat.

If you sense that your loved one has died, please call Care Dimensions at 888-283-1722. You do not need to call for an ambulance or the police. **Please do not call 911.**

A hospice nurse will come to assist you and provide support to you and your family. The nurse will notify your physician and the funeral director. The funeral director will come to your home or the nursing home after the physician has been notified. Your loved one doesn't have to be moved until you are ready.

*Tears are normal and a natural part of saying good-bye. You don't need to apologize for tears or hide them from your loved ones. Tears express your sadness and help you let go.*

All of us at Care Dimensions thank you for the privilege of caring for your loved one. We admire you for all you have done to care for her during this difficult time.

*You've provided one of the most beautiful and sensitive gifts one human being can offer to another — enabling your loved one to leave this world with a special sense of peace and comfort. We hope that you take comfort from the knowledge that you've offered the greatest gifts of all — love and understanding.*



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- Meeting the unique needs of: *Veterans, Jewish patients, Developmentally disabled adults, the LGBTQ community*
- Kaplan Family Hospice House
- Grief support
- Education and training

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Main: 888-283-1722

Referrals: 888-287-1255

Referral Fax: 978-774-4389

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90 communities in Eastern Massachusetts.**



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