



## Our Mission

The Center for Advancing Quality of Life is dedicated to provide exceptional healthcare by meeting the physical, emotional, and spiritual needs for patients and families facing advanced or life-threatening illness (Palliative Care). Palliative care is compassionate care for patients and families facing a serious illness affecting their quality of life. This unique care helps patients understand the information they need to make important decisions and participate in planning their own medical care.

Care is patient-centered, supporting the roles of family in decision-making and caregiving. The goals of Palliative Care are to maximize physical comfort and function, prevent or alleviate suffering and to enhance quality of life for patients and their families throughout the course of illness.

Families are very important as death nears. At LRMC, your care team recognizes that the definition of 'family' may be nontraditional for many families. Family can be defined not only by biologic or legal ties, but anyone who defines themselves as close to the patient. This may include a faith community, a group of supportive friends, or long-time neighbors. Approaching the death of a loved one can be a very painful time, and family issues- maybe long forgotten or ignored- may surface.

You may see all or none of these symptoms. However, it is important to remember that dying is a **natural process**. This booklet is meant to answer some questions you might have, as well as review the usual signs and symptoms of approaching death. Please let any member of your care team know if you have any additional concerns or questions. We are here to support you and your loved one.

# Preparing for an Approaching Death

During the final days of a person's life, attention is shifted from "curing" to comfort measures only. Virtually any symptom (pain, anxiety, shortness of breath, spiritual distress, etc.) can be treated with attentive palliative (comfort) care. In most cases, "something" can always be done to promote comfort and dignity for both the patient and their family.

The experience called death occurs when the body completes the physical process of shutting down and the 'spirit' releases from the body and its environment. At this time, patients and families are often confronted with many conflicting emotions: hope and despair, fear and courage, relief and guilt. As you prepare for this difficult event, members of your LRMC care team want you to know what to expect and how to respond in ways to help your loved one.

Most patients die peacefully. The process is often described as a gentle slipping away or a gentle withdrawing. This includes a decline in the ability to eat, function, think and move physically.

In most end-of-life literature, the active dying phase is divided into two phases: the pre-active phase (usually 7-14 days before death) and the active phase (usually 2-3 days before death). Not all signs and symptoms occur in every person, nor will they occur in any particular sequence; for each person is unique.

However, impending death offers its own cues- the typical physical, emotional, mental and spiritual signs and symptoms. These natural and predictable features occur as a result of the gradual lack of oxygen throughout the body, which leads to multi-organ failure (the organs stop working - like the heart, liver and kidneys). These features are listed below to help you understand the natural things that may happen.

<b>Pre-active Phase</b> (7-14 days before death)	Weakness and fatigue Increased dependence on caregivers Bed bound status in formerly active patients Increased sleep Progressive disorientation Limited attention span Restlessness Decreased interest in food and fluid Difficulty swallowing Loss of bladder and/or bowel control
<b>Active Phase</b> (2-3 days before death)	Decreased responsiveness Eyes glassy, pupils unfocused No interest in food or fluid Lowered blood pressure Abnormal respiratory pattern Blood pressure and pulse difficult to obtain Progressive cooling and mottling of extremities Excess secretions/ terminal congestion Lowered skin temperature (skin cool, clammy or damp)

## **Emotional Concerns**

### **How should I interact with my loved one?**

Sit with your loved one - do not shout or shake their body, but speak naturally.

Plan to spend time when he or she seems most alert. Speak even when there may be no response. Hearing is the last sense that is lost, so your loved one will hear all that is said. This is a good time to say good-bye, reassure them that you will be all right even though you will miss them greatly. You may tell them it is OK to 'let go' or 'just rest.' This permission is often helpful for a peaceful death.

Touch is also important this time. If you desire, the care team can demonstrate techniques for gentle hand massage. You can request the side rail be let down, so you can sit closer to your loved one.

Some families are unable to travel due to a variety of reasons. If you have family members who are unable to be present at this time, consider holding the phone to your loved one's ear. Even if they cannot respond, it is important for the absent family member to have a chance to say all the things that need to be said.

### **What should I do if my loved one seems confused?**

Confusion and agitation can be caused by a variety of things. It can range from mild to end stage agitation (trying to get out of bed, being combative, picking at the covers or at the air, seeing things that are not apparent to us). Medication can be used to control this symptom, as well as soft music and a calm atmosphere.

Talk calmly with your loved one. Identify yourself by name as you enter the room, rather than ask the person to guess who you are. Speak clearly and truthfully when you need to share something important for the patient's comfort. Your loved one may benefit from familiar things from home: music, a favorite blanket or a cherished photo.

### **Do people have 'visions' at the end of life?**

At times, a dying person will speak or claim to have spoken to people who have already died. They might claim to have been places not visible to others, or they might speak in metaphor ("I am going to catch a train.") This is normal, and occurs as a person is beginning to detach from this life. Do not contradict, belittle or argue about what your loved one claims to have seen or heard.

### **What should family and friends do when death is near?**

Many find comfort in just being present, sharing the precious time. Others find comfort in reading, recalling family stories and traditions, playing soft music, singing, or saying prayers. It is also a time for spiritual and cultural rituals and honoring a life.

Also, notify all family members, allowing them the option of visiting. Everyone handles this time of life differently; some prefer to remember the loved one healthy and active. Do not criticize other's choices- your **only** responsibility is to give others the opportunity to visit before the death occurs.

## **Is it normal to grieve?**

Grieving is the mark of having been close to another person. The only way to avoid grieving is to avoid having loved. It is normal to have some of the following: loss of appetite, feelings of hopelessness and depression, aches and pains, disturbed sleeping patterns, intense anger at the world or at God/Higher Power/Spiritual Being, inability to concentrate or deep regrets for the things left undone or unsaid. All of these are normal, human responses to loss.

## **My loved one is very attached to a pet... how do I handle that?**

People and pets find comfort in being together at this time. If your loved one is requesting to say goodbye to a pet, check with a member of the care team to see how that might be arranged.

## **Do I involve the children in this process?**

This is always a difficult decision. Your family will need to determine how involved you want any children to be in the dying process of a loved one. Children usually have a good sense that something significant is happening, even though they may not be able to express their feelings in an understandable way. Listen to children and try to identify their area of concern. In the long run, avoiding the discussion of death will leave unanswered questions and create more anxiety and fear. If your child is having difficulty, The Bethany Center of Good Shepherd Hospice is a free resource. Contact the Bereavement Department (863) 802-0456; or on the web at [www.goodshepherdhospice.org/community/services.html](http://www.goodshepherdhospice.org/community/services.html)

## **Our family has customs and rituals that are important to us. Is that ok?**

The physical process of dying may be the same for most expected deaths. But emotional, cultural and spiritual concerns are very different from family to family. Your desires and needs are important to the care team at LRMC. You are welcome to bring familiar objects from home (music, blankets, photos, etc) to comfort your loved one. Any additional concerns should be discussed with a staff member, so your traditions and customs are honored.

## **Physical Concerns**

### **Why does it seem like our loved one is not responding to us?**

Your loved one may turn inward- shown by a physical and emotional withdrawal. This is a natural process of withdrawing from everything outside one's self- when someone does not have the physical or emotional energy to engage with others. Separation begins first with the world- less interest in newspaper or television. It then proceeds to people- neighbors, family and friends. Usually, it is a result of the normal physical nature of the dying process.

## **Why don't people want food or drink at the end of life?**

Reduced fluid and food intake is the natural process of the body's death. The body has naturally started to conserve energy, so there is a decreased need for calories from food. Mild dehydration is a natural comfort measure, since the body's systems can no longer process fluid in the normal way. The patient is not starving to death- this is a result of the underlying disease process.

At no time should food or fluids ever be forced. Families can show love and concern in other ways. For example, maybe you would like to learn how to assist the staff in keeping the mouth clean and moist. The care team can assist you, if you desire.

## **Why do the extremities turn bluish in color?**

These symptoms are the result of blood circulation slowing down and do not necessarily indicate that someone is too cold. Decreased circulation can cause coolness and discoloration on the skin. The use of light covers, as well the turning from side to side frequently will promote comfort and reduce the chance of bedsores. Heating pads and electric blankets are NOT recommended.

## **What is that rattle I hear in the back of the throat?**

Terminal congestion caused by noisy and moist breathing or "rattling," and is a common sign in patients nearing death. It is a collection of fluid pooling in the back of the throat. This normal change is caused by sagging of the muscles of the tongue and your loved one's inability to swallow and cough up normal secretions. With medications and repositioning, this symptom can often be minimized. However, often this symptom is more uncomfortable for us as observers than it is for the patient.

## **Why is my loved one's urine so dark?**

Urinary output normally decreases and may become very concentrated- often "tea" colored. This is due to the decreased fluid intake, as well as the decrease in circulation through the kidneys. It is also common for patients to be incontinent of both urine and stool. Bedpans and diapers can be used to protect the bed linens. The patient can also be cleaned and bed linen can be changed to maintain comfort and protect the skin.

## **Why do I see a change in the breathing pattern?**

"Cheyne-Stokes" breathing may occur: a particular pattern of breathing irregularly (shallow, often rapid, breaths followed by period of no breathing lasting up to one minute). Changes in breathing patterns indicate a decrease in the oxygen levels in the internal organs. These symptoms are very common and do not mean that your loved one is uncomfortable or is struggling.

Remember that people breathe better in a cool room. Turn the temperature down, especially if many visitors and family members are in the room. Often, a small portable fan will stir the air and help ease the work of terminal breathing. Ask a member of the care team to provide a fan, if you wish.

## Care of the Caregiver

### **Don't overtire yourself.**

Things need to get done, but not everything has to be done right away. Pace yourself and focus on your loved one.

### **Do take time for rest.**

A life-limiting illness can consume great amounts of energy. Even simple tasks can become tiring. It is important to plan times for rest.

### **Don't isolate yourself.**

Friends and family usually want to ease discomfort, so tell others what you need. Be specific- "Please go to the store for this list of items" or "Please take my child to piano lessons on Tuesday."

### **Do express your feelings to those you care about.**

Ira Byock, MD is the Director of Palliative Medicine at Dartmouth Hitchcock Medical Center and a professor at Dartmouth Medical School. In his book *The Four Things that Matter Most: A Book about Living*, Byock speaks of the four things to say at the end of one's life- "Thank you; I love you; Please forgive me; I forgive you." These are powerful statements that have the ability to heal. If you are interested in more information, this book is sold in the LRMC gift shop.

### **Don't believe it is too late to pray or become spiritual.**

Allow yourself to be open to spiritual comfort. LRMC has chaplains on call 24 hours a day/7 days a week. They are non-denominational, and are specially trained to work with the sick. Let a member of your care team know if you wish to meet with a hospital chaplain, or the spiritual leader of your choice.

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This information has been compiled  
for you by the Palliative Care Service at LRMC.