

Approaching the End of Life

A Guide for Family & Friends



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Introduction

In this booklet you will find descriptions of some of the normal changes that can occur as your loved one approaches the end of life. These changes can bring up different responses in you and your family. After reading this booklet you will know helpful and available ways to deal with these changes and to support both you and your loved one. We encourage you to talk about your particular situation with the medical team, palliative care team, chaplains, and counselors.

Changes That May Occur

There are as many different ways to experience the end of life as there are ways to live. Even so, many of the changes that happen at this time are common and natural. These changes may happen over hours, days, or months. There will be good days and bad days.

- **Energy:**

The most common experience for someone with an advanced illness is feeling tired and weak. After doing the simplest of things, your loved one may have trouble getting back their energy the way they used to. When someone is so tired, it can be best to focus their energy on what is most important to them and get help with the less important things. For example, one person may prefer to go out for fresh air, finish a project, or talk with friends and family. This person could then get help with bathing, getting dressed, or using the bathroom. Everyone is different.

- **Sleep:**

You may notice your loved one is sleeping longer at night and napping more throughout the day. You will see them needing more and more rest. Rest is really important for someone with an advanced illness. At some point, they may seem to sleep for most of the day and night.

- **Confusion:**

Feeling very drowsy or confused after waking up or late at night is also common. It may take more time for your loved one to figure out where they are and what is going on around them. They may be confused throughout the day or sometimes have visions. The health care team can help with this by looking into the possible causes. Just seeing the familiar faces of friends and family can be a great support at this time.

- **Withdrawal from friends and family:**

As their illness moves along, your loved one may become less interested in the outside world and being social. Even the most outgoing person may prefer a more quiet environment. They may not be as talkative as they had been. Use this time to just listen. Sitting quietly is often all that is needed.

- **Appetite:**

Appetite changes as the body slows down. Your loved one may need and want less food. They may only eat a small amount of their meal or skip it entirely. These changes in eating are natural and not uncomfortable but can be very hard for friends and family. Offering smaller amounts of foods or soft foods they enjoy, like milkshakes or pudding, may help. Don't be disappointed if they don't eat like they used to. Urging them to eat more may lead to pain, nausea, or other physical problems.

- **Difficulty eating:**

Swallowing may become more difficult as time goes on. The muscles that help with swallowing are getting weak too. It may take more time to swallow small bits of food, medicine, or fluids. Offer sips of fluids as long as your loved one can comfortably swallow. Flexible straws may help if they can no longer sit up. Ice chips or swabbing the mouth with water may also help.

- **Pain and other symptoms:**

Pain, shortness of breath, fear, nausea, and constipation may all occur with advancing illness. People may have none, a few, or all of these symptoms. These symptoms can usually be managed with medicines or with other treatments offered by your health care team. If you have any concerns about your loved one's care, let your health care team know. They will provide what is needed to help them feel better or will contact the right person who can.

The Final Hours to Days

A common question is “How will I know when the time is near?” Sometimes someone dies unexpectedly with little or no warning. But most of the time there are signs that death will probably come within hours to days.

- **Sleeping & Responding:**

Your loved one may sleep almost all of the time. They may no longer be able to speak or respond when you talk to or touch them. It’s okay to continue to talk to them as they may still hear you. You might want to recall some good memories with them or play their favorite music. Just sitting quietly with them can sometimes be the best thing to do.

- **Breathing:**

The way your loved one breathes may change. Breathing may become heavy, fast, or shallow. There can be longer pauses between breaths -- sometimes for a few seconds and sometimes for as much as a minute. Don’t worry. This is a normal part of the dying process and is not bothering them. If it looks like they are having a hard time breathing, there are medicines or other ways to help.

- **Difficulty Swallowing:**

As your loved one nears the end of their life, they will become too weak to swallow their own saliva. The saliva will naturally travel to the throat or chest area. It can sometimes sound noisy as they sleep and breathe deeply. This will probably be a new sound for you but there is no cause for worry. Most of the time this is just a noise from the back of the throat and usually doesn’t bother them at all. Be sure to let your health care team know of any questions or concerns you may have.

- **Skin and Temperature Changes:**

A change that is harder to see is the heart slowing down. This causes the blood to circulate more slowly. The heart's number one job is to get blood to the brain. As the heart slows it will not be able to get as much blood to the hands and feet. This is why the feet and hands can get cool to the touch. Covering your loved one with a blanket can help if they feel cold.

- **Last Moments:**

Many times, family or friends want to be there for the last moments of their loved one's life but this is something no one can control. Often, a dying person will take their last breath when family or friends have just stepped out of the room. We do not know why this happens. Some people think that dying people choose to go when the people they care about are not in the room. If you do spend a lot of time with your loved one during these last few hours, you may want to take a break every now and then. Let them know you will be out for a short time and you will be back soon. Remember, no one can tell exactly when that last breath will be.



Caring for Yourself

Caring for another person through the dying process can be very tiring. It is important to remember to eat well and drink plenty of fluids. You need your strength to care for another person and to help yourself get through this time. It's possible you could experience feelings that you may not be used to, like helplessness, anger, fear, numbness, exhaustion, or deep sadness. These feelings are all very normal during these times. You may want to call a family member or friend, contact your health care team, the palliative care team, or just go for a walk. Only you know what is best for you. If you are someone who does not easily ask for help, remember, it is often a gift to your friends and family to be able to support you.

Practical Preparation for Death

There will be a fair amount of practical things to handle after your loved one dies. Families and friends find themselves overwhelmed if they are not prepared for the decisions that need to be made. You may want to consider taking care of some things earlier. It may seem uncomfortable or odd to be making final arrangements for someone who is still alive. However, this can help to make sure that your loved one's choices are known and followed. If you have questions, concerns, or need any assistance, your social worker can help.

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