

What to Expect at the End of Life

Signs of approaching death and things you can do

This handout was written to help you understand the natural process of dying. It includes common changes you may observe in your loved one.

Please know that each person is unique and approaches death in their own way. The stages we describe may not happen with your loved one, or may happen in a different order.

Death comes in its own time. Ask your nurses if you need help or if you have any questions.



We Are Here to Help

As your loved one faces the last stages of their life, our main goal is to keep them comfortable. You know your loved one best, and we rely on you to tell us what is needed.

Please tell the nurses if you would like to play music, to have the door opened or closed, or to have the lights dimmed. We may also turn off the monitors so they are not a distraction.

Please tell the nurse if you see any signs of discomfort in your loved one. We are here to help.

What to Expect

Your loved one might withdraw or spend more time sleeping.

They might want to be with very few people. This can be a time when your loved one needs private time to think, review life, or deal with their feelings. Sometimes, it may be hard to wake them up and they might not recognize you right away.

- Consider shorter visits by friends and extended family to avoid tiring your loved one.
- Quietly sit with your loved one. For some people, gently holding their hand is comforting.

- You can talk to your loved one. Speak in a normal voice, even if they don't always respond. Hearing is one of the last senses to be lost.
- If your loved one is withdrawn, it does not mean you are not loved. They may not have enough energy for talk. Allow for some quiet time.

In the Weeks Before Death

Your loved one may not eat or drink much.

Their sense of taste may change so that even favorite foods may not taste good. It may become hard to swallow as muscles in the throat get weaker. This is common. It is getting harder for their body to process food.

Do not try to force your loved one to eat. Eating may cause discomfort, nausea, or vomiting. It is OK for them not to eat.

- Use mouth swabs (such as Toothettes) with mouth and lip moisturizer to help keep their mouth moist and comfortable.
- You can offer ice chips, popsicles, ice cream, broth, yogurt, Jell-O, or shakes, if swallowing doesn't make them cough.
- Thicker liquids may be easier to swallow. Offer small portions or bites as often as they want. Sometimes just a small amount of a favorite food or drink on the lips can be comforting.

Your loved one may get confused.

They may not know the day and the time, where they are, and who people are. This is normal at the end of life.

Your loved one might seem like they are talking to people who are not there, or who have died. They might reach out, look past you, or talk about needing to go somewhere. This does not mean they are having a drug reaction or a hallucination. They might be starting to detach from life and getting ready to let go.

- Tell your loved one your name rather than expecting them to know who you are.
- Speak softly, clearly, and truthfully. Give more time for your loved one to respond.
- Be reassuring and validate the feelings they are telling you about. Try not to argue about what they say they have seen. Instead, use comforting words, such as "That must be nice to see your Grandma."
- If they are anxious or alarmed, ask what might help them feel safe. Try to reassure them that what they are feeling or seeing is normal.

Secretions may increase.

Your loved one may be too weak to cough up normal fluid such as saliva. Sometimes they make a loud gurgling sound. This does not mean they are having problems breathing or that they are in pain. This sound can be compared to a person who is snoring while sleeping.

We may not use suction at this time, since it can increase secretions and cause more discomfort.

- You can raise the head of the bed or gently turn your loved one's head to the side and allow gravity to drain their saliva.
- Mouth care helps. Use mouth swabs (such as Toothettes) with mouth and lip moisturizer to help keep their mouth moist and comfortable.
- Ask your nurse if there are medicines to help decrease the secretions.

In the Days or Hours Before Death

Your loved one's breathing may change.

Breathing might not be regular. They might take shallow, quick breaths or have periods of no breathing, lasting as long as a minute.

- You can raise the head of the bed or turn your loved one on their side to help their breathing.
- Hold your loved one's hand and talk to them gently.
- Let your nurse know if they seem to be struggling to breathe.

Some people get restless.

Your loved one may pull at the bed sheets or make other repeating motions. This is common and normal.

- Talk calmly about pleasant memories. Read out loud. Play favorite music.
- Try gentle massage or lotion to relax them.
- Consider a change in their position or helping them move.
- Make a calm environment if you can. Decrease activity in the area. You can close the curtains.
- Sometimes changing the lighting may be calming.
- Call the nurse if your loved one is very restless or agitated.

Hands and feet may be cool to your touch.

Your loved one's skin may change color, or might look darker and even mottled. This is a normal sign that blood circulation is decreasing.

- You can keep them warm with blankets or warm washcloths.
- Gentle massage or holding their hands or feet can help to warm them.

In the Hours or Minutes Before Death

Your loved one's eyes may be open, but not seeing. Some people keep their eyes closed.

They cannot be awakened. They are non-responsive.

Your loved one's breathing changes to "fish out of water" breathing, where their jaw moves with each breath.

- You can sit with them. Keep talking to them or read to them. Some people sing. Your voice may be comforting.

What Other Families Have Told Us

Give your loved one permission.

Your loved one might try to hold on to be sure those they love are going to be all right.

- Let your loved one know that you will take care of yourself and that they will always be remembered.

Say goodbye.

Saying goodbye is your final gift to your loved one.

- Say everything you need to say. It can be as simple as saying "I love you." It might be sharing favorite memories of things you did together.
- Four simple phrases – "Please forgive me," "I forgive you," "Thank you," and "I love you" – carry the power to help, even in the face of death.

The Grieving Process

Everyone grieves in their own way.

- Sometimes saying goodbye includes tears. Some people cry later, or not at all.
- After a loved one's death, some people need to stay at the hospital and be with their loved one. For others, it is best to grieve at home.
- Some people want to be surrounded by friends and family, while others want time to be alone.

Spiritual care providers and social workers can help you through this time. Please tell your nurse if you would like to meet with them.

We have bereavement materials available that other people have found helpful. The packet includes practical guides, phone numbers, and resources that may be helpful later on.

If you do not have a packet of bereavement resources, be sure to ask your nurse or social worker for one.

Questions?

Your questions are important. Call your social worker or spiritual care provider if you have questions or concerns.

- UWMC Social Work and Care Coordination: 206.598.4370
- HMC Social Work Department: 206.744.8030