

Approaching the Final Days

The final days of life can be difficult. It is important for caregivers, families and loved ones to talk about managing the final days together. Knowing what to expect and how to prepare for the end of life is helpful. Counseling professionals are available at The James to help you and your family during this time. Ask your doctor or nurse about these services. See the Patient Education handouts, **Conversations that Light the Way and Choices - Living Well at the End of Life.**

What are the signs that a person is dying?

Death is a natural process that happens as the body functions shut down. Here are some common signs that the end of life is near and ways to care for your loved one:

- **Changes in Appetite and Thirst**

It is normal for someone at the end of life to have a decreased appetite and thirst. They may not want any food or fluids at all.

The person is not “starving to death.” Do not try to force them to eat or drink. This will make them feel ill or uncomfortable. Your loved one may like small ice chips or frozen juices to refresh their mouth. If your loved one is unable to drink, ask the nurse if fluids may be given in small amounts with a syringe. Mouth swabs dipped in water can be used to help keep the mouth and lips moist and comfortable.

- **Skin Changes**

The person’s hands, arms, feet, and then legs may feel cooler to touch. The color of the skin may change. The underside of the body may become darker and the skin may become blue or gray in color (mottled). This is a result of blood flow slowing to the arms and legs to allow more blood to flow to vital organs. Keep the person warm, **but do not use an electric blanket.** Continue with usual affection and touching, such as holding the person’s hand.

This handout is for informational purposes only. Talk with your doctor or health care team if you have any questions about your care.

- **Sleepiness and Withdrawal**

The person may sleep more, become difficult to wake up or may not respond at all. When awake, the person may say only a few words and speak very softly. The person may wish to be with only one or two people.

Quietly being present can be comforting to your loved one. Your loved one is able to hear what is being said even if they appear to be in a deep sleep, so be aware of the conversations you have around them. You may want to state who else is present in the room.

- **Disorientation or Confusion**

Changes in the body may cause confusion. The person may not be able to focus on dates, times or places. Your loved one may not recognize people or things. Touching the person may provide comfort and relax them. Tell the person who you are. Speak softly, clearly, and truthfully. Always explain what you are doing and why.

- **Congestion**

The person may have gurgling or rattling sounds in the chest or throat. These sounds may become loud. Congestion does not mean the person is in pain or uncomfortable. This is a result of decreased fluid intake. Also, the person may be too weak to cough. Suctioning the person may not help and could cause discomfort. Gently turning your loved one's head to the side will allow the fluids to drain. Sometimes, a medicine will be given to help with congestion.

- **Restlessness**

The person may pull or pick at bed linens or repeat other odd movements. This happens because of changes in the body and a decrease in oxygen to the brain. You should not try to stop these movements. To help calm the person, speak in a quiet, natural way. Hearing the sound of familiar voices, gently massaging the forehead, reading to the person, or playing soothing music may help to calm them. Sometimes, a medicine can be given to help with restlessness, so tell the nurse if your loved one is unable to relax.

- **Incontinence**

The person may lose control of urine and bowels. This happens because muscles in those areas begin to relax. At home, you may use waterproof pads on the bed. Talk with the nurse about what can be done to keep the person clean and comfortable.

- **Decreased Urine**

It is normal for the amount of urine to decrease and the color to become darker. This is called concentrated urine. This happens due to less fluid intake and decreased blood circulation through the kidneys. If needed, the nurse may insert a tube to drain urine.

- **Changes in Breathing**

A breathing pattern called “Cheyne-Stokes” may occur. Breathing may become shallow with long pauses of up to a minute between breaths. There may be periods of rapid shallow breathing like panting. Raise the person’s head or turn the head to the side to help make them comfortable.

- **Visions and Delusions**

The person may see and hear things. They may speak to people that cannot be seen by anyone else. These visions may be very real to the person. The person may say things that you do not understand. This is normal for someone at the end of life.

Letting Go and Saying Good-bye

In the final days, it is common for the dying person to speak less and withdraw from others. This can be difficult for loved ones. On one hand, they want the suffering to be over, while on the other hand, it is very hard to say goodbye. A person near the end of life seem to be comforted by their loved one’s support and knowing that it is all right to let go and die. This helps honor the end of life and gives them permission to die. Touch your loved one, recall memories, and say what you need to say. Tears or other forms of grief are normal and do not need to be hidden.

Normal Signs of Death

- No breathing or heartbeat
- Bowel and/or bladder release
- No response
- Eyelids and mouth slightly open
- Pupils enlarged and unchanging or fixed, with no blinking
- Relaxed jaw

What do I do when death is expected and may happen at home?

Having a plan for what to do at this difficult time is very helpful for families and caregivers. You can reduce your stress or worry by knowing ahead of time what to do in your situation and who to notify. Talk with the doctor about a plan for your loved one's care.