What to Expect When a Patient is Dying: Information for Family Members

No matter what the underlying cause of death, there is a common final pathway that most patients travel.

Social withdrawal: This is normal. The dying patient will begin to withdraw from the world – no more interest in newspaper or television. Then he or she will withdraw from people – eventually even family and those persons most loved.

Food: The patient will have less need for food and drink, and a gradual loss of interest, as the body prepares to die. This is very hard for some families to accept. The patient is not starving to death; this is part of the disease. Follow his or her lead. Do not force feed, as this may cause discomfort. Swabbing the lips or mouth may provide comfort.

Sleep: The patient will spend more and more time sleeping, or may find it hard to keep the eyes open. This is due to a change in the body’s metabolism as a result of the disease. If possible, spend more time with the patient when he or she is most alert. This might be the middle of the night.

Disorientation: The patient may be confused about time, place, and people – and may see people who are not there. Some patients describe seeing family members who have died (sometimes welcoming or beckoning to the patient). There is no need to “correct” the patient if he or she is not distressed by this. Gently orient, if the patient asks.

Restlessness: The patient may become restless and pull at the bed linens. This is also due to a change in the body’s metabolism. Talk calmly and assure the patient so he or she is not startled or afraid. Certain medicines also may help.

Decreased senses: The patient may not see or hear clearly. Soft lights in the room may prevent becoming confused by what is seen. Never assume that the patient cannot hear you. Hearing is the last of the five senses to be lost.

Incontinence: Urine and bowel movements are often not a problem until death is very near. A catheter, or pads under the patient, can help with comfort and cleanliness. As death becomes near, the amount of urine decreases and the urine darkens.

Physical changes as death approaches:
• Blood pressure decreases.
• Pulse may increase or decrease.
• Temperature can vary; fever is common. The patient may perspire or feel clammy.
• Skin color may change (flushed with fever, bluish with cold). A pale yellowish pallor (not jaundice) often comes when death is near.
• Breathing rate may increase, decrease or become irregular. Periods of no breathing (apnea) are common.
• Congestion may be heard as a rattling sound in the lungs or upper throat. This occurs because the patient is too weak to clear the throat or cough. The congestion may come and go and can sometimes be very loud, depending on the patient’s position. Medications or raising the head of the bed may help.
• The arms and legs may become cool to the touch. The hands and feet can become purplish. The knees, ankles and elbows can become blotchy. These are signs of slower circulation.
• The patient may enter a coma before death and not respond to voice or touch.

How to know when death has occurred
• No breathing and heartbeat
• No response to verbal commands or gentle shaking
• Jaw relaxed and mouth slightly open
• Loss of control of bowel or bladder
• Eyelids slightly open, eyes fixed on a certain spot

The information presented is intended for general information and educational purposes. It is not intended to replace the advice of your health care provider. Contact your health care provider if you believe you have a health problem.