Information Sheet 3:
Teaching the family what to expect when the patient is dying

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Family members look to the physician and nurse to help them know what to expect when a loved one is dying. No matter what the underlying causes, there is a common final pathway that most patients travel. Indicate your desire to be helpful. Say: *Many families like to know what may happen so they will be prepared, is that true for you?* If they say yes, describe the features on this list and answer their questions.

1. **SOCIAL WITHDRAWAL** is normal for the dying patient as the person becomes less concerned about his or her surroundings. Separation begins first from the world – no more interest in newspaper or television, then from people – no more neighbors visiting, and finally from the children, grandchildren and perhaps even those persons most loved. With this withdrawal comes less of a need to communicate with others, even with close family.
2. **FOOD:** The patient will have a decreased need for food and drink as the body is preparing to die. This is one of the hardest things for some family to accept. There is a gradual decrease in interest in eating and appetite—even for their favorite foods. Interest may come and go. The patient is not starving to death—this reflects the underlying disease. Liquids are preferred to solids—follow the patient's lead and do not force feed.
3. **SLEEP:** The patient will spend more and more time sleeping; it may be difficult for them to keep their eyes open. This is a result of a change in the body's metabolism as a result of the disease. Tell family to spend more time with the patient during those times when he/she is most alert; this might be the middle of the night.
4. **DISORIENTATION:** The patient may become confused about time, place and the identity of people around him/her; he/she may see people who are not there. Some patients describe seeing family members who have already died. Sometimes patients describe welcoming or beckoning. While the patient may not be distressed, it is frequently distressing to family or health care professionals. Gently orient the patient if he or she asks. There is no need to 'correct' the patient if he or she is not distressed.
5. **RESTLESSNESS:** The patient may become restless and pull at the bed linens. These symptoms are also a change in the body's metabolism. Talk calmly and assuredly with the patient so as not to startle or frighten them. If the patient is a danger to himself or others, you may prescribe sedating neuroleptics (e.g.chlorpromazine), or neuroleptics (e.g. haloperidol) in combination with benzodiazepines (e.g. lorazepam), to help the patient rest.
6. **DECREASED SENSES:** Clarity of hearing and vision may decrease. Soft lights in the room may prevent visual misinterpretations. Never assume that the patient cannot hear you, as hearing is the last of the five senses to be lost.
7. **INCONTINENCE** of urine and bowel movements is often not a problem until death is very near. Invite family to participate in direct care; the nurse can help place absorbent pads under the patient for more comfort and cleanliness, or a urinary catheter may be used. The amount of urine will decrease and the urine become darker as death becomes near.

8. PHYSICAL CHANGES as death approaches.

a. The *blood pressure* decreases; the pulse may increase or decrease.
b. The *body temperature* can fluctuate; fever is common.
c. There is increased *perspiration* often with clamminess.
d. The *skin color* changes: flushed with fever, bluish with cold. A pale yellowish pallor (not to be confused with jaundice) often accompanies approaching death.
e. *Breathing changes* also occur. Respirations may increase, decrease or become irregular; periods of no breathing (apnea) are common.
f. *Congestion* will present as a rattling sound in the lungs and/or upper throat. This occurs because the patient is too weak to clear the throat or cough. The congestion can be affected by positioning, may be very loud, and sometimes just comes and goes. Anticholinergic medications (like transdermal scopolamine or sc/iv scopolamine or glycopyrrolate) can secretions (see Fast Fact #109). Elevating the head of bed and swabbing the mouth with oral swabs give comfort and give the family something to do.
g. The *arms and legs* of the body may become cool to the touch. The hands and feet become purplish. The knees, ankles and elbows are blotchy. These symptoms are a result of decreased circulation.
h. The patient will enter a *coma* before death and not respond to verbal or tactile stimuli.

How to Know When Death Has Occurred:

- No breathing and heartbeat
- Loss of control of bowel or bladder
- No response to verbal commands or gentle shaking
- Eyelids slightly open; eyes fixed on a certain spot
- Jaw relaxed and mouth slightly open

References

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