

**FAST FACTS AND CONCEPTS #149**  
**TEACHING THE FAMILY WHAT TO EXPECT WHEN THE PATIENT IS DYING**

**Charles F von Gunten MD, PhD**

**Introduction** Family members look to the physician and nurse to help them know what to expect when a loved one is dying. No matter 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, such as 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 (see *Fast Fact #1*).
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.
  - c. The *body temperature* can fluctuate; fever is common.
  - d. There is increased *perspiration* often with clamminess.
  - e. The *skin color* changes: flushed with fever, bluish with cold. A pale yellowish pallor (not to be confused with jaundice) often accompanies approaching death.
  - f. *Breathing changes* also occur. Respirations may increase, decrease or become irregular; periods of no breathing (apnea) are common.

- g. *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 scopolamine or glycopyrrolate) can help (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.
- h. The *arms and legs* 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.
- i. The patient will enter a *coma* before death and not respond to verbal or tactile stimuli.

### **HOW TO KNOW THAT 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.

**Acknowledgement:** This *Fast Fact* was adapted with permission from a family information handout (The 'Blue Sheet') given to families of San Diego Hospice & Palliative Care Program.

### **References**

1. Twycross R, Lichter I. The terminal phase. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine*. 2nd ed. Oxford, England: Oxford University Press; 1998.
2. Ellershaw J, Ward C. Care of the dying patient: the last hours or days of life. *BMJ*. 2003; 326(7379):30-4.
3. Ferris FD, von Gunten CF, Emanuel LL. Competency in End of Life Care: the last hours of living. *J Palliat Med*. 2003; 6(4):605-613.

**Version History:** This *Fast Fact* was originally edited by David E Weissman MD and published in February 2006. Version re-copy-edited in April 2009; revised again July 2015.

***Fast Facts and Concepts*** are edited by Sean Marks MD (Medical College of Wisconsin) and associate editor Drew A Rosielle MD (University of Minnesota Medical School), with the generous support of a volunteer peer-review editorial board, and are made available online by the [Palliative Care Network of Wisconsin](#) (PCNOW); the authors of each individual *Fast Fact* are solely responsible for that *Fast Fact's* content. The full set of *Fast Facts* are available at [Palliative Care Network of Wisconsin](#) with contact information, and how to reference *Fast Facts*.

**Copyright:** All *Fast Facts and Concepts* are published under a Creative Commons Attribution-NonCommercial 4.0 International Copyright (<http://creativecommons.org/licenses/by-nc/4.0/>). *Fast Facts* can only be copied and distributed for non-commercial, educational purposes. If you adapt or distribute a *Fast Fact*, let us know!

**Disclaimer:** *Fast Facts and Concepts* provide educational information for health care professionals. This information is not medical advice. *Fast Facts* are not continually updated, and new safety information may emerge after a *Fast Fact* is published. Health care providers should always exercise their own independent clinical judgment and consult other relevant and up-to-date experts and resources. Some *Fast Facts* cite the use of a product in a dosage, for an indication, or in a manner other than that recommended in the product labeling. Accordingly, the official prescribing information should be consulted before any such product is used.