

# Terminal Illness

## THE FACTS

In our society, it is common for people to feel uneasy talking or even thinking about death. Our level of discomfort in talking and thinking about death has changed over the years, and it is still changing. A hundred years ago family members did not often move far away from one another. It was common for three generations to live together. People tended to die at home surrounded by the family, including the young children. As we moved toward a more industrial society, more family members moved further away. Physicians and hospitals were more accessible. More people died away from home and young children were “shielded” from the realities of death. The children were often told little more than that a loved one had “gone to sleep,” or “gone to heaven,” or “passed.” Death became more mysterious and less a part of ordinary life. In recent years, however, people are increasingly deciding to die at home, surrounded by friends and family.

Attitudes about death vary tremendously from one person to another, and even from circumstance to circumstance in the same person. There are many components making up our attitudes about death. For many people, religion plays a significant role. Previous experiences with deaths or losses also help make up our attitudes. While we cannot change our experiences, we can certainly change our attitudes about death and working with patients who are terminally ill.

## EXAMINE YOUR OWN FEELINGS

Every person has his or her own deeply personal feelings about death and dying. These feelings and attitudes are developed over a lifetime of experiences. In order to feel more comfortable in working with patients who are terminally ill, it is important for every home health aide to examine his or her own feelings. Think carefully about the following:

- » What is your earliest memory about a death?
- » How old were you when you had your first experience with death?
- » What was your relationship to the person who died?
- » How did you learn about the death?
- » Was it a sudden death or an expected one following a long illness?
- » How did you feel when you first learned about the death? How did you feel later? How do you feel now?
- » How did you handle your feelings? Reflect on the methods in which you grieved and the ways you interacted with others about the death.
- » Have you ever cared for a dying patient? If so, how did the person react? What were your feelings about the person?
- » Have you ever been present when someone died? Think about how you felt at the time and later.
- » Are you afraid of dying? What do you believe happens after death?
- » How do you think you would react if a physician informed you that you have a terminal illness?

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As you reflect on these difficult questions, you will begin to realize that the way you feel about terminal illness and death is based on your own unique experiences. That is the case with every individual. No two people will react in exactly the same way. The reality is that, no matter what a person's attitude and thoughts about death are, we are all human and will not live forever. The fact is that everyone will die. In your role as a home health aide, you can be of great comfort and assistance to patients who are terminally ill.

## REACTIONS TO TERMINAL ILLNESS

Although no two people will react in exactly the same manner, there are some common emotional reactions most people experience. Extensive research by Dr. Elisabeth Kubler-Ross showed that there is a pattern of reactions among the terminally ill. These are often called the "stages of dying" or "stages of grief" but it is extremely important to note that not everyone will go through each stage. And not everyone will progress through the stages in the same order. In addition, the stages can overlap and a person may go from one stage to another and back again. A key point to keep in mind is that many people will never reach acceptance of death. One of your important roles as a home health aide is to be accepting of the patient and his or her reaction.

### » Denial

The news that an illness is terminal is overwhelming. A typical response is, "This can't be happening to me!" Despite the universality of death, most people do not want to die, so the initial response is denial. Often the patient will hope there has been a mistake of some kind and it really isn't true that he or she is terminally ill.

### » Anger

Anger is a very common reaction. Faced with a terminal illness, patients may be very angry that other people (including their own families) will go on living. It may seem unfair that they should be dying when they feel they have so many reasons to live. Everyone has unfinished business and patients may be very angry that death will rob them of the opportunity to see a child grow up, or to have grandchildren, etc. Families and friends (and home health aides) may bear the brunt of the anger. It is important to be accepting of the patient's feelings. You must recognize that the anger is not against you personally, and you should not respond with anger of your own.

### » Bargaining

Some people go through a bargaining stage in which they attempt to postpone the inevitable. They may tell themselves that if they will only be a better person, then they really won't have to face death. Religious patients often bargain with God, promising to do wonderful good works in exchange for a miracle. This stage is often the shortest, and many people do not go through a bargaining stage at all.

### » Depression

As patients reflect on the implications of facing death, they often become very depressed. They may be deeply sad and appear disinterested in normal activities. As is the case with all the other stages, you must be accepting of the patient's depression. You should allow him or her to be sad or to cry. You should not try to cheer up the patient. Be a good listener and allow the patient to discuss his or her feelings.

### » Acceptance

Acceptance is a stage that many patients do not achieve. At this stage, patients usually become calmer about the

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prospects of dying and are less angry and depressed. Some patients even begin to look forward to the end of life and the relief death will bring. For some families this can be a very peaceful time. For others, however, it is extremely stressful since it appears the patient has “given up” and wants to leave them. Home health aides need to be especially supportive of the patient and the family at this time.

It is important to realize that the family will also experience the stages during their preparation for the patient's death. Home health aides must recognize that each person in the household can be in a different stage of the process.

## THE HOME HEALTH AIDE'S ROLE IN CARING FOR THE DYING

Home health aides need to recognize that a dying patient is also a living patient; a patient with the same needs as others. The role of the home health aide is to help meet needs and provide supportive, non-judgmental care. While it can be emotionally challenging, working with terminally ill patients can also be emotionally rewarding. The home health aide's role includes:

### » **Assisting with physical needs**

Follow the assignment sheet and provide assistance with cares as assigned. Communicate with the supervisor if there are additional tasks you think are important so they can be added to the assignment.

### » **Listening to the patient**

Many terminally ill patients will talk with their aides about things they are reluctant to discuss with their families. Aides must sharpen their listening skills and provide an atmosphere in which patients can openly express their fears and hopes.

### » **Responding to difficult questions**

- Do not destroy hope or encourage false hope.

Do not dismiss a patient's concerns by saying that everything will be all right. On the other hand, do not destroy the hope that a patient might express. For example: If the patient says she is looking forward to attending her daughter's graduation next year, respond with a statement such as, “Wouldn't that be wonderful?” By reacting in this manner you are neither giving false hope nor destroying hope.

- Be honest with patients.

It is likely that you actually do not know the answers to many of the questions a terminally ill patient may ask. This is especially true of questions about his or her “timeline” or what the end will be like. It is perfectly acceptable to respond that you do not know. In reality, most patients do not expect you to know these things anyway.

- Let the patient lead the conversation.

The patient should be the one to bring up things he or she wants to talk about. You should not question the patient about his feelings or fears unless he or she has indicated the desire to talk.

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- Don't say more than you should.

No matter what your personal feelings may be, you should not interject your own feelings about religion or death. Often the best response is to gently take the patient's hand and say, "I know how concerned you are."

## » Promoting the patient's independence

This role could also be called, "Helping patients live until they die." It is crucial to recognize that dying patients have the same basic needs as others. They need to maintain independence as long as possible and continue to be decision-makers. They need recreation, humor, safety and security. In short, they need to remain as "normal" as possible. Home health aides can help by:

- Allowing the patient to make decisions and participate in care
- Encouraging the patient to do as much as possible for himself or herself
- Helping the patient schedule and prioritize activities so he or she will have the energy to do the things that are important to him or her, and
- Talking directly with the patient and not through a family member.

## THE ACT OF DYING

It is possible that you may be with the patient during his or her last hours. It is important that you are aware of the signs and symptoms of impending death as well as when you should notify the nurse. Coordination among all disciplines caring for a terminally ill patient is very important. Everyone should know what actions to take when the patient shows signs of impending death. Although some terminally ill patients die abruptly, most of them will show certain signs that death is nearing.

## » Planning ahead

When a home health aide cares for a terminally ill patient, there should be plans for what actions the aide should take in the event of impending death. These plans are usually developed in conferences with the aide, the nurse, and the family. The plan should include:

- Whether or not the patient has an advance directive, and if so, what the aide should do in accordance with the advance directive
- Whom the aide should call if he or she suspects the patient is in the act of dying
- Whom the aide should call when the patient has died
- What responsibilities the aide has for postmortem care, and
- Whether or not there are certain religious or cultural processes of which the aide should be aware.

## » Signs of impending death

- Most patients will no longer eat and drink except for sips of liquids now and then.
- Most patients will have varying levels of alertness, often drifting off to sleep and then awakening. There may be periods of confusion and periods of clearer thinking. It is not uncommon for the dying person to confuse the aide with a long-deceased relative.

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- Most patients will have cool hands and feet as the circulation of blood decreases. There is often discoloration of the hands, feet, and around the mouth. It may be difficult to feel the pulse at the patient's wrist.
- Most patients will have periods of irregular breathing. They may stop breathing for many seconds and then resume with a very quick breathing pattern. Sometimes the breathing becomes very shallow, with occasional deep breaths. Mouth breathing is common, so good oral hygiene is important to keep the lips and tongue moist. The respirations may become noisy. Sometimes elevating the head and repositioning the patient on his or her side will facilitate breathing.
- Occasionally the dying patient will have seizure activity. This is typically a jerking, localized seizure rather than a generalized seizure.
- Incontinence is likely; it is important to keep the patient clean and dry.
- Most patients will lose consciousness for a period of time before dying. It is important to know that while the patient may not be able to speak, he or she may still be able to hear. Everyone in attendance should continue talking to the patient, letting him or her know who is there and that he or she is not alone.
- When the patient has completely stopped breathing for several minutes, you cannot feel a pulse anywhere, and the pupils have dilated it is likely that the patient has died.

## HOME HEALTH AIDE NEEDS

Caring for dying patients can be a very stressful time for home health aides. It is important for them to communicate regularly about their feelings. There may be times in which you should be reassigned. It is very common for aides to develop strong emotional attachments to their patients, and aides need to grieve the deaths after patients die. Often listening sessions will be set up for nurses and aides who have been working together for a terminally ill patient. These sessions can be very helpful in allowing everyone to reflect on the patient and honor his or her memory. Above all, keep in mind that you have needs as well. You must recognize those needs as surely as you have recognized the needs of your patient.

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## CASE STUDY

Mrs. Porter is an eighty-five year old patient who had breast cancer six years ago. She was treated with surgery, chemotherapy, and radiation and was doing well until a month ago. She began having shortness of breath and studies indicated that her cancer had returned and spread to several organs. After her doctor told her that further treatment would be uncomfortable and would not likely be of help, Mrs. Porter decided not to have any more treatment. She refused hospice care since she thinks it would be like giving up.

Susan, Helen, and Louise are home health aides who are assigned Mrs. Porter and they are waiting for a conference with the nurse. While they are waiting, the three home health aides begin talking about their patient. Here is part of the conversation:

**Susan:** I just hate going there. All she talks about is dying. I do feel sorry for her, but she doesn't seem to think anyone else in the world has any problems. When I tried to cheer her up by talking about my cute granddaughter, all she said was, "Thank goodness you'll be able to keep seeing her." I tried to tell her I'd probably be gone long before she would be, and she actually got mad at me! Honestly, you'd think she would be glad someone was being a little light-hearted.

**Helen:** I really like Mrs. Porter, but I never know what kind of mood she's going to be in. One time she will be really short-tempered and irritable, and the next time she spends the whole time quiet as a mouse. I just try to keep doing my work and accept whatever mood she's in. It must be hard for her to know that she's going to die soon. During my last visit she actually talked about dying and how hard it is for her to talk with her family about it. I told her that I'd be glad to listen and she seemed to feel a lot better. I think it will help her to have someone to listen, although I worry a little about getting too attached to her.

**Louise:** I agree with Susan. For heaven's sake, the woman is 85 years old. And she knew she had cancer before. Now, I could understand if she were a 35-year-old mother leaving small children. As it is, she's really just a burden on her family. Her husband's been dead 15 years and her "baby," as she calls him, is sixty years old. Surely she didn't think she was going to live forever. I try to get in there and get my work done as fast as possible. I've got enough troubles of my own. I sure don't want to get involved. I can take care of her, but I don't want to have anything to do with listening to her whine about dying.

## THINK ABOUT IT

- » How do you feel about Susan's statements? What about Helen's? And Louise's?
- » What are some of the reactions Mrs. Porter has that are commonly seen among dying patients?
- » How well do you think Susan is filling her role in caring for this dying patient? What about Helen? And Louise?
- » Think about a terminally ill patient you may have had before. Can you identify some of the feelings you may have had? How did you manage these feelings?

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DIRECTIONS: READ EACH QUESTION CAREFULLY. THEN, DETERMINE THE BEST ANSWER. CHECK THE CORRESPONDING BOX ON YOUR ANSWER SHEET. DO NOT WRITE ON THIS POST-TEST.

1. Which of the following statements is true about dying patients?
  - a. They all react in the same way.
  - b. They are so pre-occupied with death that they don't really notice people around them.
  - c. Sooner or later they will all accept the fact that they are dying and will stop trying to fight the illness.
  - d. They still have basic human needs for recreation, safety, and security.
  
2. Which of the following is a good response to a patient who asks, "What do you really think death is like?"
  - a. "The truth is, I don't really know what death is like. But I can tell you are concerned and I'll be glad to listen."
  - b. "Oh my goodness, you shouldn't even be talking like that."
  - c. "Well, I don't know what it's like for you since you're not a Christian like I am."
  - d. "I'm not allowed to talk about things like that. I'm here to help with your bath."
  
3. Which of the following is not typically one of the emotional stages experienced by dying patients?
  - a. Denial
  - b. Depression
  - c. Giddiness
  - d. Anger
  
4. Which of the following are signs that death is near?
  - a. Periods of irregular breathing
  - b. Discoloration of the hands, feet, and around the mouth
  - c. Varying levels of alertness
  - d. All of the above
  
5. Which of the following would not help a dying patient maintain dignity and independence?
  - a. Taking over and doing everything for the patient
  - b. Helping the patient schedule and prioritize activities
  - c. Talking directly to the patient and not just to the family
  - d. Allowing the patient to participate in care
  
6. The role of the home health aide in the care of the terminally ill patient includes all of the following except:
  - a. Assisting with personal care
  - b. Telling the patient there's nothing to worry about
  - c. Listening to the patient
  - d. Promoting the patient's independence

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POST-TEST, PAGE 2

7. The stages of reaction to terminal illness occur only in the patient. The family members do not experience the reactions during their preparation for the patient's death.
- a. True
  - b. False
8. What is the best action for a home health aide who is having a great deal of difficulty caring for a terminally ill patient?
- a. Keep the problems to yourself so others won't think you are a whiner.
  - b. Try to ignore the patient as much as possible so you won't become too attached.
  - c. Talk with your supervisor about your feelings.
  - d. Wait until after the patient has died and then deal with your feelings.
9. Which of the following is not a good way to handle difficult questions from a patient?
- a. Letting the patient take the lead in conversations about his or her death
  - b. Being honest with the patient
  - c. Making sure you do not let the patient hold out hope that things will get better
  - d. Being careful that you do not say more than you should
10. Attitudes about death vary tremendously from one person to another.
- a. True
  - b. False

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NAME \_\_\_\_\_ DATE \_\_\_\_\_

DIRECTIONS: READ EACH QUESTION IN THE POST-TEST CAREFULLY. THEN, DETERMINE THE BEST ANSWER. CHECK THE CORRESPONDING BOX ON THIS ANSWER SHEET. DO NOT WRITE ON THE POST-TEST.

### MULTIPLE CHOICE ANSWER SHEET

- |     |                            |                            |                            |                            |
|-----|----------------------------|----------------------------|----------------------------|----------------------------|
| 1.  | <input type="checkbox"/> a | <input type="checkbox"/> b | <input type="checkbox"/> c | <input type="checkbox"/> d |
| 2.  | <input type="checkbox"/> a | <input type="checkbox"/> b | <input type="checkbox"/> c | <input type="checkbox"/> d |
| 3.  | <input type="checkbox"/> a | <input type="checkbox"/> b | <input type="checkbox"/> c | <input type="checkbox"/> d |
| 4.  | <input type="checkbox"/> a | <input type="checkbox"/> b | <input type="checkbox"/> c | <input type="checkbox"/> d |
| 5.  | <input type="checkbox"/> a | <input type="checkbox"/> b | <input type="checkbox"/> c | <input type="checkbox"/> d |
| 6.  | <input type="checkbox"/> a | <input type="checkbox"/> b | <input type="checkbox"/> c | <input type="checkbox"/> d |
| 7.  | <input type="checkbox"/> a | <input type="checkbox"/> b |                            |                            |
| 8.  | <input type="checkbox"/> a | <input type="checkbox"/> b | <input type="checkbox"/> c | <input type="checkbox"/> d |
| 9.  | <input type="checkbox"/> a | <input type="checkbox"/> b | <input type="checkbox"/> c | <input type="checkbox"/> d |
| 10. | <input type="checkbox"/> a | <input type="checkbox"/> b |                            |                            |

### INSTRUCTOR'S COMMENTS/SIGNATURE

Signature \_\_\_\_\_ RN Date \_\_\_\_\_

