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## End of Life Care: Patterns of Decline

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After reading the newsletter, the home health aide should be able to:

1. Describe four patterns of functional decline at the end of life.
2. Discuss how needs and care of the client and family may differ, based on the expected pattern of decline.

Mr. C was an elderly home care client who had emphysema for many years. In his last year of life, he was hospitalized several times for breathing problems, then improved and returned home each time. In his last few months of life, Mr. C's respiratory function declined more rapidly, resulting in his death.

Mrs. Y was a very active 53-year old woman who visited her doctor due to vague abdominal pain. She was diagnosed with pancreatic cancer that had spread to several organs. Within 2 weeks, Mrs. Y was bedridden due to the illness. She declined rapidly and died 6 weeks after diagnosis, despite treatment.

These two individuals both suffered from chronic illnesses requiring home care. But the course of each client's disease, and their needs, were very different.

This newsletter will discuss patterns of decline at the end of life. Description and types of patterns, related conditions and client characteristics of each pattern will be covered, as well as implications for care.

### What are Patterns of Decline?

When a person is diagnosed with an illness that may shorten his or her life, one of the first things asked is often, "How much longer will I live?" Not only do they want to know how long, but what will the quality of life be, how will this illness affect me over time? To answer these questions, the

healthcare provider counseling these clients may use knowledge of common patterns of decline.

As it relates to chronic illness and end-of-life care, a pattern of decline is the rate, degree, and order in which a person's ability to function decreases prior to death. This decline in function can be physical, such as the ability to stand and walk, and/or cognitive, the ability to think and understand clearly. Function is commonly evaluated as the ability to perform daily tasks such as ambulating, eating, dressing, bathing, toileting, communicating and decision-making.



The patterns of decline can help the healthcare team to plan for hospice care, palliative care and other client needs. They may also provide some guidance in what clients, families and healthcare providers can expect with terminal chronic illnesses. With each client and each condition, however, there is a great deal of variation in how the illness may or may not progress, so these patterns should not be considered definite or "carved in stone," but used only as a general guideline.

It is well-known that medical advances have greatly increased human life expectancy, from an average of 47 years in 1900 to almost 80 years in 2013. What is less well-known is that this prolonged life span has resulted in people now spending a longer period of time in



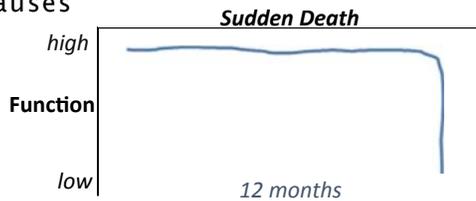
poor health before dying, due to chronic illnesses and reduced ability to function. The way in which these people spend their last 12 months of life is significant, and has implications for the type of care that will best meet their needs.

**Types of Patterns of Decline**

Studies have identified 4 major patterns of decline before death:

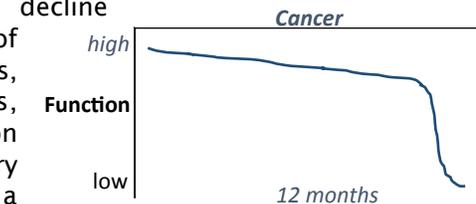
**Sudden death:** A fatal heart attack or stroke commonly causes

sudden death. These people often appear healthy and are functional up until the time of death. Since there is not a disease-related decline in function before death, the need for hospice and/or palliative care is not identified.



**Cancer:** With a diagnosis of cancer, function may show a steady decline

over a period of weeks, months, or sometimes, years. Function then declines very quickly, usually a few weeks or months before death.



**Organ failure:** Conditions such as heart failure and emphysema often cause a prolonged decline in function, with periods of worsening condition that require hospital

admission. The client usually recovers from these episodes and returns home. There is often a rapid decline at the end, and death may appear to be "sudden."



**Frailty/dementia:** An aging person is considered "frail" when function declines due to weakness, exhaustion, muscle loss and weight loss. As a result, the person has difficulty performing activities of daily living and becomes more dependent

on the care of others. Clients with frailty and/or dementia tend to have a long, slow, progressive decline at a low level of function in the year before death, and have usually been declining for years before that.



**Implications for Care**

Every client and family situation is unique, requiring assessment and planning by the nurse so that the home health aide can help to provide the care that is needed. The patterns of functional decline may provide some guidance regarding client needs. If the healthcare team can estimate a client's disease course, care can be arranged at the appropriate time to meet the client's needs. For example, Medicare and most other insurers require that clients have an estimated life expectancy of 6 months or less to receive coverage for hospice care.

Clients with cancer usually have the most rapid decline, compared to the other chronic-illness groups. Because of this, the timing of death is often easier to estimate than in other groups, and these clients are more likely to be referred for hospice care at the appropriate time. The patterns of organ failure and frailty/dementia are more difficult to estimate. Since clients with organ failure have a repeated pattern of severe worsening of the illness, followed by some degree of recovery, it is difficult to know when the client will have an episode of worsening from which he/she does not recover. And clients with frailty/dementia can decline slowly for years, making it difficult to estimate when death may occur. Signs that indicate a client may be in the last year of life include:

- progressive weight loss
- decreasing ability to function
- an increase in symptoms
- more time spent lying down
- poor response to treatments
- a decision to stop treatments

The type of care that is needed over time is another important consideration. Clients with frailty and dementia often require the most ongoing care and assistance with daily activities, compared to those with cancer or organ failure. Family members providing care to these clients are at risk for exhaustion and burnout, and may require supportive services, such as more frequent home care visits or respite care.

As you work with clients, stay aware of their abilities and symptoms on an ongoing basis. If you notice either of these becoming worse, notify the nurse promptly. Also let the nurse know if family members seem stressed or make comments about the difficulty of caring for the client, as they may need to have more support arranged.

By understanding common patterns of decline at the end of life, the home health aide can better understand the care that is provided for individual clients, and help to meet the client/family's needs.



## End of Life Care: Patterns of Decline

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

Directions: Place the letter of the one best answer in the space provided.

- \_\_\_\_ 1. As it relates to end-of-life care, a pattern of decline is best described as:
  - A. the family's reaction to their loved one's diagnosis
  - B. the depression that is common in people with a terminal illness
  - C. changes in heart rate and breathing that occur before death
  - D. how a person's ability to function decreases before death
  
- \_\_\_\_ 2. A person having a terminal illness, such as cancer, will always show the pattern of decline that is expected for that disorder.
  - A. True
  - B. False
  
- \_\_\_\_ 3. A decline in cognitive function has occurred when the client can no longer:
  - A. walk
  - B. remember his own name
  - C. sit in a chair
  - D. pick up a spoon to feed himself
  
- \_\_\_\_ 4. Because life span has increased greatly since 1900, people today spend less time in poor health before they die.
  - A. True
  - B. False
  
- \_\_\_\_ 5. Which of the following persons most likely had the highest level of function right before death?
  - A. Mr. M, who had severe heart failure
  - B. Mrs. V, who had dementia
  - C. Mr. A, who had a heart attack
  - D. Mrs. H, who had ovarian cancer

- \_\_\_6. A pattern of repeated hospitalizations over time, followed by recovery, is common with which of the following conditions?
- A. organ failure
  - B. cancer
  - C. dementia
  - D. none of the above
- \_\_\_7. A very prolonged decline, sometimes over many years, with a low level of function is most common with:
- A. emphysema
  - B. heart failure
  - C. frailty/dementia
  - D. cancer
- \_\_\_8. Clients with which of the following conditions usually experience the most rapid decline before death?
- A. frailty/dementia
  - B. emphysema
  - C. cancer
  - D. heart failure
- \_\_\_9. Signs that a client with a terminal illness may be in the last year of life include:
- A. progressive weight loss
  - B. lack of response to treatments
  - C. worsening of symptoms
  - D. all of the above
- \_\_\_10. Clients with which of the following conditions are likely to need the most care and assistance with daily activities?
- A. frailty/dementia
  - B. emphysema
  - C. cancer
  - D. heart failure

