

TITLE: Changes at End of Life

Topic: 9 (1)

Early discussion and planning by caregivers can be helpful in preparing for and addressing signs and symptoms at end of life.

Even with thoughtful and thorough preparation there are situations and symptoms that can be distressing for the patient and family. Caregivers have a difficult task in being prepared themselves and sharing pertinent information with the patient and family without causing undue distress. Knowledge, skill and thorough assessment can help manage distressing changes if and when they occur. Communication is a key element to successful management of care for the patient and the family.

Changes in food and fluid intake

- Family often worry about starvation and dehydration
- Food is a way to provide nourishment and maintain health under normal circumstances
- Feeding a loved one is a deeply rooted mode of caring
- Family may think you don't care or are giving up if you are not feeding someone

What we can do

- Ask family "you may wonder why..."
- Provide support to family, focus on good oral hygiene
- Explain that the body is shutting down and unable to use the nutrients to gain strength
- Explain lack of appetite/hunger and thirst is not the same as starvation
- Discuss the potential for choking, aspiration, nausea and sometimes vomiting
- Fluid shifting causing swelling and congestion

Changes in cognition, consciousness and impending death

- Family may be distressed by confusion, agitation and delirium
- Family often believe that the medications are hastening death
- Family may want medications stopped or reduced and worry they may be giving the "last dose"
- Conflicting desire for good symptom control and alert wakefulness

What we can do

- Provide timely explanation for the presenting symptoms
- Talk about what the patient would like if they were able to direct their own care
- Explain the effects of medications preemptively, "in order to manage these symptoms it is likely..."
- Preemptively Discuss that "the dose of medications has been the same for a few days so not likely the cause of death"
- Provide proportionate medications for the distressing symptoms including sedation for intractable symptoms