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Feeding and Swallowing Issues Related to End of Life

Information for Caregivers

WRHA
PCH Speech-Language Pathology Program
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Dying is a natural and definable event in the cycle of human life. Feeding and swallowing issues are just some of the issues commonly seen during this complicated phase. The goal of speech-language pathology and the health care team is to not only look at the underlying medical condition but to also provide comfort and support that honours the patients/residents wishes.

Poor oral intake and food/liquid refusal are commonly seen in patients nearing the end of their life. It is believed to be part of an adaptive process that allows a terminally ill individual to die with less suffering. Many individuals also experience swallowing difficulties. These may include coughing/choking when eating or drinking, difficulty initiating the swallow reflex, holding food or liquid in the mouth for an extended time before the swallow, or having food remain in the mouth after the swallow. Individuals with swallowing problems are at risk for choking, aspiration pneumonia, and those complications associated with poor oral intake. Aspiration pneumonia is the result of food or liquid entering the airway. Careful feeding and swallowing techniques may not prevent aspiration but certainly it can reduce this risk.

A state of malnutrition seems to be a consequence of both decreased food intake and metabolic abnormalities, resulting from the dying process. These metabolic changes are not considered reversible, even with nutritional support and many find that aggressive nutrition can be unpleasant and distressing for dying patients. That is, providing alternative nutrition and hydration will not reverse what it is that the body is trying to do. Although aggressive nutrition has not been shown to improve survival, families may still struggle to balance "comfort care" measures with fears of death by "starvation" and "dehydration". In a culture such as ours, providing comfort is often associated with providing food. It is deeply embedded in our beliefs so staff need to be sensitive for this "need to feed" and educate families on alternatives for providing comfort.

Misconceptions about "dehydration" and "starvation" can also cause emotional stress for family members. At this stage of life, the patient will be affected by dehydration long before suffering any pain possibly associated with lack of nutritional support. Medical evidence is quite clear that dehydration in the end stage of a terminal illness is a very natural and compassionate way to die. Dehydration actually offers the following benefits to the dying patient:

- less fluid in the lungs and therefore less congestion, making breathing easier
- less fluid in the throat and therefore less need for suctioning
- less pressure around tumours and therefore less pain
- less urination and therefore less need for changing the bed and less risk of bedsores and
- according to some research, there is a natural release of pain-relieving chemicals as the body dehydrates.

The burdens of dehydration are a dry mouth and a sense of thirst, both of which can be alleviated with good mouth care, ice chips, or sips of water. The condition of the mouth depends upon the oral hygiene provided, not on the state of hydration.

The goals of nutritional management at the end of life change; ensuring adequate nutrition and hydration is not the primary focus. What may have been the normal requirements of food and drink are no longer appropriate. The goal now is to offer food and liquid for pleasure and comfort while minimizing the risks of choking and aspiration. Comfort care at end-of-life must be guided by the need to support quality of life. Family members often seek advice as to what can be done for their loved one during this time. Following are some suggestions for providing comfort care with regards to feeding and swallowing.

Assist with oral intake for the enjoyment of eating as tolerated by the patient. The atmosphere surrounding eating and drinking is far more important than the quantity of food ingested. Nutritional value should be of secondary importance. Allowing the individual to determine the amount and type of intake is part of providing comfort care.

To maximize the patient's safety while eating:

- offer food/liquids only when the patient is alert and sitting in an upright position
- offer 1 small sip or 1 small bite of food at a time

- watch for the rise and fall of the patient's larynx or Adam's apple to indicate that they have swallowed before offering another bite or sip
- patient needs to remain sitting in upright position for 30 minutes following intake
- when significant coughing, choking, or fatigue are observed, discontinue feeding

Providing regular mouth care cannot be stressed enough. Frequent swabbing with a moist sponge every 15-30 minutes will ease any discomfort from lack of hydration. If excessive secretions are causing distress to the patient, talk to the nurse/doctor regarding medications and other ways to relieve this.

The end of life can be a distressing time for family members. This is why the importance of early family involvement in the education of feeding and swallowing issues is so important. Knowing the options, the consequences surrounding their choices, and expected quality of life that coincides with their choices can help alleviate some of the guilt and shock at this, often stressful time. Explore a variety of other ways of providing comfort care. Family members can spend time reading, reviewing photo albums, or reminiscing with their loved ones. Some patients enjoy a massage, or some time spent in quiet common areas in or outside of the facility, or listening to soothing music. Another way for family to provide comfort is to assist with the resident's oral care (following training from staff). Often, just the presence of a caring family member, regardless of the activity, is enjoyed by all. Sometimes the opportunity to rest comfortably with a loved one near by is all that is needed.

If you have any questions or concerns regarding feeding and swallowing issues at the end of life please contact the Speech-Language Pathologist for your facility.

References:

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