

Feeding Choices for Patients with Advanced Dementia



UHN

Information for patients, families and caregivers

In the later stages of dementia, different parts of the brain slowly stop working and eating and drinking become more difficult. This resource explains how advanced dementia can cause swallowing problems and how there are different options for feeding.

We hope you find this resource helpful.

Please ask your health care team if you have any questions.

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Learning about dementia

There are parts of the brain that control basic functions like chewing, swallowing, hunger, thirst and being awake.

In the later stages of dementia (advanced dementia), the parts of the brain controlling these basic functions will start to shut down.

How do I know if nutrition is affected by dementia?

The health care team may start to look carefully at swallowing and nutrition if the patient:

- has less appetite
- is losing weight
- chokes or coughs when trying to eat or drink
- forgets how to use a straw
- has food or pills that stay in the mouth after a long time

At first, the nutrition problem may be fixed by:

- working with a dietitian to change the type of food being eaten at meal times
- providing more help with preparing and setting up meals
- providing more help during feeding
- having smaller, more frequent meals

Later on, the nutrition problem may be linked to swallowing problems or serious problems with the parts of the brain that control thirst or hunger.

How is swallowing tested?

Swallowing includes all of the steps that happen between taking a sip of a drink or a bite of food and when it gets into the stomach. When food or drink goes down the wrong way into the voicebox or lungs, this is called **aspiration**.

A Speech Language Pathologist (SLP) does a swallowing test by looking at:

1. **Swallowing safety** – whether or not food or drink is going down the wrong way into the lungs
2. **Swallowing enough** – how quickly or easily a person is able to swallow different foods and liquids

Sometimes the test can be done in the patient's room. The SLP may suggest a second and more detailed test using an x-ray.

What can be done if food is going down the wrong way?

There are ways to help patients who are aspirating:

1. Keep the body in a certain position during eating. For example:
 - sit with the back straight up (like in a chair)
 - keep the chin down close to the chest
2. Change food texture to **minced** or **pureed** foods.
3. Change drinks to thickened liquids that cannot leak as easily into the lungs. For example:
 - **nectar thick** means the liquid is slightly thicker like a smoothie or milkshake
 - **honey thick** means the liquid is thicker like thick honey

What can be done if the swallowing problems lead to not eating or drinking enough?

There are many ways to add protein and calories in a diet:

- Drink supplements, such as Boost® or Ensure®
- Add protein powders, such as Beneprotein®, to food or drinks
- Choose foods that are high in calories, fats and protein

What can be done if these things don't work?

If trying ways to reduce aspiration and add calories don't work, the health care team may suggest:

- **careful hand feeding**
- **tube feeding** (also called “artificial nutrition”)

What is careful hand feeding?

Careful hand feeding means giving someone small amounts of food and drink when they are no longer able to feed themselves. Careful hand feeding can work as long as a person is comfortable and wants to be fed. Patients are never force fed food.

The health care team may suggest:

- sitting upright
- reducing distractions at mealtimes
- making sure the patient swallows a bite before giving the next bite

Benefits

- Patients can continue to taste and enjoy their favourite foods
- Patients can enjoy being around loved ones during mealtimes
- Better oral health and less pain from a dry mouth and throat
- No problems from inserting a feeding tube (see page 6 to learn more)

Possible problems

- May raise the chances of food going down the wrong way (aspiration) that could lead to a lung infection called **aspiration pneumonia**
- Patients may have pain when breathing or coughing if something goes down the wrong way
- Patient may not eat enough by mouth
- It can take a long time for patients to finish a meal

What is tube feeding?

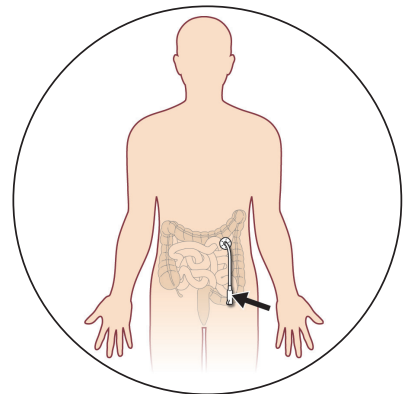
Tube feeding is a way of giving food and fluid to a patient who cannot eat or drink enough on their own. Liquid food and fluid are put into the stomach through a tube.

If you and the health care team decide to use tube feeding, there are 2 types of tubes:

1. A **nasogastric tube** or “NG tube” is a thin plastic tube that goes into the nose, down the throat and into the stomach. NG tubes are only used for a short period of time, usually less than 6 weeks.



2. A **gastrostomy tube** or “G tube” is a plastic tube that is inserted during a short operation. The tube is put through the skin of the belly so that it enters right into the stomach. G tubes can be left in place for a long time.



Once an NG tube or G tube is in place, liquid food, fluids and medicine can be put into a container and attached to the tube. The liquid can then travel down the tube and into the stomach.

Benefits

- May give a person enough calories if their stomach can absorb nutrition
- Takes less time to feed so there is more energy left for other activities
- Sends food directly to the stomach to help those who cannot swallow safely
- Medicines can also be given using the feeding tube

Possible problems

- Having the tube put in a patient's nose or stomach can be painful
- The tube may cause a patient to become agitated, which may need to be controlled with medicine or physical restraints
- The tube could get pulled out
- The site of the tube may become infected
- The tube could get blocked with food or medicine
- Tube feeding may cause stomach pains
- Tube feeding sometimes causes diarrhea
- Food from the tube can still get into the lungs and cause an infection, called aspiration pneumonia
- Tube feeding can make mealtimes less enjoyable
- Tubes need to be checked and maintained many times in a day

Important: Tube feeding does not necessarily improve the quality of life for someone with advanced dementia or help them to live longer. Careful hand feeding is at LEAST as good as tube feeding in terms of how long a person lives, the risk of aspiration pneumonia, a person's functional status and their comfort.

Who decides which feeding option to use?

After speaking with the health care team, the patient decides. The patient can only decide if they understand the risks and benefits of each choice. The patient's substitute decision-maker would choose the feeding option if the patient is unable to make this decision.

The health care team wants to make sure you understand the risks and benefits of each option and the possible results of each option.

Can a patient decide to stop tube feeding?

Feeding tubes can be removed when they are no longer needed or when they are causing more harm than good.

The health care team may talk about stopping tube feeding when:

- Tube feeding seems to be causing more pain than relief
- Tube feeding starts causing health problems
- Tube feeding has not improved the patient's health
- Tube feeding was started for a patient who was still enjoying some quality of life and their quality of life has gotten worse
- The patient receiving tube feeding or their substitute decision-maker would like to stop tube feeding for any reason

Some people may be worried that stopping tube feeding makes a person die sooner. **Stopping tube feeding is not done to make someone die sooner.** Stopping tube feeding is recommended when tube feeding has become more harmful than helpful.

Will a patient feel hunger and thirst without tube feeding?

There are no studies that look at hunger and thirst in patients with advanced dementia. As people reach the final stages of dementia, the body begins to feel less hungry and thirsty.

At the end of life, people who feel hungry feel better when they eat very small amounts of food by careful hand feeding.

People who are thirsty usually feel better once they have ice chips, liquid on mouth swabs, small sips of liquid or when their mouths are wet.

Will death come sooner if a patient does not choose tube feeding?

Current research shows there is no difference in how long people live when comparing careful hand feeding to tube feeding. For this and other reasons discussed in this pamphlet, the American Geriatrics Society does not recommend tube feeding in older adults with advanced dementia.