



ALZHEIMER'S DISEASE - FEEDING TUBES

WHEN YOU NEED THEM AND WHEN YOU DON'T

Most people in the last stage of Alzheimer's disease have difficulty eating and drinking. At this time, families/whānau may wonder if a patient needs a feeding tube. Families/whānau want to do everything possible for someone who is ill. But they often get little information about feeding tubes. And they may feel pressure from doctors or nursing home staff, because feeding is simpler with a feeding tube. But feeding tubes sometimes do more harm than good. Here's why:

FEEDING TUBES USUALLY AREN'T HELPFUL FOR SEVERE ALZHEIMER'S DISEASE

People with severe Alzheimer's disease can no longer communicate or do basic things. Chewing and swallowing is often hard. This can cause serious problems, such as weight loss, weakness, and pressure sores. Or food can get into the lungs, and cause pneumonia. So people often need help to eat.

In many cases, a decision is made to use a feeding tube. The tube may be put down the throat. Or it may be put through a small cut in the abdominal wall, into the stomach. The patient is then given liquid nutrition through the tube.

But tube feeding is not better than careful hand feeding—and it may be worse. It does not help people live longer, gain more weight, become stronger, or regain skills. And it may increase the risk of pneumonia and pressure sores.

Hand feeding gives human contact and the pleasure of tasting favourite foods.

When death is near and patients can no longer be fed by hand, families/whānau often worry that the patient will “starve to death.” In fact, refusing food and water is a natural, non-painful part of the dying process. There is no good evidence that tube feeding helps these patients live longer.

FEEDING TUBES CAN HAVE RISKS

- Tube feeding has many risks.
- It can cause bleeding, infection, skin irritation, or leaking around the tube.
- It can cause nausea, vomiting, and diarrhoea.
- The tube can get blocked or fall out, and must be replaced in a hospital.
- Many people with Alzheimer's disease are bothered by the tube and try to pull it out. To prevent that, they are often tied down or given drugs.
- Tube-fed patients are more likely to get pressure sores.
- Tube-fed patients are more likely to spit up food, which may lead to pneumonia, a term called “aspiration pneumonia”.
- At the end of life, fluids can fill the patient's lungs, and cause breathing problems.



SO WHEN ARE FEEDING TUBES A GOOD IDEA?

Feeding tubes can be helpful when the main cause of the eating problem is likely to get better. For example, they can help people who are recovering from a stroke, brain injury, or surgery.

The tubes also make sense for people who have problems swallowing and are not in the last stage of an illness that can't be cured. For example, they can help people with Parkinson's disease or amyotrophic lateral sclerosis (Lou Gehrig's disease).

CARING FOR A PERSON WITH SEVERE ALZHEIMER'S DISEASE

When caring for a person with severe Alzheimer's disease, these steps can help with eating problems and other end-of-life concerns:

Treat conditions that cause appetite loss, such as constipation, depression, or infection.

Feed by hand. Ask a health professional about the best kinds of foods to offer and the best ways to feed by hand.

Stop unneeded medicines. Some drugs can make eating problems worse, including:

- antipsychotics such as quetiapine (Seroquel and generic)
- sleeping pills or anti-anxiety drugs such as lorazepam or zopiclone
- bladder-control drugs such as oxybutynin
- some drugs for osteoporosis such as alendronate (Fosamax and generic)
- drugs for Alzheimer's disease such as donepezil (Aricept and generic).

Schedule dental care. Badly fitting dentures, sore gums, and toothaches can make eating hard or painful.

Plan ahead. Every adult should have an advance directive. It lets you say what kind of care you want and who can make decisions for you if you cannot speak for yourself.

It's OK to ask questions

If you have questions about your symptoms or the medicines managing your symptoms, speak with your health professional.

Adapted from Choosing Wisely Canada (2014), Feeding tubes for people with Alzheimer's disease. Choosing Wisely does not assume any responsibility or liability arising from any error or omission or from the use of any information in these resources.