

Decision aid

Enteral (tube) feeding for people living with severe dementia

Information to help people living with severe dementia, their family members and carers and their healthcare professionals discuss the options

What are the options?

People living with severe dementia often develop problems with eating and drinking. They may have swallowing problems. If this happens food or saliva may go down their windpipe and cause an infection in their lungs (aspiration pneumonia). This can be serious or even fatal. They may also have a reduced appetite, and in their final weeks or days they may stop eating or drinking altogether.

Enteral (tube) feeding usually involves either passing a tube through a person's nose and down into their stomach (a nasogastric or 'NG' tube), or making a cut in the person's abdomen and passing a tube into their stomach that way (a PEG tube). Liquid food can be put directly into the person's stomach through the tube.

What does NICE recommend?

NICE recommends that tube feeding should not normally be used for people living with severe dementia. It can be tried if the reasons for the person's problems with eating, drinking or swallowing are treatable and it's expected that they will be able to start eating and drinking normally afterwards. This decision aid will help your healthcare professional explain the possible benefits and drawbacks of tube feeding, and alternative options.

How likely is the person to benefit?

Studies have looked at the possible benefits from tube feeding for people living with severe dementia. These studies found no good evidence that people who had tube feeding lived any longer than people who did not. There was also no good evidence that tube feeding made any difference to people's weight or improved how well-nourished they were.

It is not possible to know in advance what will happen to any individual person.



What are the drawbacks?

Some studies have found that people living with severe dementia who have tube feeding are more likely to get an infection in their lungs (aspiration pneumonia) than people eating and drinking normally.

A nasogastric tube is inserted through a person's nose and down their throat into their stomach. Most people find this process unpleasant. Inserting a PEG tube through the person's abdomen carries risks from the anaesthetic or sedative used and from infection. Once either type of tube is in place it can cause sores around where the tube enters the body. The person may be distressed about having the tube in place if they do not understand why it is there, and may try to pull it out. This could be harmful, especially if they try to pull out a PEG tube.

The person will have to go into hospital to have a PEG tube inserted. This might be distressing and confusing for the person, and might make them less able to do things they could do before. They may not fully recover even after they go home.

It is not possible to know in advance what will happen to any individual person.

Alternatives to tube feeding

If there are treatable reasons for the person's loss of appetite (such as indigestion, constipation or a sore mouth) these should be addressed. If the person has swallowing difficulties it may be possible to make food and drink safer for them by changing its texture (such as using softer foods or having thicker drinks).

Even if the person doesn't want to eat or drink very much or is not able to do so, they can be offered food and drink they like so they can enjoy the taste. Moistening the person's lips and (if they are able to swallow) offering sips of water or fruit juice can help keep their lips and mouth feeling comfortable.

Information about how this decision aid was produced and the evidence on which it is based is available on the <u>NICE website</u>.