

Making Choices



Feeding Options for
Patients with Dementia



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Welcome

This decision aid will tell you about feeding options for someone with dementia.

This decision aid is for you if:

- You help decide about health care for a person who has memory problems
- You are likely to be the person to talk with the doctor and the care plan team at the nursing home.

You can use the decision aid to help you talk with health care providers who take care of the person with dementia.

A person with memory problems needs someone to speak for them

You may be asked to help with making decisions if you are

- The family member who is most involved in decisions about care,
- Someone the person has picked to be their health care power of attorney, or
- The person's guardian –
someone appointed by a judge to be the one who makes decisions for the person.



In this decision aid you will learn about

- Dementia and problems with eating and swallowing
- Choices you can talk over with the doctor or another health care provider
- Advantages and disadvantages of each choice
- How to make health care decisions for someone else



What is dementia?

What is dementia?

Dementia is a brain disease that causes memory loss and difficulty with other aspects of thinking, talking, and taking care of oneself.

People with dementia have a progressive illness, and they usually get worse over time.

When dementia becomes more severe, usually several years after dementia has been present, most people develop problems with eating and swallowing.



A person with dementia may

- Have difficulty swallowing some types of food
- They may become restless at meals, and spit food out or push it away
- They may not feel hungry and therefore not want to eat
- Some people with dementia simply forget to eat, or have difficulty remembering how to do this simple task.

What choices do I have?



When do we need to talk about feeding choices?

You may begin talking if problems with eating lead to

- **Aspiration:** A person with swallowing problems can accidentally get food or liquid into the lungs. This is called “aspiration,” and can cause pneumonia. People with severe dementia have problems controlling throat muscles – making aspiration happen more often.
- You might also talk because of **loss of weight**
- You might talk because you have **concerns the person with dementia might be hungry or thirsty.**

We can never really know whether people with advanced dementia feel hunger or thirst. People with other serious illnesses say they rarely feel hungry or thirsty.



What are the treatment choices?

Because your loved one has dementia and is having eating or swallowing problems, you and the doctor or other members of the health care team may talk about the choices of

- Nutrition through a feeding tube or
- Ways to help with eating by mouth



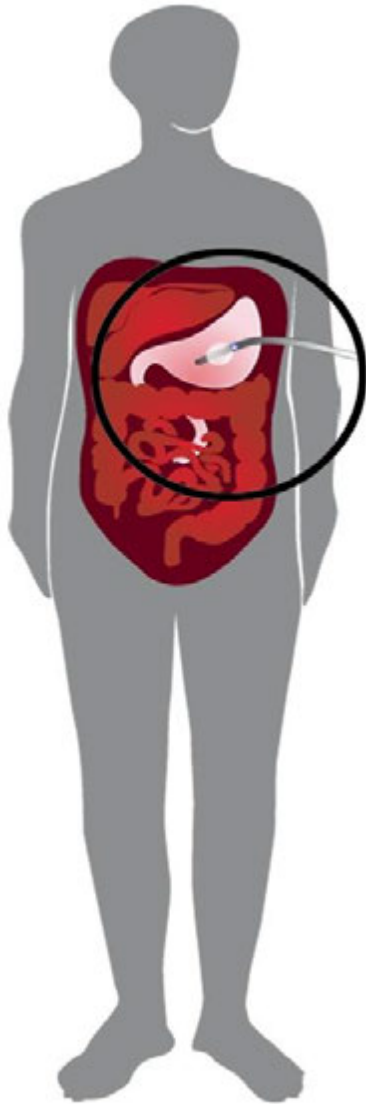
What is assistance with eating by mouth?

Assistance with eating means having another person help with taking food by mouth.

This can include feeding by hand, changing foods to make them easier to eat, offering food or drink with extra calories, and encouraging the person to eat.



What is a feeding tube?



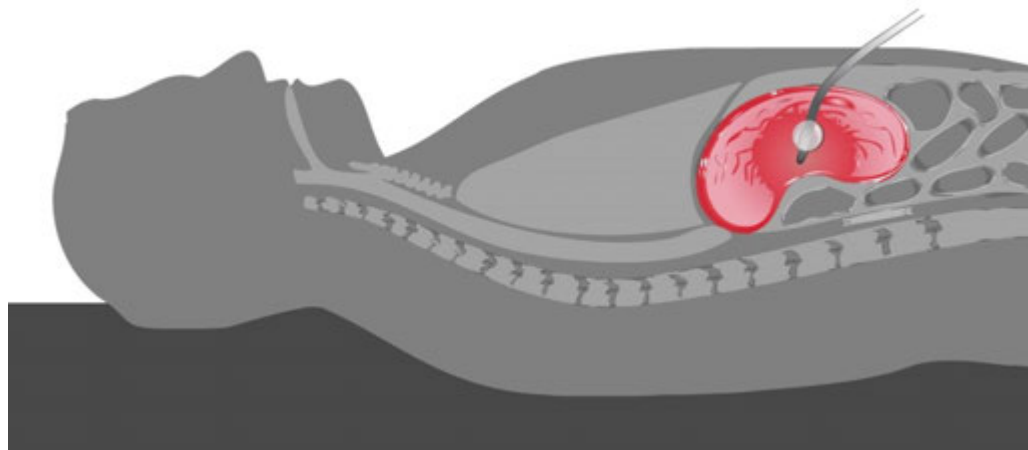
A feeding tube is a tube that goes through the skin into the stomach, so the person can receive a nutritious liquid.

What if I choose a feeding tube?



What if I choose a feeding tube -- How is the feeding tube put in?

- First, the person is given some medicine to make them relax. Then the doctor uses x-ray or a camera to see where to place the tube.
- Medicine is used to numb the skin over the stomach; then the doctor cuts a small opening in the stomach and the skin over the stomach.
- Then the feeding tube is put in through this opening.
- This takes about 15 minutes. It may cause discomfort, but it should not cause severe pain.



Are there risks when a feeding tube is put in?

Yes there are some risks to think about.

- 10 people out of 100 experience nausea or diarrhea
- 5 people out of 100 experience minor infection
- 5 people out of 100 experience minor bleeding
- 1 person out of 100 experiences a life-threatening complication



How does the feeding tube work?

A trained caregiver or family member puts liquid food through the feeding tube into the person's stomach.

This liquid food gives the person a balanced diet. Most tube feeding is done at usual meal times, and feeding takes about one hour. Some patients will receive slow feedings all day, but the total amount of nutrition is the same.

Medicine and water may also be given through the tube.

If the person is alert, they may be able to eat some food by mouth but will get most of their nutrition from the feeding tube.

What about taking care of this tube?

A nurse can check to be sure the tube does not leak or become stopped up, and will make sure the food is going in as it should.

A trained caregiver will also clean around the tube at least once a day and check the area of skin around the tube.

Some patients with feeding tubes may get upset and try to pull the tube out. Nurses or doctors may suggest ways to keep the tube in place, like medicines or physical restraints.

Must the person stay in bed all the time?

The person is usually in bed or a reclined chair while liquid is running through the tube.

At other times, he or she will move around as much or as little as they are doing now.



Can the feeding tube be removed?

Yes, if you decide later that the feeding tube isn't a good choice, a person with a feeding tube can have it removed.

- The tube can be removed by pulling it out. The tube is designed to be removed this way. It is safe and nearly painless.
- Tube feeding can be stopped if the person begins to eat by mouth again.
- Tube feeding can also be stopped if the person gets worse, and they are near the end of life. Though they will not eat full meals, they can still receive other treatments for comfort.



Will the person with dementia live longer if I choose the feeding tube?

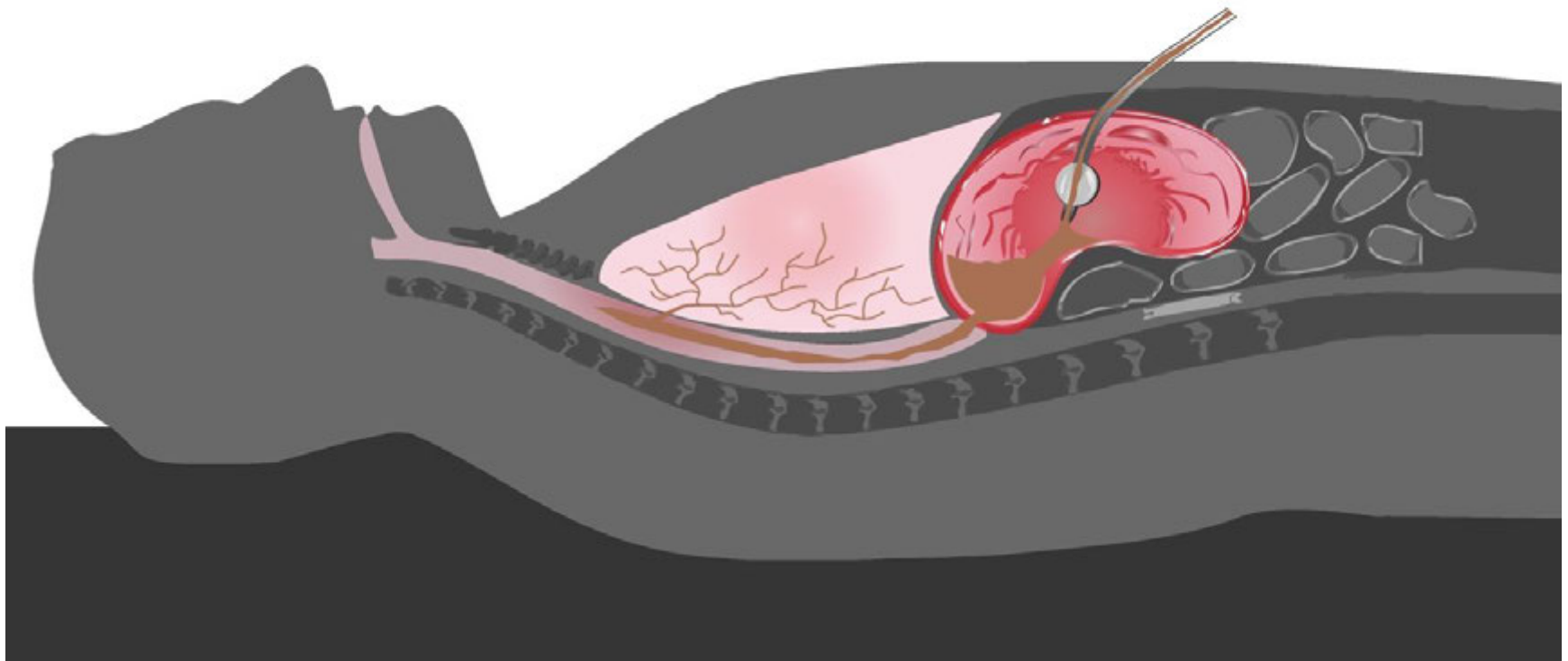
NO. Most studies of people with dementia who have eating and swallowing problems show that those who get a feeding tube **do not** live longer than people who don't get a feeding tube.

People with dementia typically get worse over time, and have other illnesses – this may be the reason that the approach to feeding doesn't clearly affect survival.

With a feeding tube, will the person be less likely to aspirate, or to have food or liquid go into their lungs?

NO. Studies of patients with feeding tubes show that they still “aspirate,” or have pneumonia from food or liquid going into their lungs.

Even with a feeding tube, liquid food can move up, going backwards from the stomach into the mouth, and then into the lungs.



What if I choose assistance with eating by mouth?



Now let's consider the other option. What if I choose assistance with eating by mouth?

Assistance with eating means having caregivers help the person take food by mouth.

The type or consistency of food may be changed to make it easier to swallow

Foods or drinks with extra calories may be added to the person's diet

Medicines may also be used to boost their appetite



How is a person with dementia given assistance with eating?

Caregivers may remind and encourage the person to eat, reminding them and helping them to pay attention to the meal

Caregivers may feed the person by hand, actually giving them each bite of food if they have trouble doing this for themselves

Caregivers may spend extra time to help the person.

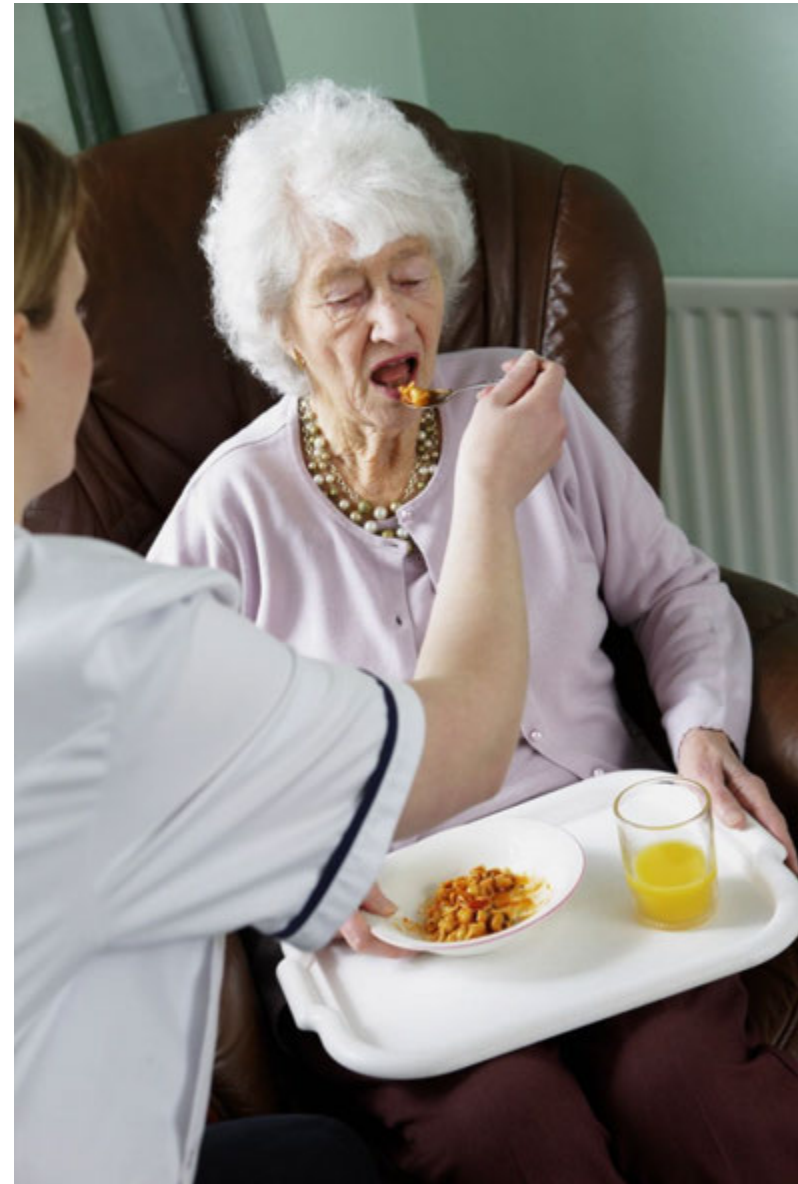
Caregivers can help to reduce the risk of choking or aspirating food. Good ways to help include:

- sitting the person up to eat
- choosing food of the right thickness, and
- cleaning their mouth out with suction. If needed nurses can teach family and friends how to do this.

Who feeds the person by hand?

Trained health care providers including a nurse, nursing assistant or aide, will usually feed the person with dementia.

Family, friends, or volunteers can also do this with some training.



Can all people with dementia be fed by hand?

Most people with dementia can be fed by hand.

The person's swallowing may be tested to see what kind of food is easiest for them to swallow.

Members of the health care team, including doctors, nurses, dietitians, speech therapists, or occupational therapists can help to decide on the best approaches to assistance with eating by mouth for each person with dementia.

How well does assistance with eating by mouth work?

- Use of special foods or drinks with extra calories – called nutritional supplements – can help keep the person with dementia at a stable weight.
- Assistance with eating, modified foods and medicines to increase appetite can also help the person take in more nourishment.
- These approaches might work for months. However, as the person's dementia worsens, their type of assistance might also need to change.

What happens if the person cannot take any food by mouth?

In very advanced dementia, some people can no longer swallow food or water.

This change means they may be nearing the end of their life.

In fact, stopping eating and drinking is a natural part of the dying process that happens in most diseases, not just dementia.



What can be done to help someone who cannot eat or drink?

Treatments can still be used to keep the person comfortable.

- Offer sips and tastes of favorite drinks or foods
- Keep the person's mouth and lips moist and clean
- Control pain with medicines
- Give treatment to help with any other discomfort, such as shortness of breath, constipation, or anxiety.

People who are nearing the end of life draw comfort from spiritual and emotional support, and the simple presence of people who care for them.



What else is there to think about?

Now that you know more about dementia and feeding options, what else is there to think about?

People with advanced dementia are approaching the end of life. Watching them and their illness may be hard for anyone who cares about them.

- You should think about how you are feeling, and what other questions you need to ask.
- You should also think about how the person's own wishes and values should guide choices about their medical treatment.

Think about how you are feeling

It may be hard for you to see someone close to you very ill, and it may be hard to see that person not eating much.

We usually find food comforting, and think about it giving strength; it is hard to consider there may be times when not eating is natural.



Think about the person's values

- Some people have told their family that they do or do not want a feeding tube – do you know what this person wants?
- Some people's religious values include strong opinions about feeding – consider whether or not the person with dementia has religious values that would affect this choice.
- For some people, favorite foods can bring pleasure, and tastes and sips of favorite foods during assistance with eating by mouth can give great comfort to someone who is ill.
- For some people, being with another person is calming and comforting, and assistance with eating by mouth can be a good way to spend time with that person.

What are the advantages of choosing a feeding tube?

- The person gets nutrition that requires less help from other people.
- Feeding the person takes less time.
- Nutrition may be the same every day, and this may be reassuring.

What are the **disadvantages** of choosing a **feeding tube**?

- The person with dementia may have complications from the feeding tube, like leaking or infection.
- The person with dementia may get upset and try to pull the tube out.
- Having a feeding tube may limit where the person can live and be cared for, in order to have help with the tube feedings.
- The feeding tube will NOT change how long the person lives, and will NOT stop them from aspirating or getting pneumonia.

What are the advantages of choosing assistance with eating by mouth?

- The person gets to enjoy tasting favorite food and drinks, and eating may seem more natural.
- Helping someone to eat is a way to show caring for the person with dementia.
- Caregivers may give the person more time and attention because of the time it takes to assist them to eat.

What are the **disadvantages** of choosing **assistance with eating by mouth**?

- Because of the person's eating and swallowing problems, the amount of food the person eats may vary from day to day.
- Assistance with feeding takes a lot of time for busy caregivers.

Can a feeding tube be put in if I don't give my consent?

No. As the surrogate decision maker a feeding tube should not be placed without your consent.



Remember:

What your loved one would want may not be the same as what you would want for yourself. If the person has a living will or has told you what he or she wants, you should respect those wishes.

Making a choice like this for someone else can be very hard, so you should ask questions and talk it over with health care providers and other people if you need more information.





Questions to ask yourself

Here are some questions to ask yourself, before you talk to the doctor or health care team:

- Has the person ever told you their wishes for treatment if seriously ill?
- Does he or she have a living will with preferences for or against tube feeding?
- What are the person's beliefs and values about medical treatments when illness is severe and incurable?
- If this person could look at the pros and cons, what do you think she or he would choose?
- Finally, what do you feel is in the person's best interest?

Here are some questions to ask when you talk with a doctor or health care team:

- Does the doctor expect that the cause of the eating problem will get better?
- Is the person with dementia likely to get upset with the tube and need restraints or calming medicine to keep it in?
- Will having a feeding tube limit where the person can be cared for?
- Does the person have any other illness that affects the decision?
- Does the person seem to enjoy taking food by mouth?

Finally, take time to reflect on questions about how this choice is making you feel:

- Do you feel pressured by others?
- Do you feel torn between your own beliefs and those of the patient?
- Do you have unanswered questions and need more information before you can decide?
- What is your overall feeling about the right choice?

You can discuss these issues, and any other questions you have, when you talk with the health care team

What next? Now it's time to talk with the doctor or other members of the health care team.

Remember, you are not alone.

- Talk to the person's doctor, nurse practitioner or nurse about feeding problems and choices for treatment
- Share the information in this decision aid with them, and ask any remaining questions you have.
- Stay involved in care planning for the person with dementia – you are their voice when they cannot speak for themselves.

Thank you

- For taking the time to consider feeding options for someone with dementia
- For being the voice of someone who has dementia, and cannot speak for themselves