

Introduction

Who is this decision aid for?

This decision aid is designed to help anyone living with motor neurone disease (also known as amyotrophic sclerosis (ALS)) to think about whether you might want a gastrostomy tube. A gastrostomy tube is a thin plastic tube which goes through a small opening in your belly directly into your stomach. It is also known as a PEG, RIG or PIG tube.

Decision aids help people make informed choices about their healthcare. They provide information and help people to think about what is most important to them.

You may want to use the decision aid for information only, or to help you make a decision on whether to have a gastrostomy tube.

The information included in this tool may also be useful to friends and family or anyone else supporting someone living with MND.

The decision aid has been designed with the help of people living with MND, their carers, and healthcare professionals.

What are my options now?

Your choice now is:

to have a gastrostomy tube

or

not to have a gastrostomy tube

If you decide not to have a gastrostomy tube now, this could mean:

you never want a gastrostomy tube

or

you do not want a gastrostomy tube now, but you will think about this again in the future

or

you are unsure at the moment and want to spend some more time thinking about the decision.

How might the decision aid help me?

This decision aid is designed to support someone living with MND to make the decision on whether to have a gastrostomy tube by:

- presenting accurate and reliable information
- clearly explaining the risks and benefits associated with each option
- helping you to recognise what is most important to you
- checking understanding.

The decision aid is designed to be used alongside discussions with your healthcare team.

Using the decision aid

The original interactive version of the decision aid can be found on the Motor Neurone Disease Association website.

This version contains the same information. The sections are as follows:

Section	Pages	Content
Introduction	1-2	Who is this decision aid for? What are my options now? How might the decision aid help me?
Introduction to gastrostomy tube	4	What is a gastrostomy tube? Why are people living with motor neurone disease offered a gastrostomy tube? Your decision
Key Information	5-7	Questions and answers chosen by people with MND and their carers based on what they felt was important to know when making the decision on whether to have a gastrostomy tube
Compare your options	8-10	Tables comparing what is involved, and benefits and disadvantages of having and of not having a gastrostomy tube.
Gastrostomy tube in MND fact checker	11-13	A short quiz to help to check your knowledge of the facts.
Pros and cons of having a gastrostomy tube	14-16	An exercise to help you to make the decision about having a gastrostomy tube by thinking about what is important to you.
The Details	17-33	Information about: <ul style="list-style-type: none">• the tube• the procedure,• using the tube,• living with the tube,• alternatives• decision timing
Useful Resources	34	Website addresses where further information can be found

Introduction to gastrostomy tube

What is a gastrostomy tube?

A gastrostomy tube is a fixed plastic tube, about the size of a drinking straw, that goes through a small hole in your abdomen (belly) directly into your stomach. Specially designed liquid food, water and some medications can be given through the tube. It is still possible to eat and drink through your mouth when you have a gastrostomy tube. More detail is provided in the next sections (see p17).

Why are people living with motor neurone disease offered a gastrostomy tube?

Motor neurone disease (MND) may cause the muscles needed for chewing, swallowing, breathing, and feeding to become weak and not work as well. A gastrostomy tube offers people with MND a way to continue to receive food and fluid, and take their medications, when eating and drinking by mouth becomes difficult.

Your decision

It is your choice whether to have a gastrostomy tube or not. Others around you may have different views but it is important that you make a decision that is right for you. Learning about your options can help you to make a decision that is right for you.

Your healthcare team will also support you to make your decision and will let you know if there are any medical reasons that might affect your options, or the timing of your decision e.g. weakened breathing or weight loss. Your healthcare team will continue to support you whether or not you decide to have a gastrostomy tube.

Key Information

People with MND and their carers helped to choose the questions below based on what they felt was important to know when making the decision on whether to have a gastrostomy tube.

Will I be able to eat and drink with a gastrostomy tube?

You can eat and drink as much as you feel comfortable with when you have a gastrostomy tube. However, the tube will not take away the risk of choking or aspirating (when food or fluid goes into the lungs) if you eat and drink.

What does it feel like when having a feed through the gastrostomy tube?

When feeding you may feel the liquid enter your stomach, a bit like when drinking. Sometimes people may feel full or bloated after a feed. This can be resolved by working with a dietitian to find a feed plan to suit you. There should be no discomfort or pain associated with feeding.

Can I take medication through the gastrostomy tube?

If you are unable to swallow your medication it will be prescribed in liquid or dissolvable form wherever possible and can be given through the gastrostomy tube. Some medications are unavailable in liquid form and your doctor, nurse, or pharmacist will need to advise you on what to do in this case.

Can I go out and about if I have a gastrostomy tube?

Yes, you can do most everyday activities when you have a gastrostomy tube, such as going shopping and visiting friends.

Will the tube restrict my physical activity or mobility?

There is no reason that the tube should restrict your physical activity or mobility, but it might take a bit of getting used to at first. Sometimes it's possible to have a 'button' tube fitted which sits closer to the skin and is more practical for some people.

Can I still be intimate if I have a gastrostomy tube?

Yes, including having sex.

How long will I be in hospital for after having tube placed?

Your healthcare team will advise on when you can go home. This can be on the same day as your procedure, but may be longer depending on you, your needs, and how local services are organised.

How does the tube stay in place?

The tube is held in place by either a small plastic disc or small water-filled balloon, which sits on the inside of your stomach.

Can the tube fall out?

Yes, this can happen if the disc or balloon fails. It is also possible to pull the tube out, for example if it gets caught on something and pulled hard. Your healthcare team will advise on what to do if the tube falls out.

Will I be attached to the feed all day?

It is unlikely that you will need to be attached to the feed all day. A dietitian will work with you to come up with a feeding plan that works for you and your needs.

Where do I get my liquid feed from?

The specially designed liquid feed will be delivered to your home, either by the company that manufacture the feed or your local pharmacy. You will be given information on this before you are discharged home with a tube.

Do I have to use the tube?

No, it is your decision when to use the tube once it is placed. You are free to start or stop using the tube at any time. However, you will need to care for the tube even if you are not using it.

Can I have the tube removed if I decide at a later date that I no longer want it anymore?

Yes, you can decide at any point to have the tube removed. Removal is usually a simple process but may require a short procedure and hospital admission. It is important to remember that if you have the tube removed, you probably will not be able to have another tube fitted in the future (unlike if the tube falls out - see Can the tube fall out?).

If I decide I don't want a tube now, can I change my mind later?

If you decide you don't want a tube now, you can change your mind at any time. However, it is important to remember that there may come a point in your disease when you are no longer fit enough for the procedure to fit the gastrostomy tube.

What happens if I decide not to have a tube?

If you decide not to have a tube your healthcare team will continue to support you to eat and drink as safely as possible and keep you comfortable. You may want to revisit the decision in the future; however, it is important to remember that there may come a point in your disease when you are no longer fit enough for the procedure to fit the gastrostomy tube.

Who will support me to look after and use my tube at home?

Some people can use and care for their own tube whilst other people need help from family, friends, or outside carers. Whoever is responsible for using and caring for the tube will need training and support from the MND care team.

How might having feed through a gastrostomy tube affect my digestion?

Receiving feed through a gastrostomy tube may alter your digestion in various ways. For example, some people experience changes in bowel habit or reflux. Your healthcare team will work with you to manage any problematic changes.

Compare your options

What does each option involve?

Have a gastrostomy tube	Not have a gastrostomy tube
<p>A gastrostomy tube is placed into your stomach, allowing you to use this to provide your body with some or all of the food and fluid it needs, as well as some medications.</p>	<p>Continue to eat and drink as much as you are comfortable with.</p> <p>You may want to come back to the decision again in the future. Although you can come back to the decision as many times as you want to, you should be aware that if your breathing is weak and/or you have lost too much weight, you may not be fit enough to undergo the procedure to fit a gastrostomy tube</p>

What are the possible benefits of each option?

Have a gastrostomy tube	Not have a gastrostomy tube
<p>Using the tube to provide some or all of the food and fluid you need, and taking less food and fluid by mouth, means that:</p> <ul style="list-style-type: none">• long and tiring mealtimes can be avoided• the risk of aspiration and chest infections is reduced. Aspiration happens when any material (e.g. food, fluids, saliva,	<p>You avoid having to have a surgical procedure and the associated risks and hospital admission.</p> <p>You don't have to think about using and caring for the tube.</p>

<p>medications) enters the airway or lungs instead of going to the stomach.</p> <ul style="list-style-type: none"> • the risk of choking is reduced • there is no need to spend time preparing soft or pureed foods <p>Providing your body with more of the food and fluid it needs may help to:</p> <ul style="list-style-type: none"> • prevent dehydration • prevent or reverse weight loss • prevent you feeling hungry and thirsty • prevent pressure sores (injuries to the skin and underlying tissue, caused by prolonged pressure on the skin) • improve your energy levels <p>Some medications can be given through the tube.</p>	<p>No need to think about whether to stop using the tube at the end of life.</p>
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What are the possible harms or disadvantages of each option?

<p>Have a gastrostomy tube</p> <p>The risk of complications when the tube is fitted (read about this in The procedure to fit a gastrostomy tube on page 19).</p> <p>Being reliant on equipment for food and fluid.</p>	<p>Not have a gastrostomy tube</p> <p>Eating and drinking may become more difficult over time and you may become dehydrated and lose weight.</p> <p>There may be a risk of you coughing or choking on foods and drinks, which can be unpleasant and distressing.</p>
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You may need assistance from others to manage your feeds and care for the tube.

Possible problems once the tube is fitted (read about this in Living with a gastrostomy tube on page 25).

At the end of life, continuing to provide the body with food and drink via a gastrostomy may extend life at a time when quality of life is poor.

Sometimes food or drinks can go into the lungs, which may result in chest infections and pneumonia. This can make you very unwell, and in some cases cause death.

You may reach a point when you are unable to eat and drink enough to keep your body going. You will gradually feel weaker and more sleepy.

If you change your mind and decide you want a gastrostomy tube later on, you may not be fit enough for the procedure.

Gastrostomy tube in MND fact checker

You might find it helpful at this point to check your knowledge of the facts. Below are 8 statements about gastrostomy tube in MND. For each one, think about if it is true or false. Turn to the next page for the answers.

	True	False
It is up to my healthcare team to decide if I have a tube	<input type="checkbox"/>	<input type="checkbox"/>
I can change my mind after making a decision	<input type="checkbox"/>	<input type="checkbox"/>
A gastrostomy tube is used to pass fluid and liquid feed directly into the stomach.	<input type="checkbox"/>	<input type="checkbox"/>
Having a gastrostomy will definitely extend how long I live.	<input type="checkbox"/>	<input type="checkbox"/>
There may come a time when I'm no longer fit enough to have a gastrostomy tube fitted.	<input type="checkbox"/>	<input type="checkbox"/>
I can continue to eat and drink once I have the gastrostomy tube fitted.	<input type="checkbox"/>	<input type="checkbox"/>
I can have a gastrostomy tube fitted at home.	<input type="checkbox"/>	<input type="checkbox"/>
I can only have a tube if I am able to use and care for it myself.	<input type="checkbox"/>	<input type="checkbox"/>

The Answers

It is up to my healthcare team to decide if I have a tube.

FALSE

It is your decision whether to have a gastrostomy tube, as long as there is no medical reason not to go ahead. Your healthcare team will support you to make this decision and will continue to support your care whatever decision you make. You can change your mind at any point.

I can change my mind after making a decision.

TRUE

Whether you decide to have a gastrostomy tube or not, you can always change your mind. However, it is important to remember that there may come a point in your disease when you are no longer fit enough for the procedure to fit the gastrostomy tube. Once you have the tube placed, you can stop using it at any point, you can also choose to have the tube removed.

A gastrostomy tube is used to pass fluid and liquid feed directly into the stomach.

TRUE

This means that fluid and nutrition can enter the body without the person needing to take food or fluid by mouth. Some medicines can also be given through the tube.

Having a gastrostomy will definitely extend how long I live.

FALSE

There is not enough evidence to demonstrate that having a gastrostomy tube will make someone with MND live longer. For ethical reasons, it is difficult to do research to investigate this.

There may come a time when I'm no longer fit enough to have a gastrostomy tube fitted.

TRUE

If you have very weak breathing or have lost a lot of weight, it may mean that it is no longer safe to undergo the procedure.

I can continue to eat and drink once I have the gastrostomy tube fitted.

TRUE

You can continue to eat and drink as much as you are able to and are comfortable with. You can use the tube to provide any other nutrition and water you need and/or to take some medications.

I can have a gastrostomy tube fitted at home.

FALSE

The procedure to fit a gastrostomy tube requires a hospital admission.

I can only have a tube if I am able to use and care for it myself.

FALSE

If you are unable to use and care for the tube yourself, you will be provided with the support you need. Some people have friends or family who are able to support them at home, while others need support from outside carers. This will be arranged before you leave hospital once the tube has been fitted.

Pros and cons of having a gastrostomy tube

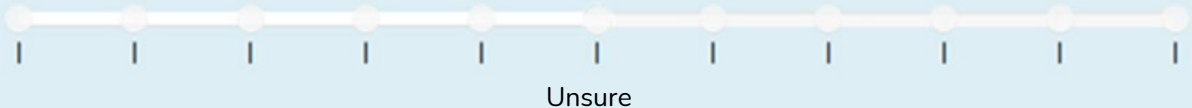
The exercise below may help you to make the decision about having a gastrostomy tube by thinking about what is important to you. Mark each line towards the option that feels most relevant to you. The stronger you feel about the statement, the further you should mark towards it.

Reasons why you may choose to *have* a gastrostomy tube

Reasons why you may choose *against* a gastrostomy tube

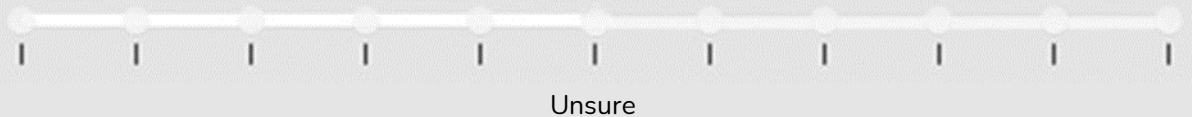
I would consider medical interventions to provide my body with the nutrition and hydration it needs

I would not consider medical interventions to provide my body with nutrition and hydration. I want to provide my body with nutrition and hydration by eating and drinking only



I want to have the option to receive feed, fluid and medications through a gastrostomy tube

Swallowing is, or may become, difficult for me, but having a gastrostomy is still not for me



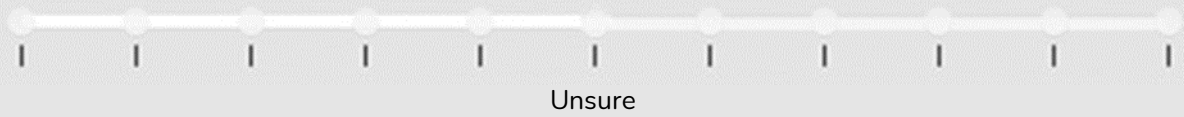
I want to have the option to receive feed, fluid and medications through a gastrostomy tube, if eating and drinking makes me breathless

I realise eating and drinking may make me breathless (now or in the future) but having a gastrostomy tube is still not for me



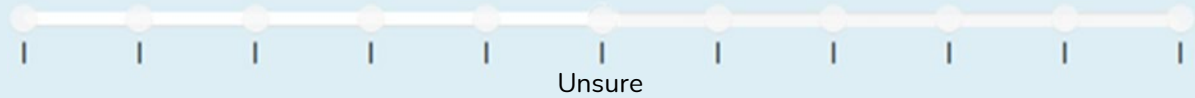
Gastrostomy feeding might slow down, prevent, or reverse my weight loss, although I know this is not guaranteed

Slowing down, preventing, or reversing weight loss is not a priority to me



Gastrostomy may help me to live longer, although I know there isn't enough scientific evidence to prove this

Maximising the length of my life is not a priority to me



For me, the benefits of having a gastrostomy tube outweigh the potential risks

For me, the risks of having a gastrostomy tube outweigh the potential benefits



I think a gastrostomy tube would have a positive impact on my quality of life

I don't think a gastrostomy tube would have a positive impact on my quality of life



I want to have a gastrostomy so I don't have to eat and drink, which may reduce my risk of choking and chest infections (now or in the future)

I know that eating and drinking may increase my risk of choking and chest infections (now or the future) and I accept this risk



The benefits of having a gastrostomy tube outweigh the extra time and effort needed to use and look after the tube

The extra time and effort needed to use and look after the tube outweigh the potential benefits of having a gastrostomy tube



If something else is on your mind, we have left some space for you to add your thoughts. You can leave this blank if you wish.

Your Decision

- If most of your marks are towards the *lefthand* end of the lines, your answers suggest you are currently leaning towards having a gastrostomy tube.
- If most of your marks are towards the *righthand* end of the lines, your answers suggest you are currently leaning against having a gastrostomy tube.
- If most of your marks are around the *middle* of the lines, or fairly evenly to the left and right, your answers suggest you are currently unsure about having a gastrostomy tube.

Feel free to use the decision aid again if you want to reconsider this decision.

The Details

In this section you can read more information about what having a gastrostomy tube involves. The main information in each section is presented first, with even more detail in the following blue boxes if you want to find out more.

About the Tube

A gastrostomy tube is made of flexible plastic and is about the size of a drinking straw. It sits on the outside of your abdomen (belly) and is held in place by either a small plastic disc or a small plastic balloon on the inside of the stomach. The hole where the tube enters the stomach is known as a 'stoma' or 'stoma site'.

There are 3 types of gastrostomy tube:

- **Percutaneous endoscopic gastrostomy (PEG)**
- **Radiologically inserted gastrostomy (RIG)**
- **Per-oral image-guided gastrostomy (PIG)**

Further details on the types of tube are available on the next page.

All of the tubes are a similar size. The main difference is how they are fitted and held in place. Your healthcare team will discuss the options suitable for you.

In some cases your healthcare team may suggest that you try a low profile or 'button' feeding tube. This type of tube has just a small 'button' that sits fairly flat against the skin on your belly. It will be seen less under tighter fitting clothing and is less likely to get caught or pulled.

Button tubes cannot be placed as the first tube; a PEG, RIG or PIG tube must be fitted first and then changed for a button once the stoma site (a small opening in the abdomen, where the tube enters the stomach) has healed. Tube types will differ in different areas. Your healthcare team will be able to advise on the tubes available and best suited to you.

Types of tube

Percutaneous endoscopic gastrostomy (PEG)

percutaneous = through the skin

endoscopic = an endoscope is used to fit the tube

gastrostomy = opening into the stomach



Radiologically inserted gastrostomy (RIG)

radiologically inserted = the tube is fitted in the x-ray department

gastrostomy = opening into the stomach

Per-oral image-guided gastrostomy (PIG)

per-oral = the tube is brought through the mouth down to the stomach

image guided = the doctor uses x-ray to find the right spot to place the tube

gastrostomy = opening into the stomach

The procedure to fit a gastrostomy tube

Having a gastrostomy tube fitted requires going into hospital for a short surgical procedure. The procedure takes around half an hour and uses local anaesthetic. Sometimes light sedation is given too, although this is not always needed.

The tube cannot be used for a few hours after being fitted. The nurses and dietitian will let you know when you can start using it. Your healthcare team will advise on when you can go home. This can be on the same day as your procedure, but may be longer depending on you, your needs, and how local services are organised.

To read more about how you will feel after the procedure and risks of the procedure, see next page.

More information about how you will feel after the procedure

After the gastrostomy tube has been inserted you will wake up in the recovery room where the nurses will look after you until you are ready to go back to the ward. If you have had sedation you are likely to feel drowsy. You may also:

- Have a sore throat for the first 24-48 hours
- Feel bloated
- Have some soreness or discomfort in your abdomen (belly) where the tube has been placed. Your healthcare team will be able to prescribe medications to help with this and the soreness should resolve within a week

Risks of the procedure

Having a tube fitted is a short procedure and for most people it goes smoothly. However, as with any procedure there is a risk of complications. Complications can include:

Sometimes it is not possible to fit the tube. This is usually because of where the stomach and other parts of the digestive tract are sitting, meaning that it is not possible for the tube to reach the stomach. This is very rare and is often only found out once the procedure has started. In this case your healthcare team will discuss other options with you.

Fluid from the stomach travels into the lungs, which can affect the breathing and may cause an infection. It is for this reason that you will be asked not to eat or drink for several hours before the procedure.

When the opening is made through your abdominal wall into your stomach there is a small risk of bleeding. This is very rare. This is usually minor, but on rare occasions can be severe and even life-threatening.

When the opening is made through your abdominal wall there is a small risk that the lining of your abdomen becomes infected. This is very rare but does require treatment with antibiotics in hospital.

A hole or tear is made in the wall of your oesophagus (food pipe), stomach or intestine. This is very rare but does require an operation to repair it.

The risk of complications will be different for each person and will depend on a number of factors. Things that may put someone at higher risk of complications are:

- Weak breathing
- Weight loss
- Frailty

Using and caring for the tube

Some people can use and care for their own tube whilst other people need help from family, friends or outside carers. It's a good idea to think about who would take on these responsibilities if you were to have a tube, and to discuss this with anyone involved.

Whoever is responsible for using and caring for the tube will need training and support from the healthcare team.

All the equipment and specially designed liquid feeds are available on prescription and will be delivered to you at home by the company that manufactures the feed, or your local pharmacy.

Using the tube

There are 4 ways to take liquid feed or water through the tube:

- **Pump or 'continuous'**
- **Pump bolus**
- **Plunger bolus**
- **Gravity bolus**

Your dietitian will work with you to come up with a feeding plan that provides the right amount of nutrition and that works for you and your lifestyle. Sometimes people use the different methods of feeding in combination to suit their needs. Your feeding plan is likely to change over time according to your needs. To find out how this might work for you, speak to your healthcare team.

Medications are given through the tube using the plunger bolus method.

You can read more about the different methods on the next page.

More information on using the tube

Pump or 'continuous' Liquid feed or water is given via a feeding pump over a number of hours. It may be possible to be fed during the day or overnight.

The pump is attached discreetly to the tube and can be placed in a specially designed rucksack if using while out and about. Rucksacks can be easily hung from the back of a wheelchair.

Pump bolus A bolus of liquid feed or water is given via a feeding pump at a higher rate (or speed) for a short period e.g. 15-30 minutes. Depending on your nutritional needs, a few boluses may be given over the day.

The pump is attached discreetly to the feeding tube and can be placed in a specially designed rucksack if using while out and about. Rucksacks can be easily hung from the back of a wheelchair.

Plunger bolus Liquid feed or water is slowly pushed down the tube into the stomach using a syringe. Depending upon your nutritional needs, a few boluses may be given over the day.

Gravity bolus Liquid feed or water is poured into a syringe and passes slowly through the tube into the stomach under gravity. Depending upon your nutritional needs, a few boluses may be given over the day.

Caring for the tube

There are a number of routine care tasks to help maintain your tube and keep your stoma site healthy¹:

- **Advancing and rotating the tube**
- **Cleaning the stoma site**
- **Checking the tube is secured**
- **Replacing worn or broken tube parts**
- **Changing the tube**
- **Changing balloon water**

There are a variety of different types of tubes and brands that are used within the UK so always talk to your local healthcare team about how to look after your specific tube.

More information about the different routine care tasks can be found on the next page.

1. The stoma site is the small opening on the abdomen, where the tube enters the stomach. There are a variety of different types of tubes and brands that are used within the UK so always talk to your local healthcare team about how to look after your specific tube.

Further information on Caring for the tube

Advancing and rotating the tube	Once the stoma site has healed, the tube will need to be 'advanced' (pushed into the stomach by 3-4cm centimetres) and 'rotated' (turned around 360 degrees). Your healthcare team will advise on when to start doing this and how often.
Cleaning the stoma site	The stoma site should be cleaned daily, using a clean cloth or piece of gauze and fresh, warm water.
Checking the tube is secured	The external fixation device is a small plastic device that helps to keep the tube in the correct position. This needs to be checked daily.
Replacing worn or broken tube parts	Over time and with daily use, parts of the tube can become worn or may break e.g. the plastic feeding end of the tube, so need to be checked regularly. These parts can be very easily replaced at home.
Changing the tube	Some gastrostomy tubes need to be changed every 3-6 months. This is a straightforward process that can usually be carried out at home.
Changing the balloon water	Some gastrostomy tubes are held in place by a small plastic balloon on the inside of the stomach. The balloon is inflated with a small amount of water. The water in the balloon needs to be changed regularly to ensure the balloon remains fully inflated. Your healthcare team will advise when to start doing this and how often.

Living with a gastrostomy tube

Quality of life

There has been very little formal research comparing the quality of life of people living with motor neurone disease with and without a gastrostomy tube. Having a gastrostomy tube may affect your daily life in many ways, both positively and negatively.

To read more about potentially positive and negative effects on daily life see next page.

Length of life

We currently do not have good evidence that having a gastrostomy tube lengthens the life of people living with MND. For ethical reasons, it is difficult to do research to investigate this.

Possible problems once the tube is fitted

When deciding whether to have a gastrostomy tube, it is important to be aware of things that can go wrong once the tube is fitted. In most cases these problems can be solved at home if acted on quickly.

Gastrostomy tube complications should always be discussed promptly with the healthcare team, who will be able to advise on how to manage them.

To read more about the problems see page 27.

To find out how common the problems are with different kinds of gastrostomy tube are, see page 28.

Further information about living with a gastrostomy tube

Potentially positive effects on daily life include:

Being fed through a tube takes away the pressure of having to finish meals, allowing eating and drinking for pleasure, both at home and at social events

Being fed through a tube takes away the need to spend long periods preparing and eating modified foods and drinks, such as purees

Being fed through a tube takes away the need to swallow food and drinks if this has become difficult or distressing. This may also reduce the risk of choking and food or drinks going down the wrong way, which can lead to chest infections that require an admission to hospital

Being fed through a tube may help to prevent feelings of hunger and thirst if you have not been able to eat and drink enough by mouth

Many people find they have more energy and feel better in themselves when taking feed through a tube because they are receiving more of the nutrition and fluid they need

Some medications can be given through the gastrostomy tube, which means they don't need to be taken by mouth if this becomes difficult

For some people eating and drinking may leave them breathless. Being fed through a tube takes away the pressure of having to eat and drink if this is the case

Potentially negative effects on daily life include:

The tube is visible on the body and may be seen through tight or lightweight clothing. Some people may be worried about how this looks which can affect their confidence

For some a gastrostomy tube might be seen as an unwanted medical intervention

The tube has to be cared for – for some this is an added burden on top of everything else

Some people may experience symptoms like bloating, reflux (heartburn), diarrhoea or constipation after starting the liquid feed. This should be discussed with the dietitian who will be able to suggest ways to help manage this

Some people find it burdensome to have to:

- find time to use and care for the tube
- store the feed at home
- take equipment with them if wanting to use the tube outside of the home
- think about where they feel comfortable to use the tube when out and about

Having to manage possible problems with the tube – these are described in the 'Possible problems once the tube is fitted'

This table provides further information about possible problems:

A blockage in the tube	this may be because liquid feed or medication has sat in the tube and solidified. Usually this can be resolved at home but if this is not possible the tube will need to be removed and replaced.
A split in the tube:	this can happen over time with general wear and tear of the tube. Sometimes this can be resolved at home but in some cases the tube may need to be replaced.
Broken tube parts:	over time and with general use, parts of the tube can become worn and may break. These parts can be very easily replaced at home by a healthcare professional or yourself or the person who cares for you if you have received training on how to do this.
Tube is displaced (falls out):	very occasionally the device holding the tube in place may fail, allowing the tube to slip out, or the tube gets caught or is pulled out.
Infection at the stoma site (the small opening on the abdomen where the tube enters the stomach):	the stoma or tube site may become infected (the stoma site will appear red and it may be sore with some discharge). In most cases this is very simple to treat.
Granulation at the stoma site (the small opening on the abdomen where the tube enters the stomach):	granulation or 'a granuloma' is typically red or pink soft tissue that appears as a bubble or bubble type lump at the stoma site. It is the body's attempt to heal the stoma site. In most cases granulation is very simple to treat.
Leakage:	leakage may come from inside the stoma (stomach contents or feed) or from the tube itself (feed or water).
Buried bumper syndrome:	is the term commonly used to describe a serious complication where the device on the inside of the stomach that holds the tube in place becomes 'buried' in the lining of the stomach. Buried bumper is rare and is avoidable with good tube care.

How common are these problems with different kinds of gastrostomy tube?

A UK research study of 323 people living with MND showed that in the first 3 months after having a gastrostomy tube fitted:

RIG tubes are more likely to fall out than PEG or PIG tubes. The tube fell out for 31% (20 out of 96) of people with a RIG tube, in comparison to just 1% (1 out of 154) of people with a PEG or PIG tube.



The figures in blue represent the proportion of people with a RIG whose tube fell out



The blue section represents the proportion of people with a PEG or PIG whose tube fell out

18% (44 out of 250) of people had an infection. The infection rate was lowest in those with a PIG tube (12% or 3 out of 25), followed by PEG (16% or 20 out of 129) and RIG (22% or 21 out of 96).



The figures in blue represent the proportion of people who had an infection

Granulation is more likely to happen with RIG tubes, when compared to PEG or PIG tubes. 20% (19 in 96 people) of those with a RIG tube experienced granulation compared with 12% (18 in 154 people) of people with a PEG or PIG tube.



The figures in blue represent the proportion of people with a RIG who had granulation



The figures in blue represent the proportion of people with a PEG or PIG who had granulation

Leakage is more likely to happen with RIG tubes, when compared to PEG or PIG tubes. 22% (21 in 96 people) of those with a RIG tube experienced leakage compared with 10% (16 in 154 people) of people with a PEG or PIG tube.



The figures in blue represent the proportion of people with a RIG who had leakage from the tube or stoma site



The figures in blue represent the proportion of people with a PEG or PIG had leakage from the tube or stoma site

What are the alternatives to a gastrostomy tube?

Some people decide that they do not want a gastrostomy tube. If you make this choice it is important to understand the alternatives.

You may decide not to have a gastrostomy tube and to continue to eat and drink by mouth

Some people decide that having a gastrostomy tube is not for them and that they would like to continue to eat and drink by mouth.

When making this decision it is important to understand that when the swallow or breathing muscles become weak, eating and drinking can become difficult.

You can read more about this on the next page.

Your healthcare team will continue to provide support. Support from your healthcare team might include advice and care from:

- **Speech and language therapist**
- **Dietitian**
- **Physiotherapist**
- **Occupational therapist**
- **Specialist nurse or doctor**

For further details see the next page.

Nasogastric Tube

A nasogastric tube may be another option for some people. This is a long, thin tube that passes up the nose, down the back of the throat, down the food pipe (oesophagus) and into the stomach. Specially designed liquid food, water and some medications can be given through a nasogastric tube. However, nasogastric tubes are not always available and can be challenging to manage at home. You may want to discuss this with your healthcare team to find out if this option is suitable for you and to understand the risks and benefits.

More information about the potential risks of continuing to eat and drink by mouth

When deciding not to have a gastrostomy tube and to continue to eat and drink by mouth, it is important to be aware of the potential risks or future challenges.

Your level of risk will depend on the strength of your swallow and breathing muscles, now and in the future. This is something you may want to discuss with your healthcare team.

- When the swallow becomes weak you may have difficulty swallowing foods, drinks and medications safely, which may result in coughing, choking and the risk of foods, drinks or medications entering the lungs, sometimes leading to chest infections
- If you are unable to drink enough due to a weak swallow or breathlessness, you may become dehydrated (not enough fluids). Dehydration can result in headaches, urinary tract infections and an increased risk of falls
- If you are unable to eat enough due to a weak swallow or breathlessness, you may not get enough nutrients. You may lose weight and start to feel weaker and more tired.

If you do decide not to have a gastrostomy tube and to continue to eat and drink by mouth, your healthcare team will support you through this.

More information on healthcare team who may provide care and advice:

Speech and language therapist

To assess how you swallow and advise on ways to make it easier or safer to eat and drink. This might include advice on softer or pureed foods and thickening drinks, or different head and neck positions to make swallowing easier. If you have difficulties with your speech, your speech and language therapist can also help you find ways to communicate your decisions.

Dietitian

To explore ways for you to continue to enjoy your food and drink and get as much nutrition from your diet as possible.

Physiotherapist

To advise on positioning when eating and drinking.

Occupational therapist

To find practical ways to enable you to eat and drink as comfortably as possible such as adapted seating, cutlery or plates.

Specialist nurse or doctor

To work with you as it becomes more difficult to eat and drink and you get weaker, to make sure you're comfortable and well supported.

When should I make the decision?

It is up to you when to make the decision...

It is a good idea to discuss the timing of your decision with your healthcare team because MND affects everyone differently. Some of the things that might trigger you to make this decision are:

- Weight loss
- Difficulty swallowing
- Prolonged mealtimes
- Recurrent chest infections
- Weakened breathing

There is some evidence that a gastrostomy tube is of more benefit to people living with MND if it is fitted before they lose a lot of weight (more than 10% of their weight at diagnosis).

...as long as you are fit enough for the procedure

It is important to know that if your breathing is weak and/or you have lost too much weight, you may not be fit enough for the procedure to be performed safely. This means your risk of harm or dying during or as a result of the procedure is too high, and so it is not safe to do the procedure. Other things to think about are:

- you may find a hospital stay more difficult or uncomfortable, if your disease is more progressed
- there may be some time between deciding to have a tube and having it fitted, depending on waiting lists in your local area.

What happens if I change my mind?

If you choose to have a tube now you can revisit this decision as many times as you like, right up to when you have the tube placed. If you change your mind once the tube has been fitted, there is no obligation to use it, and your healthcare team will continue to support you as per your wishes.

If you choose not to have a tube now you can revisit this decision as many times as you would like, but it is important to remember that as your breathing weakens and you lose weight, it may no longer be possible to undergo the procedure.

What happens next?

If you decide to have a gastrostomy tube

You should discuss this with your healthcare team, who will advise on whether you are fit enough for the procedure. If you are medically well enough to go ahead, your healthcare team will then arrange for some routine health checks to be carried out and book a date for your procedure.

At this point, you may also want to think about your wishes for using the tube in the future, when you are in a condition where you may not want to continue receiving food, fluids or medications. You may want to write down your wishes for the future. This may be as part of an advance care plan, an advance decision, an advance decision to refuse treatment (ADRT) or living will.

If you decide not to have a gastrostomy tube

Your healthcare team will continue to support you to eat and drink as safely as possible and keep you comfortable. You may want to revisit the decision in the future, but you should be clear that if your breathing becomes very weak or you lose too much weight, it may no longer be safe for you to undergo the procedure to fit the tube.

Useful Resources

The MND Association and myTube provide additional reliable information to support your discussions and decision making. Links are provided below.

- MND Association resources on swallowing, eating and drinking can be found here (<https://www.mndassociation.org/support-and-information/living-with-mnd/eating-and-drinking/>)
- For advance decisions (<https://www.mndassociation.org/support-and-information/health-and-social-care-services-for-mnd/future-care/>)
- myTube is an educational website about the use of gastrostomy tubes in MND. Information about living with a feeding tube can be found on myTube (<https://mytube.mymnd.org.uk/>)
- Information on planning your future care can be found on the Compassion In Dying Website (<https://compassionindying.org.uk/>)
- Information and resources on tube feeding can be found on the Patients on Intravenous and Naso-gastric Nutrition Treatment (PINNT) website (<https://pinnt.com/Home.aspx>)