

7B

Tube feeding

Information for people with or affected by motor neurone disease

Motor neurone disease (MND) can cause difficulties with eating and drinking. Muscles in your throat and mouth may become weak, slow or uncoordinated. This can affect your ability to chew and swallow, leading to weight loss, dehydration and lack of energy.

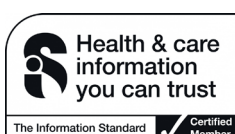
Your health and social care team may suggest a feeding tube to ease these problems, but this can feel like a difficult choice. This information sheet explains the options to help you make an informed decision. It is important to discuss this with your family, carers and health and social care team so they know how you want to be supported.

The content includes the following sections:

- 1: What is tube feeding?**
- 2: Is tube feeding right for me?**
- 3: How will a feeding tube affect my life?**
- 4: How is the tube fitted?**
- 5: How do I take care of my feeding tube?**
- 6: How do I find out more?**

 This symbol is used to highlight **our other publications**. To find out how to access these, see *Further information* at the end of this sheet.

 This symbol is used to highlight **quotes** from other people with or affected by MND.



The MND Association has been certified as a producer of reliable health and social care information.

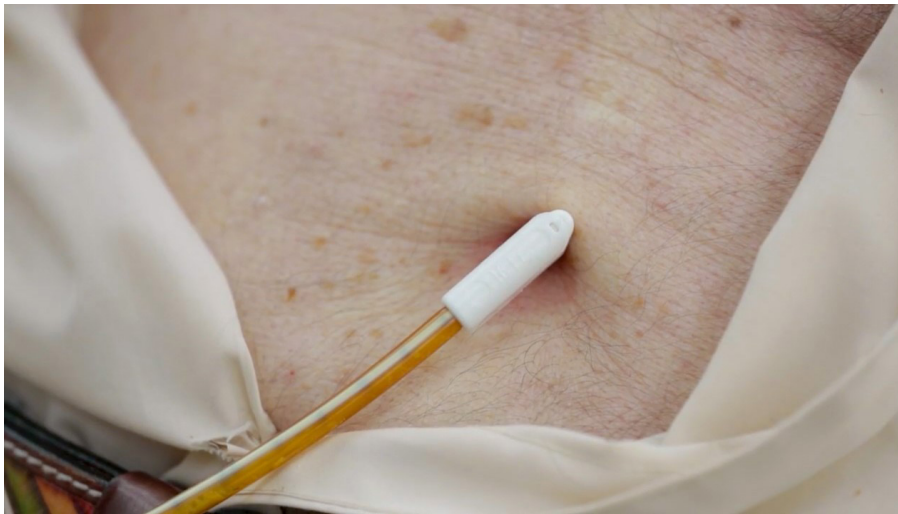
www.england.nhs.uk/tis

1: What is tube feeding?

Tube feeding is a way of passing fluids and specially prepared liquid feed straight into your stomach through a tube in your abdomen. The tube is flexible and can be discreetly hidden under clothing. It is the size of a small narrow straw.

Different brands and types of feeding tubes may look slightly different, but they are all similar in design. Each one is fitted by a minor surgical procedure.

The following photo shows an example of what a feeding tube looks like once it has been fitted:



See section 4: *How is the tube fitted?* for more information about the procedure.

With a feeding tube, you can still eat and drink by mouth if you feel safe to do so and have been advised by your health and social care team. At first, you will probably use your tube to top-up your food and drink.

As your symptoms increase, you may use the tube more. You can get all the nutrients and fluids you need through the tube if necessary. A dietitian can discuss the type and amounts of specially prepared liquid feed and fluids you need to achieve this.

See section 5: *How do I take care of my feeding tube?* for more information about daily living with a feeding tube.

If you would like to discuss tube feeding, ask your GP for a referral to a dietitian, specialised nurse or a doctor who specialises in tube feeding.

2: Is tube feeding right for me?



"I think it is particularly important to flag up this decision as soon as possible because awareness brings adjustment and adjustment assists the decision-making process."

Like any other surgery, it is entirely your choice whether or not to have a feeding tube fitted. Simply because a procedure is possible, and may bring benefits, does not mean that it is right for everyone.

Whatever decision you make, you may change your mind over time. You may wish to:

- have a tube fitted at a later date, but it can become more difficult to introduce a feeding tube as symptoms progress (ask your health and social care team for advice)
- stop using your feeding tube once it has been fitted (see later heading *What happens if I change my mind after having a tube fitted?*)

When making your decision, it is vital that you have accurate information about the advantages and disadvantages for each type of feeding method.

It is best to talk this through with your health and social care team as they can help you make an informed decision about your future health choices. It may be possible for a member of your healthcare team to introduce you to someone who is already using a feeding tube during the decision making process.

Hospitals and community services usually have guidelines about tube feeding and you may find it helpful to ask to see these.

Why would I need to consider tube feeding?

With MND, you may experience:

- difficulties chewing and swallowing your food
- reduced hand and arm control making it difficult to get food to your mouth
- weight loss due to eating less and muscle wasting
- dehydration and constipation due to drinking less
- changes to your sense of taste or reduced appetite
- lack of energy caused by eating too few calories
- food and liquid passing into the lungs, causing coughing or choking (known as aspiration, which can cause chest infections).

What are the benefits?



“By removing so much stress my friendly PEG has greatly improved quality of life for me and my loved ones. Far from being an admission of defeat it is helping me to fight against MND.”

Tube feeding allows you to get the nutrition you need and may also:

- increase your energy levels and help you regain or maintain your weight
- cause you less stress if chewing and swallowing become difficult
- reduce the risk of coughing, choking and chest infections
- increase fluid intake, helping to prevent dehydration and constipation
- be a useful way to take certain medications
- improve your sense of well-being.

All of the above may improve quality of life or comfort. However, using a feeding tube will not delay or stop the progression of MND.

What are the risks?

Having a feeding tube fitted is a common and fairly safe procedure. Major problems are rare and most issues can be resolved easily.

As with any treatment, there are some possible risks you should be aware of, such as:

- infection following the surgery
- bleeding or leakage from the wound
- discomfort or pain around the area where the feeding tube has been inserted
- a little bloating after the feeding tube is inserted caused by some air remaining in your stomach
- your breathing may be shallower for a while after the tube is fitted.

The risks to you will depend on the state of your health. You can get advice from your dietitian or relevant doctor before making your decision about tube feeding.

How will the tube affect my family and carers?

You may worry that managing tube feeds could become stressful for your family or carers. However, they may take comfort knowing that you are getting the fluid and nutrition you need.

The process is simple and everyone involved in your care will be given training to support you with tube feeding. See Section 5: *How do I take care of my feeding tube?*

Once you have decided whether or not to have a feeding tube fitted, your family or carers may disagree with the choice you have made. Discussing each other's concerns can help bring you to a shared understanding.

Can I see any video content about tube feeding?

See the myTube website for further information and video content about tube feeding: www.mytube.mymnd.org.uk

This explores decision making and usage of tube feeding, as developed by SITraN – the Sheffield Institute for Translational Neuroscience.

The website has been made with people living with MND, who wanted a way to 'meet' people and see their feeding tubes in use. Hearing their experiences and personal stories on myTube may help when making your own choice whether to have a feeding tube fitted or not.

The videos help show what life can be like living with a tube. The videos are supported by text introductions and a list of carefully selected resources from trusted organisations, including our own related information sheets and guides.

What happens if I decide against a feeding tube?

Your muscles will continue to waste whether or not you have a feeding tube. However, without a feeding tube, you are likely to lose weight and become dehydrated as eating and drinking becomes more difficult. You may worry about how this will feel, but thirst and hunger usually become less intense as your MND progresses. You may find it reassuring to discuss this with a palliative care specialist. Ask your health and social care team for a referral.

Once you have considered the options, you can make an informed decision. If you decide that a feeding tube is not right for you, your nutrition nurse, dietitian and speech and language therapist will still support you. They will advise about food, drink and prescribed supplements to suit your needs. Your palliative care team will also support you, and advise on any medication that may be needed to relieve hunger or thirst as necessary.

This advice may include adapting food textures and fluid consistencies to help you continue to eat and drink for as long as possible.



For information on eating and drinking with MND and easy swallow recipes, see: *Eating and drinking with MND*



For more details about swallowing, saliva, coughing and choking with MND, see: Information sheet 7A – *Swallowing difficulties*


If you wish to ensure that you do not have a tube fitted, even in an emergency, you can state this in an Advanced Decision to Refuse Treatment (ADRT). See next heading *What happens if I change my mind after having a tube fitted?*

What happens if I change my mind after having a tube fitted?

You may decide that you want to stop using your tube in certain situations in the future. An Advance Decision to Refuse Treatment (ADRT) can support your choices. An ADRT tells people involved in your care which treatments you want to refuse in the future and will only be used if you become unable to make or communicate decisions about this for any reason.

You must be specific about what you want to refuse and when this should happen. For example, you may wish to make a statement about the circumstances in which you would like to stop using your feeding tube.

An ADRT is legally binding if it has been completed correctly. If you become unable to make decisions or communicate, your views and wishes will be respected. However, you can review and change the ADRT at any time.

 For more details about planning for your future care, see our publications on ADRT and end of life decision making, these are listed in *Further information* at the end of this sheet.

3: How will a feeding tube affect my life?

This section answers some common questions about daily life with a feeding tube.

How long can I still enjoy food by mouth?

You may not need to use the tube immediately after it is fitted. Some people have it fitted in advance, so they can use it as soon as they need to and increase its use gradually.

With a feeding tube in place, you can still eat and drink by mouth for as long as you feel safe to do so. Get advice from your speech and language therapist and dietitian to find out what is safe for you.

You may choose to enjoy small amounts of food and drink even if there is a higher risk due to swallowing difficulties. This is entirely reasonable if you have considered the risks and have made an informed choice. Your speech and language therapist and dietitian will advise what types and consistencies of food and drink are safest for you to try.

Although tube feeding does not give the same pleasure as eating and drinking, it can relieve feelings of hunger and thirst.

Will a feeding tube help me to gain weight?

If you have lost a lot of weight, you may be prescribed a high calorie liquid feed to help you regain some of the lost weight. After this, the type and amount of feed will be adjusted to help maintain weight at an agreed level.

What about bathing, showering or swimming?

You should not immerse the tube in water until the site is fully healed. You will be advised how long to wait before you can safely shower, bathe or swim again. Once it is safe to do so, you must ensure your tube is closed beforehand and carefully dry the tube and exit site afterwards.

Advice about bathing, showering and swimming with a feeding tube can vary across regions, due to the different types of tube and how they are fitted. Always talk to your health and social care team for specific guidance.

Will this affect my body image?

You may be worried about how the tube will look and this can affect your confidence. It won't be visible when you are wearing clothes and should not cause problems with general daily activities.

You may need time to adjust to having a tube and it can be helpful to talk your feelings through with friends, family or members of your health and social care team. They can offer support to help you accept the changes to your body.

If you are worried about the appearance while you're undressed, the feeding tube can be covered over. In some cases, it can be trimmed to a shorter length, or a tube with a flatter fitting can be used. Ask your dietitian or nutrition nurse for guidance.

Does tube feeding feel uncomfortable?

You may experience some bloating or reflux after taking your feed. To help it settle in your stomach and feel more comfortable, sit upright or propped up on several pillows while you are feeding and for one hour afterwards.

If this remains an issue, ask your GP for a review from the palliative care team to look at medications that can help.

Do I still need to look after my mouth if I have a feeding tube?

Your mouth must be cared for even if you are not eating. Plaque can build up very quickly so it is important to clean your teeth at least twice a day.



For more information about mouth care, see:
Information sheet 11B - *Mouth care*

Can I still be intimate and have sex?

Your sexual function will not be affected by the feeding tube, but it could change the way you think and feel about your body. This may lower your confidence. See previous heading *Will this affect my body image?* for more information. If you are worried about your feeding tube affecting your sex life, it may help to talk this through with your partner and explore your feelings together.



For more details about sex and relationships with MND, see: Information sheet 13A – *Sex and relationships for people living with MND* and 13B – *Sex and relationships for partners of people living with MND*

Will my bowels be affected?

Any change to diet can affect your bowels and toilet routines.

Although bowel function is not usually directly affected by MND, many people with the disease still have trouble with their bowels. There can be a number of reasons for this:

- weakened pelvic floor muscles
- becoming less active
- too little fibre and water due to swallowing difficulties
- use of certain medications.

You may notice constipation or diarrhoea after having a feeding tube fitted. It can take a while for the bowels to get back to a normal pattern. Fibre in your feed can be adjusted if diarrhoea or constipation become an issue.

It is important that you adjust well to living with the feeding tube, so get advice from your dietitian, district nurse or nutrition nurse if you have any concerns.

How will I take my medication?

If you are unable to swallow your medication it will be prescribed in liquid or soluble form wherever possible. If a medication is unavailable in liquid form, ask the prescribing health professional for advice. Your doctor, district nurse, or pharmacist can also give advice about which drugs can be taken by tube.



For details about the drug riluzole, see: Information sheet 5A – *Riluzole*

If I have food allergies can I have tube feeds?

Yes. Your dietitian will know which feeds are suitable for your needs. The standard feeds are all nut free, gluten free and lactose free. If you are vegan, soya feeds are available.

4: How is the tube fitted?

This section will discuss the tube fitting procedure and things to discuss with health and social care professionals before and after the fitting.

What happens during the procedure?

You will need a surgical operation to have the tube fitted. This is known as a gastrostomy. There are 3 types:

- PEG (percutaneous endoscopic gastrostomy)
- RIG (radiologically inserted gastrostomy)
- PIG (per-oral image guided gastrostomy)

The main difference between the different types of tube is how they are fitted and held in place. This will be explained to you by the nutrition nurse, dietitian or relevant doctor. It is best to consider your options early so that you can make an informed decision.

Aftercare for RIG can take longer and there may be more discomfort. However, if MND has weakened your breathing, you may be offered RIG rather than PEG. The options given will depend on where you live, as regional guidelines can vary about the type of tube feeding available and when each type is used.

Severe weight loss before having a feeding tube fitted may increase the risks during and after the operation. It is best to consider your options before you have lost a substantial amount of weight.

You will be admitted to hospital for your operation. You will usually need a short stay afterwards, but this will depend on your own needs.

The whole operation normally takes less than half an hour and is carried out under light sedation. You will feel relaxed, but understand what is happening. Afterwards you may sleep for an hour or two, and then wake with little memory of what has happened.

Sometimes nasogastric feeding may be offered. This is where a narrow tube is passed up the nose, down the back of the throat and into the stomach. This is designed for short term use, usually less than four weeks. The tube is visible and may cause discomfort in the nose. This tube needs to be replaced often, so PEG, RIG or PIG are the preferred options with MND as your needs will be ongoing.

What do I need to know during and after the tube fitting?

While in hospital, it may help to ask the following questions to those in charge of your care.

Who will show me how to:

- place the clip and ensure it is left open when not in use (to avoid damaging the tube if closed for long periods)
- clean and flush my tube (both following the fitting and for ongoing care)
- turn and advance the tube regularly (gently move the tube in and out), so it does not become embedded
- ensure the fixing plate is the right distance from the body
- use the tube for food, drink and medicines?

After I leave hospital, which professional will:

- be responsible for my tube feeding health and any medical questions
- be my contact for tube maintenance
- advise if my tube becomes blocked or comes out for any reason?

5: How do I take care of my feeding tube?

If you choose to have a feeding tube fitted, it is important to take care of it to prevent blockages or damage. You will need to care for the tube on a daily basis. You may be able to manage this yourself, or you may need support from relatives, carers and health professionals depending on how MND affects you.



"I was surprised at the ease of the whole process. On awakening after sedation, the tube was in place with no pain and it seemed almost natural rather than invasive. Pouring liquid feed down the tube, flushing with water and cleaning very quickly became part of the daily routine."

People usually learn to cope with a feeding tube quite quickly. A specialist nurse or dietitian will visit you in hospital after the surgery to show you and your carers how to clean and take care of the tube, and the surrounding skin. You will also receive training on how to pass feeds, water and medication through the tube. If you are only in hospital for a short while, this might take place at home. Most hospitals will give you a useful written guide to help you when you are discharged.

myTube also provides information and video content on taking care of the feeding tube. See *Can I see any video content about tube feeding* in section 2: *Is tube feeding right for me?* for details.

It is very important to know who to contact if you have any difficulties. See *What do I need to know during and after the tube fitting?* In section 4: *How is the tube fitted?* for a list of questions you may wish to ask in hospital.

You should get advice if you experience:

- blockages within the tube
- leakage around the tube site
- prolonged or severe pain in the abdomen
- pain when using your tube for feeding, medications or water
- soreness of the surrounding skin
- the tube becomes loose or falls out (this is very unlikely).

How do I care for the wound after surgery?

Aftercare will vary depending on the brand or type of feeding tube, so ask for advice from staff before you leave hospital. The tube site may take up to four weeks to heal, during which it is normal to experience moderate pain and a small amount of discharge from the tube site. If you are concerned about anything, talk to your nurse or doctor.

How will I be fed?

Your dietitian will advise on the most suitable method for your needs. There are two main methods to help you find one that fits your lifestyle and needs:

- the liquid feed is fed into the tube in small doses throughout the day by syringe (referred to as the bolus method)
- the liquid feed is dripped into the tube over several hours by an electric pump, either overnight or during the day.

Sometimes a combination of these two methods can be used, if wished.

As with anything new, tube feeding is a change of routine and you may need time to adjust to these changes. Talk to your dietitian on how best to include tube feeding into your existing lifestyle to meet your individual needs.

What feed will I receive?

Your dietitian will recommend a specially prepared liquid feed with all the nourishment you need. You may also need extra water via your tube. The dietitian will advise on the amount of feed and water you should take and at what times. No other fluids, including liquidised food or yoghurt, should be passed through the tube as they may damage or block it. This can lead to the tube needing to be replaced sooner.

Do I have to order the feeds?

The feed is prescribed for you and can be delivered straight to your home. Your dietitian or nutrition specialist will advise you about ongoing supplies and feeding equipment. myTube provides information and video content on this, see *Can I see any video content about tube feeding* in section 2: *Is tube feeding right for me?* for details.

How does the tube get cleaned?

The feeding tube needs to be flushed out with water before and after use to keep it clean and avoid blockages. You will be shown how to do this if you have a tube fitted. myTube provides information and a video on cleaning the tube, see *Can I see any video content about tube feeding* in section 2: *Is tube feeding right for me?* for details.

Will the tube need replacing?

You will be advised how often your feeding tube needs to be replaced. Each hospital will have a different recommendation based on the brand of tube used.

It is worth noting that tubes with a balloon type fitting need to be changed more regularly, usually every 3-6 months. Tubes fitted by a plastic bumper tend to have a longer life and can last for a number of years. The balloon and bumper are the parts of different feeding tubes that sit inside the abdomen to help keep it in place.

Replacing a feeding tube involves a minor procedure that usually takes place in hospital as an outpatient.

6: How do I find out more?

After reading this information sheet, you may still have some questions. Your doctor, specialist nurse or dietitian will be able to talk through any issues you, your family or carers have.

Useful organisations

We do not necessarily endorse the external organisations listed here. These have been provided to help you search for further information if necessary.

Details are correct at the time of print, but may change between revisions. If you need help to find an organisation, contact our MND Connect helpline (see *Further information* at the end of this sheet for details about our helpline and how they can support you).

BDA – The Association of UK Dietitians

An organisation representing dietitians and providing those working in nutrition with advice about how they work.

Address: 5th Floor, Charles House, 148/9 Great Charles Street Queensway,
Birmingham B3 3HT
Telephone: 0121 2008080
Email: info@bda.uk.com
Website: www.bda.uk.com

Health in Wales

Online information on NHS services in Wales, including a directory of the Welsh health boards. See also NHS Direct Wales.

Email: through the website contact page
Website: www.wales.nhs.uk

MND Scotland

Care, information and research funding for people affected by MND in Scotland.

Address: 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA
Telephone: 0141 332 3903
Email: info@mndscotland.org.uk
Website: www.mndscotland.org.uk

myTube

Learning resource about tube feeding with MND.

Website: www.mytube.mymnd.org.uk

NHS UK

The main online reference for the NHS.

Website: www.nhs.uk

NHS 111

The NHS non-emergency helpline. Available 24-hours a day, 365 days a year.

Telephone: 111 (England and some areas of Wales)

Website: www.nhsdirect.nhs.uk

NHS Direct Wales

Health advice and information service for Wales.

Telephone: 0845 4647 or 111 if available in your area

Website: www.nhsdirect.wales.nhs.uk

NHS Northern Ireland

Information on NHS services in Northern Ireland. This is an online service only.

Email: through the website contact page

Website: www.hscni.net

PINNT

A support organisation for people using feeding tubes to share experiences and ideas.

Address: PO Box 3126, Christchurch, Dorset BH23 2XS

Telephone: 020 3004 6193

Email: through the website contact page

Website: www.pinnt.com

References

References used to support this document are available on request from:

Email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

Acknowledgements

The MND Association is greatly indebted to the following for their significant contributions to this information sheet:

Kay Edwards, Nutricia Nurse, Northamptonshire

Kiri Elliott, Policy Officer, The British Dietetic Association, Birmingham

Erin Forker, Senior Dietitian, University Hospitals Birmingham NHS Trust, QE Hospital

Emma Husbands, Palliative Medicine Consultant, Gloucestershire Royal Hospitals NHS Trust

Susan Rowell, Nutrition Nurse Specialist, Great Western Hospitals NHS Trust, Swindon

Joanne Simms, Community Nutrition Support Dietitian, Great Western Hospitals NHS Trust, Swindon

Beth Byrne, Home Enteral Feeding Dietitian, South Warwickshire Foundation Trust,
George Eliot Hospital, Nuneaton

Emma Wood, Dietitian, James Cook University Hospital, Middlesbrough

Further information

We provide other sheets related to this information:

7A – *Swallowing difficulties*

8A to 8D – a range of sheets about breathing and ventilation

11B – *Mouth care*

13A – *Sex and relationships for people living with MND*

13B – *Sex and relationships for partners of people living with MND*

14A – *Advance Decision to Refuse Treatment (ADRT) and advance care planning*

We also produce the following publications:

Eating and drinking with MND

End of life – a guide for people with motor neurone disease

You can download most of our publications from our website at:

www.mndassociation.org/publications or order in print from the MND Connect helpline.

The helpline team can also answer questions about this information, and direct you to our services and to other support:



MND Connect

MND Association, PO Box 246, Northampton NN1 2PR

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Association website and online forum

Website: **www.mndassociation.org**

Online forum: **<http://forum.mndassociation.org/>** or through the website

We welcome your views

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them.

If you would like to provide feedback on any of our information sheets, you can access an online form at: **www.surveymonkey.com/s/infosheets_1-25**

You can request a paper version of the form or provide direct feedback by email: **infofeedback@mndassociation.org**

Or write to:

Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

Last revised: 03/19
Next review: 03/21
Version: 1

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