

7B

Tube feeding

Information for people with or affected by Motor Neurone Disease (MND)

With MND, muscles in your throat or mouth may weaken. This can affect your ability to swallow, which makes it harder to eat or drink. This can affect some people with Kennedy's disease too. This information sheet explains how a feeding tube can provide support and help you make an informed decision. The content includes:

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 content has been evidenced, user tested and reviewed by experts. See: piftick.org.uk



This symbol highlights quotes from people living with or affected by MND or Kennedy's disease.



This symbol highlights our information resources to help you explore further. Find out how to download or order printed copies in Section 5 **How do I find out more?**

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 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 just 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.

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



"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."

2. Is tube feeding right for me?

Like any other surgery, it is your choice whether or not to have a feeding tube fitted. It can bring benefits but may not feel right for everyone. Whatever decision you make, you may change your mind over time and wish to:

- have a tube fitted at a later date (it can be more difficult to introduce a feeding tube as symptoms progress, so ask your health and social care team for advice)
- stop using your feeding tube once it has been fitted.



See later heading in this section: **What happens if I change my mind after having a tube fitted?**

When making your decision, seek accurate information about the advantages and disadvantages of each type of feeding method. Ask your health and social care team for guidance on this to help you make an informed decision.

It may be possible for your healthcare team to introduce you to someone who is already using a feeding tube during the decision-making process.



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

Hospitals and community services usually have guidelines about tube feeding. Ask to see these when finding out about your options.

Why would I need to consider tube feeding?

If your mouth and throat muscles are affected by MND, these symptoms do progress. This can impact on your eating and drinking.

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
- 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).

Some people with Kennedy's disease may also have these problems.

What are the benefits?

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

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



"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."

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 your health. Get advice from your dietitian or relevant doctor in advance

How will having a 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, it's possible that your family or carers may disagree with your choice.

Discussing concerns can help you all reach a shared understanding.



See our guide and companion web app: **Eating and drinking with MND** for help with food and drink preparation to have orally. Also see information sheet: **7A Swallowing difficulties**.

Can I see any video content about tube feeding?

A user video website called myTube has been developed by SITraN, the Sheffield Institute for Translational Neuroscience, and part-funded by the MND Association. It explores decision making and usage of tube feeding with people who have MND. Hearing their experiences and personal stories on myTube may help if you're deciding to have a feeding tube fitted or not.



See myTube at: mytube.mymnd.org.uk and more guidance at: mndassociation.org/eating.

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 could 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.

If you wish to ensure that you do not have a tube fitted, even in an emergency, you can state this in an Advance Decision to Refuse Treatment (ADRT).



See next heading: **What happens if I change my mind after having a tube fitted?** for more about ADRT.

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

You may want to stop using your tube in certain situations in the future. If you become unable to make decisions or communicate for any reason, an Advance Decision to Refuse Treatment (ADRT) can support your choices. It tells those providing your care which treatments you want to refuse or have withdrawn in the future.

You must be specific about what you want to refuse and when this should happen. For example, making a clear statement about the circumstances in which you would want your feeding tube to be withdrawn.

If completely correctly and valid, an ADRT is legally binding in England and Wales under the Mental Capacity Act 2005.

An ADRT is also legally binding in Northern Ireland under common law.

Although not legally binding in Scotland, an ADRT can still be used to guide health and social care professionals there.

Inform all those involved in your care about your ADRT, as well as any other care documents. This includes your GP and any specialists. Provide your GP with a copy of your ADRT for your medical records and ask how local systems work.

For example, some ambulance services hold copies of ADRTs or care guidance for people with life-shortening diseases, such as MND. Wherever possible, paramedics and other emergency responders take medical history into consideration, but they may not be able to access your records in an emergency. Without seeing a valid ADRT form, they may have to make a swift clinical judgment about the treatment they provide.



See information sheet **14A Advance Decision to Refuse Treatment (ADRT) and advance planning**.

3. How will a feeding tube affect my life?

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

If you choose to continue eating small amounts, consider the risks and get advice. Your speech and language therapist and dietitian can guide you on consistencies and types of food and drink that are safer to try.

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 this. 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 and you'll be advised on how long to wait. Once safe to do so, ensure your tube is closed before bathing, showering or swimming. Carefully dry the tube and exit site afterwards.

Advice about bathing, showering and swimming with a feeding tube varies across regions, due to the range of tubes and how they are fitted. Ask your health and social care team for 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.



See our booklet: **Personal care** for more about 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.

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.



See our booklets: **Sex and relationships** for impact of medical equipment on intimacy.

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.

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, your speech and language therapist and your dietitian can advise.

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 procedure is known as a gastrostomy. There are three types:

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

In some regions, PIG is referred to as POG.

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. Explore options early so 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 procedure. 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.



“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.”

Sometimes nasogastric feeding may be offered, where a narrow tube is passed through the nose, down the back of the throat and into the stomach. This is designed for short term use, usually less than four weeks. You normally stay in hospital while the tube is in place, as it may cause discomfort in the nose and needs to be replaced often. PEG, RIG or PIG are 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 about the following before you leave:

- how to avoid infection following the surgery
- what to do if there is bleeding or leakage from the wound
- how to control discomfort or pain where the feeding tube has been inserted
- how to manage any bloating (this can be caused if some air remains in your stomach after the fitting or when you start having liquid feeds through the tube)
- what happens if your breathing feels shallower after the tube has been fitted.

Also ask which professionals will provide support after you leave hospital:

- Who will be responsible for my monitoring my health with tube feeding and answer my questions?
- Who do I contact for tube maintenance?
- Who can help if my tube becomes blocked or comes out for any reason?

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, when it's normal to experience moderate pain and a small amount of discharge from the tube site. Ask your nurse or doctor if you have any questions.

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

If you have a feeding tube fitted, you, your carer or care worker will need to take care of it daily to prevent blockages or damage.

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 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.

You should get advice from your tube feeding specialist support 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, or soreness of the skin surrounding the tube
- the tube becomes loose or falls out (this is very unlikely).



See the video website: **mytube.mymnd.org.uk** for user experiences with feeding tubes, including care, feeds and maintenance. See more about myTube in section 2: **Can I see any video content about tube feeding?**

How will I be fed?

Your dietitian will provide guidance. There are two main methods, but sometimes a combination of both can be used to fit your lifestyle and needs:

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

As with anything new, tube feeding is a change of routine and you may need time to adjust to these changes. Ask your dietitian if you have any questions.

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 through 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. They can damage or block it and the tube may need 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.

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.

You will be advised how often your feeding tube needs to be replaced. This involves a minor procedure that usually takes place in hospital as an outpatient. 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.

6. How do I find out more?

Other organisations

We cannot endorse organisations, but the following may help your search for further information. Our MND Connect helpline can help you find organisations. See contact details later in this section, under the heading: Our support.

British Dietetic Association

Representing dietitians and providing those working in nutrition with advice.

Tel: 0121 2008080

Email: info@bda.uk.com

Website: www.bda.uk.com

NHS and UK healthcare

Information about NHS Services and healthcare across the UK.

Tel: 111 (England, Wales and Scotland)

Available via individual trusts website contact page (Northern Ireland)

Website: nhs.uk (England)

wales.nhs.uk (Wales)

hscni.net (Northern Ireland)

nhs24.scot (Scotland)

MND Scotland

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

Telephone 0141 332 3903

Email info@mndscotland.org.uk

Website mndscotland.org.uk

myTube

Learning resource about tube feeding with MND.

Website: mytube.mymnd.org.uk

PINNT

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

Tel: 020 3004 6193

Email: through the website contact page

Website: pinnt.com

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Beth Byrne	Home Enteral Feeding Dietitian, South Warwickshire Foundation Trust, George Eliot Hospital, Nuneaton
Emma Wood	Dietitian, James Cook University Hospital, Middlesbrough

References

References used to support this resource are available on request:

Email: infofeedback@mndassociation.org

Or write to:

Information feedback,
Motor Neurone Disease Association,
Francis Crick House,
6 Summerhouse Road,
Moulton Park,
Northampton, NN3 6BJ

Further information

We offer a wide range of information about MND and Kennedy's disease.
You may find the following resources helpful, relating to this sheet.

Information sheets

7A Swallowing difficulties

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

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

Large guides

Eating and drinking with MND

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

Booklets

Personal care

Sex and relationships

Video content

myTube website: mytube.mymnd.org.uk

Search for information by need at: mndassociation.org/careinfofinder

Find information for professionals at: mndassociation.org/professionals

Download our information at: mndassociation.org/publications

Find information in other languages at: mndassociation.org/languages

Order printed copies from our MND Connect helpline (see Our support next).

Our support

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

We also support people affected by Kennedy's disease.

MND Connect

Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at: **mndassociation.org/mndconnect**

Tel: 0808 802 6262

Email: mndconnect@mndassociation.org

Support services

Find out about our support services at: **mndassociation.org/our-services**

Local and regional support

Find out about our branches and groups at: **mndassociation.org/local-support**

MND Association Benefits Advice Service

For help to identify claims and how to apply, visit: **mndassociation.org/benefitsadvice** or call our MND Connect helpline.

Tel: 0808 802 6262

MND Association website and online forum

Website: **mndassociation.org**

Online forum: **forum.mndassociation.org**

We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with MND or Kennedy's disease, their families and carers.

Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns, and applications for funding.

To give feedback on this or any of our information sheets, access our online form at:
smartsurvey.co.uk/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
Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton NN3 6BJ

Would you like to help with user review of our information?

If you are living with MND or Kennedy's disease, or you are a carer, contact us at:
infofeedback@mndassociation.org

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