

## WILL I HAVE TO GO INTO HOSPITAL?

Yes, you will be admitted the day before the procedure. Depending on where you live you may stay in hospital for 1-4 days.

## HOW DO I LOOK AFTER THE TUBE?

You will be shown how to look after the tube by the hospital team, and be supported by local community dietetic, district nursing or enteral feeding teams. Caring for your feeding tube may include turning the tube round twice a day, keeping the area around the tube clean and flushing water through the tube with a plastic syringe. You may need a family member or carer to assist with this.

*"MY WIFE WAS A LITTLE BIT WORRIED ABOUT LOOKING AFTER THE TUBE INITIALLY, BUT LOOKING AFTER THE TUBE IS FAIRLY STRAIGHTFORWARD."*

## WHAT HAPPENS WHEN I NEED TO USE MY FEEDING TUBE FULL-TIME?

Your local community dietetic will advise on when and how to use your feeding tube full-time.

*"THERE MAY COME A POINT WHERE I HAVE TO USE IT, AND AT LEAST I HAVE THE COMFORT IN KNOWING IT'S DONE, IT'S READY, SO WHEN I DO HAVE TO USE IT, IT'S THERE."*

## FIND OUT MORE

If you want to find out more about feeding tubes, ask your local Dietician, Speech and Language Therapist and MND Clinical Specialist.

There's more information online at:  
[www.mndscotland.org.uk/living-with-mnd](http://www.mndscotland.org.uk/living-with-mnd)

Thanks to NHS Lothian and to all people living with MND who have shared their tips and advice.

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# WHEN TO GET A FEEDING TUBE FITTED

IT'S YOUR DECISION

*"I GOT THE FEEDING TUBE FITTED A YEAR AGO. IT WAS MY DECISION, 100%. IT REALLY WASN'T AS BAD AS I THOUGHT IT MIGHT BE."*

FRASER

## WHEN TO GET A FEEDING TUBE FITTED

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Having a feeding tube inserted can seem like a scary thought, but it is advised that people with Motor Neurone Disease (MND) should get a feeding tube fitted while they are still fit and healthy, so that it's ready to use if, or when, you need it. The decision is yours.

## WHAT IS A FEEDING TUBE?

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A feeding tube is a short tube that is fitted directly into your stomach to allow fluids, liquid food and medication to be delivered directly

to your stomach, bypassing your mouth. You will hear it called many names, depending on how your tube is inserted e.g. PEG (Percutaneous Endoscopic Gastrostomy) or RIG (Radiologically Inserted Gastrostomy).

## WHY SHOULD I GET A TUBE FITTED?

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*"IT WAS IMPORTANT TO GET THIS DONE BEFORE I HAD DIFFICULTIES IN EATING OR DRINKING."*

MND can affect your ability to swallow making it difficult to eat and drink. This can lead to dehydration, weight loss, and constipation. If you are advised to consider getting a tube fitted, it will be because the MND team believe it will help your quality of life, and prevent problems such as choking and weight loss.

*"MY ADVICE IS GET THE FEEDING TUBE FITTED WELL BEFORE YOU NEED IT, WHILE YOU'RE STILL FIT AND HEALTHY TO HAVE THE OPERATION DONE."*

Around 33% of people with MND in Scotland have a feeding tube inserted. It is better to have the procedure carried out while you are fit and well, and before your breathing muscles are affected by MND. Health boards in Scotland can have different policies on when they will not insert a feeding tube due to increased risks to health, and they can have waiting lists for the procedure. So it is recommended to consider having your tube inserted before you need it.

*"THE BIG THING WAS TO GET THE TUBE FITTED BEFORE I NEEDED IT, ESPECIALLY BEFORE MY BREATHING WAS COMPROMISED."*

## CAN I STILL EAT AND DRINK?

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Yes, as long as you are safe to do so without choking on liquids or food. Your Dietician, Speech and Language Therapist and MND Clinical Specialist will help advise you on this. Many people use their tube at first just to boost their nutritional intake or fluid intake. Then they move on to more of a tube feeding regime if they continue to lose weight or if choking becomes a problem.

