

Don't let MND trip you up: Preventing trips and falls

Did you know that the most common reasons for hospital admissions for people with Motor Neuron Disease (MND) are trips and falls which could have been prevented?

"I couldn't stop the MND and what it was doing to my mum, but there were simple things that I could do to help prevent her falling."

-Gemma

Trips, falls and MND

MND can affect someone's balance, posture, and ability to walk. All these things could lead to people with MND tripping or falling, which could land you, or your loved one, in hospital.

Did you also know a stay in hospital could result in someone losing their care package?

"I would recommend speaking to an occupational therapist who can come out, have a good look at how you manage, and see if there's anything they can put in place to help you at home."

-Gemma

"The stairs were becoming a hazard so we had a stair lift put in and that really helped."

-Pamela

Coping with an MND diagnosis can be so overwhelming that we often don't stop to think about things that could be a trip risk.

"We moved all sorts of obstacles. There was a rug which had to be removed completely because there are things that are trip hazards that you don't consider to be trip hazards."

-Stan

"Especially children's toys on the floor!"

-Carol

Don't risk it!

Here are 5 steps you can take to minimise your risk of falling:

Ask your occupational therapist (OT) to carry out a falls risk assessment in your home

An OT's role is to help you maintain your normal activities of daily life. They may recommend specialist equipment.

Remove any obstacles around the house

There are lots of things in our homes that we might not realize are hazards.

Use your walking aids

If you are given a splint, walking aid or any equipment, please use it.

Wear appropriate footwear

Footwear like slip-on slippers can cause trips and falls. Wear sturdy shoes like trainers. If you have problems with your dexterity, choose shoes with Velcro fastenings.

Personal alarm

If you have a personal alarm, wear it! It is no good sitting on the side.

Equipment and Aids

If your Occupational Therapist recommends any equipment, they will get it for you from statutory services. Buying equipment yourself, or borrowing from loan services, may mean council carers cannot use it for health and safety reasons.

Please discuss with your local team before purchasing.

"My advice with riser-recliner chairs is to get it as soon as possible, because it really will help you be able to get up on your own, and get it sooner rather than later."

–Pamela

Don't let MND take your breath away: Coping with choking

How to prevent choking

Talk to your MND Clinical Specialist and/or Speech and Language Therapist (SLT). The MND Clinical Specialist may be able to provide aids such as suction units, nebulizers, and medication. The SLT can suggest different approaches to eating/drinking or diet/fluid modifications.

"If somebody had said to me you'll learn all these things, I would have never thought I could do it, but you can, you know."

–Pamela

What to do if choking continues

If the episode continues for longer than usual, medication is not working and the person with MND is very distressed, you should call 999. Tell the ambulance controller the person has MND, and have any care information to hand.

"You can feel quite helpless, but just by providing a bit of reassurance and helping them to stay calm, that's a positive thing you can do to help."

"It was really the technique that she was taught by her speech and language therapist that helped the most: Focusing on Breathing."

–Gemma

Coping with choking

"For me, the choking was the most frightening aspect of MND"

–Gemma

Choking can be extremely distressing for people with Motor Neuron Disease (MND) and also for their family members.

Although it may not feel this way at the time, choking does not mean someone is dying. The sensation will pass. However, there are ways you can help your loved one if choking occurs.

Choking and MND

Motor Neuron Disease (MND) may affect someone's ability to swallow and breathe, and this can lead to choking. People with MND rarely choke on food. It's usually secretions that trickle down the throat, due to weakness in the muscles which help us swallow: this can cause the sensation of not being able to breathe.

What to do when someone with MND is choking

- Try to remain calm.
- Encourage the person to focus on slow and steady breathing.
- Assist the person to the most upright position possible.
- If the person has been prescribed medication to help manage choking episodes, use it.
- Encourage the person to cough and then swallow their saliva if possible.
- Open a window to give the feeling of air on the face.
- Use suction equipment as appropriate, if trained to do so.

"First time it happens is the scariest, but you just cope with it."

-Stan

Find out more

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

There's more information online at: 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.

When to get a feeding tube: 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

Having a feeding tube inserted can seem like a scary thought, but it is advised that people with Motor Neuron 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?

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?

"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 believes 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 consider having 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?

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 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.

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 the 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.

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

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