

## **TIPS FOR HEALTH CARE AND SOCIAL CARE PROFESSIONALS**

Most people with MND are cared for in their home by their spouse or a family member.

When you go to the house of a person with MND remember you are a guest in their home.

Remember the person with MND and their family are going through emotional trauma, as well as changing physical abilities.

The carer of the person with MND is facing the loss of their loved one. Treat them with kindness and respect and include them in conversations.

Conversely, don't ignore the person with MND by talking only to their carer.

If you don't already hold multi-disciplinary meetings with all the other health and care professionals who look after all the MND patients in your area, consider setting them up. This will enable you all to share information about the patient and gain a more all-round view of what they're dealing with.

If the person with MND is in a wheelchair, try not to stand up when talking to them. Instead, pull up a chair or crouch down, so you are at their eye level.

People with MND can still feel touch even if they are paralysed. They need to be moved gently.

Areas of skin that could break down need to be protected with a suitable barrier cream.

If the person with MND is towards the end of life they may have a syringe driver fitted to deliver drugs. Handle the person with care to avoid dislodging the needle under their skin.

Never say you know how to use the equipment if you don't. You may want to appear knowledgeable, but if in doubt, do not handle the equipment. Ask for training.

### **PERSON WITH MND IS ON A NON-INVASIVE VENTILATOR (NIV)**

These machines are critical to the life of the person with MND.

- Never leave a person off their ventilator – they will die.

- It is often hard for a patient to speak effectively without their NIV mask - another reason for keeping NIV on.

- It's hard to understand a person when they use a mask over their mouth or nose. Listen carefully and be patient. You may have to get close to the person's face to hear them clearly.

- When putting on, or taking a mask off somebody using a NIV, remember to pull the mask away from their face before lifting it up or pulling it down. This will avoid catching their nose and causing injury to their face.

## PERSON WITH MND IS FED VIA A PEG TUBE IN THEIR TUMMY

Professional training is needed. Never attempt to clean or rotate the tube unless you have been fully trained.

When washing the person with MND be careful near the stoma

## PERSON WITH MND CANNOT SPEAK

If the person with MND has lost their voice, or is having difficulty in speaking, it's incredibly frustrating for them. They may get agitated if they cannot get their message across. You may get frustrated because you feel inept and helpless. Stay calm. Try these tips.

- Only ask closed questions - in other words questions that require a yes or no answer (You will need to understand in advance how they indicate YES or NO. It could be a single or double eye blink, or a head nod).
- Anticipate their needs - offer sips of water, lip salve, something to eat, painkillers, to scratch an itch, to hitch them up in the bed if they are slumped, etc
- Ask them to describe their comfort level using a number out of 10 (1 being very comfortable, 10 being very uncomfortable), then ask a closed question , for example, if I do X will it improve your comfort. After making their suggested changes, check their score again. (If necessary you can use the fingers on your hand to help them tell you their score)
- Regularly ask the person with MND if they are in pain/uncomfortable/too hot/too cold/thirsty/hungry/feeling low.
- Give the person with MND time to answer – have patience.

**Please note: This article does not provide medical advice.**

**No content is intended to be a substitute for professional medical advice, diagnosis, or treatment. The views expressed in the book, Life's Good, are purely the views of the author. The author is not a medical expert and recommends readers affected by MND always consult their GP, MND specialist and other medical specialists appropriately.**

<https://lifegoodbook.co.uk>