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# Motor Neurone Disease

## Care Guide

### Motor Neurone Disease (MND)

MND, also known as ALS, is a neurodegenerative disease that rapidly causes muscle weakness and visible wasting. It affects a person's ability to control the muscles that enable them to move, speak, breathe and swallow. MND usually affects people in their mid-50s and those with a family history of MND or a related condition called frontotemporal dementia. There is no cure for the disease as yet but there are medications that slow down its progression.

### Caring for someone with MND

When a person is diagnosed with MND they will most likely be referred to [Palliative Care](#) services to maintain the best quality of life possible. This type of care will help in controlling symptoms and provide practical and emotional support for the person and their family members.

The respiratory problems experienced during MND can be improved with either Invasive Ventilation or Non-Invasive Ventilation methods to support the person's breathing. However, Invasive Ventilation may not be an option depending on what stage of MND the person is at. Ask your health and care teams for further guidance on which route to take.

If a person has difficulty eating and drinking, Tube Feeding may be the best option for them to get the nourishment and hydration they need. However, this is only a short term solution to being unable to swallow as a tube is passed through their nose to their stomach. A small surgery, gastrostomy, may be a better long term solution – speak to your GP to understand if this procedure is suitable.

### Palliative Care

Palliative Care can be provided in your home or at a hospital, wherever you are comfortable, and focuses on managing pain. The aim of this type of care is to ensure that the person and their family live the best life possible until they pass.

- Controls symptoms
- Psychological and spiritual aspects of care
- A support system to enable people to live as actively as possible



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- Help with decision making
- Assistance to help your family cope

### Your rights as a Carer

In addition to Palliative Carers, you may find yourself caring for a loved one with MND. It is important to know your rights and the benefits available to you and your family. As a carer you have the right to:

- have your opinions taken into consideration by the local social services/adult care services when they are assessing the needs of the person you support
- an assessment of your needs as a carer
- have your interests, work, family life and life 'outside of caring' taken into account
- take a break from caring
- benefits and financial support, where applicable
- request flexible working from your employer

You may wish to contact the MND association's helpline, [MND Connect](#), if you have any specific questions

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