

About motor neurone disease (MND):

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- It attacks the nerves that control movement so muscles no longer work. MND does not usually affect the senses such as sight, sound and feeling etc.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- Over 80% of people with MND experience changes to their speech, which may become slurred or quieter. Some people lose their ability to speak entirely.
- It affects people from all backgrounds.
- Around 50% of people with MND experience some form of cognitive change while living with the disease. This can affect their thinking and behaviour. This percentage rises to around 80% for people who are in the advanced stages of the disease.
- It kills a third of people within a year and more than half within two years of diagnosis.
- A person's lifetime risk of developing MND is around 1 in 300.
- Six people per day are diagnosed with MND in the UK.
- It affects up to 5,000 adults in the UK at any one time.
- It kills six people per day in the UK, just under 2,200 per year.
- It has no cure.

About the Motor Neurone Disease Association:

The MND Association was founded in 1979 by a group of volunteers with experience of living with or caring for someone with MND. Since then, we have grown significantly, with an ever-increasing community of volunteers, supporters and staff, all sharing the same goal – to support people with MND and everyone who cares for them, both now and in the future.

The MND Association focuses on improving access to care, research and campaigning for those people living with or affected by MND in England, Wales and Northern Ireland.

Our Promises

To harness the hope within our community to speed up progress towards a world free from MND, the MND Association has committed to five Promises.

Our Promises give us focus to work faster and fight harder to strive for better – together with our community. Simply put, they drive everything we do.

We promise we won't rest until:

- MND is treatable and ultimately curable
- Everyone gets the care they need they need it
- Every day with MND counts
- You are heard
- No one faces MND alone.

Our vision

A world free from MND

How we talk and write

Motor neurone disease is lower case and then abbreviated to MND. When writing please refer to motor neurone disease (MND) and then MND.

The Motor Neurone Disease Association can be shortened to the MND Association or the Association, but never the MNDA.

The Association refers to **people living with MND** and their networks as **people affected by MND**.

The Association NEVER says 'people suffering with'.

The Association refers to **death** and **dying** rather than using euphemisms such as 'passed away'.

MND is a terminal illness and the Association describes it as such.

Media Team:

We offer journalists, influencers and broadcasters access to expert information about MND and the MND Association.

We can organise interviews with people affected by the disease, and regional and national spokespeople covering England, Wales and Northern Ireland, on a wide range of topics including:

- Living with MND
- The latest research into possible causes of MND
- The search for treatments and a cure
- Specialist social and health care affecting people with MND
- Our current campaigns
- Fundraising

For interview, comment or personal story requests, as well as imagery and logo files please :

Email: communications@mndassociation.org

Phone: 01604 611838

Our website: www.mndassociation.org

Further information:

Videos: A collection of short films are available on our website <https://www.mndassociation.org/videos/> under the following sections:

- Awareness campaigns
- Care for people living with MND
- Campaigning
- Conferences
- Research
- For professionals
- From our supporters

The below provide a starting point:

The Ride

'The Ride' shows the devastating effects of motor neurone disease portrayed as a terrifying rollercoaster ride. https://www.youtube.com/watch?v=2668TvHs_dw&feature=youtu.be

What is MND? A short animation

This animated video provides a simple overview about motor neurone disease.
<https://youtu.be/tq0MO2x31NA>

How can the MND Association help?

This animated video explains how the Association can help families affected by motor neurone disease and explains our services
<https://youtu.be/Rblkgq7jvPw>

