

Motor neurone disease



This fact sheet provides information on motor neurone disease (MND). Our fact sheets are designed as general introductions to each subject and are intended to be concise. Sources of further support and more detailed information are listed in the Useful Contacts section. There are different types of MND and each person is affected differently. You should speak with your doctor or specialist for individual advice.

What is MND?

Motor neurone disease (MND) is a rare neurological condition that causes the degeneration (deterioration and loss of function) of the motor system (the cells and nerves in the brain and spinal cord which control the muscles in our bodies). This results in weakness and wasting of the muscles. MND is progressive and symptoms worsen over time. Sadly, MND severely reduces life expectancy and most people with MND die within five years of the onset of symptoms.

The motor system

The motor system controls all of the movements we make with any part of our bodies, from a simple nod of the head or wave of the hand to more complex movements like walking or running.

A key part of the motor system is the complex system of motor neurones. These are nerve cells which control the function and activity of our muscles by transmitting messages through the central nervous system (the brain and the spinal cord) and through the peripheral nervous system (the network of nerves outside the central nervous system).

Motor neurones are divided into two groups: upper motor neurones (in the brain) and lower motor neurones (in the brainstem at the base of the brain, the spinal cord, and in the arms, legs and torso). Both upper and lower motor neurones can be affected by MND.

What causes MND?

We do not know what causes MND. Various studies have been carried out around the world and the risk of developing MND does not appear to be affected by race, diet or lifestyle. MND does not occur in epidemics, it is not infectious and it does not appear to be caused by any other disease. It is more common in men than women. Most people experience the onset of symptoms after the age of 40 years and MND is most common in people aged between 50 and 70 years.

Although rare, for some people there is a genetic factor and they inherit from their family an increased risk of developing MND.

What are the symptoms of MND?

MND symptoms are progressive and worsen over time. Symptoms initially experienced in distinct parts of the body will eventually spread to the rest of the body. MND does not usually cause cognitive problems or affect an individual's intellect.

The main symptoms of MND:

- Muscle wasting (this is often first noticed in the muscles in one hand, or in one arm or leg)
- Muscle weakness (it might be difficult to open bottles or jars, carry heavy objects, or climb stairs)
- Fasciculations (involuntary contractions of part of a muscle, often felt as flickers of movement or small twitches just under the skin)
- Speech problems
- Swallowing problems and excessive saliva (drooling)
- Cramps and muscle spasms (spasticity)

In the latter stages of MND, the muscles weaken in the chest, back and neck and people experience difficulties with breathing.

Are there different types of MND?

Yes, there are several different types of MND. Each type can progress slightly differently from the others.

- **Amyotrophic lateral sclerosis (ALS):** this is the most common form of MND. People with ALS experience muscle wasting, weakness, fasciculations, speech and swallowing problems, and muscle spasms.
- **Progressive muscular atrophy (PMA):** this is a less common form of MND and tends to progress more slowly than ALS. People with PMA do not experience muscle spasms. Some people with PMA go on to develop ALS.
- **Progressive bulbar palsy (PBP):** this form of MND mainly affects the muscles in the throat, tongue and face and causes difficulties with speech, swallowing, coughing and clearing the throat. PBP can also affect the expression of emotions and people might laugh or cry for no apparent reason. This is called emotional lability.
- **Primary lateral sclerosis (PLS):** this is a very rare form of MND in which people experience spasticity but do not experience muscle wasting or fasciculations.

Tests and investigations

When people first notice symptoms developing, they usually visit their GP who can refer them to a neurologist or other specialist. MND cannot be diagnosed with one specific hospital test and doctors will usually carry out a series of tests and investigations. The symptoms of MND are similar to those of other conditions that need to be ruled out as part of the process. The first stages of a diagnosis of MND will involve checking your medical history and carrying out a thorough neurological examination.

Electromyography (EMG)

An EMG examination is used to measure the extent of damage to the motor neurones transmitting messages to a particular muscle. Small needles are used to record the amount of nerve impulse activity in the muscle.

A variation of the EMG test called a **nerve conduction test** can also be used to measure the speed at which messages (nerve impulses) are travelling via nerves to particular muscles. The results are checked for any abnormalities.

Transcranial magnetic stimulation (TMS)

A TMS examination uses a special magnetic coil to measure motor neurone activity in the brain (the activity of the upper motor neurones). The results are checked for any abnormalities.

MRI scan

An MRI scan (Magnetic Resonance Imaging scan) produces detailed pictures of the brain and spinal cord using strong magnetic fields and radio waves. The scan cannot confirm whether you have MND but it can help doctors rule out other conditions which could potentially be causing your symptoms. (You might like to read our fact sheet on brain and spine scans for further information.)

Blood tests

Blood tests cannot confirm whether you have MND but they are carried out to rule out other conditions that might be causing your symptoms, such as kidney or liver disease, problems with the thyroid gland, or inflammatory conditions such as lupus.

What are the treatments?

Unfortunately, there is no cure for MND. However, there are different treatments available. Some aim to slow the progress of the condition and others aim to treat your specific symptoms and improve your quality of life.

- **Riluzole** is the only drug treatment specifically for MND. It is used to slow the progression of MND symptoms. Riluzole can increase the life expectancy of people with MND by three to six months.
- Different specialist health professionals can provide therapies for your specific symptoms. A speech and language therapist can help with speech and swallowing problems. A physiotherapist can help with physical symptoms like mobility problems, pain from stiff joints and muscle spasms. An occupational therapist can advise on maintaining independence and using equipment around the home. A dietician can advise on nutrition and maintaining a healthy weight.
- Drug treatments are available for cramps and muscle spasms (spasticity).
- You might develop swallowing problems that affect your ability to eat and drink safely. You might need to be fed through a tube in your nose, or by PEG (percutaneous endoscopic gastrostomy). This is a procedure to insert a feeding tube directly into the stomach.
- People with breathing difficulties might benefit from oxygen therapy (usually given at night) or assisted ventilation (usually given through a face mask).

Complementary therapies

Some people with MND find complementary and alternative therapies helpful. They are unlikely to provide a specific treatment for your MND or your symptoms but they might help to improve your general well-being.

Diets high in specific vitamins have been suggested as helpful for people with MND. These diets might not provide a specific treatment for your MND or your symptoms but maintaining good nutrition is important and most people can improve their general health and well-being with a healthy, balanced diet.

Clinical trials

Researchers are investigating a variety of potential treatments for MND. Sometimes there is an opportunity for people with MND to take part in a clinical trial as part of their treatment. Clinical trials test new treatments on patients and compare the results with standard treatments. Your medical team can discuss any clinical trial options with you. (You might be interested in reading our fact sheet on clinical trials for further information.)

Hospice care

A hospice is a home providing palliative care (the care and support given at the end of someone's life). Hospices are usually smaller than hospitals. People are looked after by a medical team of doctors and nurses. Hospices cater their care and support services to meet the specific needs of people with MND and their families. They can also arrange for people to receive palliative care at home.

Useful contacts

Brain and Spine Helpline

0808 808 1000

www.brainandspine.org.uk

Run by neuroscience nurses, providing support and information on all aspects of neurological conditions for patients, their families and carers, and health professionals.

Motor Neurone Disease Association

PO Box 246

Northampton NN1 2PR

08457 626262

www.mndassociation.org

MND Scotland

76 Firhill Road

Glasgow G20 7BA

0141 945 1077

www.mndscotland.org.uk

The Brain and Spine Foundation provides support and information on all aspects of neurological conditions. Our publications are designed as guides for people affected by brain and spine conditions - patients, their families and carers. We aim to reduce uncertainty and anxiety by providing clear, concise, accurate and helpful information, and by answering the common questions that people ask. Any medical information is evidence-based and accounts for current best practice guidelines and standards of care.

Brain & Spine Foundation

LG01 Lincoln House, Kennington Park, 1-3 Brixton Road, London SW9 6DE

Helpline: 0808 808 1000

www.brainandspine.org.uk

Registered Charity Number: 1098528

Published: July 2015

Review date: July 2018

