

Why me?

We don't know why some people get MND and others don't. The cause of MND is not known. There is a lot of research taking place around the world to try and answer this question.

How long have I got?

How the disease progresses varies from person to person. About 90% of people live for 3-5 years from the onset of symptoms, with about 10% living for over 5 years and a number of these living for 10+ years.

Research

The **Scottish MND Register** is vital for us to monitor the number of cases of MND in Scotland, It also allows people living with MND to have direct access to MND researchers. Since 2010 the research team has registered 72% of all known MND patients. We want to do better than this, we want to aim for 100%, so please ask your MND nurse for details, or sign up online at

<https://dcnapp1.dcn.ed.ac.uk/mnd/patientRegistrationForm.asp>

The Internet

Please be aware that not all the information you may find on the internet is correct or trustworthy. If you are unsure about the information you have found, print it off and discuss it with your doctor or MND clinical specialist. Some useful sites which have good, trustworthy information are:-

MND Scotland

www.mndscotland.org.uk

Motor Neurone Disease Association (England, Wales & N. Ireland)

www.mndassociation.org

International Alliance of ALS/MND Associations

www.alsmndalliance.org

The ALS Association (USA)

www.alsa.org

For further help and information contact:

MND Clinical Specialist

Clinical Specialists Details

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Scottish Charity number SC002662

Company limited by guarantee, Registered in Scotland SC217735

Published August 2016

Motor Neurone Disease

Essential Information

This leaflet contains a summary of some helpful information for someone who has been newly diagnosed with motor neurone disease.



What is Motor Neurone Disease (MND)?

Motor Neurone Disease (MND) is the name given to a group of similar illnesses. These illnesses all cause damage to the nerves called motor neurones. These are the nerves that carry the messages which control our muscles. A common early sign of MND is increasing muscle weakness. This can show up in many different ways such as not being able to do something you could easily do before. Depending on which muscles are affected this early weakness could perhaps cause you trouble walking or lifting your arms. In about one case in four, it can start in the muscles we use to speak, chew and swallow; this can cause slurred speech and eating difficulties for some people.

There are many different kinds of problems that motor neurone disease can cause. However, it is important to remember that not everyone is affected in the same way. Just because something is mentioned here it doesn't mean it will definitely happen to everyone who is affected by MND. Some people with MND never lose the use of their hands, others never lose the use of their voice and others are always able to walk.

The damage caused by MND is progressive. This means that the damage gets worse with time. As the disease progresses any affected muscles will weaken until, perhaps, the muscle can no longer do its job. As well as this, the effects of the disease will normally spread to other muscles in the same area. This can often cause the loss of use of that limb or part of the body

Why can it take so long to diagnose MND?

MND is an extremely difficult condition to diagnose in its early stages because few cases of MND follow exactly the same pattern. Which muscles are

affected, the order in which they are affected and the way they are affected can vary so much that there are almost no rules to help predict how any one case will develop. The first symptoms can be so subtle that it is difficult for a doctor to decide exactly what is wrong. As the area of body affected by weakness spreads it becomes easier to decide what is, and what isn't, MND. An experienced neurologist might be reasonably sure that something is or isn't MND but might want to see the development of more symptoms in an early or slowly developing case before being sufficiently confident that something is definitely MND. There is currently no test for MND. Where tests are carried out, these are used to rule out other conditions.

What help is available to me?

Each person who is diagnosed as having MND will be given the opportunity to meet an MND clinical specialist. This person has many years experience of dealing with MND and is an expert in the management of the disease. The clinical specialist might be introduced to you at a neurology clinic after diagnosis, or should make contact with you within a couple of days.

The clinical specialist will assess what help needs to be pulled in from community and health services in order to give you the support you need to live at home. Once the initial issues are dealt with the clinical specialist will keep in contact. If your circumstances or symptoms change it is important that you let the clinical specialist know about this change as soon as possible. You will be looked after by a team of professionals which can include a neurologist, MND clinical specialist, occupational therapist, speech and language therapist, dieticians and district nurses amongst others. Members of this team will change depending on your symptoms and needs as the disease progresses. If you or members of your family need to talk to someone then counselling can also be offered.

What treatments are there for MND?

MND itself is not curable, but the symptoms that come with it can be managed in different ways. The only drug available to directly affect MND is called Riluzole or Rilutek. It is thought this drug slows down the progression of MND.

The symptoms of MND can often be managed by drugs or in other ways. In general MND tends to affect the following areas, although not every person with MND will have problems in all of these areas, nor in this order.

- **Mobility** (walking can gradually get more difficult)
- **Hand and Arms** (may become difficult to move and control)
- **Speech** (can become slurred)
- **Swallowing** (may become difficult)
- **Muscles of the Trunk** (tummy and chest may become weak)
- **Weight Loss**
- **Changes in Mood or Thinking**
- **Breathing** (may get breathless easily)

Things can be done to help with each of the areas above.

Can MND be passed on to others?

MND is not infectious, but a small number of cases are inherited or "run in the family." This type of MND is called "Familial MND" and affects between 5 and 10 people in every 100 cases. If MND has been inherited there will usually be a family history of the disease having affected other blood relatives before you. If yours is the first case of MND in your family, then you probably have "Sporadic MND". Most cases of MND (90 to 95 out of every hundred) are thought to be sporadic. Experience has shown there is little risk of the disease being passed on to future generations from someone who develops this kind of MND.