

An easy read guide to Motor Neurone Disease (MND)



What is Motor Neurone Disease (MND)?

Motor Neurone Disease is often called MND.

MND is a disease which changes the way your body moves.



This booklet tells you about MND and how it can change your body.



Why does my body move?

Your body moves to help you do the following:



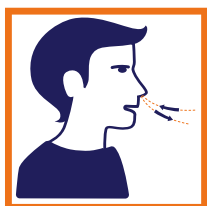
It helps you to walk.



It helps you to talk.



It helps you to use your hands.



It helps you to breathe.



It helps you to swallow, eat and drink.

If you have MND you may find it gets harder to do these things.

How will my body change?

The way your body changes may be different to someone else with MND.

The following things don't change:



You can still wee and poo, but you may need help to get to the toilet.



You can have sex, but it may not be as easy to move your body.



Most people with MND can still see, smell, hear, taste and feel things.



The following things can change:



You may find it harder to move your hands, arms, legs and feet.



You may feel your muscles twitch, or tingles under your skin.



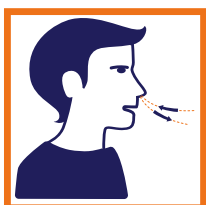
You may feel pain in your muscles and joints.



You may find it harder to talk.



You may find it harder to swallow, eat or drink.



You may find it harder to breathe, which can make you feel tired.



You may laugh or cry when you don't mean to.

Who gets MND?

Adults get MND, but it doesn't happen to many people.

Most adults who get MND are over 40 years old.

It is nobody's fault if you get MND.



Doctors are still trying to find out why people get MND and how to stop it happening.



How do doctors know I have MND?



It can take a long time to find out, and you may see more than 1 doctor.



There are no tests for MND, but there are tests to find out if something else is making you poorly.



When these tests are done you might be told by a doctor that you have MND.



How poorly will I get?

People can die from some illnesses. MND is one of those illnesses.



You will feel more poorly in time.

For some people this can take months.

For others, it can take years.



You will not get better with MND and it will shorten your life.

But you can get lots of help.



Who can help me?



You may see many doctors and nurses.

Lots of people can help with your care.



They can all help you to do things on your own for as long as possible:



You may be given equipment to help you move and do things.



You may be given help to eat and drink more easily.



You may be given help to exercise and feel more comfortable.



You may be given medicine to feel more comfortable.



You may be given help to breathe more easily.



You may be given help to communicate if you find it hard to talk or use sign language.

What other help will I need?

You may need to get help with the following things:



You may need help with care at home.



You may need help with treatments and medicines.



You may need help with money.



You may need help with travel.



You may need help with your feelings.

How do I get help?

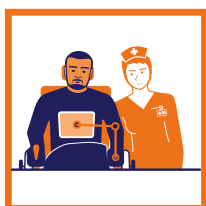


Ask your doctor, family or carer what to do if you are worried.



Doctors and care workers may ask you questions to find out what you need.

How do I answer their questions if I have problems with my speech?



You can use a communication aid if you need help with these conversations.



Some communication aids are simple, like word or image boards.



Some communication aids can be used on phones or computers.

How to contact our helpline



You can contact our helpline team to ask questions or find out about our services.



Our helpline is called: MND Connect

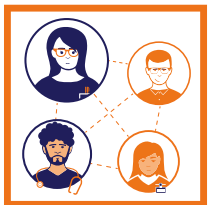
Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

Website: www.mndassociation.org



They can also tell you about our branches and groups, where you can meet other people with MND if you want to.



You can also watch and listen to our animations about MND using this web link:

bit.ly/animations-mnd



We would like to thank the following for their help with this information:

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**This guide won second place for Easy Read,
at the 2016 BMA Patient Information Awards.**



**This guide has also been
endorsed by Mencap.**



Let us know what you think about this
guide, using this web link:

bit.ly/easyguide-mnd

What you tell us may be used to help
other people find out more about MND.

This guide was updated in November 2020.

This is the first version printed since that update.

It will be checked again in November 2023.

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