



11: Inherited MND and genetic counselling

This section provides guidance on how to explore whether you have a family history of MND and what to do should you wish to leave a genetic history for your current and future blood relatives.

The following information is an extracted section from our full guide *End of life: A guide for people with motor neurone disease*.

All of the extracted sections, and the full guide, can be found online at: www.mndassociation.org/eolguide

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org



End of life:
A guide for people with
motor neurone disease

11: Inherited MND and genetic counselling



This section provides guidance on how to explore whether you have a family history of MND and what to do should you wish to leave a genetic history for your current and future blood relatives.

As you approach end of life, you may find yourself making various legal and financial arrangements to assist your family in the future.

See Part 3: What do those close to me need to know?

As you put your affairs in order, you may think more widely about the future of your family and this could include thoughts about the impact of MND if you have a family history of the disease.

You may have questions about genetic counselling and genetic testing that you would like to explore. This section provides an overview of what to consider and how to access specialist advice.

What causes MND?

It is still not possible to give a clear answer about the precise causes of MND as each individual may be affected by a different combination of triggers. However, during consultations with your neurologist in the early stages, you may be asked about any family history of MND. You may also be asked if there is a family history of frontotemporal dementia, as this may indicate that MND could have been present, even if not diagnosed at the time. It is worth asking the consultant to discuss family history, as this may help determine if an inherited gene is one of the likely factors.

“ My father died of MND 25 years ago and his brother also died two months after of MND. When this happened I didn't know much about MND and was told it wasn't inherited. Due to this I wasn't worried and didn't imagine it would happen to me in the future, or even think about it again until it 'hit me!' ”

MND with no apparent family history:

Most cases of MND occur with no apparent family history of the disease, which is sometimes referred to as sporadic MND.

The precise causes in these instances are not yet known. Multiple genetic and environmental triggers are thought to be involved. The environmental triggers may be different for each individual, so there is no simple way of identifying what may have caused the onset of the disease.

In these cases, other family members are at no greater risk of MND than anyone else in the population.

MND where there is a family history:

In some cases, there is a family history and the role of genes is more significant. Where this occurs, the disease is caused by a mistake in the genetic code which can be passed down.

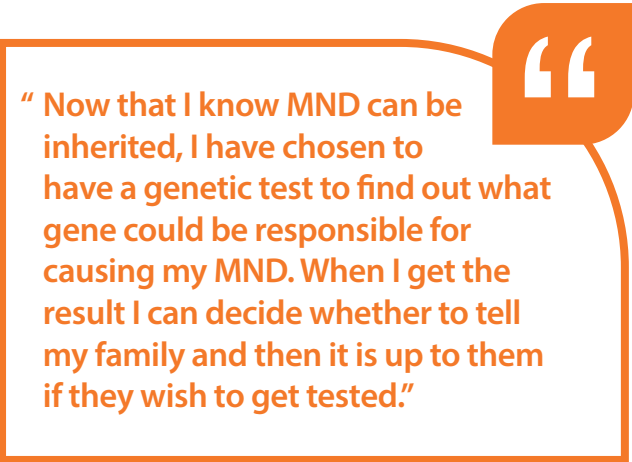
Even where this is the case, it is important to emphasise that other triggers may still be necessary for the disease to emerge.

If you are concerned about the possibility of a family history of MND and what this could mean for those close to you (in terms of inheriting the change in the genetic code), you may wish to seek genetic counselling.

Although sensitive to the emotional aspects of the situation, genetic counselling is not a form of psychotherapy. A genetic counsellor explains the facts as clearly as possible, and gives you accurate information on the implications for your family.

This will include information about options such as genetic testing, to help you make up your own mind if this is a choice you wish to make.

Some genetic testing is possible, but not everyone with a family history would benefit. Currently, testing is only available for some of the genes that play a part in inherited MND and results may not be conclusive.



“ Now that I know MND can be inherited, I have chosen to have a genetic test to find out what gene could be responsible for causing my MND. When I get the result I can decide whether to tell my family and then it is up to them if they wish to get tested.”

Choosing to be tested can be a very difficult decision, as it affects the wider family and may raise questions about options relating to pregnancy.

There are currently no preventative measures that can be taken to delay or prevent disease onset (although not every carrier will go on to develop the disease).

We would advise that you seek genetic counselling from a neurological expert experienced in MND. In the first instance talk to your neurological consultant, who will be able to advise.

See *Further information at the end of Part 4: What else might I need to know?* for a list of our research sheets on *Inherited MND*, including detailed information about genetic counselling, genetic testing and options for starting a family.

There has been an acceleration of world-wide research into the disease and its causes, including projects funded by the MND Association. As a result, our understanding of MND and the way motor neurones function is constantly advancing.

Key points

- If tests show that your inherited MND is caused by an identified gene, then unaffected family members can also be tested for the gene defect (if they wish). This 'pre-symptomatic testing' should only be undertaken after genetic counselling due to the psychological and practical implications.

See Further information at the end of Part 4: What else might I need to know? for a list of our research sheets on Inherited MND, which include detailed information about genetic counselling and genetic testing.

- If gene testing reveals that your disease is caused by a mistake in an unidentified gene, then genetic testing will not be available for unaffected family members.
- Some research projects and clinical trials need the participation of people with MND and occasionally their families. We know how keen some people are to help in this way and have developed a research register to help record this interest. Find out more at: www.mndassociation.org/researchlist or contact us to see if you meet the qualifying criteria: Telephone: **01604 611880** Email: research@mndassociation.org

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refer to the full guide, *End of life: A guide for
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www.england.nhs.uk/tis