Inherited MND and genetic testing

Guidance for people with Motor Neurone Disease (MND) and their families

Every day, helping you make informed decisions that feel right for you, matters.

Contents

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Patient Information Forum

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How can this booklet help me?

You may be worried about a possible family history of motor neurone disease (MND), where it can be passed down through a changed gene. Where this history exists, parents may pass the changed gene to biological children, but this is not always the case.

This booklet explores how genetic testing can identify changed genes that are known to play a part in MND. It also explains what to think about if you wish to get tested. This can be an emotional decision, but being informed about all your options can help.

💬 This symbol highlights quotes from people living with or affected by MND.

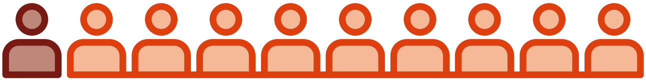
ℹ This symbol highlights our information resources to help you explore further. Find out how to download or order printed copies in section 8: **How do I find out more?**

Can I get involved with research?

New drugs are being researched that may link to changed genes and impact on the way MND progresses. Find research news and ways to get involved at: **mndassociation.org/research**

Find a list of our MND care centres and networks, where research trials are often held, at **mndassociation.org/carecentres.**

1. What is inherited MND and how could it affect me?



About 1 in 10 people diagnosed with MND have a family history of the condition, known as inherited MND.

You may also hear it called hereditary or familial MND.

How proteins are made can affect our motor neurone cells and this can play a part in motor neurone disease. Sometimes a change in a gene within our DNA can affect how proteins are made. A changed gene may then be passed on from an affected parent to their biological child.

Inheriting a changed gene linked to MND carries a higher risk of getting the condition, but doesn't mean you will definitely get MND.

It is not yet possible to be clear about the exact causes of MND. Most cases are likely due to more than one risk factor, including genetics, lifestyle and things you may come into contact with in your environment.

Risk factors are not yet fully understood, as individuals may be affected by many different things. Research is ongoing.

It is thought that a combination of risk factors is usually needed for MND symptoms to begin.

If I have MND, why is family history important?

Where there is no evidence of family history, it's known as sporadic MND. Most cases are sporadic, which means the risk of other family members getting MND is usually low. Genes can still play a part in sporadic MND, but other risk factors seem to play a larger role. As each person can have different risk factors, it's not clear how MND starts in these cases.

With inherited MND, a known changed gene may be involved. This is why your neurologist may ask about your family's medical history during diagnosis. Ask about this if you want to know more.

Medical histories of blood relatives, such as your parents, brothers and sisters are explored. Also aunts, uncles and grandparents, where related by blood (but not your partner or partner's family).

> **"Once we realised that this was something in our family, it preyed on my mind quite a lot."**

You may be asked if any of your relatives:

- were diagnosed with MND or had undiagnosed speech or mobility problems towards the end of their life
- were diagnosed with frontotemporal dementia (FTD), as research shows this is often linked to MND
- showed dementia-like symptoms or signs of unusual behaviour that might have been FTD.

> See our booklet: **Changes to thinking and behaviour with MND** for more about FTD.

If you have a clinical diagnosis of MND, you can choose to have genetic testing whether you have a family history of the condition or not.

See sections 2 and 3 to find out about genetic counselling and diagnostic genetic testing if you have MND.

If I have a family history of MND, what does this mean for me?

If a changed gene linked to MND has been identified in one or more of your relatives, ask your GP to refer you to clinical genetics.

You can then learn more about MND and discuss how it could affect you and your family. One option is predictive genetic testing to find out if you have the same changed gene. This is your choice.

If you decide to be tested and you haven't inherited the changed gene identified in your family, your risk of getting MND is probably low.

If predictive genetic testing shows you have inherited the changed gene in your family, the risk of getting MND is higher. However, other risk factors usually need to be present for the condition to actually begin. Some people have a changed gene and never get MND.

See sections 2 and 3 for more on genetic counselling and predictive genetic testing if you have a family history of MND.

For how a changed gene can be inherited, see section 5: **Could a changed gene affect my family and children?**

Which changed genes are likely to cause MND?

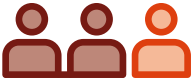
Genetic testing can’t diagnose MND, but looks for changes in genes known to play a part. There are many changed genes and more are likely to be discovered that impact on MND. The most common changed genes are:

- **SOD1**
- **TARDBP**
- **FUS**
- **C90RF72**

> **“Genetic changes are like spelling mistakes in your DNA and some of these mistakes are linked to motor neurone disease... But if we know the genetic mistake, we can screen for that by taking a simple blood sample for genetic testing.”**

Dr Amina Chaouch, Neurology Consultant, Co-director at the Motor Neurone Disease Care Centre, Manchester Centre for Clinical Neurosciences.

Genetic testing can only provide an answer for about two thirds of those thought to be affected by inherited MND. This is because we don’t yet know all of the gene changes linked to MND and your genetic counsellor may discuss other reasons too.



Genetic testing can provide an answer for about 2 out of 3 people with inherited MND. (where there are known faulty genes)

2. What happens with genetic counselling?

It is your choice to have genetic testing or not, but you will always be advised to have genetic counselling first. You are recommended to take someone with you to each session.

Although sensitive to emotion, genetic counselling isn't a form of psychotherapy or emotional counselling. Your genetic counsellor explains the possible outcomes and impact of genetic testing, to help you make a decision. What's covered will depend on whether:

- you have MND and you're seeking diagnostic genetic testing
- you don't have MND, but you're seeking predictive genetic testing, for a known changed gene in your family.

"It's a dilemma for a lot of people."

With either type of testing, discussion is likely to explore your family history and who else in your family may be at risk. This may include:

- what the possible result may be and how this could affect you and your blood relatives
- what's involved with genetic testing, and the advantages and disadvantages of having this done
- how long it's likely to take and how you will get the results.

See section 4: **How can I manage the impact of inherited MND?**

Genetic counselling if I've had a clinical MND diagnosis

If you have a clinical diagnosis of MND, genetic counselling explores how diagnostic genetic testing can help you:

- identify if you have a known changed gene, that may have played a part in your MND diagnosis
- find out if you might qualify for research studies about that gene
- be ready if a new drug treatment is developed for that gene
- give relatives the option for predictive genetic testing if you have the changed gene (now or in the future).

> **"Initially, my dad was very worried about genetic testing and took his time to make a decision... The clinic gave a lot of information and explained it can take a long time for results to come through, because it's so detailed."**

With diagnostic genetic testing, you are usually referred to a clinical genetics service for this counselling, but your MND neurologist may also offer this service in some areas.

Genetic counselling if I do not have MND, but have a family history of the condition

If you don't have MND, genetic counselling explores how predictive genetic testing may help find out if you inherited a changed gene identified in your family.

This may need several sessions and is essential before making a decision about predictive genetic testing.

With predictive genetic testing, you are referred to your local clinical genetics service for genetic counselling. It should be given by specialist genetic counsellors and clinical geneticists.

For more on both diagnostic and predictive genetic testing, see section 3: **How does genetic testing work?** See the Genetic Alliance UK website **geneticalliance.org.uk** for regional clinical genetics services.

Is there an example of how genetic counselling can help with the impact of my choice on my family?

A simple example is that your grandfather on your mother's side has MND and a test finds that he has a known changed gene. You may want to find out if you inherited that same changed gene, but your mother may not want to know if she is at risk.

Genetic counselling can help you:

- explore difficult situations for understanding
- consider how your family may be affected if you are tested
- think about ways to approach emotional conversations.

> **"I am trying to do some research into the family tree because initially all my siblings thought that it was my father who carried the gene, but I don't think it is, because nobody in his family had it."**

Your relatives may need information and support too.

There may be waiting lists for genetic counselling and predictive genetic testing. If you would like to explore this testing now or later, ask your GP or neurologist about referral times in your area.

3. How does genetic testing work?

You usually have a blood sample taken for genetic testing. This is then tested in a laboratory. Results can take weeks or months.

What can diagnostic gene testing show if I've been diagnosed with MND?

Within the NHS in England, diagnostic gene testing uses a technique called whole-genome sequencing. Special filters look for changes in the genes linked to MND and other similar disorders. This includes commonly affected genes and those rarely linked to the disease.

The type of genetic testing offered in Scotland, Wales and Northern Ireland may vary, but ask your GP, neurologist or local healthcare provider for guidance.

If you have MND, you can get diagnositic genetic testing following genetic counselling. You can be tested whether or not you have a family history of the condition.

There are three possible results:

1. **A clear change is found in a gene known to play a part in MND**
In this case, you are then diagnosed as having a genetic form of the condition. If they wish, blood relatives would then qualify for genetic counselling to consider their options, including predictive genetic testing to see if they have the same changed gene.

2. **No known changed gene is found**
In this case, blood relatives who do not have MND cannot be tested, as predictive genetic testing needs to know which changed gene to identify.

3. **The result is uncertain**
We are still learning about our genes. Sometimes it's not clear if a gene change would cause a problem or not. In this case, it is not always possible to offer predictive testing to a blood relative. Your local genetics team will give guidance for a result like this.

What can predictive testing show If I don't have MND but do have a family history of the disease?

If you haven't been diagnosed with MND, you won't be offered diagnostic genetic testing as would someone with the condition. There are various reasons for this, but it could lead to unclear results. Your genetic counsellor can give further guidance.

If a blood relative has a clinical diagnosis of MND and genetic testing finds they have a changed gene linked to the condition, you can ask for genetic counselling.

As a first step, this helps you discuss the possible risks of getting MND and all of your options.

This would include the option of predictive genetic testing, which looks for the same faulty gene that has been identified in your affected blood relative.

If you decide to go ahead with predictive genetic testing:

- a negative result means you don't have the changed gene and your risk of getting MND is usually low
- a positive result means you carry the changed gene. This doesn't mean you will definitely get MND, but it does create a higher risk.

ⓘ See section 5: **Could a changed gene affect my family and children?** to see how a changed gene can be inherited.

If a family history of MND is caused by a changed gene that has not yet been discovered, predictive genetic testing cannot give a result.

This is because it won't know what gene change to look for.

You usually have to be 18 years old for predictive testing, but ask your genetic counsellor for guidance.

Does a predictive test predict if I will get MND from a changed gene?

No. Predictive genetic testing can only identify if you have a known changed gene, as found in your family. It cannot predict if you will get MND.

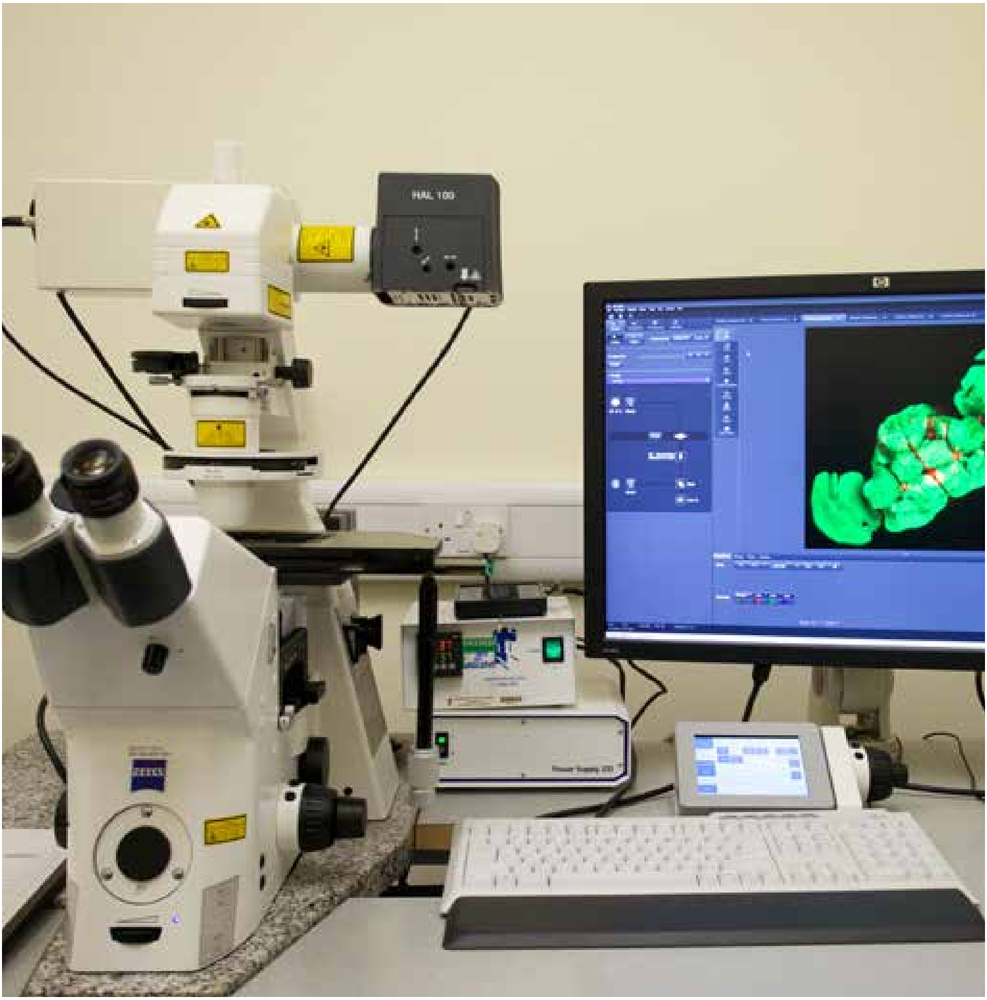
There is no single test to diagnose MND. You would still need to go through a clinical diagnosis if you showed any symptoms.

For clinical diagnosis, your symptoms are assessed and monitored. A range of tests are also completed to help rule out other causes and conditions.

Depending on your family history and possible risk factors, you may get MND if a changed gene is found.

However, you may still be less likely to get MND than other relatives with that same gene.

The way this can vary is still being researched and one of the many reasons why genetic counselling is essential to understand your potential risks of getting MND.



4. How can I manage the impact of inherited MND?

Being diagnosed with MND is challenging, but finding out you have an inherited form can make emotions more complex. You may worry the changed gene has passed to your children or that other blood relatives may be affected.

Challenges are to be expected and it may feel hard to explain the risk to family members, especially when distant or if your relationship is strained. A genetic counsellor can support in approaching this.

Emotional support can help you identify mixed emotions, such as guilt, anxiety and depression. Counselling can help you find ways to manage any difficult feelings. Contact our helpline, MND Connect, your GP or healthcare team about support, for you and your family.

See our booklet: **Emotional and psychological support** and section 8: **How do I find out more?** for our MND Connect helpline details.

If you do not have MND, but find out that you have a family history of the condition, you may feel overwhelmed. It's common to worry that any clumsiness, twitching or cramp could be a sign of MND, but this is not usually the case.

> **"There is a great benefit to be able to talk to someone who is not a family member, someone with whom you can share all your hopes and fears without worrying about the impact this might have, as with family."**

Will a genetic test affect insurance?

Living with a life-shortening and disabling condition can affect life and travel insurance, but specialist companies can help.

Our helpline, MND Connect, provides contacts for companies currently offering insurance for people diagnosed with MND.

If predictive genetic testing shows that you have a changed gene linked to MND, you do not have to disclose this to insurance companies that are members of the Association of British Insurers.

This is laid out in The Code on Genetic Testing and Insurance. This policy helps ensure that people who have had a predictive test are not unfairly discriminated against on account of their decision to have genetic testing.

Genetic Alliance UK provides information and support for people affected by all genetic disorders, including MND. They help explain The Code on Genetic Testing and Insurance, with guidance about:

- life and travel insurance
- genetic testing and family history
- privacy and what to do if rejected by an insurer.

ℹ See other organisations in section 8:
How do I find out more? for contact details


aeriaparking.com
Aparca en el aeropuerto.
El mejor servicio y al mejor precio.
Só con tarxeta de embarque
Only with boarding card
Sólo con tarjeta de
Portas
Gates
Puertas

5. Could a changed gene affect my family and children?

The way our bodies look, grow and function is guided by our genes, within pairs of chromosomes in our cells.

Most of our genes also come in pairs. We inherit one copy of each gene from our father and one copy of each gene from our mother. Our genes can be analysed to look for any known changes.

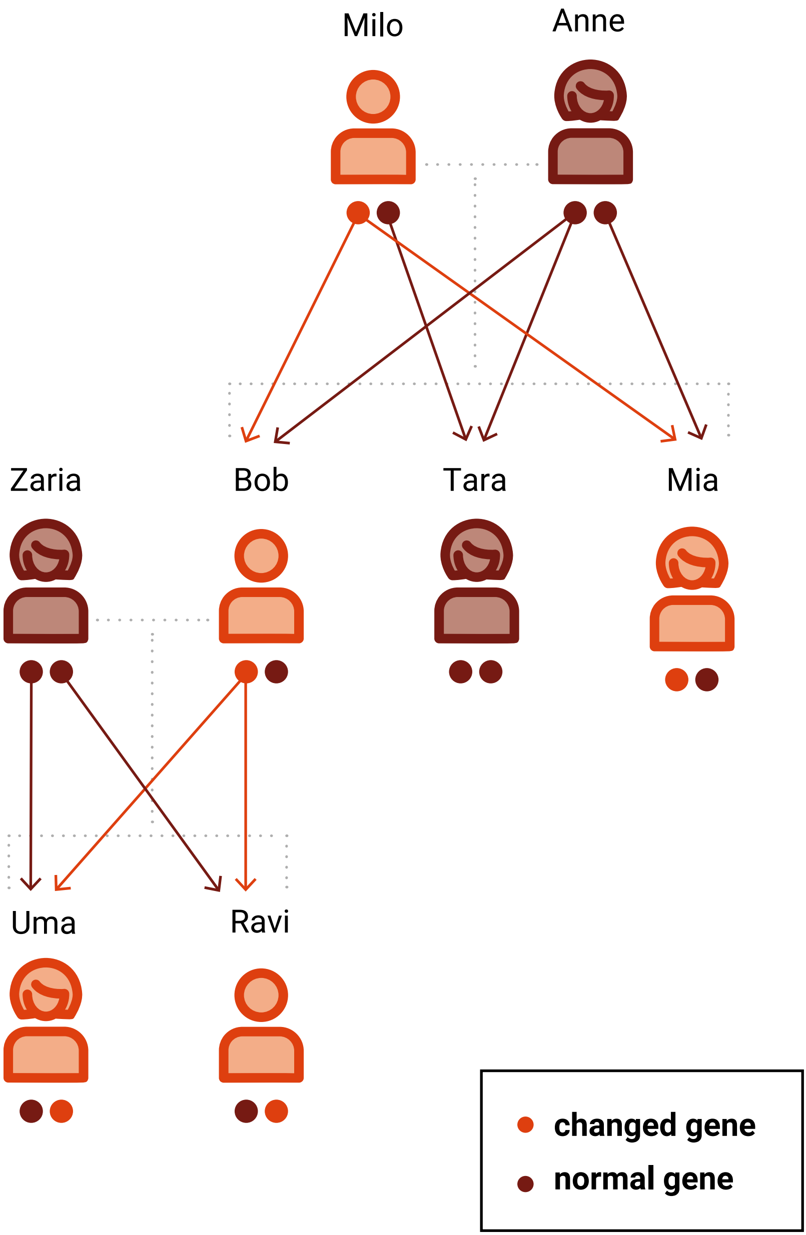
> **"Advanced technology allows us to screen the whole DNA and check for spelling mistakes in the genes thought to play a part in MND. It's important to remember this type of testing may also find other genetic mistakes which could impact on you and your family."**
>
> **Dr Amina Chaouch,** Neurology Consultant, Co-director at the Motor Neurone Disease Care Centre, Manchester Centre for Clinical Neurosciences.

How does a changed gene get inherited?

In most cases, it's possible for just one changed copy of a gene to be inherited from one parent, known as a 'dominant inheritance pattern'. If you have inherited MND, your neurologist can help work out your likely pattern.

The following diagram shows a simple scenario. An affected parent can pass on either their changed copy or normal copy of the gene to any of their children.

For example, Milo has passed on the changed gene to Bob and Mia, but the normal gene to Tara. Tara is at no greater risk of getting MND than anyone else who does not have a changed copy of the gene.


Milo
Anne
Zaria
Bob
Tara
Mia
Uma
Ravi
● changed gene
● normal gene

This means that each child has a one in two risk of inheriting the changed gene. As with getting two tails in a row tossing a coin, two children of an affected parent can both inherit the changed gene.

See Uma and Ravi in the previous diagram. Both have inherited a changed gene, but there was an equal chance that neither of them would inherit that gene.

This one in two risk is always the same, regardless of gender.

“My two younger sisters and brother got tested and they haven’t got the gene.”

What happens if you inherit the changed gene?

Even though there is a higher risk with a changed gene, other risk factors (such as environmental) still play their part.

For example, even when the same changed gene reappears within the same family, symptoms of MND can start at different ages and in different parts of the body.

If the gene in question is linked to frontotemporal dementia (FTD), this also applies.

For example, Uma may start getting symptoms of MND at the age of 40, whereas Ravi may not get any signs until past 60 years of age. It’s also possible that neither of them will get MND.

6. Are there any options to help start a family?

If you have a family history of MND or frontotemporal dementia (linked to MND), you may have concerns about the risks of passing on a changed gene.

Options are available for alternative ways to start a family. Some pregnancy options look for a known gene, but others are not dependent on genetic testing.

We realise some choices may not feel right for you, due to beliefs or ethical views. Ask your GP or another member of your health an social care team about referral to your local genetics service, where you can discuss your options and needs with a genetic counsellor.

Find further information about the options in this section from:

- your genetic counsellor
- the Human Fertilisation and Embryology Authority (HFEA), with a search facility for fertility clinics and success rates
- Genetic Alliance UK with a list of genetics services
- national information on adoption and regional adoption agencies
- your GP and your local health and social care team
- your midwife (if you are already pregnant).

See other organisations in section 8:
How do I find out more? for contact details

See the following for brief descriptions of the main options. Ask your service provider for details about what to expect and if there are any costs to pay. NHS funding may be possible for some of the options.

Having a child without genetic testing

Many people with a family history of MND choose to go ahead with pregnancy without any form of genetic testing. Genetic counselling can still help with guidance on risk and discoveries in MND research.

Pre-implantation genetic testing (PGT-M)

If you know the changed gene in your family, pre-implantation genetic testing for monogenic disorders (PGT-M) may be possible.

Using in vitro fertilisation (IVF), multiple embryos are created outside the womb and tested for the changed gene. Only an unaffected embryo is used to attempt a pregnancy.

With PGT-M, ask your GP for referral to a local clinical genetics service to explore the process, any risks and whether you qualify.

Prenatal diagnosis (PND)

If you know the changed gene that has affected your family, prenatal diagnosis (PND) may be possible through the NHS.

This process tests whether the baby has the changed gene, during pregnancy. Samples for genetic testing are taken with a fine needle through the tummy into the womb, by using either:

- chorionic villus sampling (CVS) to take a small sample of placenta
- amniocentesis to take a small fluid sample from around the baby.

Both sampling methods carry a small risk of miscarriage.

PND is considered if you are sure that you would end an affected pregnancy. It’s not possible to have PND simply to find out if your baby carries the changed gene because of the miscarriage risk with an unaffected pregnancy.

The result would also go on the child's medical record, removing their choice to be tested or not as an adult. This would take away their right not to know their genetic status.

Using donor sperm or eggs

If you don't know the changed gene that may be causing MND in your family, using donor sperm or eggs may be an option. You will need fertility treatment using in vitro fertilisation (IVF) or artificial insemination. Ask your GP or local fertility clinic about this.

For guidance on fertility options, visit the Human Fertilisation and Embryology Authority (HFEA) at: **hfea.gov.uk** and search for the following as needed:

- pre-implantation genetic testing
- in vitro fertilisation
- using donated sperm
- using donated eggs.

Adoption

If you don't know the changed gene causing MND in your family, or you don't wish to use other options, you may be thinking about adoption. You must be aged 21 years or more. If successful, you will be taking legal parental responsibility for a child, either as an individual or as a couple.

You and your partner would both need a health assessment. If you have MND, this is likely to impact on adoption, as MND will raise concerns about ongoing care for a child.

If you have a family history of MND, but don't have the condition, you may be able to adopt. Possible impacts on parenting are explored, but they also consider strengths.


alpha

7. What do the words mean?

You may hear these terms used at appointments.

Amniocentesis: a test using a needle to take a sample of amniotic fluid, that surrounds a baby during pregnancy.

Cells: when grouped together, the cells in our bodies form all our different living tissues, including muscles, nerves, organs, bones, tendons, blood and skin.

Chromosomes: our cells hold 23 pairs of chromosomes, containing genes to tell our bodies how to grow. We inherit one chromosome in each pair from our mother and the other from our father.

Chorionic villus sampling (CVS): a test using a needle to take a sample of the placenta that helps feed a baby during pregnancy.

DNA: the chemical material that forms our chromosomes and genes is called DNA (deoxyribonucleic acid).

Frontotemporal dementia (FTD): a type of dementia, not the same as Alzheimer's. FTD affects behaviour, emotions and communication. Up to half of those diagnosed with MND have mild changes to thinking and behaviour. A small number have the more severe FTD.

Genes: genes are the instructions in your cells that tell your body how to grow, function and look. They are made of DNA and we generally have two copies of each gene, one copy being passed down from our father and the other from our mother.

Genome: refers to all of the genetic material in an individual, including all your genes and the material between your genes.

Inherited: in genetic terms, 'inherited' can refer to any trait, feature or genetic material passed to you from your parents.

In vitro fertilisation (IVF): fertilising a human egg with sperm outside of the body to create an embryo to attempt a pregnancy.

Monogenic disorder: a condition caused by changes in a single gene.

Pre-implantation genetic testing for monogenic disorders (PGT-M): This uses in vitro fertilisation, where embryos are tested for a specific gene change. Only an unaffected embryo is placed in the womb.

Pre-natal diagnosis (PND): where a sample is taken from placenta or amniotic fluid during pregnancy to test if the baby has a changed gene already known to be present in the family.

Pre-symptomatic: before symptoms of a potential condition appear. With MND, a changed gene does not necessarily mean you will become symptomatic.

Proteins: every part of your body is built from proteins, that help you function. In general, each gene contains the DNA code instructions for how to make a particular protein. How proteins are managed by the cells in our body plays a part in MND.

Risk factor: see ‘trigger’ in this list.

Sporadic MND: a case of MND with no apparent family history.

Trigger: a risk factor or something that causes a condition to begin. Often, more than one risk factor or trigger is needed for this to happen. MND triggers may come from genes, environment, lifestyle or activity. These are so varied, it’s not yet possible to predict what could affect a specific individual.

8. How do I find out more?

Other organisations

We cannot endorse organisations, but the following may help your search for further information. Our MND Connect helpline can help you find organisations. See contact details later in this section, under the heading: Our support.

Adopting a child (government guidance)

National guidance on adoption.
Website: **gov.uk/child-adoption** (England and Wales)
nidirect.gov.uk/articles/adopting-child (Northern Ireland)
mygov.scot/adopting-child-scotland (Scotland)

Antenatal Results and Choices (ARC)

Provides information and support around antenatal testing.
Tel: 020 7713 7486
Email: info@arc-uk.org
Website: **arc-uk.org**

British Society for Genetic Medicine

Offers a directory of UK regional genetic centres.
Email: membership@bshg.org.uk
Website: **bsgm.org.uk**

Coram BAAF Adoption and Fostering Academy

Provides information about adoption and fostering in the UK.
Tel: 0207 520 0300
Email: membership@corambaaf.org.uk (to access Advice Line)
Website: **corambaaf.org.uk**

The Donor Conception Network

Support for families going through donor conception.
Tel: 0207 278 2608
Email: enquiries@dcnetwork.org
Website: **dcnetwork.org**

First 4 Adoption
National information service to support adopting a child in England.
Email through website contact page
Website **first4adoption.org.uk**

Genetic Alliance UK
Guidance if you have a genetic condition, including about insurance.
Tel: 0300 124 0441
Email: contactus@geneticalliance.org.uk
Website: **geneticalliance.org.uk**

Human Fertilisation and Embryology Authority (HFEA)
UK regulator on fertility treatment, with guidance on pregnancy options involving genetic testing and licensed fertility clinics.
Email: enquiriesteam@hfea.gov.uk (all enquiries by email)
Website: **hfea.gov.uk**

LGBT Mummies
Support and information for LGBT+ people on ways to have a child.
Email: contact@lgbtmummies.com
Website: **lgbtmummies.com**

Mind
Support about mental health and how to find a local therapist.
Tel: 0300 123 3393
Email: info@mind.org.uk
Website: **mind.org.uk**

National Adoption Service (Wales)
National information service to support adopting a child in Wales.
Email: see contact page for local agency details
Website: **adoptcymru.com**

Surrogacy UK
Support and helping to connect surrogates and intended parents.
Email: through the website contact page
Website: **surrogacyuk.org**

Acknowledgments

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Dr Amina Chaouch
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Dr Laura Furness
Specialist Registrar, Manchester Centre for Genomic Medicine.

Dr Rhona MacLeod
Consultant Genetic Counsellor and Honorary Senior Lecturer, Manchester Centre for Genomic Medicine, The Human Fertilisation and Embryology Authority (HFEA).

References

References used to support this resource are available on request:
Email: **infofeedback@mndassociation.org**

Or write to:

Information feedback,
Motor Neurone Disease Association
Francis Crick House
6 Summerhouse Road
Moulton Park
Northampton NN3 6BJ

Further information

We offer a wide range of information about MND and Kennedy's disease. You may find the following resources helpful, relating to this booklet.

Information sheets

Our range of information sheets can help with managing symptoms.

Booklets

What you should expect from your care
Types of care
Telling other people about MND
Emotional and psychological support
Changes to thinking and behaviour with MND
Kennedy's disease

Large guides

Living with MND
Caring and MND - support for you

Search for information

By need: **mndassociation.org/careinfofinder**
In other languages: **mndassociation.org/languages**
As short animations: **mndassociation.org/animations**
As video content: **mndassociation.org/mndviews**
For professionals: **mndassociation.org/professionals**
About research: **mndassociation.org/research**
For all resources: **mndassociation.org/publications**
Order printed copies from our MND Connect helpline (see Our support next).

Our support

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

We also support people affected by Kennedy's disease.

MND Connect

Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at:
mndassociation.org/mndconnect
Tel: 0808 802 6262
Email: mndconnect@mndassociation.org

Support services

Find out about our support services at:
mndassociation.org/our-services

Local and regional support

Find out about our branches and groups at:
mndassociation.org/local-support

MND Association Benefits Advice Service

For help to identify claims and how to apply, visit:
mndassociation.org/benefitsadvice
or call our MND Connect helpline.
Tel: 0808 802 6262

MND Association website and online forum

Website: **mndassociation.org**
Online forum: **forum.mndassociation.org**

We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with MND or Kennedy's disease, their families and carers.

Your anonymous comments may also help us raise awareness and influence within our resources, campaigns, and applications for funding.

To give feedback on this booklet, access our online form at:
smartsurvey.co.uk/s/genetic

You can request a paper version of the form or provide direct feedback by email: **infofeedback@mndassociation.org**

Or write to:
Information feedback
Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton NN3 6BJ

Would you like to help with user review of our information?

If you are living with MND or Kennedy's disease, or you are a carer, contact us at: **infofeedback@mndassociation.org**

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Registered Charity no. 294354

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