

# Inherited MND and genetic testing

Guidance for people with  
motor neurone disease (MND)  
and their families





**“Being involved in research gives me a little bit of hope, and something to concentrate on and be positive about.”**

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

# Contents

---

<b>How can this booklet help me?</b>	<b>4</b>
<b>1: What is inherited MND and how could it affect me?</b>	<b>5</b>
<b>2: What happens with genetic counselling?</b>	<b>9</b>
<b>3: How does genetic testing work?</b>	<b>12</b>
<b>4: How can I manage the impact of inherited MND?</b>	<b>15</b>
<b>5: Could a changed gene affect my family and children?</b>	<b>18</b>
<b>6: Are there any options to help start a family?</b>	<b>21</b>
<b>7: What do all the words mean?</b>	<b>24</b>
<b>8: How do I find out more?</b>	<b>26</b>



*Patient Information Forum*

**This content has been evidenced, user tested and reviewed by experts**

<https://piftick.org.uk>

## How can this booklet help me?

You may be worried about a possible family history of 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 or Kennedy's disease.

## How do I download or order your information resources?

To help you explore further, you will see our information resources mentioned throughout this booklet, as relevant to a subject.

Download our resources at: **[www.mndassociation.org/publications](http://www.mndassociation.org/publications)** or contact our MND Connect helpline to order printed copies:

Telephone: **0808 802 6262**

Email: **[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)**



See also section 8 *How do I find out more?* for a list of suggested resources.

## 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: **[www.mndassociation.org/research](http://www.mndassociation.org/research)**

# 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?

Your neurologist may ask about your family's medical history, to work out if an inherited gene may be involved. This could happen during diagnosis or you can ask about this if you want to find out more.

Where there is no evidence of a 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 risk factors can be different for each person, it's not clear how MND starts in these cases.

To help work out if your MND was inherited, medical histories of immediate relatives, such as your parents, brothers and sisters are explored.

Your aunts, uncles and grandparents can also help, where related by blood (but not your partner or partner's family).



**“Another brother got it, then another sister and then I got it too. Once we realised that this was something in our family, it preyed on my mind quite a lot.”**

It may help your health professionals to know 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 discuss all of your options and learn more about MND and how it could affect you and your family.

One of the options would be predictive genetic testing to find out if you have the same changed gene. This is your choice.

If you do choose to be tested and you have **not** inherited the changed gene identified in your family, your risk of getting MND is probably low.

If predictive genetic testing shows that you **have** inherited the changed gene in your family, there is a higher risk of getting MND. 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 cannot diagnose MND, but your genes can be analysed to look for changes in genes known to play a part in the condition.

There are many of these, but the most common changed genes are:



The number of known changed genes is likely to increase, as more changes in genes are discovered that impact on MND.



**“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 and Co-director of 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. We don't yet know all of the gene changes linked to MND and your genetic counsellor may discuss other reasons too.

### Those affected by inherited MND



**Genetic testing can provide an answer**  
(for known faulty genes)



**Genetic testing cannot provide an answer yet**  
(unknown faulty genes)



## 2: What happens with genetic counselling?

It is your choice whether or not to have genetic testing, but you are always advised to have genetic counselling first.

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 choose whether or not to go ahead.



**“It’s a dilemma for a lot of people.”**

You are recommended to take someone with you. What’s covered in each session 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.

With either type of testing, discussion is likely to explore:

- your family history and who else in your family may be at risk
- what to think about with genetic testing, including the advantages and disadvantages of having this done
- what the possible results may be and how this could affect you and your blood relatives
- what’s involved in genetic testing, how long it will take and how you will get the results.



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

## Genetic counselling after an MND diagnosis

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

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



To find out more about diagnostic genetic testing, see: *section 3 How does genetic testing work?*

Genetic counselling for diagnostic genetic testing may be offered by your MND neurologist, but you are usually referred to a clinical genetics service.



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

If you do not have MND, genetic counselling explores how predictive genetic testing works. It can help you find out if you inherited a changed gene previously identified in your family.



To find out more about predictive genetic testing, see: section 3 *How does genetic testing work?*

Genetic counselling is essential before you decide whether to have predictive genetic testing. This usually involves several sessions.

In the UK, genetic counselling for predictive genetic testing happens through referral to your local clinical genetics service. It should be given by specialist genetic counsellors and clinical geneticists.



See *Useful organisations* in section 8, for the Genetic Alliance UK website, with a list of regional clinical genetics services.

### **Example of impact:**

Your grandfather on your mother's side has MND and a test finds a changed gene. You may want to find out if you inherited that changed gene, but your mother may not want to know if she is at risk. Genetic counselling can help with this difficult situation and how your family may be affected if you are tested. Your relatives may need information and support too.

### **Waiting list:**

There may be a waiting list for genetic counselling and predictive genetic testing. If you would like to explore genetic testing now or later, ask your GP or neurologist for more information about referral and how long this might take in your area.

## 3: How does gene 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 does diagnostic gene testing show if I'm living 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 local healthcare provider for guidance.

If you have MND, you can get diagnostic 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:** 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.

## **If I don't have MND but have a family history of the disease, what can predictive testing show?**

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 with a clinical diagnosis of MND has an identified 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 find out 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.

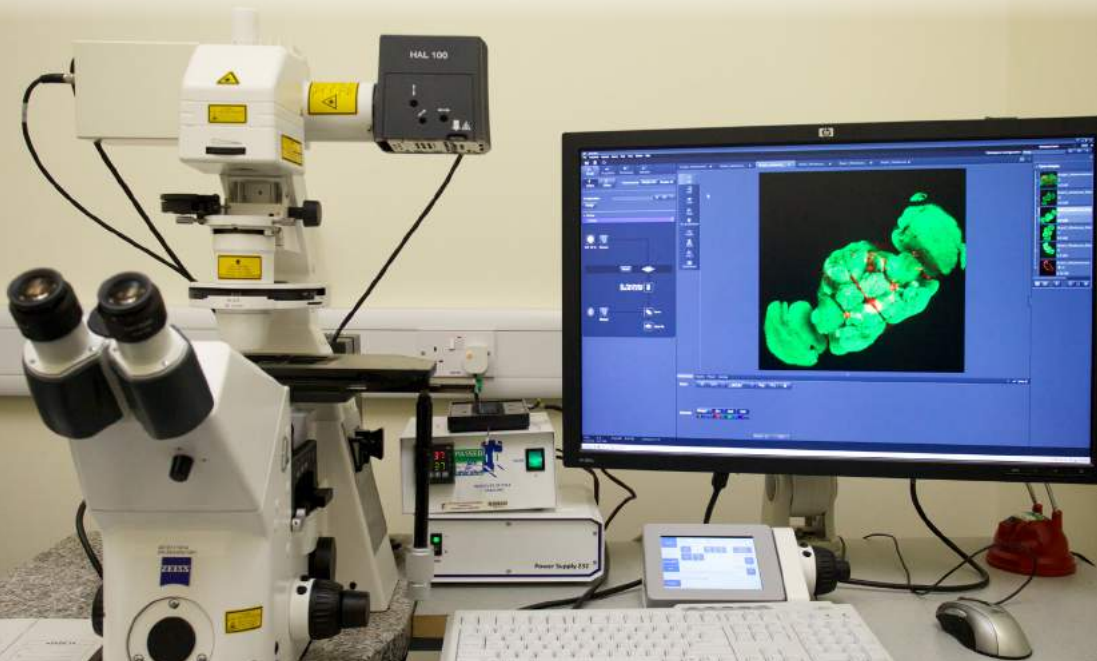
## Does a predictive test predict if I will get MND from a changed gene?

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 that can diagnose MND. You would still need to go through a clinical diagnosis if you showed any symptoms. During a clinical diagnosis, your symptoms are monitored, and a range of assessments and tests 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.



## 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 that the changed gene has passed to your children or that other blood relatives may be affected.

It can feel difficult to explain the risk to family members, especially if they are distant or your relationship is strained.

A genetic counsellor can support in approaching this.

Your health care team can also help you with difficult emotions, such as guilt, anxiety and depression. Often emotions can be mixed, but identifying them can help. Counselling may help you find ways to manage the feelings you are experiencing.

Challenges are to be expected, but emotional support is available. Contact our MND Connect helpline or your GP for guidance on who can support you and your family members.



See our booklet on *Emotional and psychological support* to find out more about relevant therapies that can help.

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 sign of clumsiness, twitching or cramp could be a sign of MND, although this is not usually the case.



## 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.



See section 8 *How do I find out more?* for contact details.

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*, along with guidance about:

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



See section 8 *How do I find out more?* for contact details in *Useful organisations*.



aenaparking.com

Aparca en el aeropuerto.  
El mejor servicio y al mejor precio.

Intimato de las nuevas tarifas en aenaparking.com

Só con tarjeta de en  
Duty with boarding card  
Solo 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.”**

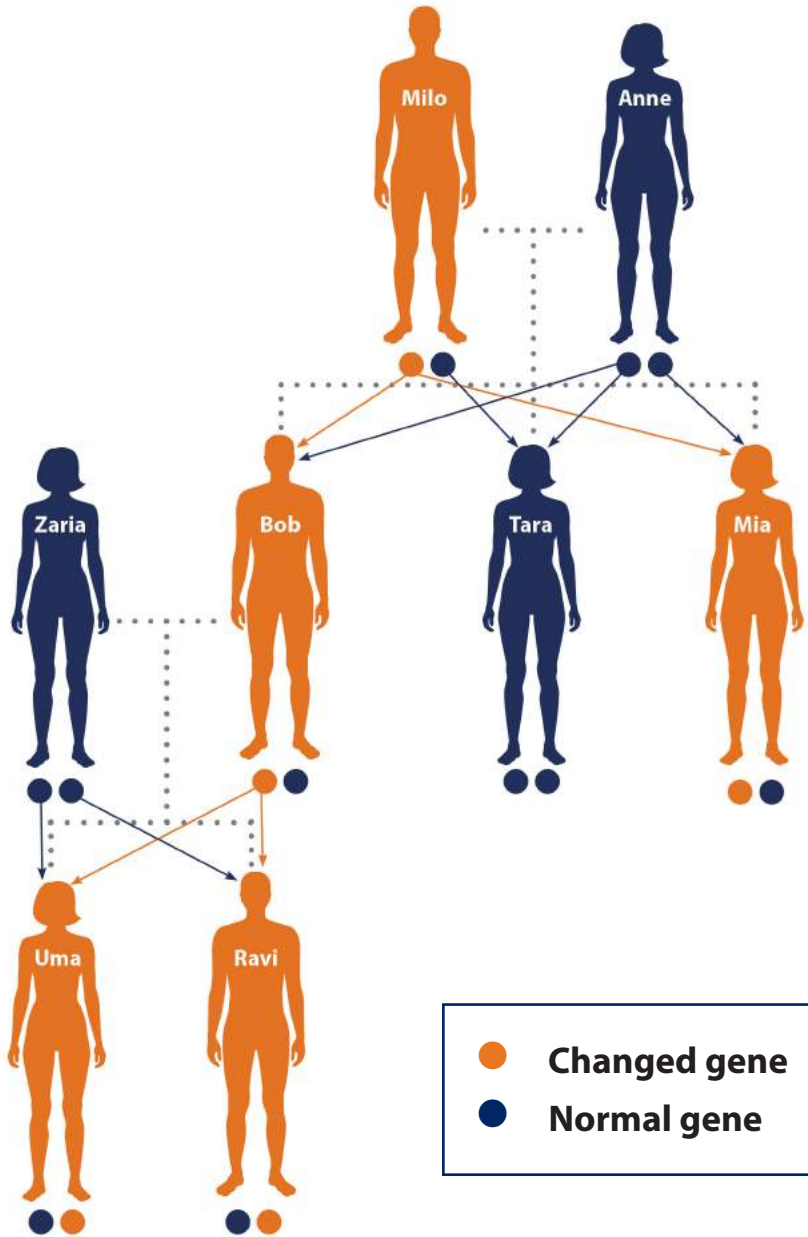
Dr Amina Chaouch, Neurology consultant and co-director of the motor neurone disease care centre, Manchester Centre for Clinical Neurosciences

### 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.



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.

This also applies if the gene in question is linked to frontotemporal dementia (FTD).

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 due to beliefs or ethical views. Ask your GP about referral to your local genetics service, where you can discuss options and your needs with a genetic counsellor.

Find further information about the options covered 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 about adoption and regional adoption agencies
- your GP and your local health and social care team
- your midwife (if already pregnant).



See in section 8 to find contact details for a range of *Useful organisations*.

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 amount of fluid from around the baby.

Both sampling methods carry a small risk of miscarriage.

Only consider PND if you are sure that you would end an affected pregnancy, as it's not possible to have PND simply to find out if your baby carries the changed gene.



This is because PND could risk a miscarriage with an unaffected pregnancy. The result would also go on the child's medical record, removing their choice to be tested as an adult and taking away their right not to know their genetic status.

## Using donor sperm or eggs

Using donor sperm or eggs may be an option if you don't know the changed gene that may be causing MND in your family.

You will need fertility treatment using in vitro fertilisation (IVF) or artificial insemination. Ask your GP or local fertility clinic for guidance.



For guidance on fertility options, visit the Human Fertilisation and Embryology Authority (HFEA) at: **[www.hfea.gov.uk](http://www.hfea.gov.uk)** and use the following search terms as needed:

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

## Adoption

Adoption may help if you don't know the changed gene causing MND in your family or do not wish to use the previous options. You must be aged 21 years or more to adopt, which means taking legal parental responsibility for a child, as an individual or a couple.

You and your partner would 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.

## 7: What do all the words mean?

**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 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):** a technique using in vitro fertilisation, where embryos are tested for a specific gene change and 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?

## Useful organisations

We cannot endorse organisations, but the following may help you search for further information.

Details can change between revisions, but our MND Connect helpline can help you find organisations (see *Further information* later in this section).

### Adopting a child (government guidance)

National guidance on adoption.

England and Wales: [www.gov.uk/child-adoption](http://www.gov.uk/child-adoption)

Northern Ireland: [www.nidirect.gov.uk/articles/adopting-child](http://www.nidirect.gov.uk/articles/adopting-child)

Scotland: [www.mygov.scot/adopting-child-scotland](http://www.mygov.scot/adopting-child-scotland)

### Antenatal Results and Choices (ARC)

Provides information and support around antenatal testing.

Telephone: 020 7713 7486

Email: [info@arc-uk.org](mailto:info@arc-uk.org)

Website: [www.arc-uk.org](http://www.arc-uk.org)

### British Society for Genetic Medicine

Offers a directory of UK regional genetic centres.

Telephone: 0203 925 3675

Email: [membership@bshg.org.uk](mailto:membership@bshg.org.uk)

Website: <https://bsgm.org.uk>

## **Coram BAAF Adoption and Fostering Academy**

Provides information about adoption and fostering in the UK.

Telephone: 0207 520 0300  
Email: [membership@corambaaf.org.uk](mailto:membership@corambaaf.org.uk)  
(for access to their Advice Line)  
Website: <https://corambaaf.org.uk>

## **The Donor Conception Network**

Support for families going through donor conception.

Telephone: 0207 278 2608  
Email: [enquiries@dcnetwork.org](mailto:enquiries@dcnetwork.org)  
Website: <https://dcnetwork.org>

## **First 4 Adoption**

National information service to support adopting a child in England.

Email: through website contact page  
Website: [www.first4adoption.org.uk](http://www.first4adoption.org.uk)

## **Genetic Alliance UK**

An organisation that aims to improve the lives of people affected by a genetic condition. They provide information, including on insurance.

Telephone: 0300 124 0441  
Email: [contactus@geneticalliance.org.uk](mailto:contactus@geneticalliance.org.uk)  
Website: <https://geneticalliance.org.uk>

## **Human Fertilisation and Embryology Authority (HFEA)**

The UK government regulator of fertility treatments with impartial, accurate information about IVF and pregnancy options involving genetic testing, including details for local HFEA licensed fertility clinics. All enquiries must be submitted via email.

Email: [enquiriesteam@hfea.gov.uk](mailto:enquiriesteam@hfea.gov.uk)  
Website: [www.hfea.gov.uk](http://www.hfea.gov.uk)

## **LGBT Mummies**

Support and information for LGBT+ people on ways to have a child.

Email: [contact@lgbtmummies.com](mailto:contact@lgbtmummies.com)

Website: <https://lgbtmummies.com>

## **Mind**

Support about mental health and how to find a local therapist.

Telephone: 0300 123 3393

Email: [info@mind.org.uk](mailto:info@mind.org.uk)

Website: [www.mind.org.uk](http://www.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: [www.adoptcymru.com](http://www.adoptcymru.com)

## **Surrogacy UK**

Support when looking to start a family through surrogacy. They also help to connect surrogates and intended parents.

Email: through the website contact page

Website: <https://surrogacyuk.org>

Find a list of our MND care centres and networks, where research trials are often held, at: [www.mndassociation.org/carecentres](http://www.mndassociation.org/carecentres)



## References

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

Or write to:

Information feedback  
MND Association  
Francis Crick House  
6 Summerhouse Rd  
Moulton Park  
Northampton  
NN3 6BJ

## Acknowledgments

Our thanks to the following, for independent expert review:

Dr Amina Chaouch, Neurology Consultant and Co-director of the Motor Neurone Disease Care Centre, Manchester Centre for Clinical Neurosciences, Salford Royal NHS Foundation Trust, Salford

Dr Andrew G. L. Douglas, Consultant in Clinical Genetics, Oxford Centre for Genomic Medicine, Nuffield Orthopaedic Centre, Oxford

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)



## Further information

Download our resources at: [www.mndassociation.org/publications](http://www.mndassociation.org/publications)  
Order printed copies from our MND Connect helpline (see next page).

### Resources relevant to this booklet:

*Telling other people about MND* – ways to communicate about the condition with family, friends, colleagues and professionals.

*Emotional and psychological support* – types of support.

*Changes to thinking and behaviour with MND* - how thinking and behaviour may be affected for some people with MND.

*What you should expect from your care* – a pocket guide to help guide discussions at appointments, about your care needs.

*Living with motor neurone disease* – guidance to help manage MND.

*Caring and MND: support for you* – to help the wellbeing of unpaid or family carers who support someone living with MND.

Our *Care information finder* helps you search by need, grouping together all resources on selected topics. Access the finder at:  
[www.mndassociation.org/careinfinder](http://www.mndassociation.org/careinfinder)

We provide introductory information in languages other than English. Contact MND Connect as shown in this section or ask someone to contact them on your behalf. Find out more at:  
[www.mndassociation.org/languages](http://www.mndassociation.org/languages)

Find our information for health and social care professionals at:  
[www.mndassociation.org/professionals](http://www.mndassociation.org/professionals)

## **Our services**

### **MND Connect**

Our helpline team can provide emotional support, guidance and information. They can help you search for other organisations, our local branches, groups and volunteers, and explain our services and grants for people with and affected by MND or Kennedy's disease.

Telephone: **0808 802 6262**

Email: **[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)**

### **Benefits Advice Service**

The MND Association Benefits Advice Service can help you identify available benefits and how to claim them. Find details at:

**[www.mndassociation.org/benefitsadvice](http://www.mndassociation.org/benefitsadvice)** for England, Wales and Northern Ireland, or contact our MND Connect helpline for guidance.

### **Equipment loans and MND support grants**

If statutory funding is not available or delayed, we may be able to provide a grant or certain equipment on loan. Grants may be given to help with care or quality of life, for people with MND or Kennedy's disease, their carers and younger members of the family. Applications for some grants and equipment loans must be made by a relevant health or social care professional.

Telephone: **0808 802 6262**

Email: **[support.services@mndassociation.org](mailto:support.services@mndassociation.org)**

Website: **[www.mndassociation.org/support-and-information](http://www.mndassociation.org/support-and-information)**

### **Communication Aids Service**

Contact our service with queries about communication aids. We also provide some financial support. Certain items can be loaned if unavailable or delayed through health and social care services.

Telephone: **0808 802 6262**

Email: **[communicationaids@mndassociation.org](mailto:communicationaids@mndassociation.org)**

## Local and regional support

To find out our contacts in your area, go to [www.mndassociation.org/local-support](http://www.mndassociation.org/local-support) or ask MND Connect as shown in this section. Local support may include:

**Regional staff:** with knowledge about the management and care of people with MND. They can work with volunteers and families affected by MND or help to influence local service providers. Their aim is to help ensure care and support is made available at the right time.

**Association visitors (AVs):** our trained volunteers, who provide information and guidance about MND and local services by phone, email or home visits. Contact MND Connect to find out if there is an AV near you.



**“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 you would with one of the family.”**

**Branches and groups:** are volunteer-led and provide local support, practical help and an opportunity to get together with others living with or affected by MND.

## MND Association website

Find support and information about membership, fundraising, campaigning, research and news at: [www.mndassociation.org](http://www.mndassociation.org)

## MND Association online forum

Our online forum is a safe place to share experiences with other people living with or affected by MND. You can just view if you wish or join the online chats. You can access the forum at:

<https://forum.mndassociation.org>

## **We welcome your views**

Let us know what you think of this booklet. We'd love to hear what you feel we did well and how we can improve this content for people with or affected by MND or Kennedy's disease.

Your anonymous comments may also be used to support and influence, as they help us share real MND experiences and raise awareness in our resources, campaigns and applications for funding.

Please use our online feedback form at:  
**[www.smartsurvey.co.uk/s/genetic](http://www.smartsurvey.co.uk/s/genetic)**

Email your comments to: **[infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)**

or write to:

Information feedback  
MND Association  
Francis Crick House  
6 Summerhouse Rd  
Moulton Park  
Northampton  
NN3 6BJ

**“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.”**

Created: April 2024  
Next review: April 2027  
Version: 1

Registered charity No. 294354  
Company limited by  
Guarantee No. 2007023  
© MND Association 2023





