

Inherited MND: Options when starting a family

Information Sheet B3

This publication gives information about the options available for those who have a confirmed inherited form of motor neurone disease (MND) and are wishing to start a family but do not want to pass on the risk of developing MND to their children. This information sheet has been written to explain the range of options available and their implications.

This information sheet is **part three** of our information on inherited MND.

- **Part one** of this information sheet looks at how MND can be inherited and the importance of taking a full family history.
- **Part two** looks at genetic testing and how a diagnosis of inherited MND can affect insurance.

The content is split into the following sections:

- 1: Introduction**
- 2: Pre-implantation genetic diagnosis (PGD)**
- 3: Pre-natal diagnosis (PND)**
- 4: Using sperm or eggs from a donor**
- 5: Adoption**
- 6: Comparison table**
- 7: Care and support**
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Disclaimer: *Please note that information provided in this information sheet is based on a review of the currently available literature. This information sheet was written by MND Association staff who are not clinicians, so any information provided in this sheet should not be considered clinical advice. You should always discuss potential treatments with your clinician.*



This symbol is used to highlight **our other publications**. To find out how to access these, see *Further information* at the end of this sheet.

What do the words and abbreviations mean?

Amniocentesis	An invasive procedure using a needle to take a sample of the amniotic fluid.
Chorionic villous sampling (CVS)	An invasive procedure using a needle to take a sample of the placenta.
In vitro fertilisation (IVF)	A procedure during which an egg is fertilised by sperm outside of the body.
Pre-implantation genetic diagnosis (PGD)	A technique using in-vitro fertilisation to ensure only embryos without the faulty gene are placed in the womb
Pre-natal diagnosis (PND)	A procedure during pregnancy in which a sample is taken from the placenta or amniotic fluid to test the baby for an MND-causing gene.

1: Introduction

Around 10% of people with MND have a family history of the disease. This form of MND is known as familial, or inherited, MND. Inherited MND is caused by a mistake in the genetic code that holds the instructions for making every protein in our bodies; this mistake may be passed down from one generation to the next.

If you have a family history of MND (two or more 'blood relatives'), or a family history of a type of dementia known as frontotemporal dementia (FTD), then you may be at risk of developing MND and passing the MND-causing gene on to your children.

Whether or not an MND-causing gene has been identified in you or your family, there are several different options available for those wishing to start a family, which are explained in this information sheet.

We acknowledge that some of these choices may not be an option for everyone due to individual beliefs and ethical views. Therefore, it may be useful to talk over these options with a genetic counsellor. If you need additional mental health support, it may also be useful to talk to a therapist.

Is there any way to prevent MND being passed on to our baby?

The options open to you depend on your individual circumstances. For example, if you know which gene is causing MND in your family, it may be possible to test for it using pre-implantation genetic diagnosis (PGD) or pre-natal diagnosis (PND). These are tests which look for a particular gene defect which has been identified as causing MND in your family.

If you do not know the gene defect that is causing MND in your family, but wish to have children, you may want to consider using sperm or eggs from a donor or adoption.

Each of these options will be discussed in this information sheet, providing information in order for you to consider which may be the best option for you.

2: Pre-implantation genetic diagnosis (PGD)

If you know which gene defect is causing MND in your family, it may be possible to undergo a technique called pre-implantation genetic diagnosis (PGD).

PGD is a special type of in vitro fertilisation (IVF) which aims to avoid passing on a genetic condition, like MND, to a child. In PGD, embryos are created outside the body. They are genetically tested for MND and only embryos which are not affected are placed into the womb.

Is PGD possible for all prospective parents who are at risk of passing on MND to their child?

PGD will not be an option for everyone. For PGD to take place the faulty gene that is causing MND in your family must be known. This gives rise to a number of issues; for example, if the MND is caused by a faulty gene that is yet to be identified then it will not be possible to develop a test, and therefore PGD will not be possible.

PGD can be a lengthy process (around 9 - 12 months before the start of treatment), and for this reason there are age restrictions for those wishing to go ahead. In all cases prospective parents may be eligible for treatment on the NHS if, at the time of being referred for PGD, the prospective gestational parent is under 40 years old. This age limit is set because the success of PGD decreases significantly with age. However, in some cases, the age limit may be lower if it is a new form of MND that has not been tested before (e.g., a new gene). This is because it takes longer to prepare PGD for such prospective parents.

For each first case of this nature an application for a licence needs to be approved by the Human Fertilisation and Embryology Authority (HFEA) before PGD can take place. Furthermore, once a licence has been issued, a new test needs to be developed which is specific to that gene.

Licences are currently approved for MND caused by mutations in several genes. You can find out which on the HFEA website (contact details in 'How do I find out more?' section).

Will I need to find out my carrier status?

The implications of finding out for sure whether or not you have inherited the faulty gene are significant, and for this reason many people choose not to do so. Most people going through PGD have had a test and know that they have the MND causing-gene. This type of PGD is called '**direct testing PGD**'.

However, it may be possible for you to go ahead with PGD without finding out whether you have inherited the faulty gene, provided other family members have been tested for the faulty MND gene and been found to carry it. This is called '**non-disclosure PGD**'.

If your parent has MND and has been tested, and the gene defect has been identified, PGD may still be possible. If there are cases of MND in your family and, if you or the at-risk person does not wish to know their carrier status, PGD may be possible by means of non-disclosure testing. This means that the at-risk person will be tested for the known MND mutation but won't be told the result. The IVF process then begins. If the at-risk person's test was positive, the embryos are tested for MND and only those without the mutation are placed into the prospective gestational person's womb. If there are no mutation-free embryos, the cycle stops there. The couple are told that the process failed but not why. IVF can fail for many reasons, so a failure to get pregnant can't be interpreted to mean that the at-risk person has the MND gene.

First steps

The first step will be to speak to your GP, who will make referrals to your local genetic service. It is important to note that some PGD centres only accept referrals from genetic centres.

For further information and to download an information sheet on PGD, please see the Genetic Alliance UK and HFEA resource (find the link in the 'How do I find out more?' section).

3: Pre-natal diagnosis (PND)

If you know which gene defect is causing MND in your family, it may be possible to undergo a process called pre-natal diagnosis (PND) during pregnancy to see whether the developing baby is carrying the MND-causing gene. This test involves one of the following procedures:

Chorionic villous sampling (CVS)

This test can be taken between 11-14 weeks of pregnancy. A needle is passed through the abdomen (or very occasionally via the cervix) to take a tiny sample of placental tissue which is then tested for the MND-causing gene. This test carries a risk of miscarriage in about 1 in 100 pregnancies.

Amniocentesis

This test is carried out between 15-20 weeks of pregnancy. A needle is passed through the abdomen to collect a sample of the amniotic fluid surrounding the baby. This test carries a risk of miscarriage in about 1 in 100 pregnancies.

Deciding whether to test an unborn baby is a difficult decision. It is important to understand that PND for motor neurone disease can only be performed when the couple feel sure they would terminate the pregnancy if the baby is found to be carrying the faulty gene. Importantly, the decision must be made beforehand because testing a pregnancy but not going ahead with a termination after a positive test result would take away the child's right to choose whether to have the genetic test later in life.

Is PND possible for all prospective parents who are at risk of passing on MND to their child?

PND will not be an option for everyone. For PND to take place the gene defect that is causing MND in your family must be known. If the MND is caused by a faulty gene that is yet to be identified, then it will not be possible to develop a test for it.

It is best to speak with a genetic centre about testing before you become pregnant, so you can make sure a test, and PND, would be available to you. PND is not a lengthy process and for this reason there are no age restrictions for those wishing to go ahead with it. As the test is done after conception has occurred, the only requirement is that the faulty gene in the family has been identified so the foetus can be tested.

Will I need to find out my carrier status?

It may be possible for you to go ahead with PND without finding out whether you have inherited the faulty gene by means of exclusion testing, provided other family members have been tested for the faulty MND gene and been found to carry it.

DNA samples are taken from the at-risk person, at least one of their parents and their partner. DNA is also collected from the unborn baby by CVS. Testing the baby's DNA directly for the MND-causing gene can't be done, because if the test were positive, it would mean that the at-risk parent must have the MND-causing gene too - and we want to avoid knowing that. So instead of doing the genetic test directly, exclusion testing looks at the chromosome in which the faulty gene is found in all the DNA samples, without looking at the gene, and finds out whether the baby has inherited a copy of that chromosome from the grandparent with MND - this means the baby has a 50% chance of having inherited the faulty gene. If it has inherited that chromosome, the pregnancy would be classified as high risk and a termination would be offered. The problem with exclusion testing is that there is as much chance of terminating an unaffected pregnancy as an affected one as giving any more certainty would require testing the at-risk parent for the mutation. Exclusion testing makes it really important to

consider all the possible outcomes.

How much does PND cost?

PND is available on the NHS without any special need to apply for funding. PND testing is usually arranged through your regional genetics service.

First steps

The first step will be to speak to your GP, who will make referrals to your local genetics service.

4: Using sperm or eggs from a donor

If you do not know which gene is responsible for causing MND in your family, or do not want to risk passing on the MND-causing gene to your child, you may wish to consider using sperm or eggs from a donor.

Is using donor sperm or eggs possible for all prospective parents who are at risk of passing on MND to their child?

Using sperm or eggs from a donor might be an option, whether the faulty gene in your family has been identified or not. However, it is a very personal decision and may not be suitable for everyone.

If a sperm and/or egg donor is used, some form of fertility assistance will be required. This could be by IVF, artificial insemination, or surrogacy. In all cases, the first thing to do is to contact your GP or local fertility clinic. They will be able to advise you which options are available in your situation.

There are several different organisations and charities which can support you along your journey to have a family. Go to the 'How do I find out more?' section of this information sheet for further information and contact details. In this section you will also find the HFEA website which provides detailed information on the different fertility options.

How much does using sperm or eggs from a donor cost?

If you decide to use donor eggs or sperm through either IVF or artificial insemination, you may be eligible for funding through the NHS. You would need to make an application for funding through your local funding body. Self-funding is an option. IVF costs in the region of £5,000 for one cycle but could be more depending on the clinic used. Artificial insemination costs in the region of £700 to £1,600 for one cycle.

If you are thinking about having a baby using donor sperm, eggs or both, the best thing to do is contact your GP who will be able to find out what NHS funding is available in your local area and if you are eligible.

If you are looking to have a child through a surrogacy agreement, this is not available on the NHS. You cannot pay a surrogate in the UK, however the intended parent(s) would be responsible for reimbursing for reasonable expenses, such as maternity clothes and loss of earnings. The intended parent(s) would also have to pay for the cost of the clinic treatment too, and the costs would vary depending on whether IVF or artificial insemination is used.

Deciding to have a child with the help of a donor is a difficult decision but avoids the need to consider termination of a pregnancy. It can be done for people who have had a predictive test, as well as those at risk who don't want to be tested themselves. Prospective parents should be aware that pregnancy success with IVF and artificial insemination is not guaranteed.

The HFEA website has a list of fertility clinics along with their success rates. If you are investigating clinics for treatment you should ask if they are accredited centres, how many cycles they have done, and what their accuracy rate and success of treatment are.

Will I need to find out my carrier status?

No. Prospective parents can use sperm or eggs from a donor without knowing their carrier status as the gene defect does not need to be known.

Should I tell my child about their origins?

Evidence from experiences of adoption and studies of donor-conceived people suggests that it is best to tell someone about their origins in childhood as finding out later in life may be emotionally damaging. Being open with your child from an early age is important and it is advisable to explore this issue thoroughly before proceeding so that you have a good understanding of the implications of creating a family using a donor.

If you have received treatment at an HFEA licensed clinic, you can contact the HFEA to find out information about the donor.

First steps

The first step will be to speak to your GP and local fertility clinic.

For further information on using donated sperm and eggs please see the Donor Conception Network and HFEA resource (find the link in the 'How do I find out more?' section).

5: Adoption

If you do not know which gene defect is responsible for causing MND in your family, or if you do not fit the criteria/cannot afford the previous options or find them unacceptable, then you may prefer to consider adoption.

Adoption is a legal procedure in which all the parental responsibility is transferred to the individual or couple who have adopted the child.

Is adoption possible for everyone who is at risk of passing on MND to their child?

Adoption will not be an option for everybody; however, it is an alternative if you do not want to undergo genetic testing or do not know the faulty gene causing MND in your family.

Adoption is a service designed to find loving and secure families for children who are unable to be cared for by their birth families. When considering adoption, it is important to learn more about the process and the children who need a new family through adoption. Information can be obtained from the agencies listed at the end of this information sheet.

Adoption agencies hold information and preparation sessions where these topics can be explored. Following an application to adopt, a full assessment is carried out on all applicants to determine their suitability to adopt, and this includes a comprehensive health assessment.

The assessment process typically takes at least 6 months, while the social workers get to know you and understand what you have to offer as parents. You must be over the age of 21 and there is no upper age limit. At the end of the assessment period, an adoption panel will hear all about you and make a recommendation to the agency about your suitability to adopt.

The **Coram BAAF Adoption and Fostering Academy** state that although "health issues will need to be explored prior to adoption, health problems and disabilities are not barriers to adoption, provided you can care for the child you adopt".

Each applicant is considered on an individual basis, which involves completion of a health form and a comprehensive assessment by their GP, with a report sent to the adoption agency's medical adviser. Further information may be requested from relevant consultants with your consent, for example a clinical geneticist, in order to assess current and potential future risks to your health. Any concerns about your health will need to be explored with your social worker, to see how you might manage different possible scenarios and how these might impact on parenting. If you have had experience of MND in your family, then this may give you added strengths that the adoption agency and panel will also consider, such as coping with grief, care, life experiences, commitment and flexibility in responding to needs. During the assessment process you will also have opportunities to consider the age and characteristics of the child/children you are best suited to parent.

It is important to provide information to the adoption agency so that they understand that a family history of MND, whether or not the MND-causing gene has been identified, only increases your risk of developing MND, and you may or may not develop it in the future.

It is also important to know that when applying as a couple, if there are concerns about the health of the at-risk partner then the adoption panel will take into consideration the health and motivation of the other partner before making a decision.

Children who are being placed for adoption will have experienced loss, and may have experienced inadequate parenting, neglect and/or abuse so you would need to be aware of this and consider how best to meet the needs of that individual child.

It may also take a long time for the right child to become available, particularly if you want to adopt a younger child or a baby.

How much does adoption cost?

Adoption is free, although some agencies expect applicants to pay for the required health assessment. As the fee for this is set by their GP, it can be up to £200.

Will I need to find out my carrier status?

No, you can go ahead with your application to adopt without knowing your carrier status. If the gene causing MND in your family has been identified, you may need to discuss your reasons for not wanting a genetic test with your social worker. If the gene causing MND in your family has not yet been identified, then you will be unable to find out your carrier status.

How do I tell my child they are adopted?

This can be a challenging topic but being open with your child from an early age is important. Coram BAAF has produced a booklet called 'Talking about adoption' which aims to prepare and support parents when telling their child about their origins.

First steps

The first step will be to speak to your local adoption agency, which can be found using this website: www.corambaaf.org.uk/agencies. For more detailed information about the adoption process in your part of the UK, the following organisations can help:

England: www.first4adoption.org.uk
Wales: www.adoptcymru.com
N. Ireland: www.adoptionandfostering.hscni.net
Scotland: www.scottishadoption.org

For further information on adoption, see the Coram BAAF resource (find the link in the 'How do I find out more?' section).

6: Comparison table

The choices available for prospective parents when starting a family are compared in the table below so that you can quickly see which options may be most suitable for you. For example, if the prospective gestational parent is over the age of 40 then PGD may not be an option, but PND and adoption will be.

If you do not know which gene is causing MND in your family, as it has not yet been identified through research, or you have not undergone genetic testing, then PGD and PND may not be an option, but using donated eggs and sperm and adoption will be.

	PGD	PND	Using a donor	Adoption
Will I need to know which gene is causing MND in my family?	Yes	Yes	No	No
Will I need to know my carrier status?	Yes*	Yes*	No	No ⁺
How much does it cost (private treatment)?**	~£10,000	Free	~£5,000 per IVF cycle; £700-£1,600 per artificial insemination cycle	Up to £200 health assessment fee
Is there an age limit?	<40 years (prospective gestational parent)	No	<40 years (prospective gestational parent for IVF)	>21 years
Will my child be biologically mine?	Yes	Yes	No	No
How long does it take?	Can be lengthy, depends on funding	Up to 20 minutes for procedure + 2-3 weeks for results	Can be lengthy, depends on funding	>6 months

* It may be possible to go ahead with PGD/PND without knowing your carrier status by means of exclusion testing.

** Correct at time of publishing

+ If the gene causing MND in your family has not been identified through research, then you will not know your carrier status. If the gene has been identified, then you may need to know your carrier status when undergoing a full health assessment.

7: Care and support

The care required by someone with inherited MND is no different to a person who has the non-inherited form of the disease, and the MND Association has a range of services available to help. You can speak to your GP, local fertility clinic or adoption agency regarding the choices available when starting a family. Referral to a neurologist who understands the particular needs of people with inherited MND may be helpful.

I would like to know more about genetic testing

If you have MND and would like to know which gene is responsible for causing the disease in your family, you may be able to have a genetic test. This will allow you to know if you have a disease-causing gene that has been shown by research to cause inherited MND.

Once a gene defect has been identified your unaffected family members may wish to be

tested to see if they too have the gene responsible for causing MND in your family.

A family history of inherited MND could affect life and travel insurance, which may be something that worries you and your family. It is important to know that there is a great deal of information and support available regarding this topic.



For more information on inherited MND, see Information sheet: B1 - Introduction to inherited motor neurone disease.



For more information about insurance, see Information sheet: B2 - Genetic testing and insurance.

8: How do I find out more?

Useful organisations

We do not necessarily endorse any of the following organisations but have included them to help you begin your search for further information.

The contact details are correct at the time of publishing but may change between revisions. If you need help to find an organisation, contact the Research Development Team (see *Further information* at the end of this sheet for details).

Genetic Alliance UK

The Genetic Alliance UK is an organisation that aims to improve the lives of people affected by a genetic condition. They have a number of leaflets and documents under the 'Information Centre' tab on their website, including one on insurance.

Address: 3rd Floor, 86-90 Paul Street, London, EC2A 4NE

Email: contactus@geneticalliance.org.uk

Telephone: 0207 831 0883

Website: www.geneticalliance.org.uk

British Society for Genetic Medicine

Has a directory of UK regional genetic centres so that you can find your local centre.

Address: 1 Naoroji Street, Islington, London, WC1X 0GB

Email: membership@bsgm.org.uk

Telephone: 0203 925 3675

Website: www.bsgm.org.uk

Human Fertilisation and Embryology Authority (HFEA)

Has a large amount of information on PGD, IVF and using sperm or eggs from a donor, as well as a list of the genes PGD is currently approved for testing, as well as those awaiting consideration. They can also provide details for local HFEA approved fertility clinics. They do not provide information over the phone, all enquiries **must be** submitted via email.

Address: 10 Spring Gardens, London, SW1A 2BU
Email: enquiriesteam@hfea.gov.uk
Telephone: 0207 291 8200
Website: www.hfea.gov.uk

Antenatal Results and Choices (ARC)

Provides non-directive information and support around antenatal testing and its consequences.

Address: 12-15 Crawford Mews, York Street, London, W1H 1LX
Email: info@arc-uk.org
Telephone: 0207 713 7486 - Monday-Friday, 10.00am-5.30pm
Website: www.arc-uk.org

CoramBAAF Adoption and Fostering Academy

Provides information about adoption and fostering throughout the UK, and the criteria and assessment procedure. They produce a range of information booklets and can provide you with details of your local adoption agency.

Address: Coram Campus, 41 Brunswick Square, London, WC1N 1AZ
Email: advice@corambaaf.org.uk
Telephone: 0207 520 0300 or Advice Line 0300 222 5775 (Mon-Fri, 9am-1pm)
Website: www.corambaaf.org.uk

The Donor Conception Network

Aims to support families through donor conception. They have information and personal stories of donor conception and produce a number of information booklets.

Address: 154 Caledonian Road, London, N1 9RD
Email: enquiries@dcnetwork.org
Telephone: 0207 278 2608
Website: www.dcnetwork.org

Surrogacy UK

Aims to support those who are looking to start a family through surrogacy. They also help to connect surrogates and intended parents.

Website: www.surrogacyuk.org

LGBT Mummies

Aims to support LGBT+ women and people globally who are on the path to motherhood or parenthood. They provide guidance on the different ways to have a child.

Address: 3rd Floor, 207 Regent Street, London, England, W1B 3HH
Email: contact@lgbtmummies.com
Website: www.lgbtmummies.com/

Two Dads UK

Aims to support those on a journey to become parents via surrogacy. They also campaign to help all who are own their own route to parenthood or fertility journey.

Address: Church Court, Stourbridge Road, Halesowen, West Midlands, B63 3TT
Email: contact@twodadsuk.com
Website: www.twodadsuk.com/

mind

Aims to support those experiencing a mental health problem or someone who requires some additional mental health support. They can also provide information on how to find a local therapist.

Address: 2 Redman Place, London, E20 1JQ
Telephone: 0300 123 3393
Email: info@mind.org.uk
Website: www.mind.org.uk/

Acknowledgements

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Further information

You may find these information sheets from the MND Association helpful:

B1 – *Introduction to inherited MND*

B2 – *Inherited MND: Genetic testing and insurance*

We also provide the following guides:

Living with motor neurone disease – our main guide to help you manage the impact of the disease

Caring and MND: support for you – comprehensive information for unpaid or family carers, who support someone living with MND

Caring and MND: quick guide – the summary version of our information for carers

You can download most of our publications from our website at www.mndassociation.org/publications or order in print from the MND Connect helpline, who can provide further information and support.

MND Connect can also help locate external services and providers, and introduce you to our available services, including your local branch, group, Association visitor or service development manager.



MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

Research Development Team

Telephone: 01604 611 880

Email: research@mndassociation.org

MND Association website and online forum

Website: www.mndassociation.org

Online forum: forum.mndassociation.org or through the website

We welcome your views

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them. If you would like to provide feedback on any of our information sheets, you can access an online form at: www.surveymonkey.co.uk/r/infosheets_research

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