



Huntington's  
Disease  
Association



**Starting a family**

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## Starting a family

If you are at risk of Huntington's disease, you may want to have a conversation about your family planning options with a genetic counsellor. It's really helpful to talk about these options well before you plan to start a family, whenever that might be.

While many individuals at risk of Huntington's disease generally don't alter their family planning choices because of it, some may explore specific options that allow them to have a child who is not at risk of Huntington's disease.





# Preimplantation Genetic testing (PGT -M)

PGT-M (formerly known as pre-implantation genetic diagnosis - PGD) uses In vitro fertilisation (IVF); a procedure where a woman's ovaries are stimulated with medications to enhance egg production, the eggs are removed from the ovaries and then fertilised with sperm to create embryos which can then be re-implanted into the woman's womb to hopefully achieve a successful pregnancy.

For genetic conditions like Huntington's disease which are caused by a single gene or are 'monogenic' PGT-M can be undertaken alongside IVF. In the case of PGT-M, after the fertilised embryos have developed for a few days, one or two cells are removed from each one. Genetic testing can be carried out on the embryos and only unaffected embryos would then be available for transfer. If the pregnancy is successful, the baby will not be at risk of the condition.

Whilst PGT-M is a very good option for many couples, like all IVF, it is a physically and emotionally demanding process and it may not result in a successful pregnancy. Unlike IVF, only a few clinics are licenced to carry it out.

The NHS in England will fund up to three cycles of PGT-M until there is a successful pregnancy but people have to meet certain eligibility criteria in order to be eligible for NHS treatment and the waiting times can be long. However, this can depend on where you live in England.





In Wales, it is up to two cycles. However, this needs to be applied for. This will be arranged for you.

More information about clinics, PGT-M and other assisted conception techniques can be found by visiting the Human Fertilisation and Embryology Authority website at: [www.hfea.gov.uk](http://www.hfea.gov.uk)

Information can also be found on the Genetic Alliance UK website at: [www.geneticalliance.org.uk](http://www.geneticalliance.org.uk)



# Prenatal Testing

Another option is to conceive naturally and consider a test called prenatal diagnosis (PND). Prenatal testing can be performed early in pregnancy, starting from around 11 weeks. It is conducted using a needle inserted through the pregnant woman's abdomen into the placenta (Chorionic villus sampling, CVS) or the fluid surrounding the fetus (Amniocentesis) to collect a sample of DNA that matches the developing fetus. Genetic testing on this sample can determine if the fetus has inherited a CAG repeat expansion. Results typically return within a couple of weeks. In most cases, this test is only conducted if the individual would consider ending the pregnancy if the fetus is found to be at risk of Huntington's disease. This is because the test is a predictive test on the fetus, and predictive testing is generally only carried out once you reach 18. Otherwise, a child would grow up knowing their status.

Individuals with predictive testing indicating they carry an expanded copy of the HTT gene may consider both PGT-M and Prenatal testing. These options might also be relevant for those who opted against predictive testing, a process known as exclusion testing. Although exclusion testing is not suitable or feasible for everyone, it can be explored with a genetics team.





## Alternative options

Other options would include the use of donated eggs, sperm or embryos. This would result in a pregnancy that is not genetically related to the parent with the CAG repeat expansion.

Adopting a child is another option that somebody with Huntington's may choose. Various organisations can help match somebody who wants to adopt with the right child for them. These include local authorities, as well as charities. The adoption process can be long and is not without its challenges, but some people may decide it is the best option for them.

When someone is at risk of Huntington's disease or is showing symptoms, the agency will consider the implications for the child, the person's health, and their ability to care for a child. It is crucial to think carefully about whether a person at risk of Huntington's disease would be able to take on the responsibility of adopting a child.

More information about adoption is available from Adoption UK at: [www.adoptionuk.org](http://www.adoptionuk.org)





# Support from the Huntington's Disease Association

## Specialist Huntington's Disease Advisers (SHDAs)

Our Specialist Huntington's Disease Advisers have a background in health or social care and are knowledgeable about Huntington's disease. They operate throughout England and Wales and support the person with Huntington's, their carers and any professionals involved in their care. To get in touch with your local Huntington's Disease Adviser, contact us at: **0151 331 5444** or **info@hda.org.uk**



## Specialist Huntington's Disease Youth Engagement Service (HDYES)



At the Huntington's Disease Association, we have a Youth Engagement Service (HDYES) operated by youth workers who work with young people whose families are affected by Huntington's. This confidential service is for anyone aged 8-25 living in a family affected by the disease. To get in touch with your local Specialist Youth Adviser, contact us at: **0151 331 5444** or **info@hda.org.uk**

## Website

Our website offers practical advice and sources of help and support, it has pages on genetics and starting a family. It also holds information about events and activities that you can attend and details of local branches and support groups.





Additionally, the website hosts an online message board for people to access peer support, information and advice. **[www.hda.org.uk](http://www.hda.org.uk)**  
**[hdmessageboard.com](http://hdmessageboard.com)**



### **Mailing list**

We send out monthly newsletters and keep people updated about events, news and research via email. You can join our mailing list via the website.

**<https://www.hda.org.uk/information-and-support/keep-up-to-date/>**



# Resource Library

The following charities, organisations and public bodies have been mentioned throughout this guide. Their details have been summarised and grouped below for easy reference.

Organisation	Contact details	Support
<b>Huntington's Disease Association</b>	0151 331 5444  info@hda.org.uk  www.hda.org.uk	Advice, support resources, online resources, advice
<b>Huntington's Disease Youth Organisation (HDYO)</b>	info@hdyo.org  en.hdyo.org	Advice, support resources, online forum
<b>NHS - GP finder tool</b>	www.nhs.uk/service-search/find-a-gp	Advice referrals
<b>Human Fertilisation and Embryology Authority</b>	www.geneticalliance.org.uk	Information about PGT-M and assisted fertility techniques
<b>Adoption UK</b>	www.adoptionuk.org	Information about adoption
<b>HD Buzz</b>	https://en.hdbuzz.net/036	Making babies: having a family, the HD way



# Glossary

The decision to start a family is a difficult one. To help understand some of the key terms within this guide, we've put together this glossary:

PGT-M	Stands for Preimplantation Genetic Testing for Monogenic (single gene) disorders. It is a test that focuses on discovering gene mutations that cause diseases like Huntington's. This term replaces PGD.
PGD	Stands for Preimplantation Genetic Diagnosis. It is the former name given to the PGT-M process.
IVF	Stands for In Vitro Fertilisation. This is a fertility procedure wherein eggs are fertilised in a laboratory.
PND	Stands for Prenatal Diagnosis. This is a test performed on a developing fetus that helps to determine whether there are any underlying health issues.
CVS	Stands for Chorionic Villus Sampling. This is a prenatal test that involves taking a small sample from the placenta to help determine whether there are any underlying health issues affecting a developing fetus.
Amniocentesis	This is a prenatal test that involves taking a small sample of the amniotic fluid found within the uterus. It helps to determine whether there are any underlying health issues affecting a developing fetus.
HTT	This is the Huntingtin gene.
CAG	Is a term given to a specific DNA sequence: Cytosine, Adenine and Guanine.
DNA	Stands for Deoxyribonucleic Acid. This is the molecule that holds the genetic instructions that make up all living organisms.

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## Get in touch

For advice and support or  
to speak to a Specialist  
Huntington's Disease  
Adviser

Email: **info@hda.org.uk**

Phone: **0151 331 5444**

**www.hda.org.uk**

 Huntington's Disease Association

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## Huntington's Disease Association

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