Having children

HDYO has more information about HD available for young people, parents and professionals on our site:

www.hdyo.org

Knowing that you are at risk of Huntington’s disease may have an impact on whether you decide to have children or not. The decision to have children is a very personal choice between you and your partner. This section looks at some of the options available with regards to having children.

The genetic risk to children

The risk of passing on Huntington’s disease is usually the main concern when people at risk are thinking of having children. A lot depends on whether the person wanting children knows their gene status or not. Some people decide to test before they have children in order to find out whether there is a risk of passing the disease on to their children.

A person with a Huntington’s disease affected parent has a 50% risk of having inherited the Huntington’s disease gene. Each child of that person has a 25% chance of inheriting the condition. But this ‘25%’ only applies while the person is untested.

If a person has been tested and received a negative result, meaning they will not get Huntington’s disease, then that person will not pass on the risk of inheriting the condition to children. However, if a person has tested positive, meaning they will develop Huntington’s disease at some point in life, then each child will have a 50% risk of inheriting the condition.

Making decisions

Having children is a passionate and emotional issue that often causes debate amongst families affected by Huntington’s disease. People may not agree with the decisions others make, but it is important to remember that everybody has a right to make their own mind up and make their own decisions in life.

Some people take the stance that they will never have children because they do not want to have a child at risk or have that child grow up in a family affected by Huntington’s disease. Other people go ahead and have children at risk, because there is a chance the child will not have the expanded gene, or they feel there will be good treatments or even a cure available by the time the child grows up.

Others want to have children, but want to reduce the risk of them inheriting Huntington’s disease. Technology and science has made this more of a possibility, and there are a number of options available that may provide a child free of the risk of Huntington’s disease.

HDYO has put together a list of the options available to people looking to have children.

Having children: The options

- Having Children Naturally
- Prenatal Testing
- Exclusion Testing
- Preimplantation Genetic Diagnosis (PGD)
- Egg/Sperm/Embryo donation
- Adoption/Fostering

Support

Support and advice for having children can come from various places. Your national Huntington’s disease organisation should be able to provide both support and advice with regards to decisions about having children. HDYO can also help by discussing things in this section that you possibly did not understand fully or would like to learn more about. We can also put you in touch with local support in your area.

If you want specialist information and would like to discuss your options with a professional then your local Huntington’s disease clinic or clinical genetics department can help you with that. Talking through your options with a genetic counsellor or therapist can help you to see your own thoughts more clearly and provide strategies to help you cope in difficult situations which may arise on your journey to start a family.
You may want to do this as a couple or on your own.

Having children is a big decision, one made even more complicated by the impact of Huntington’s disease. As you have seen, there are options available and selecting the right one for you and your situation can involve a lot of thinking and discussions with those around you. Friends and family play a vital role in providing support, but you may find that they do not always understand what you are going through, no matter how well you explain how you are feeling. They may not agree with the decisions that you and your partner make. Ultimately, the important thing is making a decision that you and your partner agree on and can live with. You may find that you change your mind over time, and there’s no harm in having a Plan B if things don’t work out quite as you first intended.

**Having Children Naturally**

Although a lot of this section focuses on the options of having children without the risk of Huntington’s disease, it is important to highlight that having children at risk is an option too. Many people have children at risk for various reasons. A person may feel that with Huntington’s disease research going very well, that there will be good treatments, or even a cure, by the time the child grows up. Another reason people have children at risk is the fact there is always a chance the child will not have the expanded gene and will never get Huntington’s disease.

Some people may want to have a child without the risk, but feel that the options to do that are not available to them - this could be as a result of fertility techniques not being available in their country, a lack of financial support or a religious belief for example.

Having children at risk is something that often causes debate amongst families affected by Huntington’s disease. People may not agree with the decisions others make on this issue, but it is important to remember that everybody has a right to make their own choices and decisions. That decision, like any on this topic, should be respected.

If you decide to have children at risk, HDYO has created material to help inform and educate children appropriately about Huntington’s disease and the genetic risk, so that children can learn and understand more about the condition as they grow up.

**Prenatal Testing**

Prenatal testing involves testing a fetus (unborn baby) around 10-15 weeks into a pregnancy to see if it has the expanded gene that causes Huntington’s disease.

Prenatal testing is usually only done when a couple is certain that they’ll terminate the pregnancy if the genetic test is positive. That decision has to be made beforehand. That’s 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.

If the fetus does not have the expanded gene, then there is no risk to that child and the pregnancy can continue as normal.

If prenatal testing ends with a positive genetic test result, and a termination, then that person/couple could try again and hope that the next pregnancy produces a fetus with no risk of Huntington’s disease.

**Who can have prenatal testing?**

Prenatal testing can be done for those where the affected parent already knows their Huntington’s disease status, meaning they have tested and received a positive result. However, another form of prenatal testing can be taken by those who are at risk and wish to remain untested, but want a child without the risk of Huntington’s disease. This type of prenatal testing is known as Exclusion testing (non-disclosing testing).

**Exclusion Testing**

Exclusion testing involves testing a fetus (unborn baby) around 10-15 weeks into a pregnancy to see if it has the tracking marker for Huntington’s disease. It is essentially the same process as prenatal testing but with a couple of key differences.
Who can have exclusion testing?

One difference between prenatal and exclusion testing is that exclusion testing is specifically for people who want to remain untested, but want to have a child without any risk of passing on the condition to them.

Exclusion: The process

The other difference between exclusion testing and prenatal is that exclusion testing takes samples from three people, as opposed to two. Exclusion testing involves taking a blood sample from the fetus, the person at risk of Huntington’s disease and that person’s affected parent (the fetus’s grandparent). This can be a problem as you may not be able to get a blood sample from your affected parent for a variety of reasons. The affected parent’s sample is key to the whole process, as the extra sample is used to link and trace what genes the fetus has inherited.

Exclusion testing focuses on the section of DNA that contains the Huntington’s disease gene, and tries to show whether or not the fetus has inherited that section from the affected grandparent. If the fetus has not inherited it, then the risk of Huntington’s disease is very low. However, if it has inherited it, then there is a 50% risk to the fetus.

The major problem with exclusion testing is that it doesn’t reveal whether the fetus has inherited the healthy gene or the expanded gene - only whether or not it’s inherited the stretch of DNA from the affected grandparent or not. This is to protect the person at risk who does not want to learn their own status during this process. So, exclusion testing cannot be as precise as prenatal testing. This is why some people may choose to either be tested themselves or use a process such as PGD, where affected embryos are screened out before implantation.

Preimplantation Genetic Diagnosis (PGD)

PGD is a procedure in which a woman’s eggs and her partner’s sperm are taken and fertilised in a laboratory. From this, embryos are then formed and these embryos are tested to see if any carry a risk of Huntington’s disease. Only the embryos that do not have a risk of Huntington’s disease will be implanted back into the woman’s womb, where the hope is a pregnancy will follow. The success rate is quite low (around a 1 in 3 chance of a pregnancy) as the cycle can be affected by a range of factors including how the woman responds to the drugs, the number of eggs fertilised, the number surviving the test and the number with the expanded Huntington’s disease gene. Once the embryo has been implanted, the chances of success increase to 1 in 2. If the procedure is successful then the child will be born free of the risk of Huntington’s disease. Any remaining unaffected embryos can be stored for later use if required.

The PGD process can be a lengthy and emotional journey, with the woman having to undergo various tests and procedures which can be strenuous at times. There may also be a lot of travelling involved to have the treatment and some may have to take time off work. In addition, failed attempts may be difficult to cope emotionally. But for those that come out of the process with a successful pregnancy, PGD can be a very worthwhile option. Also, success rates tend to be slightly higher with couples from a Huntington’s disease family, due to most of the couples being younger when they request PGD.

Who is PGD available to?
PGD can be done by either those who have tested positive or those at risk. For someone who is untested, the process can be done without that person having to learn their Huntington’s disease status - using techniques similar to exclusion testing, described above. Again, this requires getting blood samples from the affected parent of the person going through PGD - although this is not always necessary. This is usually called exclusion PGD, or non-disclosure PGD.

PGD is also not available everywhere, with countries like Austria, Switzerland, and Ireland banning PGD for religious, ethical and moral reasons. Again, speak with a genetic counsellor to see whether PGD is available in your country.

**How much does PGD cost?**

The procedure is expensive if there is no financial support available. The cost is somewhere in the region of US $15,000 (£9,000 or EUR11,000) for each attempt. Health insurance usually does not cover the cost of PGD. However, in some countries, like the UK, the public health care system may fund one or two PGD attempts, but even this can vary within individual countries, and sometimes may be limited to couples with no existing children. As you can see, financial support tends to vary quite substantially, so if you are interested in this option, speak with a genetic counsellor or a health care specialist first about any financial support that may be available to you.

**Egg/Sperm/Embryo Donation**

This method uses a donated egg or sperm in place of that of the affected parent - meaning the child will be free of risk from Huntington’s disease. Embryo donation is also available. The process is done through a qualified donor clinic. Pregnancy success rates vary between clinics but can be as high as 50%.

The downside of taking this route is that the affected person will not be the genetic parent of the child, which may be an issue for you and your partner, but you will still get to carry the baby through pregnancy and be able to impact on his or her life biologically and environmentally from the very beginning without passing on Huntington’s disease.

Also, at some point the child will need to be informed that the affected person is not their genetic parent and why this is the case. Statistics show that 1 in 3 children born through egg/sperm donation want to know who their genetic parent is once they are grown up. Depending on which country you have had your treatment, information about their genetic parent will be available via the donor bank. Some donors are what they call ‘non-anonymous’, meaning that their information is available should the child want to contact them later in life. Other donors are anonymous and contact cannot be sought in the future. Whether the donor is anonymous or not can depend on the rules of the country the procedure is being conducted in. Procedures vary in different areas, so be sure to check and discuss what is available in your area. Again, this is something that you will need to discuss as a couple if you want to go down this route, but support may also be available through organisations such as the Donor Conception Network.

**Who can use the egg/sperm/embryo donation option?**

The egg or sperm donation option can be used by anyone (at risk or tested). The egg/sperm donors themselves are screened and tested for genetic conditions, to avoid inheriting any conditions from a possible donor. So the risk of the child developing Huntington’s disease or any other genetic condition is extremely low. Again this can be an expensive option if funded privately, but may be cheaper than PGD depending on your clinic.

**Adoption/Fostering**

Adoption is when a couple or a family take in a child who may have come from a difficult background, has been taken into care and needs a family to look after them. Adoption is generally considered an option for those wishing to have a child free of the risk of Huntington’s disease.

However, the downside is that couples at risk of Huntington’s disease may find it difficult to adopt, because of the fact the disease is in their family. At the beginning of the adoption process an assessment is done on every couple/family wanting to adopt a child, and each situation is carefully considered for the child’s sake. The adoption agency want to make sure that the child has a stable home to go to, and the risk that one of the parents could have Huntington’s disease can be seen as too much of a chance for them to take. But each case is assessed individually, so do not rule out adoption straight away. It is certainly worth looking into and discussing with your local adoption agency, a genetic counsellor or another health care professional in your area.
You may find that your adoption agency does introductory sessions that you can attend without making any firm commitments to adopt. They will be able to tell you more about both adoption and the potential impact of Huntington’s on your prospects of adopting. You may also be able to meet parents who have adopted in the past, who can tell you about their experiences and answer any questions you might have.

Depending on the country you live in, adoption can be a long process, as it takes time to go through the preliminary assessments, workshops and formalities before matching can begin. The time taken to match will depend on your requirements and theirs, how many children you are looking to adopt, what ages you would consider etc.

Fostering is also an option, even if you have been turned down for adoption on the basis of the future risk of Huntington’s disease. You may still be eligible for fostering because it is a more short term option caring for children for weeks or months at a time. Again, discuss this with your local adoption agency, a genetic counsellor or another health care professional in your area to find out more.

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