scottish huntington's association

Planning a family

Many people find themselves considering whether or not they wish to have a family at some point in their lives. If you have had a positive gene test for Huntington's disease or are known to be at risk, then you may have questions about what options are available to you.

1. What is the chance of passing Huntington's disease to my children?

If you have a positive gene test for Huntington's disease, each of your children has a 50% risk of inheriting the condition. If one of your parents has Huntington's disease but you have not been tested, then your children would be at 25% risk (i.e. half of your own 50% risk). If you have a negative gene test then your children are not at risk.

2. I want to have children but I'm worried about them inheriting Huntington's disease – what are my options?

Conceiving naturally

Given that many people enjoy a good quality of life whilst living with Huntington's disease, some people choose to conceive naturally. You may hope that an effective treatment for Huntington's disease will available for your child by the time they are an adult should they need it, although there is of course no guarantee of this. Natural conception also means avoiding extra medical appointments and tests, which is important for some people.

Pre-implantation genetic diagnosis (PGD)

Pre-implantation-genetic diagnosis is a type of assisted conception. The first stage is the same as with IVF (in-vitro fertilisation) - doctors extract eggs from the ovaries of the mother and mix them with sperm from the father in a laboratory. Some of the eggs will be fertilised by the sperm, forming embryos. In the second step, the embryos are screened by scientists to see which ones have not inherited the HD gene fault from the affected parent. One or more of these unaffected embryos are then transferred into the uterus (womb) of the mother. Sometimes the embryos do not implant into the lining of the uterus, meaning a successful pregnancy is not guaranteed.

PGD is only carried out in specialist centres and both partners must meet specific eligibility criteria for the treatment to be funded by the NHS. There is a limit to the number of NHS-funded cycles you will receive.
If you do not meet the criteria or are no longer eligible for further NHS cycles, there is the option to self-fund the treatment if you have the means.

Find out more about PGD

Using donor sperm

If the male partner in your couple has tested positive for Huntington's disease, then it is possible to use donor sperm to become pregnant. This would typically be screened to ensure that it is healthy before being used. Using donor sperm is typically less expensive than self-funding PGD.

Adoption

Applying to adopt is not straightforward and pre-existing medical conditions, such as Huntington's disease, will influence whether or not you are considered as a potential adoptive parent by your adoption agency.

Find out more about adoption

3. I am at risk of Huntington's disease. Getting the test isn't right for me as I don't want to know my HD status. What options do I have when it comes to having a baby?

If you wish to have a baby that you know will be unaffected by Huntington's disease but you don't wish to be tested yourself, there is a technique available called non-disclosing prenatal testing. This can only be used if you are undergoing PGD and it is carried out at the embryo screening stage. The parents of the partner at risk of Huntington's disease will need to consent to having a blood test taken.

The laboratory does not examine the HD gene of the embryos. Instead, they compare other genetic markers linked to the HD gene with the same markers in the grandparents. The lab can then identify which embryos have not inherited the faulty copy of the HD gene from the affected grandparent, without revealing your own HD status.

4. I am already pregnant and either me or my partner is HD positive/at risk. Can my baby be tested for HD before birth?

If you have already become pregnant, it is possible to have a test to see if the developing foetus has inherited the disease. This option is not available if you intend to continue with the pregnancy regardless of the result, because this removes the right of the child who would later result from the pregnancy to make that decision for themselves once they become an adult.

Testing is done via one of the two following methods:

- **Chorionic villus sampling (CVS)** A small number of cells is taken from the placenta (the tube connecting the foetus to the wall of the mother's uterus) using a needle. These are analysed to see if they contain the faulty copy of the HD gene. CVS is usually done between 11 and 14 weeks of pregnancy.
- **Amniocentesis**: A small amount of fluid around the foetus (called the amniotic fluid) is sampled and analysed in the same way to see if the cells within it contain faulty copies of the HD gene. Amniocentesis is

usually done between 15 and 20 weeks of pregnancy but can be done later on than this.

Both these procedures can occasionally result in complications and side-effects so make sure to explore these with your doctor.

Useful links

Contact a Scottish Huntington's Association HD Specialist

National and Regional Care Frameworks for Huntington's disease

Sign up for regular updates from Scottish Huntington's Association

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