

The decision to start a family can be challenging if you are affected by Huntington disease (HD) or at-risk of HD. This fact sheet will provide some general information about family planning options. Procedures involved and costs associated with each parenting option will vary across provinces, so any reference to costs or process should be verified by the local expert in your area.

There are many ways to have a family. Below is a list of options that will have varying degrees of challenges and success rates. There will be regional differences in the timing, risks, availability, and costs of the tests and procedures. You are encouraged to talk to a local genetic counsellor who will be able to go over your specific options and help you gather all of the information you need to make an informed decision that is right for you.

Family Planning Options

1. Conception with no prenatal testing or medical intervention

People who are at-risk of HD choose to have children for a variety of reasons. This method could mean that the children are at-risk of HD. Parents may feel that there is a chance that the child will be gene negative, or they may be very hopeful that there will be treatments or a cure available for their children. Parents may also have other reasons for choosing this method of conception, like a lack of fertility treatment options available to them, religious or cultural beliefs, or a lack of financial means to pay for fertility treatments.

2. Conception followed by prenatal testing

Prenatal testing for HD can be done using one of two methods: chorionic villus sampling (collects a small sample of the placenta around 11-13 weeks gestation) or amniocentesis (collects a small sample of amniotic fluid after 15 weeks gestation). Both are invasive procedures and carry an approximately 1% and 0.5% risk of miscarriage, respectively. Since the international guidelines do not recommend testing minors, only couples who plan to terminate a gene positive pregnancy would pursue prenatal testing.

3. Pre-implantation Testing

Pre-implantation genetic diagnosis (PGD) is an option for parents who want to avoid having a child at-risk of HD but also want to avoid terminating an affected pregnancy. The woman would undergo in vitro fertilization (IVF) which involves taking medication so that she produces many eggs in one cycle. These eggs are collected and fertilized in the laboratory by the father's sperm. The developing eggs are tested for HD, and only embryos that are gene negative are transferred to the woman's uterus where they will hopefully implant. In Canada, the cost is in the range of \$15,000 - \$35,000 per attempt to conceive. More than one procedure may be required. Provincial funding and private insurance funding will vary.

4. Exclusion Testing (or non-disclosure testing)

For individuals who do not want to know their own gene status, non-disclosure pre-implantation genetic diagnosis (PGD) can be done. This involves in vitro fertilization followed by pre-implantation testing, as described above. However, embryos are tested for the presence or absence of the affected grandparent's chromosome. In this way, embryos are sorted into those at 50% risk of HD, and those not at-risk of HD. Alternatively, some PGD labs may use an approach where the embryos are tested directly for the HD gene, but the results are not shared with the prospective parents. It is thought that this latter testing method is less commonly used, particularly in Canada. Both approaches allow parents at-risk to remain unaware of their genetic status, while ensuring that their children are not at-risk. The cost range is the same as for Option #3.

5. Conception using donor egg/sperm/embryo

This procedure uses a donated egg or sperm rather than the egg or sperm of a person affected by HD (either at-risk or gene positive). This greatly reduces the chance that the child will be at-risk of HD. Embryo donation may also be available. It is important to note that health history and personal information about the donor (i.e. the biological parent) may be very limited, depending on the wishes of the donor and the amount and type of information collected from the donor at the time of donation.

6. Adoption

Adoption involves the process of legally taking a child to care for as your own - when that child's biological parents are not able to look after him/her. It is important to note that there are situations where the family health history of the adopted child is unknown or unavailable.

There are three ways to adopt:

- Internationally - adopting from another country.
- Publically - through an agency such as the Children's Aid Society (Ontario) or other provincial children's services agencies across Canada, Jewish Family and Child and others.
- Privately - which means you are chosen by the birth parents to become parents of their child. Private adoptions are facilitated by a licenced agency or intermediary. Speak with your Family Services team member who can direct you to a list of local agencies.

Regardless of the way you decide to adopt, parenting classes and a home study conducted by a qualified adoption practitioner are required, as is a medical from your doctor. The home study involves a series of intensive interviews with you. A wide range of factors, including finances, health and medical history, will be considered in the final decision about your eligibility to adopt a child.

7. Foster Parenting

Foster care involves the short-term or sometimes long-term care of children by foster parents. There are various screening, training and orientation processes for prospective foster parents. If adoption is not possible, sometimes fostering a child or children is an option.

There are many ways to pursue family planning and parenthood. After discussing and considering the options, you and your partner can decide the path that is right for you. Along the way, the Family Services team is there to provide information and support.

Resources

The information in this fact sheet was gathered from a number of sources including Emily Alderman MSc, CGC, CCGC, Erin Paterson, author (<https://www.erinpaterson.com/>), Clare Gibbons, MS, CCGC, CGC and *Having Children* information on the HDYO website: <https://en.hdyo.org/you/articles/45#2>

Ongoing support, education and information about HD is available from HSC. You can find a listing of our Family Services team members at: www.huntingtonsociety.ca/family-services-team

Additional helpful information is available at these links:

- <https://www.huntingtonsociety.ca/genetic-testing-q-and-a/>
- <https://en.hdbuzz.net/036>
- <https://www.canada.ca/en/public-health/services/fertility/genetic-testing-screening.html>

For personal stories about individuals' journeys, please see the HSC website: <https://www.huntingtonsociety.ca/erins-story/>