FAMILY PLANNING AND HUNTINGTON DISEASE (HD)

Deciding whether to start a family can feel especially complex when Huntington disease (HD) is part of your life. People who are living with HD or who are at risk may have questions about genetics, health, and the future. These decisions can bring up strong emotions and may involve medical, financial, cultural, or personal considerations. The information in this factsheet can help individuals and couples understand their family planning options and support informed decisions that feel right for them.

Important Things to Know

- HD is a genetic condition, which means it can be passed from parent to child
- Family planning options vary across provinces, including:
  - Availability of services
  - Costs
  - Wait times and processes
- Costs and procedures should always be confirmed with local experts
- A genetic counsellor can explain options, answer questions, and help you make informed choices
- There is no single “right” choice. Families are constructed in many ways

FAMILY PLANNING OPTIONS

1. Conception Without Medical Testing

Some people choose to conceive naturally without medical testing, understanding that a child may be at risk for HD. Reasons for this choice may include:

- Hope the child will not inherit the gene
- Belief that future treatments or cures may exist
- Religious or cultural values
- Limited access to fertility services
- Financial considerations

2. Conception With Prenatal Testing

Prenatal testing allows parents to learn whether a pregnancy is affected by HD, which may help guide difficult decisions during pregnancy. Prenatal testing can check for HD during pregnancy using:

- Chorionic Villus Sampling (CVS) (11–13 weeks)
- Amniocentesis (after 15 weeks)
- These tests are invasive and carry a small risk of miscarriage
- Prenatal testing is usually chosen only if parents would consider ending an affected pregnancy

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3. Pre-Implantation Genetic Diagnosis (PGD)

PGD is an option for parents who want to reduce the chance of passing on HD while avoiding the need to end a pregnancy.

- PGD is done with in vitro fertilization (IVF)
- Eggs are fertilized in a lab, and embryos are tested for HD
- Only embryos without the HD gene are implanted
- In Canada, costs may range from $15,000 to $35,000 per attempt
- More than one cycle may be needed
- Public funding and insurance coverage vary by province

4. Exclusion (Non-Disclosure) Testing

Exclusion testing allows people to reduce the risk of HD in their children without learning their own genetic status.

- IVF and PGD are used, but results are handled so parents remain unaware of their HD status
- Embryos are selected to reduce the chance of HD without revealing genetic results
- Costs are similar to standard PGD

5. Donor Egg, Sperm, or Embryo

Using donor eggs, sperm, or embryos is an option for families who want to greatly lower the chance of HD being passed on.

- Uses donated eggs, sperm, or embryos instead of those from a person with HD or at risk
- This greatly reduces the chance of passing on HD
- Donor medical and personal history may be limited, depending on donor agreements

6. Adoption

Adoption is another way to build a family when biological parenting may not feel like the right choice. Types of adoption include:

- International adoption
- Public adoption (through provincial child services agencies)
- Private adoption (chosen by birth parents and arranged through licensed agencies)

Common requirements:

- Parenting education
- Home study and interviews
- Medical assessment
- Review of finances and health history

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7. Foster Parenting

Foster parenting offers the opportunity to care for children who need a safe and supportive home

- Foster care may be short-term or long-term
- Screening, training, and orientation are required
- For some families, fostering may be an alternative when adoption is not possible

Moving Forward

There are many ways to build a family. After learning about the options, you and your partner can decide what feels right for you. The Huntington Society of Canada Family Services team is available to provide information, guidance, and emotional support along the way.

Factsheet developed by the HSC Family Services team. Reviewed by Tanya Greaser, BA, BSW, Registered Social Worker and Family Services Educator, and David Macgregor, MSc, CCGC, Genetic counsellor, Provincial Medical Genetics Program, St. John's, Newfoundland

RESOURCES

Reach out to your local Resource Centre Director (RCD) of the Family Services Program at HSC for ongoing support and education at hdsupport.ca

If you are ready to receive individual or group support from the Huntington Society of Canada, you can self-refer here: http://contactme.cloud/form/huntingtonsociety

Informational fact sheets for family and friends impacted by HD are available to view, print and download at hdfactsheets.ca

Healthcare professionals and caregivers needing a more in depth understanding on caring for someone with HD can find guides at hdresources.ca

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