



**Abortion Rights
Coalition of Canada**

**Coalition pour le droit à
l'avortement au Canada**

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Position Paper #25

Abortions for Genetic Reasons

Background

As part of routine prenatal care, all women in Canada are offered an ultrasound scan to look for fetal anomalies. While all women are offered extensive prenatal screening, some women are offered testing for other genetic diseases based on their particular risk factors.

Over the past several years, both genetic testing and prenatal diagnosis have progressed and become increasingly sophisticated. Prenatal testing is available for everything from neural tube defects and Down syndrome to DiGeorge syndrome, Tay Sachs disease, and hemoglobinopathies. The spectrum of disease being tested for ranges from mild to severe disability and early death as in Tay Sachs disease.¹

The purpose of prenatal testing is to provide women and families with as much information as possible regarding their pregnancy. Doctors can be held liable via a wrongful birth lawsuit if they do not inform pregnant women of detected abnormalities that result in the birth of a disabled child. Informed consent is the cornerstone of ethical medical practice.²

Pregnant women and couples need to be prepared for the arrival of an affected child (for example, ensuring delivery in a tertiary care centre if the fetus has a major cardiac anomaly), or make decisions regarding continuing with or terminating a pregnancy in which the fetus has a severe genetic problem. The purpose of prenatal testing is not to ensure any fetus with a genetic disorder or anomaly is aborted, but to ensure that pregnant women and couples are informed about the health of their fetus. In Canada, most abortions for reasons of fetal disorder or anomaly occur before 20 weeks gestation. A few occur up to about 23 weeks, but only when the fetus is gravely impaired. Very rarely, abortions may be done during the third trimester in cases of lethal fetal abnormality, where the fetus cannot survive after birth.

Response of Advocates for the Rights of the Disabled

Some members of the disabled community and advocates for the rights of the disabled have equated abortion for genetic reasons with eugenics. Some feel that allowing abortions based

on genetic testing devalues the lives of disabled people and implies that living with a disability is inferior to living without one.³ ARCC disagrees with this interpretation.

ARCC-CDAC Position

The issue of abortion for genetic reasons is not about eugenics or discrimination against disabled people. It is about a woman's ability and preparedness to bear and raise a disabled child, or any child. It is about a woman's choice. It is not different from her right to decide about any other pregnancy. Only SHE can decide what to do, because she must bear (and raise) the child. To presume the right of a disabled fetus, or any other fetus, to survive, presumes the obligation of the woman to continue the pregnancy and care for the resulting child, and negates a woman's autonomy and rights.

In Canada, women do not have to provide a reason to obtain an abortion, since abortions are available upon request. Also, being pro-choice means supporting a woman's right to decide whether or not to continue a pregnancy, for whatever reason, even if one personally does not agree with her reason. Moreover, a woman's constitutional right to choose abortion does not stop as soon as she becomes pregnant with a child with a genetic disorder. In fact, this situation is a widely-accepted moral justification for abortion, even by anti-choice people, because bringing a severely ill or disabled child into the world has momentous and lifelong consequences for everyone involved.

Being disabled, in and of itself, is unrelated to the quality and importance of life. Once born, the disabled have rights like everyone else, and very often lead full, productive lives. On the other hand, severe genetic defects or illnesses can impose a poor quality of life on people. Many disabled people, especially the severely disabled, depend upon the care of others. Such care consumes substantial time and resources on the part of the caregiver. It can also involve much heartache and trauma, especially where a child's life may be cut tragically short because of the illness or disability.

Pregnant women and couples are the only ones in a position to evaluate what is in the best interest of themselves and their potential child. The most loving and responsible women and couples will consider all options and circumstances and make the wisest choice for themselves, and their family. Society cannot compel people to forfeit their own rights (or life) to save the life of another. Such a sacrifice must be entirely voluntary.

¹ Canadian College of Medical Geneticists, Society of Obstetricians and Gynaecologists of Canada. Canadian guidelines for prenatal diagnosis of genetic disorders: an update. *J Soc Obstet Gynaecol Can* 1993;15 (suppl):15-39.

² *Arndt v. Smith* (1994), 21 C.C.L.T. (2d) 66 (B.C.S.C.); *Arndt v. Smith* (1997), 148 D.L.R. (4th) (S.C.C.); E. Nelson and T. Caulfield, "You Can't Get There From Here: A Case Comment on *Arndt v. Smith*," *University of British Columbia Law Review*, Vol. 32 (1998), p. 353; Nelson E and G Roberston. Liability for Wrongful Birth and Wrongful Life. *Canadian Journal of Policy Research (isuma)*. Autumn 2001, Volume 2, N° 3.

³ *The Guardian*, Manchester, Nov 3, 1999; *The Toronto Star*, Toronto, Oct 23, 1999.