2.1.6 What Does this Mean for Children and Families?

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When a genetic diagnosis is suspected or confirmed, the child and his or her family members often require complex support and care, perhaps for a significant period of time. Parents will have questions about what the condition will mean for their child and also how the condition originated, either through genetic inheritance or through a spontaneous genetic mutation, what the risks are of it happening again or in future generations, and what their reproductive choices might be for another pregnancy. They may be concerned about their health and the health of their child, privacy, stigma, or discrimination, and parents often experience guilt.[1, 2] Often other relatives are concerned about themselves or their children. Because there is no cure or effective treatment for many genetic conditions, the disclosure of a genetic diagnosis can be incredibly difficult for all family members involved.

Personal, family, cultural, and religious beliefs influence how families interpret and share information about genetic conditions. There has been an explosion of knowledge and information regarding the genetic bases of disease. It is therefore critical to ensure appropriate clinical services are available to families who need them.

[1] Wilcken B. Ethical issues in genetics. Journal of Paediatrics and Child Health.2011;47:668–71.

[2] Canadian Association of Genetic Counsellors, https://cagc-accg.ca/content/view/12/26/