



## Adjusting to the Diagnosis: Down Syndrome

Down Syndrome is a chromosomal condition caused by the addition of a third copy of the 21<sup>st</sup> chromosome. As such this syndrome is also known as Trisomy 21. Prior to birth, Down Syndrome can be tested for by amniocentesis, a process of retrieving cells from the interior area of the uterus for the purpose of genetic examination.

If not tested for prior to birth, Down Syndrome is sometimes suspected by observable physical characteristics seen at delivery. A few recognizable features can include flattened facial features, small ears and short curved fingers. Genetic testing after delivery is the only way to confirm the condition.

The challenge facing the new parent is at times less taking care of and raising their newborn, than coming to terms with a child who possesses a disability. Understandably parents hope to have a fully healthy child. The disappointment and fright of a child with a disability requires a psychological and emotional adjustment. With respect to the fright, parents may have overwhelming concerns and often even misperceptions as to what may be entailed for child and parent in view of the determination.

Compounding the difficulty for some new parents in this situation is the belief that they are supposed to overlook the loss of the fantasy of the child that was expected. These parents may feel a pressure to adjust quicker than their own feelings permit. Thus parents are at risk of adding shame and embarrassment to the list of feelings they must overcome.

Upon confirmation, what is needed most is support. The support provided must include permission and a safe place to feel and discuss the loss of the fantasy of a child without disability. The support must also include accurate information regarding the nature of the condition and what life for child and family may really mean in view of present or emergent problems.

Permission and a safe place to express feelings is also known as emotional support. Family or friends may offer this kind of support. However, the feelings and attitudes of family and friends may interfere with the quality of support they may offer. Hence, parents are advised to seek out and make use of local support

groups within their community. Upon confirmation, it is never too soon to get connected to a local support group. Therein the parents can learn and discuss the myriad of issues they face while at the same time have their feelings and fears normalized such that they do not add shame and embarrassment or guilt to their list of bad feelings.

While support groups will help with one's feelings and psychological adjustment, attending presentations and meeting with healthcare service providers can address the need for tangible information, particularly as it relates specifically to your child's needs. It is important to have a network of professional helpers to advise and provide whatever service, medical or social, to facilitate the care of the child as necessary.

As parent must adjust, present siblings may need support to manage their parents' upheaval. These children are most likely to have views on the matter that parallel their parents. However, as parents adjust, so too do these children. Siblings are known to grow up stronger, more determined and compassionate as a result of their experience.

A good starting point after receiving a determination of Down Syndrome is contacting your local Down Syndrome Association. They offer both information and support to parents and children. While it may be the information that draws a people to the association, it is typically the friends that develop that provide for lifetime connections.

In Canada: [www.cdss.ca](http://www.cdss.ca)

In the USA: [www.ndss.org](http://www.ndss.org)

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Gary Direnfeld is a social worker. Courts in Ontario, Canada, consider him an expert on child development, parent-child relations, marital and family therapy, custody and access recommendations, social work and an expert for the purpose of giving a critique on a Section 112 (social work) report. Call him for your next conference and for expert opinion on family matters. Services include counselling, mediation, assessment, assessment critiques and workshops.