

Imagine your feelings if you and your spouse were informed unexpectedly that your newborn has Down syndrome. You may experience emotions that are both intense and confusing. You may feel overwhelmed with shock, frustration, disappointment, ambivalence, and even anger, along with a sense of caring and love that accompanies the birth of your baby. When you are working with parents of a newborn with Down syndrome, it is important for you to remember that *all* of these emotions are normal and valid, and that there is no single series of emotions that a parent may experience.

One fairly common reaction for newly-informed parents is an overwhelming sense of grief. Grief is not simply a static response that manifests itself at a particular period in time; it is a dynamic process that can reassert itself when you least expect it. The swirling intensity of these possible emotions (including shock, denial, anger, guilt, and sadness) can mix together, often recurring in unique environments with different configurations as a child grows. Parents report that these emotions usually do not occur in an orderly or predictable progression, and that their feelings can be difficult to understand. However with time, most parents find that their emotions evolve until they achieve a greater proportion of acceptance and joy. In fact, some authorities and families themselves have spoken about an emotional level that is "beyond" mere acceptance of their child's disability, a level that is characterized as a positive and enduring "appreciation" for the child's unique gifts and contributions to the family (Hodapp, 2007). (See "An Open Letter to Mothers," included as a link in the References section of the Brighter Tomorrows website).

## ***Confronting Challenges***

The medical complications that children with Down syndrome often experience, including heart defects, can understandably cause worry and stress for parents. With improvements in medical treatment, most of these problems are correctable. Many parents benefit from being given information on medical conditions encountered by children with Down syndrome, since up-to-date information can reduce the stress and fears associated with conditions that used to be considered untreatable or even life-threatening.

New parents of a child with Down syndrome may sometimes have difficulty explaining to other family members and friends that their child has Down syndrome. Parents will at times "retreat" and become socially isolated. Encouraging parents to share with family and friends their hopes and fears of raising their child can help them work through their emotions and strengthen their bond with their child. They might also benefit from enlisting the help of a friend or family member to inform others of their baby's diagnosis. In fact, parents often attest to the importance of a supportive group of friends and family who can help them in their journey as their newborn grows.

## ***Important Supports***

One particularly invaluable resource for parents is the support of other parents of children with Down syndrome. In both informal and formal meetings, these “veteran” parents readily help those with newly diagnosed children. They can discuss changes in parental expectations for their children, and they can suggest practical guidelines for raising children with Down syndrome. The National Down Syndrome Society (<http://www.ndss.org/>) and its local chapters, as well as the National Down Syndrome Congress (<http://www.ndsccenter.org/>), are skilled at facilitating such interactions. NDSS’s video entitled, “Parent to Parent,” features experiences of actual parents of children with Down syndrome, and can be a valuable educational tool. Additional resources can be found throughout the Brighter Tomorrows Website.

Finally, physicians can support parents by recognizing the amazing gains that children with Down syndrome have accomplished in the last few years. In fact, parents attest to the biggest surprise of all, and that is the many successes they have celebrated with their child with Down syndrome. Even though life events or markers may at times remind them of the loss of the “dream child”, the love and acceptance that develop between child and parents most often diminish the impact of these lost dreams by creating new ones. Recognizing that stress and grief may recur unexpectedly, even with a hopeful future, may enable this family and their child to move beyond the limits of past expectations.

Ultimately, each child with Down syndrome (like every other child) develops his or her own personality and adaptations to life. With a loving, hopeful environment, parents accept and appreciate their child as they watch his or her unique personality emerge. They begin to see and understand that children are more similar than they are different, and that while the presence of Down syndrome alters the family’s experience, it can create new possibilities that enhance their relationships in unforeseen ways. When physicians communicate this reality early on, both the child and the family benefit.

## **Reference:**

Hodapp, R.M. (2007). Families of persons with Down syndrome: New perspectives, findings, and research and service needs. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 279-287.