



It is important to note that you may feel some or all of these emotions or you may feel none – but whatever you are feeling is your experience and is perfectly normal.

Fluctuations of feelings may occur over time, however once through the initial period most grandparents adjust and report great pleasure in watching their grandchild grow and learn. Grandparents also generally report that their grandchild with Down syndrome is healthier and more capable than they had anticipated.

"I needed time to realise my granddaughter was not a diagnosis, but a beautiful baby girl, perfectly unique and one I am so pleased is an important part of our family."

Our Story – a Grandmother's Perspective

"This is a very condensed version of the journey of our little Granddaughter Elizabeth. Elizabeth was born on 13.2.1999 she was our first grandchild. There was no indication that everything wasn't as it should be and we received a phone call from our son conveying the good news. The next day we were shocked and anxious for our son and daughter-in-law when we received the news that our precious grandchild had Down Syndrome.

We made the 700km journey with many tears shed on the way, to meet Elizabeth and from that moment our lives changed so for the better. Elizabeth has brought so much joy and inspiration to our family it is difficult to express. We have gone through the journey with her from her first steps and words to this day where she is the most adorable little girl that we forget she has a disability. She attends St. Anthony's School and is in Grade 3 and so far progressing very well. She loves to read or have someone read to her - she received an award for her reading and enjoys school. She loves fashion and dressing up, singing, dancing, music, swimming and all the things a little girl of her age enjoys. She now has two younger brothers.

I cannot stress how much pleasure this precious little girl has brought to our family and never ceases to inspire us all. We love you Elizabeth."



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Down syndrome

Information for New Grandparents



GRANDPARENTS CAN FEEL A RANGE OF COMPLEX EMOTIONS WHEN LEARNING THAT A GRANDCHILD HAS A DEVELOPMENTAL DISABILITY. THEIR CONCERNS ARE NOT ONLY FOR THEIR GRANDCHILD, BUT ALSO FOR THEIR CHILD WHO HAS JUST RECEIVED THE UNEXPECTED NEWS ABOUT THEIR PRECIOUS NEW BABY.

Grandparents can feel a range of complex emotions when learning that a grandchild has a developmental disability. Their concerns are not only for their grandchild, but also for their child who has just received the unexpected news about their precious new baby.

Parents of the new baby may need support as they go through the initial adjustment phase. It is usual to feel a sense of helplessness, but know that you can play a meaningful role too. New parents will benefit from those around them celebrating their baby in the same way any new arrival would be celebrated.

The bonds of love between grandparent and grandchild can be genuine and profound. The relationship can enhance and nurture a grandchild's feelings of self-esteem and worth. Your grandchild is first and foremost a child more like other children than unlike. The needs of your grandchild differ only in degree, not in kind. Your grandchild with Down syndrome will respond to your love, your jokes and games, and your abiding affection, just like any of your grandchildren.

"As grandparents, you can offer your children much love and support through this time of adjustment."

"When our daughter phoned to give us the good news that we had a grand-daughter, the fact that she may have Down syndrome left us feeling perplexed and somewhat apprehensive as we knew very little about the syndrome. There was never any doubt that we would love her but once we held our tiny beautiful grand child, we were captivated."

About Down syndrome

What is Down syndrome?

Down syndrome is one of the most common congenital syndromes. A 'syndrome' is a condition associated with a number of distinguishable characteristics. Down syndrome was named after John Langdon Down, who first described the specific features of Down syndrome in 1866.

What causes Down syndrome?

Down syndrome is not a disease or a medical condition. A chromosomal anomaly, it is the addition of an extra full or partial copy of the chromosome 21 to all or some of the body cells which causes Down syndrome. There are no known factors to explain the error in cell development which results in 47 chromosomes rather than the usual 46.

What are some characteristics of Down syndrome?

Over 100 characteristics have been described for Down syndrome however most children and adults have less than 10 of these and no one has all of them.

Some of the more common features include:

- Upward slanting eyes
- Low muscle tone (as a baby they may feel 'floppy')
- Smaller stature, shorter fingers
- Intellectual impairment to varying degrees (usually within the mild to moderate range)
- Higher than average incidence of heart and respiratory conditions

Having Down syndrome does not define who people are. It is an attribute not a deficit. People with Down syndrome have unique personalities, abilities, skills and interests. Although the syndrome is associated with developmental delays and learning difficulties, how 'disabling' these are depends as much on community attitudes and support as it does on an individual's level of ability.

Relationships and Feelings

Although all grandparents react slightly differently to the news that their grandchild has Down syndrome, most share some common feelings. You may find it helpful to know that others have felt the same. Some of these shared feelings are shock, disbelief, sorrow, anger and guilt.