

Down syndrome and your family

Down syndrome is nobody's fault and there is nothing that you did before or during pregnancy to cause it. Babies with Down syndrome are born to parents of every age, social class and race.

While parents generally experience shock on learning that their baby has Down syndrome, the majority of families adjust relatively quickly to this new situation. Parents may experience some degree of 'appointment stress' in the early days as a result of regular health and medical checks and early intervention appointments, but this period is usually short-lived.

Research suggests that despite the demands of living with a child with a disability, families can and do make the adjustment, often with little disruption to family life. Families generally find their feet and continue leading their regular lives, incorporating the additional needs of their child with Down syndrome into their family circumstances.

Learning to cope

Every family is different. Some families will feel that their lives have hardly been affected by the addition of a family member with Down syndrome, others may experience this as a life-altering event.

Almost all families report that there continue to be highs and lows, times of elation and times of despondency. Periods of transition, such as moving into school or between schools, the onset of puberty, leaving school and entering adult life tend to be where new peaks of stress and emotion occur in families.

Support, either among families or through peer support groups, can contribute significantly to family wellbeing.

Individual personalities

No two children with Down syndrome are alike, and they have the same physical and emotional needs as any other child. They need:

- To be recognised as a unique personality
- To know that their family loves them
- To be treated like their brothers and sisters
- To be seen as a person first, rather than as a person with special needs
- To have access to education and leisure activities.

Importance of a supportive family

Over recent decades, people with Down syndrome have shown what they can achieve and this has completely changed our understanding of their abilities.

Family members have an important role in encouraging a person with Down syndrome to show what they are capable of. If a family has high expectations of the person, better behaviour and higher levels of achievement can result. On the other hand, low expectations can limit the person's potential.

Families are also crucial in providing leadership for the rest of the community. The attitude and expectations of the family are usually mirrored by the community at large.

Families can have an important role as advocates for their family member with Down syndrome. By speaking up for a family member, families have been the driving force behind many of the progressive changes that have been made in the lives of people with Down syndrome over the years.

Support available

Many of the professional services available for people with Down syndrome recognise just how important families are. For this reason, many services have a 'family-centred' approach that allows families to decide what services that they need and use. This can help build resilience and develop independence. Sharing experiences with other families and taking part in support networks can also help to build resilience.

Where to get help

- Your doctor
- Down Syndrome Victoria Tel. 1300 658 873

Things to remember

- Children with Down syndrome need to be treated like their siblings.
- A supportive family background will help your child to make their way in the world.

This page has been produced in consultation with, and approved by:

Down Syndrome Association of Victoria

Content on this website is provided for education and information purposes only. Information about a therapy, service, product or treatment does not imply endorsement and is not intended to replace advice from your doctor or other registered health professional. Content has been prepared for Victorian residents and wider Australian audiences, and was accurate at the time of publication. Readers should note that, over time, currency and completeness of the information may change. All users are urged to always seek advice from a registered health care professional for diagnosis and answers to their medical questions.

For the latest updates and more information, visit www.betterhealth.vic.gov.au

Copyright © 1999/2012 State of Victoria. Reproduced from the Better Health Channel (www.betterhealth.vic.gov.au) at no cost with permission of the Victorian Minister for Health. Unauthorised reproduction and other uses comprised in the copyright are prohibited without permission.