

A baby with Down syndrome

A parent's reaction to the news that their baby has Down syndrome can include shock, anger, and grief. Many worry that they will not cope. But most families do cope with support and information.

It often helps to talk to other families who have faced the same situation. We can meet and talk with you (with an Interpreter) about what it's like to have a child with Down syndrome, or we can try to put you in touch with another family that speaks your language.

There are two very important things to do in the first few weeks

- Enjoy your baby. What your baby needs more than anything at this point is the same as any baby: your closeness and your love. Take whatever time you need to get to know this new member of your family. Everyone's experience will be different – some parents find it harder to relate to a new baby than others, and there will be days when you feel really close to your new baby and days when that bonding process seems remote. It is quite normal to experience very mixed emotions in the early days.
- Take care of yourself... and your family. Reassure yourself that all parents have good and bad days, and not all parents have to cope with the adjustment you are dealing with. Be easy on yourself, rest whenever possible (sleep deprivation plays havoc with your emotions) and don't hesitate to seek support from others if you need it. Remember too that other family members – and siblings in particular – are also adjusting to this new family member. Take particular care not to lose sight of brothers and sisters in the first intense weeks of your new baby.

Other important information for the early days – A CHECKLIST:

- ✓ **Health matters** - Included, in this pack are Down syndrome specific growth charts and a checklist of recommended health checks for babies with Down syndrome. Remember that babies with Down syndrome generally grow at a slower rate than many other children. Make contact with your local Maternal and Child Health (MCH) Service. The nursing staff there will be able to support you with information and advice relating to general health and development of children from 0-5 years and can conduct regular routine health and development checks. In addition to a local GP, many families also find it useful to see a pediatrician regularly, to monitor health and development and to offer referral to any relevant specialists.

- ✓ **Submit an application for Carer Allowance with Centrelink** - As a parent of a child with Down syndrome, you are entitled to a monthly allowance and Health Care Card for your child until s/he turns 16. A claim form and further information is available from your local Centrelink Office (13 27 17) or at their website (www.centrelink.gov.au). The Carer Allowance form is in two sections. Part 1 is to be filled in by you, the parent, and Part 2 is to be filled in by your doctor.

This allowance (which is not income or assets tested) is a provision made for you by the Federal Government – you are not depriving others by claiming an allowance to which you are entitled. Other payments your family may be eligible for (depending on your personal situation) are Carer Adjustment Payment and/or Carer Payment.

- ✓ **Register for Early childhood intervention services (ECIS)** - Early stimulation and development intervention plays an important part in the development of children with Down syndrome. A range of services are available from birth to 6 years of age, including physical therapies and speech and language therapy.

Call your local ECIS intake team to discuss the range of services and early intervention options available in your area (*Call ASAP to register as there is often a wait list of up to 12 months*).

Find your regions contact number here:

- North Western (Metro) – 9304 0755
 - North Western (Rural) – 1300 363 514
 - North Eastern (Metro & Rural) – 1800 336 010
 - South Western (Metro & Rural) – 9291 6500
 - South Eastern (Metro) – 1300 720 151
 - South Eastern (Rural) – 1800 336 101
- ✓ **National Disability Insurance Scheme (NDIS)** - is the national disability insurance scheme - a new way of providing community linking and individualised support for people with permanent and significant disability, their families and carers. Currently in its first stage the scheme is only available to families in the Barwon area in Victoria. ph: 1800 800 110
 - ✓ **Register for Better Start funding** - This Australian Government initiative provides \$12,000 of early intervention funding to parents of children with Down syndrome under six years of age. Families have until the child's seventh birthday to access the financial assistance. Down Syndrome Victoria suggest that you register straight away even if you are not ready to use the funding. You can register for the Better Start funding, once you have the baby's Centerlink paperwork, by contacting Carers Victoria on ph: 1800 242 636 (families in the Barwon area should register by calling 1800 052 222).

- ✓ **Join Down Syndrome Victoria** - Membership is FREE to families for the first 4-6 months and a stamped envelope for ease of return is in this pack. Please contact us whenever we can be of assistance, with information, advice or support.

Please keep in contact. Even if you do not feel the need to become a Down Syndrome Victoria member it is vitally important that you are on our database and a receiving email updates from us, otherwise you may miss out on relevant information or funded programs that will benefit you and your family.

- ✓ **Register to attend a New Parent Information evening** (*Early Days Support Workshop One*) at Down Syndrome Victoria – our Early Days Workshops are held every few months, they provide a great chance to meet other parents, share information and find out more about what Down Syndrome Victoria offer. An invitation will be sent to you if we have your address or you can refer to our website for the next session then ring or email the office to book in as places are limited.
- ✓ **Call The Association for Children with a Disability (ACD)** - to get your free copy of 'Through the Maze' – an essential resource for all new families. Phone 9818 2000 or 1800 013 654 (rural callers). It is also available in Arabic, Vietnamese and Chinese.

About Down Syndrome

Down syndrome is a common genetic condition. It's not an illness or disease.

Our bodies are made up of millions of cells. In each cell there are 46 chromosomes. The DNA in our chromosomes determines how we develop. Down syndrome is caused when there is an extra chromosome. People with Down syndrome have 47 chromosomes in their cells instead of 46. They have an extra chromosome 21.

Although we know *how* Down syndrome occurs, we don't yet know *why* it happens. Down syndrome occurs at conception, across all ethnic and social groups and to parents of all ages. It is nobody's fault. There is no cure and it does not go away.

One of every 1100 babies born will have Down syndrome. This number has not changed a lot throughout the time that data has been collected.

People with Down syndrome have some:

- characteristic physical features
- health and development challenges
- level of intellectual disability.

But these things will vary from one person to another.

What does it mean to have Down syndrome?

Mostly young people growing up with Down syndrome today will lead quite ordinary lives in the community. Some people with Down syndrome may not need much help to lead an ordinary life, while others require a lot of support.

Having an intellectual disability

Everyone with Down syndrome has some level of intellectual disability. There will be some delay in development and some level of learning difficulty. Because everyone is unique, the level of delay will be different for each person.

At birth, there is no way to tell what level of intellectual disability the child may have or the way in which this may affect a person's life. However, having Down syndrome won't be the most important influence on how they develop and live their life. Instead, what happens *after* birth will be much more important and family, environmental, cultural and social factors will shape their life, just like everyone else.

For many people with Down syndrome, speaking clearly can be difficult. Although lots of people with Down syndrome speak well, many will need speech therapy to achieve this. Often, people with Down syndrome can understand more than they can express with words. Their abilities are sometimes underestimated, which can make them feel frustrated.

Some people with Down syndrome find it very difficult to develop language and speak clearly. This may be made worse by hearing loss.

Living an ordinary life

People with Down syndrome are basically the same as everyone else. They have the same needs and aspirations in life that we all do, including:

- a good place to live
- meaningful employment
- the opportunity to enjoy the company of friends and family
- intimacy
- having a role in our community.

However, achieving these goals is harder for people with Down syndrome than it is for everyone else so they are likely to need some support to achieve the kind of life that most people take for granted.

In the past, many people with Down syndrome didn't have the opportunity to develop to their full potential. Often, they were separated from the rest of the community, living in segregated settings such as institutions. Low expectations were placed on them and there were limited opportunities for learning and personal growth.

Today, we know that growing up in families and communities, with the same rights and responsibilities as everyone else, is important for the development of people with Down syndrome.

To be a part of a community you have to be in it.

People who have only experienced life in segregated settings may find it difficult to be included in general community. Life for people who grow up included in families and communities will be happier and more successful.

Sending children with Down syndrome to local schools with siblings and peers has many benefits. It helps towards a smooth transition to adulthood and encourages meaningful inclusion in the community.

People with Down syndrome need opportunities to reach their full potential, like we all do. When given these opportunities, they become valued and productive members of their families and the community.

Best wishes from....

THE FAMILY SUPPORT TEAM

Down Syndrome Victoria

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