



**What happens after birth will be far more important in shaping the outlook for any individual with Down syndrome than the presence of an extra chromosome.**

## Down Syndrome Victoria

Down Syndrome Victoria is the statewide peak membership organisation representing people with Down syndrome and their families. It is a not-for-profit organisation established in 1978 to provide support, encouragement, information and resources to people with Down syndrome, their families and the broader community.

Down Syndrome Victoria provides a whole of life service offering:

- Personal support and information to families
- Advocacy, information, support, mentoring and training for adults with Down syndrome
- An education support service to assist students with Down syndrome and their teachers in mainstream schools
- Peer support groups around the state
- An annual Family Fun Day and other events
- Annual conference and education/information sessions
- A quarterly journal
- Information and professional development for health and education professionals
- A library of Down syndrome specific resources.

Donations are gratefully accepted  
Donations over \$2 are tax deductible



**down syndrome**  
VICTORIA

219 Napier Street Fitzroy 3065

Phone: 1300 658 873 Fax: (03) 9486 9601

Email: [info@dsav.asn.au](mailto:info@dsav.asn.au)

[www.downsyndromevictoria.org.au](http://www.downsyndromevictoria.org.au)



**What do you  
know about  
Down syndrome?**



**down syndrome**  
VICTORIA

## About Down syndrome

Down syndrome is the world's most common chromosomal disorder and cause of intellectual disability. It is not an illness or disease, and occurs at conception. It occurs in one of every 700 to 900 births worldwide and affects people of all ethnic and social backgrounds. In Victoria, 45 to 65 babies are born each year with Down syndrome.

The human body is made up of millions of cells, and each cell there are 23 pairs of chromosomes, or 46 chromosomes in each cell. Down syndrome is caused by the presence of an extra chromosome, chromosome 21 (Down syndrome is also known as trisomy 21). People with Down syndrome therefore have 47 chromosomes in their cells instead of 46. This results in a range of physical characteristics, health and development indications and some level of intellectual disability. Down syndrome is usually recognisable at birth and confirmed by a blood test.

Down syndrome affects, but does not determine, development. People with Down syndrome are unique, with their own talents, abilities, thoughts and interests. Everyone with Down syndrome will experience some delay in all areas of their development, and some degree of learning disability. This will however vary significantly from individual to individual. What happens after birth will be far more important in shaping the outlook for any individual with Down syndrome than the presence of an extra chromosome.

With appropriate health and education services, and with the support and opportunities available today, people with Down syndrome can look forward to long and fulfilling lives as valued contributing members of their families and the broader community.



**Each person with Down syndrome is unique, with his or her own personality, talents, abilities, thoughts and interests.**

## The power of language

An individual's quality of life is dependent on their ability to fully participate in community life. Words, and the way we communicate, profoundly influence acceptance and participation. Language can empower individuals or can reinforce unhelpful stereotypes.

Communication should be based on respect. To ensure your communication with and about people with a disability is positive and inclusive please:

**Put the person first, not their disability.**

Please use "a person with Down syndrome" or "a person who has Down syndrome".

**Avoid stereotypes and labels such as "the disabled".**

Statements which reinforce stereotypes and suggest that everyone with Down syndrome is the same may cause offence. It is also important to remember that people do not "suffer" from Down syndrome. Other phrases that imply the same thing such as "a victim of" or "afflicted by" should also be avoided.

Avoid using words and phrases that can be demeaning.

People with Down syndrome are not "special", "poor" or "unfortunate". They are individuals who should be afforded the same dignity and respect as everyone else.

By using appropriate terminology and encouraging others to do the same, you are actively seeing the person first and respecting their individuality as more important than their disability.

For further information please refer to *Inclusive Consultation and Communication with People with a Disability* available from the Office for Disability.