

Down Syndrome in New Zealand



Support

Include

Educate

Celebrate



**A brief introduction
to Down syndrome &
the New Zealand Down
Syndrome Association.**

About The New Zealand Down Syndrome Association

The New Zealand Down Syndrome Association is a family/whānau-driven organisation

VISION

People with Down syndrome are respected, valued and equal members of their community fulfilling their potential and aspirations.

MISSION

Support, inform and advocate alongside people with Down syndrome, families, whānau and professionals.

Aims

The primary aims of the Association are:

- To inform and support families/whānau of people with Down syndrome.
- To promote and advocate for positive attitudes in the wider community.
- To further the understanding of Down syndrome.
- To promote the rights and inclusion of people with Down syndrome.
- To review policies and lobby government and other institutions.
- To promote positive public awareness through educational and media initiatives.
- To promote STRIVE – our self-advocacy leadership group.

Objectives

The Association was established for educational and charitable objectives and purposes within New Zealand only. The Association was established:

- To promote the welfare of people with Down syndrome and their families/whānau.
- To provide up-to-date information that is accessible to families/whānau, particularly new parents and other interested parties.
- To publish a quarterly journal.
- To provide information to medical practitioners, students, educators and community organisations, to enhance their interactions with people with Down syndrome.
- To provide ongoing links with and among families.
- To establish and maintain relationships with other disability organisations.
- To respond to political and social issues by making submissions to government bodies and through the media.
- To initiate and manage projects that will have a direct benefit to people with Down syndrome and their families/whānau.
- To maintain links with international Down Syndrome Associations to ensure flow of current knowledge and information.
- To do any other legal and lawful acts to attain these objectives which are conducive to our mission statement.

What we do and provide

- We provide a New Parent information pack and connect with regional groups with volunteer support people for new parents providing face-to-face and/or telephone support. Regional groups can also offer opportunities for parents and families to connect, network and support each other.
- Where regional groups may not exist the NZDSA can offer support and opportunities to connect with families. Additionally, we have adult support and grandparent support contacts.
- 0800 number – 0800 693 724
- Website – www.nzdsa.org.nz
- Information and a variety of written and visual resources.
- Quarterly journal providing up-to-date information, real life stories, and a section for people with Down syndrome which is written by people with Down syndrome.
- Facebook page.
- Enews – email updates on upcoming events from around the country and the latest stories, news items and other items of interest to our community.
- Self-advocacy workshops and youth development camps for young adults with Down syndrome.
- Represent the interests of people with Down syndrome and their families/whānau across a range of forums and at Government level.

- Liaise with other disability groups to advocate for the rights of disabled people, or to advocate for improved disability services across the life span including education and health.
- Promote positive attitudes towards Down syndrome through forums such as awareness campaigns and media stories.

Please visit our website for membership, resources and further information.

nzdsa.org.nz

What Matters Most



A positive attitude

- Your attitude can make a difference to the lives of people with Down syndrome.
- With a positive accepting attitude, you will be able to include people with Down syndrome in everyday life and overcome any challenges.
- Let's aim to make New Zealand a place where people with Down syndrome can say they are accepted as individuals and live in a society where they feel valued and included.

See the person rather than Down syndrome

- This book is a general guideline.
- People with Down syndrome are individuals, just like anyone else, with their own likes and dislikes, achievements, interests and personality.
- Don't blame everything on Down syndrome. Their traits and behaviours are part of their individual character.
- Always say 'people with Down syndrome' not 'suffering from Down syndrome' or 'Down's people.'

"My 3-year-old was having tantrums. I asked some mothers whether it was because he had Down syndrome. They said, 'no it's because he's a toddler'".

"My child's new teacher said "I've taught 'Down syndromes' before". My reply was "Yes but you have not taught my child".

"I was picking my daughter up from school one day when a mother said to her daughter "I see you have a little girl with Down syndrome in your class". The girl said, "No that's just Lily".

"My son went to a scout camp. He had a wonderful time on the flying fox, on the minibikes, abseiling and doing what everyone else was doing but more important to us was he felt he belonged and was accepted".

First Questions



What is Down syndrome?

- Down syndrome is a life-long condition that may cause delays in learning and development.
- Down syndrome cannot be cured but with early intervention and the right support networks a child with Down syndrome can flourish.

Why does Down syndrome happen?

- Down syndrome occurs when a person's cells contain an extra chromosome number 21.
- Down syndrome is never anyone's fault, it just happens.
- It has never been linked with foods, actions or pollution and it occurs in all races and religions.
- In New Zealand, approximately one baby in about 1000 is born with Down syndrome; that is one or more babies born every week.

What are the features of Down syndrome?

Firstly remember:

- Each person is unique with different features.
- People look like the rest of their family. The Down syndrome accounts for only a few of their looks.

- The abilities and achievements of people with Down syndrome are not linked to their appearance.
- However, there are some common features which may include:
 - Low muscle tone (hypertonia is the medical term) and flexible joints.
 - Excess skin on the back of the neck.
 - Almond-shaped eyes.
 - Small ears.
 - A single crease across the palm of the hand/s.
 - A gap between the big toe and the second toe.
 - The nasal bone may be flatter than usual.

People with Down syndrome

- Like all children, children with Down syndrome will learn and develop. Their development can be enhanced with specialist therapy and additional help at school.
- People with Down syndrome are participating members of their families and their communities and can contribute to society.

History



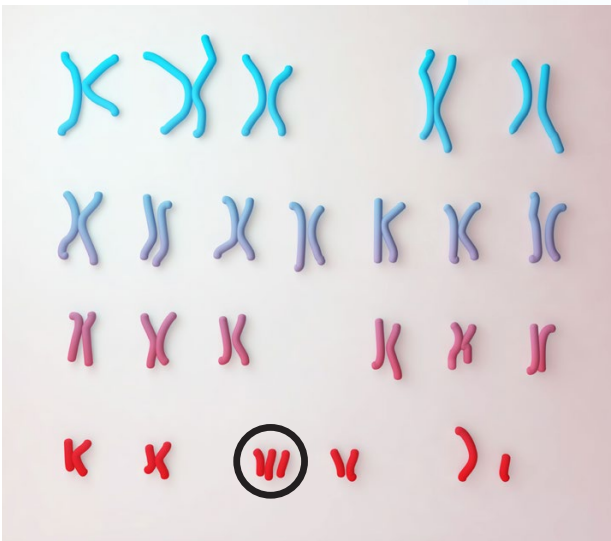
Why is it called Down syndrome?

- People used to think that all people with learning disabilities were alike. Doctor Langdon Down was the first to divide people into groups by their unique features.
- In 1866 he wrote about the features of Down syndrome. He noticed the shape of the face, the tendency to get infections and that people with Down syndrome were able to learn and are good at copying others.
- In 1961 leading geneticists suggested to Lancet medical journal that the condition should be called Down's syndrome to honour Langdon Down. This has been simplified to Down syndrome.

What causes Down syndrome?

It took almost a hundred years after Langdon Down's description of Down syndrome to find a cause.

- In 1959 Jerome Lejeune in Paris and Patricia Jacobs in Scotland studied chromosomes. They discovered that people with Down syndrome had an extra chromosome 21. It was the first time that a disability and a chromosome disorder had been linked and is now just one of many chromosomal disorders in the world.
- Lejeune believed this information would lead to a cure for Down syndrome. He was disappointed that it led in 1968 to ante-natal diagnosis by chromosome analysis and the possibility of aborting babies with Down syndrome. Before his death in 1994 he said, "I was the doctor who was supposed to cure them and as I leave, I feel I am abandoning them."
- In 2000 the complete DNA sequence of chromosome 21 was discovered showing that there are around 350 genes on the chromosome.
- Research about Down syndrome still continues today.



Chromosomes and Inheritance

What chromosomes do most people have?

- Cells of the body have 22 pairs of chromosomes and 2 sex chromosomes, 46 chromosomes altogether.
- One chromosome of each pair comes from the mother and one of each pair from the father.
- The pairs are arranged by size. Chromosome 1 is the largest and chromosomes 21 and 22 are the smallest. The sex chromosomes are called X and Y.
- Chromosomes can be seen with a microscope during a chromosome analysis test. Test results are 46XX for females (this means there are 46 chromosomes including two X chromosomes) and 46XY for males (this means there are 46 chromosomes including one X and one Y chromosome.)



What about people with Down syndrome?

People with Down syndrome have either a complete extra chromosome 21 or a partial copy of chromosome 21.

There are three types of Down syndrome:

1. The most common type is Trisomy 21 which occurs in about 95% of people with Down syndrome and means all cells will have three complete copies of chromosome 21.
2. Translocation Down syndrome occurs in about 4% of people with Down syndrome. There are only 46 chromosomes, but one is extra long and has an extra chromosome 21 stuck to it. People with translocation Down syndrome have the same features as people with Trisomy 21.
3. Mosaic Down syndrome occurs in about 1% of people with Down syndrome. Some cells will have the extra chromosome 21 and some will not. People with Mosaic Down syndrome may have fewer physical features, medical problems and learning difficulties.

Is Down syndrome inherited?

- Trisomy 21 and Mosaic Down syndrome are not inherited, it occurs spontaneously and randomly.
- The chance of having another baby with Down syndrome is very small, only slightly higher than usual.
- Other family members (the baby's sisters, brothers, aunts, cousins, etc.) do not have an increased chance of having a baby with Down syndrome.
- Very few people with Down syndrome have been known to have children. If they do have children, the chance of them having a baby with Down syndrome is high.
- Translocation Down syndrome can be inherited but it can also be spontaneous.

Our Resources

An overview of some of the online resources currently available in the NZDSA's resource library.

Living with Down syndrome

Downloadable PDF
Providing you with a greater understanding of Down syndrome.

Little One

Downloadable PDF
From parents who have gone before you.

Creating a positive hospital experience

Online video
Creating positive hospital experiences.

Plan for the future

Online video
Empowering individuals and their families to positively take the step from school into adult life.

Turn the page with me

Online video
How to support your child's literacy development from birth to school.

Learn through play & daily routines

Online video
How to support your child's development through play and routines.

Transition to School

Online video
An overview of parents' and educators' perspective on the transition process.

Emergencies

Downloadable PDF
How to navigate accidents and emergency care.

Antenatal Testing

Downloadable PDF
Antenatal testing and Down syndrome.

Tips for Health Professionals

Downloadable PDF
Some useful tips for conversations with parents.

Dress to Impress

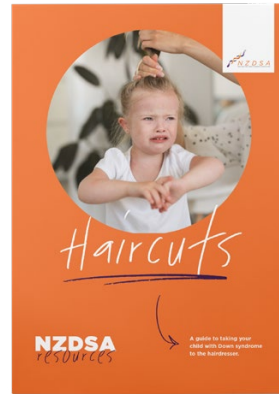
Online video
Learn what to wear and how to wear it.

Power of Attorney

Downloadable PDF
How power of attorney in New Zealand works.

Mental Health

Downloadable PDF
A guide on mental health issues and Down syndrome.



Coeliac Disease

Downloadable PDF
What you need to know about coeliac disease.

Hospital Stays

Downloadable PDF
A guide on what to expect when a child's in hospital.

AAI

Downloadable PDF
Navigating AAI in people with Down syndrome.

Haircuts

Downloadable PDF
Taking your child with Down syndrome to the hairdresser.

Hearing Tests

Downloadable PDF
Navigating hearing tests for under ones with Down syndrome.

Vision

Downloadable PDF
A guide to vision disorders common in people with Down syndrome.

Toilet Training

Downloadable PDF
How to toilet train your child with Down syndrome.

Independence

Downloadable PDF
Teaching your child with Down syndrome how to be independent.

Home Alone

Downloadable PDF
When you could be letting your teen stay home alone.

Nutrition

Downloadable PDF
A guide to nutrition — including some important extras concerning children with Down syndrome.

Down syndrome & Autism

Downloadable PDF
Helping parents who may be concerned about Down syndrome and Autism.

Lunchboxes

Downloadable PDF
Tips and tricks from other NZDSA families on school lunches.

Tongue Protrusion

Downloadable PDF
A guide to tongue protrusion in people with Down syndrome.

Hearing Aids

Downloadable PDF
Navigating hearing aids for people with Down syndrome.

Behaviour

Downloadable PDF
How to support appropriate behaviour and communication.

Glasses

Downloadable PDF
Visual development in children with Down syndrome and how to get them used to wearing glasses.

Wandering

Downloadable PDF
Strategies for children with Down syndrome who wander.

Decisions

Downloadable PDF
How to support someone with Down syndrome with making decisions.

Please note that this is not a full list of our resources and we continue to add more... head to nzdsa.org.nz to view our updated resource library.

Assist

Welcome

Promote

Empower

NZDSA
resources

Want to know more?

The NZ Down Syndrome website can provide more information and link you to many more articles and organisations.

www.nzdsa.org.nz



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