



LIVING WITH DOWN SYNDROME

**Whatever your
reason for reading
our booklet, we
hope it will give
you a greater
understanding of
Down syndrome**

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About The New Zealand Down Syndrome Association Inc

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

VISION

People with Down syndrome are valued and equal members of their community, fulfilling their goals.

MISSION

To work alongside families, whānau and carers to support and empower people with Down syndrome to realise their potential and aspirations through all life stages and within all communities.

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 – 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.
- Representation on the Disability Consumer Consortium which informs and advises the Ministry of Health Disability Support Services on policy and service provision.

- 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

We acknowledge Angela Harper, Hannah Harper, Bronwyn Rydon and Annie Williams for the original Living with Down Syndrome booklet written in 2004. It was updated in 2020 by the then standing members of the National Committee.

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 the 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



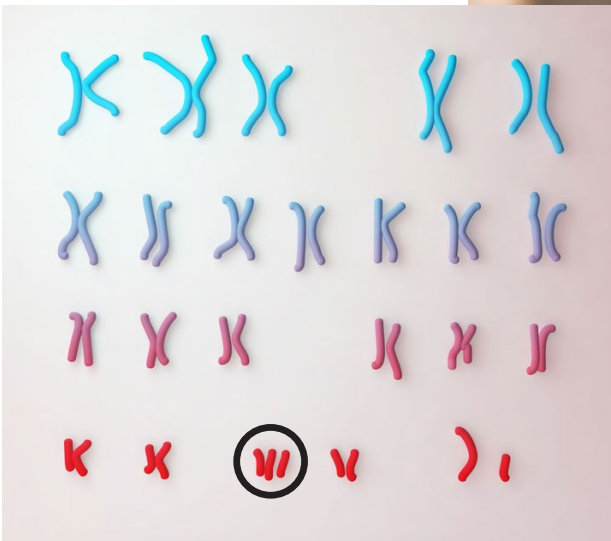
Why is it called Down syndrome?

- 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.
- He wrote “In all these patients one is able to trace a marked physiological and psychological agreement ... the face is flat ...the eyes obliquely placed ... the nose is small.”
- 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.



Health

- Certain medical conditions can be linked to Down syndrome and it can be overwhelming and rather scary to read about them.
- Not all people with Down syndrome have medical conditions. Many are born fit and healthy. However, it is important to know about potential medical conditions so that we don't miss treatable conditions which would make life harder for someone with Down syndrome.
- Like everyone else, people with Down syndrome may have a range of medical conditions and need the same medical care as everyone else and they will learn to adapt their lives around the condition.
- Some conditions occur more frequently in people with Down syndrome than other people. Sometimes we waste time worrying about them when in reality the condition is still fairly rare.
- Having annual health checks is important for treatable medical conditions associated with Down syndrome.



Health Conditions

Vision

- Often people with Down syndrome need glasses.
- Children with Down syndrome are more likely than other children to have squints and blocked tear ducts than other children.
- People with Down syndrome are more likely than others to have cataracts or keratoconus (thinning of the cornea).
- Seek advice from your optometrist or eye specialist on how often eye checks should be performed.

Hearing

- Most children with Down syndrome have too much fluid in their middle ear which can develop into 'glue ear'.
- This causes hearing loss (like listening underwater) which varies day by day.
- Many children need grommets; small tubes to drain the fluid.
- Hearing loss can also occur due to a problem in the nerves of the ear.
- Deafness that comes with age may start earlier in people with Down syndrome.
- Hearing should be tested at least every two years.

Atlanto-axial instability

- This is a weakness between the bones at the top of their neck and means that pressure on the neck could cause spinal cord injury.
- Whenever people with Down syndrome have surgery, anaesthetists should remember they could have atlanto-axial instability and take care when extending their necks.
- People with atlanto-axial instability may develop neck pain, have problems going to the toilet, drag their feet and have increased tone.
- The atlanto-axial instability is sometimes seen on special neck x-rays.
- People with atlanto-axial instability should avoid strain on the neck (e.g. diving or trampolining).

Growth

- Babies and children with Down syndrome grow more slowly than other children.
- Teenagers and adults with Down syndrome are generally short and may gain weight easily.

Immunity

- People with Down syndrome generally have poor immunity. They easily pick up coughs, colds and other infections.

Constipation

- People with Down syndrome may need medicines for this.



Skin

- People with Down syndrome may have dry skin which easily gets a mottled pattern.
- Some get boils.

Coeliac Disease

- Coeliac disease is a reaction to gluten. It causes bowel and growth problems and can be treated by a gluten-free diet.
- If coeliac disease is suspected, the person may have blood taken to test for specific antibodies that, if found, are suggestive of coeliac disease when other symptoms are present. A formal diagnosis is then confirmed by a small bowel biopsy.
- Some symptoms may include nausea or vomiting, irritable bowel symptoms, either diarrhoea or constipation, bone and joint pain, difficulty concentrating, Vitamin B12, A, D, E and K deficiencies, weight loss and skin rashes.

Autistic Spectrum Disorders

- Some children with Down syndrome may be on the autistic spectrum.
- Like other children with an Autism Spectrum Disorder they may have language, behaviour or social difficulties, which can be improved with specific therapies.

Thyroid

- Thyroid symptoms are often just put down to having Down syndrome.
- Most people with Down syndrome who have developed a thyroid condition have hypothyroidism (under active thyroid) but some can have hyperthyroidism (overactive thyroid).
- People with Down syndrome should have thyroid levels checked every year.

**Sleep Apnoea**

- People with Down syndrome may stop breathing for short periods when they are asleep. This can disturb sleep and cause tiredness and irritability during the day.

Alzheimer Dementia

- Adults with Down syndrome have a higher chance than others of this and it may start at an earlier age.

High pain threshold

- People with Down syndrome often don't make a fuss even when they are badly hurt.

Leukaemia

- Pre-schoolers with Down syndrome have about a 1% chance of developing this, often acute megakaryoblastic leukaemia, which is very rare in other children. It usually responds well to treatment.



Congenital Disorders

Congenital disorders

- Just over half of children born with Down syndrome are born with a health issue; usually a congenital disorder of their heart, bowel, eyes or blood.
- These are never anyone's fault or due to anything a mother did or didn't do during pregnancy.
- Information from years ago may not be relevant and you should always seek out information from the last five years.
- Treatment and outcomes for babies has improved dramatically.

- Congenital disorders can often be totally corrected by surgery and cause no further problems.

Congenital heart disorders

- Sometimes babies with Down syndrome seem perfectly well but have major heart defects, which can lead to serious problems if not treated.
- It is very important that all babies with Down syndrome have their hearts checked carefully soon after birth by an echocardiogram. Echo is short for echocardiogram; an ultrasound scan of the heart.



Echocardiograms show that:

- 55% have a healthy heart with no defect.
- 20% have a severe and unusual atrioventricular septal defect (AVSD). These can almost always be operated on successfully with open-heart surgery.
- 25% have another heart defect, usually a form of 'hole in the heart'. Some are minor and need no treatments, others need surgery.

“We found out about our son’s heart defect when he was three days old. He was given a routine echocardiograph. The results were not good; a complete atrioventricular septal defect. The term was completely foreign to me. He was my eighth child; all the rest had been completely ‘normal’. I had a lot to learn. Any sadness I felt at this baby having Down syndrome paled significantly when I found out about his heart. I just wanted my child to live and I knew I would love him”

“We are really celebrating the successful closure of the hole in our four-year old’s heart. She’s home with energy to burn, running, climbing, laughing, talking - it’s just wonderful”.

Other congenital disorders

- About 10% of babies are born with a bowel disorder, usually duodenal atresia, imperforate anus, Hirschsprung’s disease or trachea-oesophageal fistula. All these disorders cause blockage in the bowel, so the babies are often very unwell and need to be in a neonatal intensive care unit. They often need major surgery.
- A few babies are born with congenital cataracts. If untreated, vision cannot develop properly.
- Babies often have unusual blood results at birth and about 10% have a transient form of leukaemia.

“For at least the first 14 days of his life, we as a family were embroiled in our son surviving his initial health problems, which entailed a bowel operation at 5 days old. This directed our thoughts and feelings towards his survival, rather than dwelling on him having Down syndrome”.

Antenatal Testing

Position Statement on Prenatal Screening for Down syndrome

The New Zealand Down Syndrome Association believes that people with Down syndrome have a right to life.

- We value babies, children and adults with Down syndrome.*
- We believe people with Down syndrome lead full and satisfying lives and enrich the lives of those around them.*
- We provide support and information to parents, whānau and people with Down syndrome.*
- The NZDSA advocates that the primary goal of prenatal screening should not be to reduce the birth prevalence of Down syndrome in the population, but rather to improve prenatal health care and delivery care for the mother and baby.*

The NZDSA respects the rights of parents and realises that parents need to choose whether to decline or engage in prenatal screening and that this decision is influenced by a complex interplay of factors.

If parents choose to have prenatal screening, the NZDSA believes that screening must be presented in a way that does not discriminate against people with Down syndrome. In addition, people must not be pressured into having prenatal screening for Down syndrome. The screening process must include the following:

- Non-directive counseling.*
- Support and up-to-date information about Down syndrome for parents.*
- Information about prenatal screening must be available and this should include accuracy,*

waiting time for results and associated risks of further testing.

- Professionals involved in prenatal screening must have up-to-date information about Down syndrome and the lives of people with Down syndrome.*

Position Statement on Termination.

The New Zealand Down Syndrome Association does not consider Down Syndrome in itself a reason for termination.

The NZDSA first adopted a position statement on prenatal testing for Down syndrome in 2004.

Following a number of reviews, the current position statement was adopted in April 2012 and reviewed again in April 2019.

Antenatal Tests (sometimes called Prenatal tests) are screening tests that aim to detect whether a baby might have Down syndrome or some other rare chromosomal condition. Antenatal screening tests are generally offered to pregnant women toward the end of the first trimester at 10-13 weeks of pregnancy although a screening test is available that can be done as late as 20 weeks of pregnancy.

If a screening test result indicates there is a higher chance the baby could have Down syndrome, then a diagnostic test will be offered to the mother.

Antenatal screening tests only test for a very small number of congenital conditions and therefore do not guarantee the baby will not have any disability. There are many more conditions or disabilities that the baby could have, as all babies/children are at risk of a disability both pre- and post-birth.



Antenatal Tests Are Optional

- NZ law requires that people are fully informed and give informed consent.
- This means that women should have a full understanding of what the tests are for and what the results mean before deciding whether to do the tests or not.
- It is the woman's choice whether she wants to do screening tests or not.
- Some people think the tests, especially 'the 12-week scan' are a routine part of pregnancy, when in fact it is one part of the first trimester screening tests.
- Women should consider whether they want antenatal screening before having this and other tests.
- To be able to choose whether to have the tests, women should be given information about the test and information about what choices they will be given if the test gives an

increased chance of Down syndrome.

- Women should also be given information about Down syndrome which does not just give medical information but also gives information about the lives of people with Down syndrome.
- It is good to take some time to think about whether to do the tests or not.

Why choose to have Antenatal Screening Tests

- Some families decide they want to know whether or not their baby has Down syndrome.
- Some have the screening tests expecting reassurance that their baby is unlikely to have Down syndrome.
- Some will have the tests because it is offered and think it is routine, without considering it much at all.



Why choose not to have Antenatal Screening Tests

- Some families decide that they will love their baby regardless of whether they have Down syndrome or not, so see no reason to have the tests.
- Some women do not want to be put under pressure to have diagnostic tests if an increased chance of Down syndrome is given because they would not want to risk miscarriage in any circumstance.
- Some families have cultural reasons for deciding not to have antenatal tests.

The woman's decision should be respected by health professionals and others and she should not be put under any pressure to make one choice or the other. She must do what she feels is right for her.

More Information

The Ministry of Health's National Screening Unit puts out an information brochure to provide information to help women make the decision whether to have screening tests or not.

Ask the midwife for a copy or search it online using either the ISBN number ISBN 978-0-478-19368-8 or visit our website to download.

What are Antenatal Screening Tests

Antenatal Screening Tests calculate a woman's individual chance or risk of having a baby with Down syndrome or one of the other screened conditions, and only say if the chance is high risk, or low risk. Screening tests do not give a definite yes or no.

Screening tests are non-invasive, meaning they are safe for the baby. If a result is high risk a woman will be offered diagnostic testing.

There are a variety of screening tests. Some are funded by the Government and others may only be available if you pay privately. Your Lead Maternity Carer (LMC), who is usually a Midwife, can advise you about the tests and what regime is funded.

NT Scan:

This is an ultrasound scan of the baby that measures the fluid-filled nuchal space at the



back of the baby's neck. This is called the Nuchal Translucency (NT). This scan is offered in the first trimester.

- The NT measurement is ideally taken at 12 weeks of pregnancy, but it may be done between 11 weeks 2 days and 13 weeks 6 days.
- Risk results are no longer provided on NT scans alone as it is less accurate than other screening regimes. The NT scan is now only used in combination with the MSS1 calculation.

First trimester combined screening (also known as MSS1)

MSS1 stands for Maternal Serum Screening (a blood test from the mother) which is taken in the first trimester and uses the results of 2 blood markers. These blood results are then combined with the NT scan measurements. This screening is offered if you are less than 14 weeks pregnant.

- The best time for the blood test is between 9–10 weeks pregnant, but it can be done up to 13 weeks and 6 days pregnant.

- The laboratory computer combines the blood test and scan results with other information, such as maternal age and weight, to work out the chance of the baby having Down syndrome or another of the screened conditions.
- This blood test detects 80–85 % of babies with Down syndrome.
- The blood test is free, however, the scan is only free in some areas or it may incur a part-charge in other areas.

Second trimester maternal serum screening (also known as MSS2)

MSS2 is a blood test taken from the mother and uses 4 blood markers, there is no scan. This screening is offered if the mother engages with antenatal services too late for first trimester screening and is 14–20 weeks pregnant, or when the mother prefers not to have ultrasound scans of her pregnancy.

- The best time for MSS2 is at 14–18 weeks pregnant, but it can be done up until 20 weeks of pregnancy.



- Again the laboratory computer combines the results of the blood test with other information, such as age and weight, to work out the chance of the baby having one of the screened conditions.
- Accuracy levels are said to be about the same as MSS1 combined screening.
- This blood test is free.

Non-Invasive Prenatal Testing (or Screening) – NIPT (or NIPS)

This is a newer blood test which is different to MSS1 or MSS2. It uses cell-free fetal DNA found in the mother's blood to identify chromosomal conditions.

- The NIPT can be done any time from 10 weeks of pregnancy.
- This screening is said to be 99+% accurate for Down syndrome.
- This blood test is expensive and is not currently Government funded (as at 2020).

What does a high or increased risk screening result mean?

- For MSS1 and MSS2 screening, a result of 1 in 300 or higher is given as an increased chance or high-risk result.
 - For example, a 1 in 200 chance would be given as a high-risk result and means that there is one chance in 200 that the baby has Down syndrome. A result of 1 in 400 would mean there is less chance the baby has Down syndrome and would be classed as low risk.
- A high-risk result does not mean the baby has Down syndrome. Only a few (approximately 5%) of mothers with a high or increased chance screening result will actually be carrying a baby with Down syndrome. That means 95% of mothers identified as high risk will not have a baby with Down syndrome.
- When an increased chance result is given, the mother is offered referral to a specialist and

will be offered diagnostic testing. It is the mother's choice to accept the referral or not.

- Sometimes a high-risk result may be associated with an increased risk of pre-eclampsia, or low birth weight, or prematurity, or the baby may have a heart condition.

Does a low risk screening result always mean NO Down syndrome?

- No. Although 80% or more of babies with Down syndrome are identified by MSS1 or MSS2 screening there are always some babies that are not picked up by the screening.
- NIPT is 99% accurate that the baby does or doesn't have Down syndrome.
- Only diagnostic testing can tell for sure whether the baby has Down syndrome or not.

Diagnostic Tests

- Diagnostic tests are offered to women who receive an increased chance screening result.
- Diagnostic tests will tell for sure if the baby has Down syndrome or another chromosomal condition.
- Diagnostic tests cannot tell how the baby will be affected by that condition or the range of abilities the child will have.
- It is the mother's choice whether to accept diagnostic tests.
- Parents should ask as many questions and take as much time as they need before deciding whether to have the diagnostic test.
- Before deciding, a mother should have access to more information about the tests and the risks associated with the test. She can be provided with information about the identified condition and advised how to contact support groups such as the New Zealand Down Syndrome Association. She should also consider her cultural values and what she would do if the diagnostic test identifies the baby as actually having Down syndrome or another condition.
- There are 2 diagnostic tests, both are done under ultrasound guidance and take samples to look at chromosomes from the baby's cells to find out if the baby has Down syndrome or another condition.

- Chorionic villus sampling (CVS) is done before 14 weeks and takes a sample of the developing placenta for analysis.
 - Amniocentesis - the most common test, is done after 14-15 weeks of pregnancy. This test draws a sample of the amniotic fluid (or waters around the baby) which contains the baby's cells that can then be used for analysis.
- Both tests carry a risk of miscarriage. CVS carries a slightly higher risk of miscarriage than amniocentesis but on average about 0.5 - 1.0% of mothers who have diagnostic testing will have a miscarriage. For this reason, some mothers may choose not to have diagnostic testing.

Receiving Results

- Results can take up to 2 weeks, and the specialist will provide the results of the diagnostic testing. If a result is positive for Down syndrome, support and information is to be given to help the mother make decisions that are right for her.
- The mother should be given as much time as she needs to consider her options and make decisions.
- The mother should not be put under any pressure to make one decision over another.
- The New Zealand Down Syndrome Association welcomes calls from parents who are seeking more information.

"It is difficult to know what we would've done if we knew about Kirsty during pregnancy. It worries me that people are making choices that are not fully informed. I suggest parents with a positive result of Down syndrome meet with existing parents and children. Antenatal testing does not guarantee perfection! All children pre- and post-birth are at risk of a disability".

Learning





People with Down syndrome have a learning disability, but this does not mean they cannot learn. In the past, expectations were often low and people with Down syndrome often had very limited opportunities. However, in the last generation, expectations for people with Down syndrome have increased dramatically. They are now expected to learn and contribute to society.

- They now live with their families rather than in institutions.
- They attend school with everyone else.
- Their health needs are better managed.
- They have more opportunities.

This has led to achievements far higher than previously thought possible, for example people with Down syndrome usually learn to read and write. With support, many get jobs and live independently. They continue to learn into their adult lives.

Areas of development

Learning is often divided into:

- Gross motor skills - big movements like walking.
- Fine motor skills - small movements like writing.
- Language - understanding others, communicating with others and being able to speak.
- Social skills - getting along with other people and behaving in an acceptable way.
- Cognitive skills - being able to solve problems and think.
- Although people with Down syndrome have some learning disability, we should never forget that each individual is different with their own strengths and weaknesses.
- People with Down syndrome have delays in all areas of development - speech and language have the most delay and social skills have the least delay.

To Help Learning



Think ahead

- What skills will be useful in everyday life for the person you support?
- Remember social skills may matter more than academic skills.

Minimise weakness

Motor skills

People with Down syndrome:

- Have low tone in their muscles, commonly known as 'floppy' but known medically as hypotonia which means balance can be more difficult and they will tire easily.
- They tend to have short arms, legs and fingers which may make movement and using usual equipment harder.

So, we should:

- Try to stop unusual movements or posture which may harm their joints and make future development harder.

- Provide supportive furniture and easy-to-use pens and other equipment. Then they can concentrate on their learning rather than their motor problems.
- Consider orthotic aids.

Language

People with Down syndrome:

- Understand more language than they can produce.
- Usually find it hard to learn through listening.
- Often find speaking hard. Speech may not be clear. They may use key words not long sentences.

So, we should:

- Judge their learning through other skills not by their speech.
- Chat to them as we would anyone else.
- Only give one instruction at a time and try to back it up visually.
- Use sign language.



- Engage in speech language therapy.
- Engage with an early intervention provider.

Cognitive Skills

People with Down syndrome:

- May not automatically learn skills just by exploring things around them.
- May not think quickly or in complex ways.
- May often have a poor short-term memory.
- May find new and unfamiliar situations difficult.

So, we should:

- Plan to teach each skill they need and how to use it in different situations.
- Teach in small steps with repetition.
- Be consistent in the language we use and the way we teach something.
- Have patience. Wait... for a response.

Work with strengths

- Many people with Down syndrome have good social skills.
- It is easy to forget how important people skills are.
- Social skills can be more important than academic skills in helping adults to have a good everyday life and be part of their community.
- People with Down syndrome often learn best working directly with other people.

So, we should:

- Set learning situations up for success.
- Guide people with Down syndrome to make the right choices and praise them often. This is known as 'errorless learning'.

Learn through their eyes

- Many people with Down syndrome are visual learners so it helps if we use pictures to support other ways of learning.
- Using sign language may help with general language development.
- They may find it quite easy to sight read.
- They learn more easily by copying someone else rather than listening to instructions.

“My son went straight from breastfeeding to drinking from a normal cup. Why bother to teach him to drink from a sipper cup in between”.

“The school got new equipment for my daughter. Her handwriting is much better now her feet can touch the floor, her desk slopes and she has a pen that is easy to use”.

“We made a step-by-step picture sequence to show at bath time. It took a lot of practice but now he manages all by himself”.

“I was teaching my daughter to write letters of the alphabet. It was hard work doing it in the order the book suggested but she loved it when instead we did the letters in her name, which she already recognised”.

Early Days



Finding out

- Families never forget the moment they find out their baby has Down syndrome.
- They react in many ways and any way is OK.
- Most families go through a grief process but mixed with this are feelings of love and joy for their baby. Expect emotions to fluctuate.

Family and friends

The support of friends and relatives is very important. They can help by:

- Just being there.
- Offering congratulations, cuddling the baby and buying gifts.
- Cooking and giving practical help.
- Following the family's lead and understanding that sometimes they need to talk about Down syndrome and sometimes they need to talk about something totally different.

Development

- Babies with Down syndrome benefit from Early Intervention. Therapists (e.g. speech language therapists, physiotherapists and early intervention teachers) and the family help the baby learn through play.
- Therapists help children to be fully included in an early childhood setting and help plan the transition to school.
- Families learn skills and exercises to help development.
- Sign language can assist children with Down syndrome communicate and help develop speech.
- Milestones may take longer to achieve.

“At times my tears were unstoppable and appeared for no reason. At the same time my new daughter gave me strength, joy and happiness.

When I told my friend she said, “I don’t know what to say” and that was the best thing she could have said. I didn’t want her to know all the answers, I just wanted her to listen”.

School Days

Attitudes

- Attitudes have changed dramatically in New Zealand with the introduction of the Education Act of 1989 which says, “People who have special educational needs (whether because of disability or otherwise) have the same rights to enrol and receive education in state schools as people who do not.”
- Today the Government wants “children with learning support needs to be welcome at their local schools.”
- Families can send their child with Down syndrome to any state school of their choice (if in zone).

Support

- Children with Down syndrome usually need extra help at school:
 - The curriculum often needs to be adapted to suit them.
 - They may need special equipment.
 - They usually need a teacher aide to work with them for some or all the school day.
- Most children with Down syndrome get funding for this through Ongoing Resourcing Schemes (ORS).
- Each child has an Individual Education Programme (IEP) to set goals for learning and monitoring progress. The IEP is developed by the child’s family, teachers and relevant specialists.

Inclusive education

- Many children with Down syndrome attend local schools with other children in their community. This is called inclusive education or inclusion.

- **Inclusive education helps children with Down syndrome have an ordinary life, going to school like their brothers and sisters and other local children.**

- They learn from the other children and other children learn from them, as they learn that the world is made up of all sorts of people and they learn to accept differences.
- Ongoing research has shown that children with Down syndrome in inclusive education have higher academic levels than those in special schools.
- Inclusive education needs proper funding and support which should come through the Ministry of Education.

Other settings

- Some areas of New Zealand have special schools or units and some families choose this kind of education for their child.
- Other families choose correspondence schooling or home-schooling for their child.

Out of school activities

- School age children with Down syndrome can often be included in many of the same activities as other children. Examples can include scouts, girl guides, sports groups and other sporting events.
- There are also other organisations that provide activities for children with additional needs e.g. Special Olympics.



“Mainstreaming meant my son was in his local community and mixing with other children from the area. He could walk to and from school. He copied typical children’s behaviour – good and bad – and he gained knowledge and skills”.

“I went to a surprise birthday party the class were putting on for my daughter at her mainstream secondary school. In the middle of the table sat a lovely big cake made especially for her. The students had made her favourite foods, pizza, waffles, sausage rolls, ice cream and fancy biscuits. My daughter was so pleased with everything. They all sang happy birthday to her – big smiles all round. It’s so positive to see the interaction in the classroom and know that these kids all accept her special needs, are interested in what she is doing and delight in her achievements. I left with a lump in my throat”.

“I guess through my daughter’s education the clear lesson has been to evaluate, re-evaluate and feel free to follow what is best for your child. There are several educational options for children with special needs. Each option will affect your child differently. As children develop, the educational setting may vary as well”.



Growing Up

Teenagers

- Like other teenagers, teenagers with Down syndrome may become moody and develop different interests and values from their parents.
- Puberty occurs at around the same age as other children, sometimes slightly earlier.
- Friendships between children with Down syndrome and other children may alter or stop as they become teenagers.
- Typically developing teenagers may be embarrassed about having a friend or brother or sister with Down syndrome. Usually this resolves in a few years into an accepting relationship.
- During teenage years the need for people with Down syndrome to also have friends with intellectual disabilities becomes important. Local groups like Down syndrome support groups or Special Olympics may be valuable.
- Young people with Down syndrome can usually remain at school until the age of 21, if they wish.
- Education should provide both academic and life skill opportunities to help with the transition to adult life and work.



Adult Life

- Adults with Down syndrome need opportunities and experiences in work, education, recreation and social activities.
- People with Down syndrome continue learning into their adult life. They don't stop learning as people used to think.
- People with Down syndrome live much longer than they used to. It is important that they get good health care and are monitored for conditions common in Down syndrome.
- Some adults are part of the workforce and live independent lives in their communities. Many more people with Down syndrome are capable of this.
- Vocational support services can help adults find paid or voluntary work, continue their education or find leisure activities.
- People with Down syndrome often need their income to be supplemented by benefit allowances. They may get other benefits to assist with living and health costs. Benefits come through Work and Income New Zealand (WINZ)
- Adults with Down syndrome may choose different living arrangements which could include flatting, own their own home, live in a supported living environment or live at home with their parents or other family members.
- Relationships and sexuality are important to everyone. People with Down syndrome may need support to maintain loving and safe friendships or sexual relationships.

*Always remember
With the right opportunities adults, with Down syndrome can work, have relationships and live where they choose.*





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Want to know more?

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

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