MYTHS & FACTS

ABOUT DOWN SYNDROME

DOWN SYNDROME
NEW SOUTH WALES

THE Inclusion
INSTITUTE

CEO *Message*

We are pleased to develop a range of booklets for our community across key topics and areas of interest, covering the full lifespan and proudly codesigned with people with Down syndrome, parents and siblings to share lived experience insights and evidence based information.

In this booklet, we explore a range of myths and facts about Down syndrome that we are often asked or that we often hear. We share some key myths and deliver facts that many may not know. In doing so, we hope to raise awareness and promote inclusion for our loved ones with Down syndrome to be valued and active contributors within their thriving, diverse and inclusive communities.

We are humbled to have Amelia Burfitt share her expertise as well as her lived experience as a wonderful parent. We are so grateful for her contribution to bring this to life.

We trust you enjoy this resource and learn more about Down syndrome along the way. We are here with you, at every stage.

Emily Caska, CEO Down Syndrome NSW

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NEW SOUTH WALES

“Awareness” is more that just understanding that something exists. It’s about learning the truths behind a condition, rather than believing the common misconceptions that are often told and shared. In that vein, we’ve created some fun facts about Down syndrome, supported by research where possible. So many parents have been convinced of many myths and outdated ideas about Down syndrome.

Wife, mother of 3, Health Manager and Blogger *Amelia Burfitt* shares a couple of common myths you may have heard!

Myth 1.

Parents are more likely to divorce if they have a Child with Down syndrome

Divorce rates are actually lower in families of children with Down syndrome, as found in a recent study. A large study (one of the largest to date!) done in 2008, by the Vanderbilt Kennedy Center and published by the in the American Association of Intellectual Disabilities found that divorce rates are lower in families of children with Down syndrome than in the group that had non-disabled children.

So many people have been told their relationship will suffer if they were to go ahead with a pregnancy. Many people assume that given the challenges that may come, this is what will happen to their marriage or relationship if they have a child with Down syndrome. What great news for couples facing this unexpected news in their path to becoming parents.

Myth 2.

Children with Down syndrome are only born to older parents

The majority (around 80%) of children with Down syndrome are born to women younger than 35.

The average age of women in Australia giving birth is around 30 years of age. So it makes sense most babies with Down syndrome are born to younger mothers, because that's when most people are having children!

However, the likelihood of having a child with Down syndrome years does gradually increase to a small extent with the age of the mother after the age of 35.

Whilst we're here - Down syndrome has nothing to do with what the parents did, or did not do. It is a total random episode that occurs at conception!

Myth 3.

People with Down syndrome cannot form relationships

People with Down syndrome are perfectly capable of forming all types of relationships (and experiencing all types of emotion) with people they encounter in their lives; be it friendship, love or enemies. You may be surprised to know that many adults with Down syndrome are in relationships, and it's becoming more common for them to get married.

Most adults want to find love and companionship. People with Down syndrome are no different. They feel the full range of emotions that anyone else feels. They definitely experience affection and love, and many express desire to find a partner and settle down.

Why should they be condemned to a life of being single, because they have Down syndrome, if that is not what they wish?

This is more than just what many see as a 'cute gesture between kids'. Adults with Down syndrome have every right to dating, marriage, housing, employment, education, and pretty much anything everyone else is entitled to about the future.

Myth 3.

It is well known in the non-disabled population that partnership and marriage have lasting benefits; leads to greater longevity, learning and improved memory, greater motivation, improved status and improved self-image. People with Down syndrome are entitled to these positive outcomes, and perhaps even more so.

Loneliness is very typical and a difficult experience for a lot of adults with disabilities. They have to work harder to live an ordinary life, and having a relationship can help by leaning on each others strengths.

We need to move towards viewing them as not just as adults with intellectual disabilities but as; people, individuals and as adults. It may come with certain hurdles. But if it means they need a little bit more support to make it happen, then we should give it to them. They should define their own lives.

If you google ‘couples with Down syndrome’ you will read many, many success stories of those making it work.

Myth 4.

People with Down syndrome cannot learn to read or write

The majority of children with Down syndrome can learn to read and write. Teachers who are well trained and have high expectations of their students have shown to have the best success. The more we expect, the more we will achieve.

Our kids with Down syndrome often learn in different conditions to typical kids (visual, sensory, via singing games etc). Historically we haven’t given them much of an education at all, so it’s no surprise that the outcome was they couldn’t read or write.

Before the 1980s, the overwhelming majority of people with Down syndrome were placed in institutions, often times as infants or young children. Because of neglect, abuse, and lack of access to education and

Myth 4.

medical care, people with Down syndrome would die an early death in these institutions and it was not blamed on institutionalisation, it was simply Down syndrome.

During this time most professionals considered it impossible for people with Down syndrome to learn how to speak properly, let alone read and write. They were not allowed to attend public schools and most people believed they should not be allowed in public spaces such as movie theatres, shopping centres or parks.

Fast forward and now, people with Down syndrome now live at home (versus an institution).

Their IQs have increased 20 points and the overwhelming majority will learn how to read and write. Most are attending school and some are graduating with a typical degree. There are a handful who have gone on to achieve college degrees. More and more are holding down jobs.

The more we expect, the more we will achieve.

Myth 5.

People with Down syndrome can't attend public schools

It is not only advisable that children with Down syndrome attend regular schools, it is required by law that it be available to them. If you want to check out the research, its overwhelming positive. For both disabled AND non disabled students. Studies show that including students in the classroom with disabilities improves academic progress of their non- disabled peers.

Children with Down syndrome are the greatest teachers of virtue. If you send someone away, or you don't take it upon yourself to nurture a child in your school environment – you have not only missed the greatest opportunity for that particular child - but also an opportunity to teach virtues to all the other children at that school who would have experienced immense intangible benefits.

Some children with Down syndrome go to regular schools, and some go to special needs schools. Which, should be decided because of the needs of the child, not the needs of the school or any opinions others may have.

Myth 6.

A child with Down syndrome will negatively impact their siblings

A recent study published in the Journal of Intellectual Disability Research found no significant differences between the siblings of the children with Down syndrome and the comparison siblings on the measures of behaviour or competence. They also found no differences in the children's own reports of their relationships with friends or with academic performance.

In fact, mental health professionals point to the psychological advantages – they have documented siblings who have increased tolerance, compassion and awareness, in contrast to all typical siblings. That's a pretty amazing benefit if you ask me!

Myth 7.

People with Down syndrome cannot have children

People with Down syndrome can have children. Women more easily than men, yet both appear to have lower fertility. However it is not impossible as there are cited cases of BOTH throughout the world.

The information about fertility in people with Down syndrome is very outdated and based on research in institutions where men and women with intellectual disabilities were kept apart.

Have you read about the gorgeous story of the Syrian man whose father has Down syndrome?

He talks so lovingly about how his father has inspired him, as well as worked incredibly hard to provide him with a good life. He, the son, does not have Down syndrome and is now studying to be a Dentist.

Myth 8.

All people with Down syndrome will develop Alzhiemer’s disease (dementia)

Believe it or not, the gene responsible for dementia is actually located in the 21st chromosome! As people with Down syndrome have a 3rd copy of the 21st chromosome they have 1.5 times the gene, making it more likely.

However! Not all people with Down syndrome develop Alzheimer’s. One study shows the number to be between 20-55% will develop the disease before the age of 50. 100% carry plaques and tables in the brain associated with the disease because the gene responsible for dementia is located in the 21st chromosome.

How many people with Down syndrome will actually develop symptomatic Alzheimer’s disease needs additional research as the most recent study was done in 1989, 31 years ago.

More importantly – how cool is it that people with Down syndrome are now living longer and longer in order to find out!! Who knows – considering the strong link with the extra chromosome, maybe someone with Down syndrome will be the key to fully understanding Alzheimer’s for all the population one day.

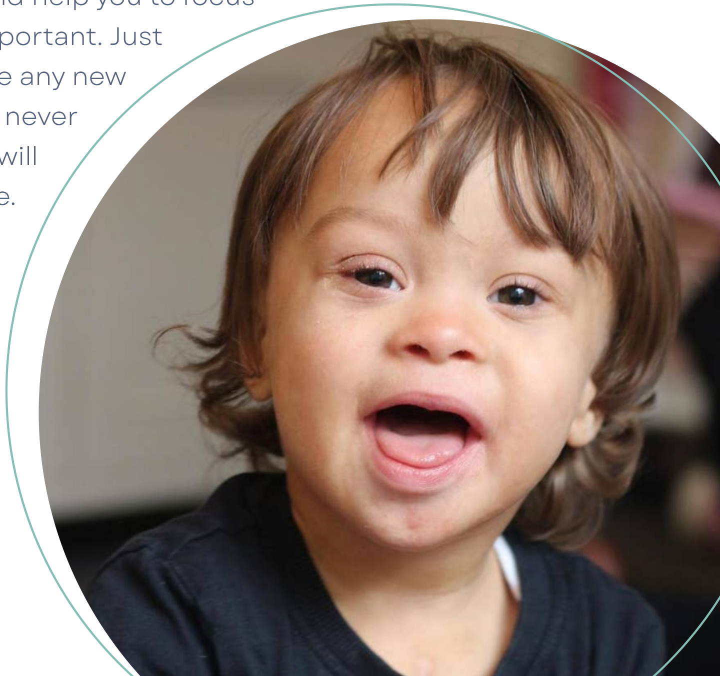
Myth 9.

Your life will never be the same

Just like having any baby, no your life will not be the same! It will be wonderful, full of love joy and purpose.

Everyone’s life changes with each baby that comes along. There is no easy path to parenthood. Like many challenges we face, parenting helps you to come out stronger, resilient, softer and more refined.

Having a child with Down syndrome will upturn all your ideas about joy and help you to focus on what’s truly important. Just like when you have any new baby, your life will never be the same, you will never be the same. Only better.



About
Down Syndrome

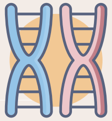
ABOUT DOWN SYNDROME

FOR PARENTS | FAMILIES | MEDICAL PROFESSIONALS | COMMUNITY

Down syndrome occurs at conception. People from all different backgrounds and ages have children with Down syndrome.

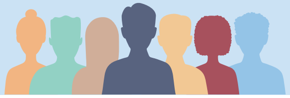
Our bodies are made up of trillions of cells. In each cell there are tiny structures called chromosomes. The DNA in our chromosomes determines how we develop.

Most people have 23 pairs of chromosomes in each of their cells (46 in total). People with Down syndrome have **47 chromosomes** in their cells. They have an extra chromosome 21, which is why Down syndrome is also sometimes known as trisomy 21.

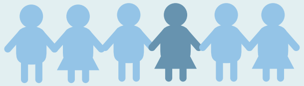


There is no national data collection on the number of people with Down syndrome in Australia.

According to Western Australia data, there are **13,000 - 15,000** individuals with Down syndrome in Australia as of 2019.



Applying these numbers to the Australian population, **every 10,000 people there are 5.14 people with Down syndrome**. This is similar to other countries like the UK.



Down syndrome is the most commonly occurring chromosomal condition.

Approximately **1 in every 1100** babies born in Australia will have Down syndrome.

Each year there are approximately **290 new babies** who have Down Syndrome.

THE INCIDENCE OF BIRTHS OF CHILDREN WITH DOWN SYNDROME **INCREASES** WITH THE AGE OF THE MOTHER.

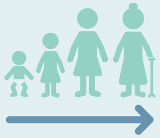
The chance of a woman conceiving a child with Down syndrome varies from

1 in 1400 for a woman 20 years of age to 1 in 30 at age 45 years.

Younger women have babies more frequently, so the majority of babies born with Down syndrome are born to women **under 35 years of age.**

People with Down syndrome are living **longer and healthier** lives than they have in the past.

Life expectancy of people with Down syndrome has dramatically **increased** over the past 50 years



With the average life expectancy of a person with Down syndrome in Australia **being 60 years of age**

About Down Syndrome NSW

About
DOWN SYNDROME NSW

Once upon a time in NSW, Australia, there was a remarkable group of individuals who had children who were born with Down syndrome. Inspired by their children's journey and fueled by their desire to create a more inclusive society, the parents embarked on a mission to establish an organisation dedicated to supporting individuals with Down syndrome and their families. And so, the seeds of Down Syndrome NSW were sown.

As the word spread, more families joined these gatherings, forming a tight-knit community that offered support, understanding, and hope.

The parent group worked tirelessly to run programs and collaborated with healthcare professionals, educators, and community leaders to raise awareness about Down syndrome and advocate for improved services and opportunities.

With the growing momentum, Down Syndrome NSW vision expanded beyond support groups and advocacy. They envisioned a dedicated organisation that could provide a wide range of services to individuals with Down syndrome, from newborn babies right through to support for the aging. With the help of passionate volunteers and the backing of the community, Down Syndrome NSW began to take shape.

Today, Down Syndrome NSW continues to evolve and adapt to the changing needs of the community. We have become a catalyst for change, breaking down barriers and championing the rights and abilities of individuals with Down syndrome. These parents and their story stand as a testament to the power of compassion, determination, and the enduring spirit of individuals, who make a profound impact on the world by turning their dreams into reality.

Our Programs

Our Vision

All people with Down syndrome in NSW live meaningful lives as valued and contributing members of their communities.

Our Mission

At Down Syndrome NSW:

(i) advocate for change to achieve social transformation by building systems that promote self-determination;

(ii) create opportunities for people with Down syndrome that promote connection, capacity and autonomy; and

(iii) provide information and support to families, carers and supporters, informed by best evidence and lived experience.

OUR CURRENT PROGRAMS

You can be a part of our story and make a difference for generations to come in one of these areas:

The Congratulations Initiative – This initiative aims at educating medical professionals in their delivery of a diagnosis, providing up to date information about Down syndrome through our Medical Professionals Packs, linking Down Syndrome NSW as key support partner and most importantly saying congratulations not sorry.

play.gro.UP! – We hope to offer a range of therapy, play, and music-based playgroups specially designed for toddlers with Down syndrome and intellectual disabilities. These playgroups are available both online and in person, providing flexibility and accessibility to families.

The Inclusive Education Initiative – We look to introduce our comprehensive Primary and Secondary School Support Program, designed to benefit both mainstream and special schools. The program's core objectives are to strengthen the capacity of schoolteachers, principals, and SLSOs (School Learning Support Officers) and to foster strong connections among key stakeholders, including families, therapists, and behavior support specialists, all with a focus on putting the student at the center.

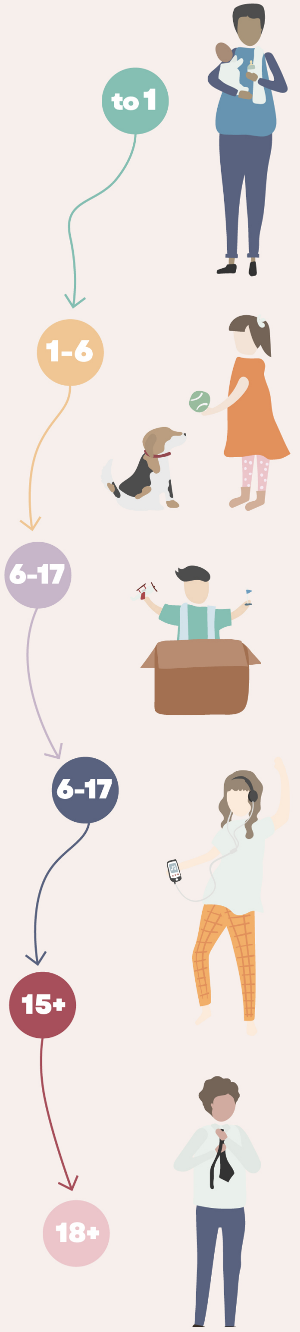
Up! Up! and Away – Specially curated for kids and teens with Down syndrome and intellectual disability. This program is designed to promote active engagement and offers enriching experiences through a series of capacity-building workshops. Additionally, we have integrated mental wellbeing workshops to ensure holistic development and emotional support for all participants.

Employment Connections – Supporting prospective employees with Down syndrome to be job ready and secure meaningful placements, alongside inclusion and diversity capacity building for employers.

UP! Club – We are dedicated to providing capacity building and community participation opportunities for adults with Down syndrome, enabling them to learn, engage, and connect. Our programs focus on reducing isolation, fostering further education, skill-building, promoting independence, and assisting with future planning.

The Inclusion Institute – We are committed to providing a wide range of support and resources for all individuals with Down syndrome, their families, carers, professionals, students, and the community at large. Our offerings include information, fact sheets, books, as well as access to our helpline via phone and email. Additionally, we maintain a comprehensive website and private social media groups for ongoing engagement and support.

Our mission is to create a nurturing and empowering environment for everyone affected by Down syndrome. By fostering connections, providing resources, and promoting advocacy, we aim to empower individuals with Down syndrome and their families to lead fulfilling lives.



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