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Understanding and supporting people with Down syndrome



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We recently hosted a webinar on Understanding and Supporting People with Down Syndrome, with guest presenters Liz and Claire from [Down Syndrome Australia](#).

Liz is the World Down Syndrome Congress Coordinator, and Claire is the first independent director with Down syndrome on the Down Syndrome Australia Board and an advocate member of the Down Syndrome Australia Advisory Network.

In this article, we share highlights of the webinar and some practical support strategies for those [supporting people with Down syndrome](#).

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Understanding and Supporting People with Down Syndrome

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Liz
Down Syndrome Australia

Claire
Down Syndrome Australia

What is Down syndrome?

[Down syndrome](#) is a lifelong genetic condition when a person is born with an extra copy of chromosome 21.

Most people have 23 pairs of chromosomes within each cell—46 chromosomes in total. However, people with Down syndrome have 47 chromosomes, resulting from the extra chromosome 21—which is why the condition is also known as trisomy 21.

The extra chromosome affects the development of the brain and body. It may impact intellectual and cognitive development, physical characteristics, and aspects of a person's health—with an increased risk of some health conditions.

It is the most common genetic cause of intellectual disability and can result in learning disabilities and present physical challenges for the person.

Living with Down syndrome

support.

Advances in research and medical science, including improved health through social sciences, have increased the life expectancy of people with Down syndrome—from around 15 years in the 1950s to a longer lifespan today.

“We’re reaching an ageing population, and you may be supporting people well into their

Myths and assumptions about Down syndrome

There are several common myths and misconceptions about people with Down syndrome, including:

- There are varying degrees of Down syndrome
- People with Down syndrome all look alike
- People with Down syndrome don’t experience a full range of emotions
- People with Down syndrome can’t learn new skills
- People with Down syndrome have a short lifespan
- People with Down syndrome are always happy.

Liz quickly dispels these myths and informs us that:

- There are no degrees of Down syndrome; you either have it or you don’t
- A person with Down syndrome will look like their biological family, not like the next person who has Down syndrome
- People with Down syndrome experience a full range of emotions
- People with Down syndrome can learn new skills when given the opportunity
- People with Down syndrome are living well into their elderly years
- The belief that people with Down syndrome are always happy is a big misconception.

Intellectual Disability

“One key characteristic of people with Down syndrome is intellectual disability—a lifelong condition that affects a person’s intellectual skills and behaviour in different situations,” says Liz. This can include difficulties in communication, memory, problem-solving, self-care, and social and practical skills.

When working with people with Down syndrome, it’s important to consider:

- Their language, reading, writing, maths, reasoning, knowledge, and memory may be affected.
- It impacts on a person’s empathy, social judgement, communication skills, and ability to follow rules—whether excessively or not at all.
- It can affect independence in personal care, responsibilities, organising tasks, and following instructions.

“Research now shows that many people with Down syndrome also have co-occurring diagnoses. These can include hearing loss, autism, ADHD, and other medical conditions,” says Liz. “You may find that someone you are supporting has ADHD or autism along with Down syndrome. This is important to keep in mind when managing behaviours and other characteristics.”

Practical strategies to provide support

[Communication plays a crucial role in supporting people](#) with Down syndrome, and simple, open communication fosters participation in all aspects of the community.

“Language can empower people with a disability or do the opposite by strengthening limiting stereotypes,” says Claire. “The words we use and the way we communicate reflect how a person is accepted in the community”.

This also means avoiding outdated or degrading terminology that refers to differences in cognitive ability and using commonly accepted terms— ‘person with Down syndrome’ or ‘person who has Down syndrome’ or ‘person with an intellectual disability’.

Some practical communication and support strategies include:

- Engage directly with the person with Down syndrome, not just their support person or family members.
- Use simple, straightforward language without jargon, acronyms, or complex terms. Avoid abstract concepts and open-ended questions.

frustration or behavioural issues.

- Help the person understand information and consider possible consequences when making decisions that suit them and their goals.
- Allow the person to make mistakes and learn from them, which is essential for personal growth and learning.
- Recognise that each person's goals and needs are unique. Focus on supporting them in the way they want to be assisted with their goals.
- As a paid support worker, recognise the potential conflict of interest in decision-making. As such, you should not make decisions about their paid support. Instead, you should involve families and support networks in significant decisions.

Good support principles

Liz also outlines good principles for support workers, such as

- Have high expectations for the person's potential achievements.
- Support independence and strong communication within their network.
- Be engaged and active during support activities.
- Maintain consistency in schedules and clearly communicate any changes.
- Ensure interactions are meaningful.

Supporting people with Down syndrome

"Support does not mean being a mother but being a friend who respects the boundaries of our personal interactions," emphasises Claire.

Understanding behaviours and dispelling myths about Down syndrome can foster a sense of belonging and respect, helping to build more meaningful connections. It also improves the quality of support so that people with Down syndrome are seen, heard, and included as equal members of society.

As Claire aptly concludes, "People with Down syndrome want to be as independent as they can be. We want to fit in, have opportunities, and live happy and fulfilling lives".

You can [watch the full webinar](#) to gain more in-depth information. For helpful resources on Down syndrome, explore our [Down Syndrome Topic Library](#).

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