

CONDITION GUIDE

Down syndrome: a plain-English guide

For people with Down syndrome and their families. What it is, the questions people ask most, what helps at home and out in the world, and where the NDIS and Kinship fit in.

Down syndrome is a genetic condition, not an illness or disease. Most people have 46 chromosomes in each cell. People with Down syndrome have 47, with an extra chromosome 21, which is why it's also called trisomy 21 (Down Syndrome Australia).

It happens at conception, by chance. It's nobody's fault. Everyone with Down syndrome has some level of intellectual disability and some developmental delay, and there's a higher chance of some health conditions, many of them treatable.

Every person is an individual, with things they're good at and things they find harder. Down Syndrome Australia puts it simply: most young people growing up with Down syndrome today go to school and get a job, just like everyone else.

A note on words: Down Syndrome Australia asks people to say "a person with Down syndrome", and to avoid "suffers from", "victim of" or "afflicted by". We do the same.

Key facts

- **13,000–15,000** people with Down syndrome in Australia (best estimate, 2019)
- **1 in 1,158** babies born in Australia, 2016–2020
- **60 years** average life expectancy in Australia today
- **No levels** there are no degrees of Down syndrome, just individuals

Figures: Down Syndrome Australia (Statistics and FAQs).



What helps, day to day

- **Talk to the person, not about them.** Assume competence. Speak directly to the person, give them time to respond and take their lead on the support they need (Down Syndrome Australia).
- **Regular health checks.** Hearing, vision, thyroid, bones and teeth are worth checking regularly. People with Down syndrome are more likely to have low thyroid hormone levels and osteoporosis (healthdirect).
- **Plan for work and home.** Some people with Down syndrome work full time, others have a mix of activities during the week. Down Syndrome Australia has employment and community inclusion resources.
- **Notice change early.** Changes in behaviour, attention or planning in an adult can be worth a GP visit. Other health issues can cause similar changes, so get them checked (Down Syndrome Australia).
- **Talk to someone who's been there.** Your local Down syndrome association can connect you with other families. Call 1300 881 935 to reach your state or territory organisation.

How the NDIS can help

To be eligible for the NDIS you need to be younger than 65 when your application is received, an Australian citizen or permanent resident (or Protected Special Category visa holder) living in Australia, and have an impairment that's likely to be permanent and substantially reduces your ability to do everyday things.

For children younger than 9, the NDIS uses its early childhood approach, working with an early childhood partner. From age 9, families work with an NDIS partner (NDIS).

- 1 Connect with an NDIS partner (use the office finder at [ndis.gov.au](https://www.ndis.gov.au)) or call the NDIS on 1800 800 110.
- 2 Work with your treating health professional to gather evidence about your disability and how it affects daily life.
- 3 Complete your application with your NDIS partner, or by yourself using the access request form.
- 4 Submit it. Your NDIS partner can do this for you, or use the NDIS service hub, post it (NDIA, GPO Box 700, Canberra ACT 2601) or take it to a local office.
- 5 Wait for the decision. The NDIS tells you within 90 days once your application and all your evidence are in. You can ask for a review if you disagree.

The NDIS is changing. New NDIS laws passed in August 2026. From 1 October 2026, budgets for social and community participation and for daily living skills are being reduced as plans are reassessed or newly approved, and a new way of planning is due from April 2027. Check [ndis.gov.au](https://www.ndis.gov.au) for the latest.



How Kinship Uniting Services can help

We support people, not diagnoses. For someone with Down syndrome, at any age, that can look like this.

- **Daily living and personal care.** Help with routines, meals and personal care at home, at a pace that suits the person.
- **Community participation.** Getting out to work, sport, classes and friends, with someone who knows the person well.
- **Life skills for independence.** Cooking, shopping, catching the bus: real skills practised in real places.
- **As needs change with age.** Dementia and behaviour support is on our registered high intensity list, alongside medication management.
- **The same face every visit.** The same support worker comes every visit, so nobody has to explain themselves to a stranger each week. Families get updates as standard.

Continence support. If continence support is part of daily life at any age, the National Continence Helpline (1800 33 00 66) gives free, confidential advice from nurse continence specialists, including on funding options. Equipit sells continence products such as adult nappies and continence briefs. Equipit is the product-supply arm of Kinship Uniting Services, an NDIS registered and CHSP approved provider since 2017. Order online at equipitdsp.com. Disclosure: Equipit is part of the same family of businesses as Kinship, and Equipit itself is not NDIS registered. You're free to buy from any supplier. Agency-managed NDIS funds can't be spent with Equipit; if you're self-managed or plan-managed, check with your plan manager first.

Where to get help

- **Down Syndrome Australia:** 1300 881 935 (connects to your local association), downsyndrome.org.au
- **NDIS:** 1800 800 110
- **healthdirect:** 1800 022 222 (24/7 nurse advice)
- **Carer Gateway:** 1800 422 737
- **National Continence Helpline:** 1800 33 00 66
- **Kinship Uniting Services:** 0437 733 744 or 0424 756 143, info@kinshipunitingservices.com, 39 Victory Road, Colebee NSW 2761



Your checklist

- ☐ Keep a record of regular health checks: hearing, vision, thyroid, teeth
- ☐ Write down the person's goals in their own words
- ☐ Collect reports that describe how the disability affects daily life
- ☐ Child under 9? Contact an NDIS early childhood partner
- ☐ Adult? Check NDIS eligibility (under 65 when you apply) and call 1800 800 110
- ☐ Note any change in behaviour, memory or planning and raise it with the GP
- ☐ Connect with your local Down syndrome association (1300 881 935)

Questions people ask

Can people with Down syndrome live independently?

Many do, often with support through the NDIS. Others choose to live with family. Down Syndrome Australia says independent living is becoming more common for adults.

Are there levels or degrees of Down syndrome?

No. A diagnosis means the extra chromosome 21 is present. People with Down syndrome have a range of abilities, like everyone else (Down Syndrome Australia).

What is the life expectancy for someone with Down syndrome?

In Australia the average is now 60 years. As recently as the 1950s it was as low as 15 (Down Syndrome Australia; healthdirect).

Do adults with Down syndrome get dementia?

They are more likely to, and on average at a younger age. It doesn't mean everyone will, and Alzheimer's disease is uncommon under 40. Early signs are often changes in behaviour or personality, so raise any change with a GP (Down Syndrome Australia).

Is Down syndrome covered by the NDIS?

The NDIS looks at the impairment and how it affects daily life. Down Syndrome Australia reported more than 10,000 people with Down syndrome in the NDIS in 2019.

Are people with Down syndrome always happy?

No, and the stereotype doesn't help anyone. People with Down syndrome feel the full range of emotions: sad, angry, scared, excited, joyful (Down Syndrome Australia).

Talk to a real person. Call Kinship Uniting Services on **0437 733 744** or email info@kinshipunitingservices.com. Deaf, or have a hearing or speech impairment? Contact us through the National Relay Service: Speak & Listen 1300 555 727, TTY 133 677, SMS relay 0423 677 767.



Sources

Down Syndrome Australia: What is Down syndrome? —

<https://www.downsyndrome.org.au/about-down-syndrome/what-is-down-syndrome/>

Down Syndrome Australia: How to talk about Down syndrome —

<https://www.downsyndrome.org.au/about-down-syndrome/how-to-talk-about-down-syndrome/>

Down Syndrome Australia: Statistics — <https://www.downsyndrome.org.au/about-down-syndrome/statistics/>

Down Syndrome Australia: FAQs — <https://www.downsyndrome.org.au/about-down-syndrome/faqs/>

Down Syndrome Australia: Dementia and Down syndrome —

<https://www.downsyndrome.org.au/resources/health/dementia-and-down-syndrome/>

healthdirect: Down syndrome — <https://www.healthdirect.gov.au/down-syndrome>

NDIS: What are the NDIS disability requirements —

<https://www.ndis.gov.au/applying/eligibility-requirements/what-are-ndis-disability-requirements>

NDIS: How to check your eligibility — <https://www.ndis.gov.au/applying/eligibility-requirements/how-check-your-eligibility>

NDIS: Guide to the early childhood approach — <https://www.ndis.gov.au/applying/children/guide-early-childhood-approach>

NDIS: How to apply — <https://www.ndis.gov.au/applying/application-process/how-apply>

NDIS: Securing the NDIS for future generations (new NDIS laws) —

<https://www.ndis.gov.au/ndis-laws/securing-ndis-future-generations>

NDIS: New way of planning — <https://www.ndis.gov.au/changes-ndis/new-way-planning>

Continence Health Australia: National Continence Helpline —

<https://www.continence.org.au/help-and-support/national-continence-helpline/>