

CONDITION GUIDE

Living with cerebral palsy

A plain-English guide for people with cerebral palsy, parents and carers in Australia

You know exactly how you like your transfers done, your breakfast set up and your week planned. Cerebral palsy is lifelong, and so are the plans that come with it. This guide brings together practical ideas from Cerebral Palsy Alliance, healthdirect and Raising Children Network, the NDIS pathway, and the questions worth asking along the way.

It is general information only. Your GP, paediatrician and therapy team know your situation and should guide your care.

Cerebral palsy in plain English

Cerebral palsy (CP) is a group of conditions that affect movement, muscle tone, coordination, posture and balance. Cerebral Palsy Alliance explains it is usually caused by an injury to the developing brain during pregnancy or shortly after birth. It is permanent and does not get worse over time. Raising Children Network lists causes including prematurity, lack of oxygen at birth, stroke around birth and infection; healthdirect notes that sometimes no cause is found.

Cerebral Palsy Alliance says about **1 in 700** Australian babies is diagnosed with CP, and about 34,000 Australians live with it (figures checked October 2026). Raising Children Network calls CP the most common childhood physical disability in Australia. It is usually diagnosed before age 2, and early intervention is the best way to support a child's development.

- **Types:** spastic (stiff, tight muscles; the most common), dyskinetic (involuntary movements) and ataxic (shaky, unsteady movement). Many people have a mix.
- **Severity varies:** from weakness in one hand to very little voluntary movement. The Australian CP Register reports that 63% of people with CP move about without equipment, 11% use mobility equipment such as a walker and 26% always use a wheelchair.
- **Related conditions (Cerebral Palsy Alliance, checked October 2026):** about 3 in 4 experience pain, about 1 in 4 have epilepsy, about 1 in 4 are unable to talk, about 1 in 4 have bladder problems, and about 1 in 5 have a sleep disorder. About 1 in 5 have a moderate to severe intellectual disability, and some people with a severe physical disability have no intellectual disability at all.

Everyday tips that help

These ideas come from healthdirect, Cerebral Palsy Alliance and continence.org.au. Your health team can tailor them to you.

- **Equipment:** physiotherapists and occupational therapists may suggest splints or orthotics, walking frames or wheelchairs, and can assess changes at home or work.
- **Communication:** augmentative and alternative communication (AAC) includes speech-generating devices, switch controls and eye-gaze access. A speech pathologist or OT can assess what suits.
- **Energy:** adults may need flexible hours and more rest. A UK survey published in 2023 found pain, fatigue and difficulty standing were more common in older adults with CP, so keep up regular health checks.
- **Pain:** pain is common and treatment is available. Don't accept it as just part of CP; raise it with your GP.

Tip: keep a one-page profile with how you communicate, how you like transfers and personal care done, and your equipment details. Give it to every new worker or clinician.

Bladder and bowel

Cerebral Palsy Alliance says continence and constipation are issues for many people with CP, especially those with an intellectual disability or a severe form of CP. continence.org.au suggests scheduled toilet times, continence products and treating constipation, which can make incontinence worse. The National Public Toilet Map, the MLAK key and Changing Places facilities help with outings. The National Continence Helpline (1800 33 00 66) is free.

Kinship's sister business, Equipit, supplies continence products such as adult nappies, continence briefs and bed protection (equipitdsp.com). Equipit is the product-supply arm of Kinship Uniting Services, an NDIS registered and CHSP approved provider since 2017. Equipit is part of the same family of businesses and you are free to buy from any supplier. Equipit is not NDIS registered, so agency-managed NDIS funds can't be spent there; self-managed and plan-managed participants should check with their plan manager first.

The NDIS pathway

Applying: you must be younger than 65 on the day you apply and meet the residence and disability (or early intervention) requirements. The NDIS document *Applying to the NDIS* lists cerebral palsy assessed as severe, for example Level 3, 4 or 5 on the Gross Motor Function Classification System (GMFCS), on **List A**, conditions likely to meet the disability requirements. At other levels, you'll usually need to show how CP affects daily life.

Children younger than 9: the NDIS early childhood approach helps children with developmental delay or disability through local early childhood partners, even if the child isn't eligible for the NDIS.



Thriving Kids: began on 1 October 2026 for children aged 8 and under with developmental delay or autism and low to moderate support needs. The NDIS says there will be no change to NDIS access or eligibility until 1 January 2028, and children with permanent and significant disability or high support needs will continue to access the NDIS.

Continence and equipment: the NDIS may fund continence supports and assistive technology that relate to your disability, with evidence from your health team.

NDIS laws changed in August 2026 and more changes are coming. Always check [ndis.gov.au](https://www.ndis.gov.au) or call 1800 800 110.

Questions to ask your GP, paediatrician or therapy team

- What type of CP is it, and what GMFCS level has been assessed?
- What can we do about pain, sleep or constipation?
- Would a communication device or other equipment help, and who can assess it?
- Can you refer us to a continence nurse?
- Can you write a report on how CP affects daily life for the NDIS?

Questions to ask your NDIS planner or partner

- Which budgets cover equipment, communication devices and daily support?
- Can continence products and complex care, like PEG feeding or bowel care, be included?
- How will my plan change as I get older or my needs change?
- Can I keep the same support workers if the plan changes?
- For children: does the NDIS or Thriving Kids apply, and what changes in 2028?

How Kinship Uniting Services can help

From Colebee and Blacktown to Box Hill, Rouse Hill and Riverstone. The same support worker every visit, who learns how you like things done.

We understand. Living with cerebral palsy, you've probably spent years teaching new people how to help: how you like a transfer done, how to set up a meal, how long things really take. Starting again with a stranger every week is exhausting.

For families of young people, the big moments bring big questions: finishing school, finding work, moving out of home. Support should follow your goals, at your pace.

We're qualified. Kinship Uniting Services is a registered NDIS provider (4-GWVHCEY), operating in disability and aged care since 2017, and we've supported hundreds of clients and families. Our founder, Shazia Begum, has spent more than 15 years alongside people living with disability. Our registered high intensity supports include complex bowel care, catheter care, PEG feeding and



medication management. We're registered to deliver Supported Independent Living (SIL). The same support worker comes every visit, and families get updates as standard.

Here's how we can help.

- **Personal care and daily living.** Showering, dressing, transfers and meals, done your way, by someone who knows your routine. Daily living support
- **Complex care at home.** Complex bowel care, catheter care, PEG feeding and medication management are on our registered high intensity list. High intensity support
- **Community participation.** Sport, study, work, friends. Getting to the things you want to do. Community participation
- **Life skills.** Building the skills you choose, from cooking to running a household. Life skills and group activities
- **Supported Independent Living.** For young adults and adults ready to move out of home and live with housemates, with support at home. We're registered to deliver SIL; call us to talk about current availability. Supported Independent Living
- **Respite for the family.** A familiar support worker stays with your son or daughter at home or takes them out, so you can rest, get to your own appointments or simply have the afternoon. NDIS-funded or booked privately. Respite care
- **Continence products.** See the continence section earlier in this guide for Equipit, our sister business, and the disclosure that goes with it.

For families, carers and referrers

For families and carers. Parents are often the coordinator, the driver and the carer all at once. We keep you updated as standard, and respite gives you time back for yourself.

For support coordinators and plan managers. If you coordinate supports or manage plans for someone with CP, call us about high intensity supports, life skills, or a move towards more independence, including SIL. We'll be upfront about current availability. More at kinshipunitingservices.com/for-referrers.

Where to get help

- **Cerebral Palsy Alliance:** 1300 888 378, cerebralpalsy.org.au
- **NDIS:** 1800 800 110, ndis.gov.au
- **National Continence Helpline:** 1800 33 00 66
- **Carer Gateway:** 1800 422 737, carergateway.gov.au
- **healthdirect** (24/7 health advice): 1800 022 222. In an emergency, call 000.



Your checklist

- ☐ Write a one-page profile: communication, transfers, routines, equipment
- ☐ Ask your GP about pain, sleep and constipation
- ☐ Ask for a continence assessment if needed
- ☐ Check your GMFCS level is written in your reports
- ☐ Gather therapy and specialist reports for the NDIS
- ☐ Contact your local NDIS partner or early childhood partner
- ☐ Find accessible toilets near the places you go (National Public Toilet Map)
- ☐ Carers: call Carer Gateway (1800 422 737) for your own support

Ready to talk? We're here

If you'd like us to help with this, call 0437 733 744 and we'll talk it through. Tell us your goals and how you like things done. We'll tell you plainly whether and how we can help.

Call 0437 733 744 or 0424 756 143 · info@kinshipunitingservices.com · 39 Victory Road, Colebee NSW 2761 · kinshipunitingservices.com/get-support

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

Cerebral Palsy Alliance: What is cerebral palsy? —

<https://cerebralpalsy.org.au/our-research/about-cerebral-palsy/what-is-cerebral-palsy/>

Cerebral Palsy Alliance: About cerebral palsy — <https://cerebralpalsy.org.au/our-research/about-cerebral-palsy/>

Cerebral Palsy Alliance: How cerebral palsy affects people — <https://cerebralpalsy.org.au/cerebral-palsy/how-affect/>

Cerebral Palsy Alliance: How CP affects people — <https://cerebralpalsy.org.au/cerebral-palsy/how-affect/>

Cerebral Palsy Alliance: Australian CP Register — <https://cerebralpalsy.org.au/our-research/cp-register/>

Cerebral Palsy Alliance: Assistive technology — <https://cerebralpalsy.org.au/services/assistive-technology/>

Cerebral Palsy Alliance: Contact us — <https://cerebralpalsy.org.au/contact-us/>

healthdirect: Cerebral palsy — <https://www.healthdirect.gov.au/cerebral-palsy>

healthdirect: Living with cerebral palsy — <https://www.healthdirect.gov.au/living-with-cerebral-palsy>

Raising Children Network: Cerebral palsy — <https://raisingchildren.net.au/guides/a-z-health-reference/cerebral-palsy>

continence.org.au: Functional incontinence —

<https://www.continence.org.au/types-incontinence/urinary-incontinence/functional-incontinence>

BJGP Open (2023): Adults with cerebral palsy, UK survey — <https://pmc.ncbi.nlm.nih.gov/articles/PMC11176684/>

NDIS: Applying to the NDIS (List A) — <https://www.ndis.gov.au/media/7752/download?attachment>

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

NDIS: First phase of Thriving Kids supports start today —

<https://www.ndis.gov.au/news/11706-first-phase-thriving-kids-supports-start-today>

NDIS Our Guidelines: Continence supports — <https://www.ndis.gov.au/media/7806/download>



Carer Gateway — <https://www.carergateway.gov.au/about-us/access-carer-gateway-services>