

CONDITION GUIDE

Living with an acquired brain injury

A plain-English guide for people with a brain injury, their families and carers in Australia

“He looks fine, so people expect him to be fine.” A brain injury can change things other people can’t see: memory, energy, mood, the way a day holds together. This guide brings together practical ideas from Synapse, healthdirect and NSW Health, the NDIS and compensation pathways, and the questions worth asking.

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

Brain injury in plain English

An acquired brain injury (ABI) is damage to the brain that happens after birth. healthdirect lists the causes: a blow to the head (traumatic brain injury, or TBI), stroke, lack of oxygen, infection, tumours, alcohol or drugs, and degenerative conditions. ABI is different from an intellectual disability or a mental illness.

NSW Health describes ABI as a “hidden disability”. A person can look the same as before while living with changes to thinking, communication, emotions, social skills or independence. The AIHW reports that in 2020–21 someone in Australia was hospitalised for a head injury about every four minutes. That year, head injuries led to 406,000 emergency department visits and 142,000 hospitalisations, and males made up 2 in 3 of those emergency visits.

The biggest gains usually come in the first few months, but healthdirect says recovery can continue for years, and some effects may be lifelong.

- **Physical:** weakness, poor balance, tiredness, sleep changes, headaches, seizures.
- **Thinking:** memory, concentration, planning, confusion, communication.
- **Emotions and behaviour:** mood swings, irritability, personality changes.

Everyday tips that help

These ideas come from Synapse's *ABI: The Facts* guide and healthdirect. Use what works and drop the rest.

- **Fatigue:** Synapse calls it common and highly disabling, and overload can bring on fatigue that lasts days. Learn the early signs (withdrawal, irritability, slower speech, forgetfulness) and rest straight away. Schedule rests, and do harder things at your best time of day.
- **Memory:** a notepad by the phone, a noticeboard, a fixed place for keys and glasses, labelled cupboards, a diary, phone alarms and a pill box. Synapse says these tools don't get in the way of natural recovery.
- **Overload:** keep spaces quiet and uncluttered, and do one thing at a time. Have a plan for when fatigue hits in public.
- **Behaviour:** Synapse says all behaviour serves a purpose and communicates a message, such as an unmet need, a mood, or too little or too much stimulation. Be consistent, notice and encourage what goes well, and get support. Violence or abuse is never OK.
- **Routine:** predictable days and familiar faces reduce the effort every task takes.

Tip for families: keep a simple log for two weeks of when fatigue, confusion or behaviour changes happen and what came before. It helps the rehab team and any NDIS application.

Bladder and bowel changes

A brain injury can affect the brain's control of the bladder and bowel, and changes in memory, judgement, mobility or communication can add to it. Continence problems can be assessed and managed. Start with your GP or rehab team, and call the free National Continence Helpline on 1800 33 00 66.

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, icare and compensation

The NDIS: you can apply if you are younger than 65 on the day you apply, meet the residence requirements, and have an impairment that is likely to be permanent and substantially affects daily life. Evidence about memory, fatigue, communication and behaviour matters, not just scans.

Motor accidents in NSW: icare Lifetime Care pays for treatment, rehabilitation and care for people severely injured in a NSW motor accident, on a no-fault basis, where eligibility rules are met. The Lifetime Care and Workers Care line is 1300 738 586.

Workplace injuries: some people with a serious brain injury from work are covered by workers compensation.

How they fit together: the NDIS says statutory schemes like Lifetime Care sit alongside your NDIS plan, and you may get both, but the NDIS can't fund supports the scheme already gives you. You must tell the NDIS about any compensation claim.

65 or older: help comes through My Aged Care on 1800 200 422.

The NDIS is changing through 2026 and 2027. Always check the latest at [ndis.gov.au](https://www.ndis.gov.au) or call 1800 800 110.

Questions to ask the rehab team or your GP

- What parts of daily life is the injury likely to affect, and for how long?
- Can we be referred to the NSW Brain Injury Rehabilitation Program or community rehab?
- What should we do about fatigue, sleep and headaches?
- Can you assess bladder and bowel control, or refer us to a continence nurse?
- Can you write a report on how the injury affects daily life, for the NDIS or an insurer?

Questions to ask your NDIS planner or case manager

- Which scheme pays for what: NDIS, icare or workers compensation?
- Can the plan include help with daily routines, life skills and getting out in the community?
- Can behaviour support, medication management or continence supports be included?
- Can we keep the same support workers if the plan changes?
- How do we review the plan as recovery continues?



How Kinship Uniting Services can help

From Colebee and Blacktown to Marsden Park, Schofields and Windsor. Predictable support from the same support worker every visit, at a pace that respects fatigue.

We understand. After a brain injury, the hardest parts are often invisible: forgetting what was said an hour ago, running out of energy by mid-afternoon, feeling overwhelmed in a busy shop, getting frustrated faster than before. Other people may not notice, and that can be lonely.

Families often become the memory, the planner and the buffer all at once. Routine, a familiar face and calm, clear communication help a day hold together.

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 medication management, complex bowel care, and dementia and behaviour support. 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.

- **Daily living and personal care.** Help with the routine of the day, done the same way each time so it takes less effort. Daily living support
- **When needs are complex.** Medication management, complex bowel care, and dementia and behaviour support are on our registered high intensity list. High intensity support
- **Life skills and groups.** Practising everyday skills, from cooking to the weekly shop, at a pace that respects fatigue. Life skills and group activities
- **Community participation.** Getting back to the gym, the footy or the shops, with someone who knows when to call it a day. Community participation
- **Supported Independent Living.** For people who need support at home day and night. We're registered to deliver SIL; call us to talk about current availability. Supported Independent Living
- **Private services.** Anyone can book support privately while funding or a claim is sorted. For private nursing, send us an enquiry and we'll talk it through; for other services, call us for a quote. Private services
- **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. If you've become your son's, daughter's or partner's memory and diary, you're not alone in that. We keep families updated as standard, and respite with a familiar worker gives you real time off.

For support coordinators and plan managers. Support coordinators, plan managers, case managers and insurers are welcome to call us about support at home during recovery. Tell us the goals and we'll say plainly what we can offer. More at kinshipunitingservices.com/for-referrers.

Where to get help

- **Synapse** (brain injury information and referral): 1800 673 074, synapse.org.au
- **Brain Injury Australia**: 1800 272 461, braininjuryaustralia.org.au
- **icare Lifetime Care and Workers Care**: 1300 738 586, icare.nsw.gov.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

- ☐ Get copies of hospital discharge and rehab reports
- ☐ Set up one shared calendar and a noticeboard at home
- ☐ Start a two-week fatigue and behaviour log
- ☐ Ask the GP about a continence assessment if needed
- ☐ Work out which scheme applies: NDIS, icare Lifetime Care or workers compensation
- ☐ Under 65? Contact your local NDIS partner and gather evidence
- ☐ Call Synapse (1800 673 074) for information and referral
- ☐ 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 about the person and the goals first. 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

healthdirect: Acquired brain injury: <https://www.healthdirect.gov.au/acquired-brain-injury-abi>

NSW ACI: Acquired brain injury:

<https://aci.health.nsw.gov.au/publications/brain-injury-rehab/part-a-specialist/acquired-brain-injury>

NSW ACI: Injury, impairments and impacts:

<https://aci.health.nsw.gov.au/publications/brain-injury-rehab/part-a-specialist/injury-impairments-impacts>

NSW ACI: Adult services (BIRP): <https://aci.health.nsw.gov.au/publications/brain-injury-rehab/part-d-programs/adult-services>

AIHW: Head injuries in Australia 2020-21:

<https://www.aihw.gov.au/reports/injury/head-injuries-in-australia-2020-21/contents/summary>

Brain Injury Australia: <https://www.braininjuryaustralia.org.au/>

Synapse: ABI The Facts (6th ed.):

<https://synapse.org.au/wp-content/uploads/2021/01/Synapse-ABI-The-Facts-Sixth-Edition-2021.pdf>

Synapse: Memory: <https://synapse.org.au/fact-sheet/memory/>

Synapse: Behaviour changes after brain injury:

<https://synapse.org.au/news/understanding-behaviour-changes-after-brain-injury/>

NDIS: How to check your eligibility: <https://www.ndis.gov.au/applying-access-ndis/am-i-eligible>

NDIS: What is a statutory scheme: <https://www.ndis.gov.au/participants/creating-plan/compensation/what-statutory-scheme>

icare: Motor accident injuries: <https://www.icare.nsw.gov.au/treatment-and-care/what-we-do/motor-accident-injuries>

icare: Lifetime and Workers Care contact: <https://icare.nsw.gov.au/contact-us/lifetime-and-workers-care-program>

Royal Children's Hospital: Brain injury, bladder and bowel:

https://rch.org.au/kidsinfo/fact_sheets/Brain_injury_Bladder_and_bowel_incontinence

Brain Injury Australia: Contact: <https://www.braininjuryaustralia.org.au/contact-us/>

Carer Gateway: Contact us: <https://www.carergateway.gov.au/contact-us>