

Recovering after a severe brain injury

This information is for people who have experienced a traumatic (acquired) brain injury and their family/carers. It was developed in consultation with patients, their families and carers.

Brain injury from trauma is a serious medical event that often involves rescue and emergency transport, followed by immediate admission to hospital for lifesaving intensive care with medical and surgical treatments.

One minute life is normal, but the next, it has completely changed. Not knowing what the future holds can be a very stressful time for you and your family.

The doctors, nurses and therapists will talk with you and your family/carer about what is happening and why. It is important that you understand and ask questions. See page 4 for a glossary with definitions of common words or acronyms.

I worried about my wife and girls – I was meant to be their provider and protector.

– Person with brain injury

Traumatic (acquired) brain injury

A brain injury affects each person in a different way.

The length of time you are in coma or confused (called post-traumatic amnesia) shows how severe the brain injury was. It sometimes takes a few months before the swelling, bleeding and bruising of the brain goes away and the brain begins to work better.

Not everyone recovers after brain injury at the same rate. Recovery takes time and depends on many factors, such as how your brain was injured, the severity of the injury, and if you have other health problems.

A brain injury may cause disabilities that change a person's life, as well as the lives of family members.

What happens after acute care?

When you are medically stable, the hospital team may talk about the need for rehabilitation (rehab) and ongoing therapy and care.

In rehab you can recover lost skills and learn different ways of managing personal and daily living. Some people need specialised brain injury interventions.

Rehab can occur in different places and involve several services. Some people will stay at one hospital. Other people will be transferred to a different hospital that may be closer to home, or return home to continue therapy as an outpatient or with community visits.

The NSW Brain Injury Rehabilitation Program

The NSW BIRP is a network of metropolitan and rural inpatient, transitional and community specialist rehabilitation services for children, young people and adults following a severe traumatic brain injury.

You are at the centre of your BIRP rehabilitation planning. BIRP staff members work together with you and important people in your life to deliver needed therapy and support services.

BIRP staff have specialised knowledge and skills in assessing the brain after severe injury, and help you to:

- determine how your skills and strengths can help you to adjust to changes
- learn and practice different ways of getting things done
- work together with you and important people in your life to deliver therapy and support services.

What does it mean for me?

The changes to the brain after injury are individual and complex. You may find that things that were easy before the brain injury are now difficult. You may experience changes with:

- thinking and memory
- eating and talking
- mobility (movement)
- getting along with others.

Some changes are immediately obvious (for example, if you have problems using your hand); others may not be a problem until you need to use the skills (for example, problem solving or doing a puzzle).

BIRP staff members will talk with you about working on goals in therapy and setting priorities. Goals can be specific for everyday tasks (such as walking safely across the road) or broader goals for education, employment, social participation and recreation.

How do we know what is happening?

BIRP staff will attend regular meetings with you and your closest family/carers to make sure everything is going as well as possible.

Everyone involved has the chance to:

- hear about assessments and test results
- plan what can be done
- discuss progress and challenges
- plan for any program changes
- start planning for transition out of hospital, when it's the right time
- identify and access the services and resources needed for discharge.

Being involved [with rehab] meant we knew what was happening – we had to keep family and friends up to date... to translate the situation for them.

– Carer

How long will I stay?

How long a person spends in the BIRP depends on what they need. People who had severe injuries or who are still in a state of confusion may need to stay in the metropolitan BIRP for an extended period of time.

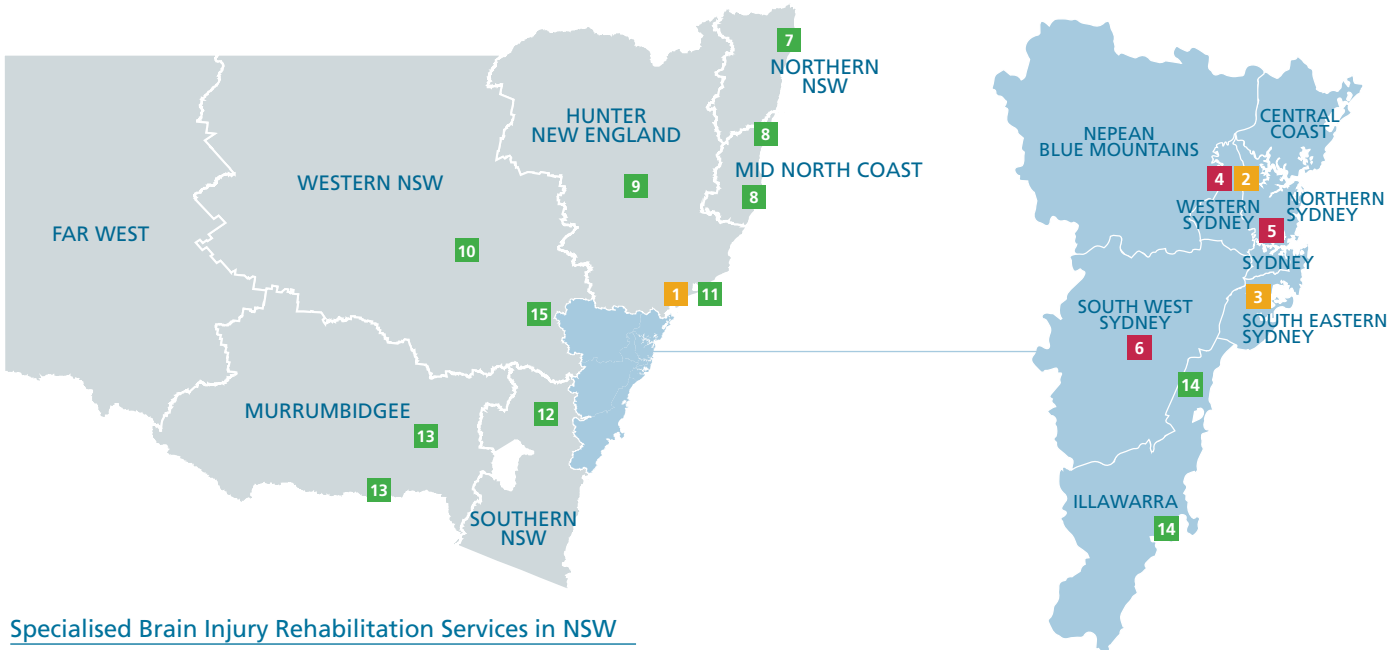
Others may benefit from referral to the transitional living program closer to home where they can continue to work on independent living goals.

Discharge home may be an option if therapy, care and support services are available. As your recovery progresses and discharge is being planned, the BIRP team may start to involve local services and community agencies.

Who may be involved in your rehabilitation?

- **Case manager** – Works with you, your family and carers to ensure that rehab services are appropriate, timely, available and accessible. Case managers usually start when you are discharged from the BIRP ward, but can start earlier or later.
- **Neuropsychologist** – Performs assessment of your condition and the impact of the injury, including thinking (cognitive) skills, such as memory, attention and concentration, problem solving and reasoning.
- **Occupational therapist** – Helps you with daily activities, such as eating, using public transport and dealing with money. The occupational therapist may be involved in contacting employers, teachers and others to assess skills needed for return to work and educational activities.
- **Physiotherapist and exercise physiologist** – Develops your muscle strength, range of movement, sensation, balance and coordination. This includes sitting, standing and activities, such as climbing stairs or crossing the road safely.
- **Psychologist or clinical psychologist** – Monitors your emotional state, mood and any behaviour changes after brain injury, supporting you to adjust to the situation and engage in rehabilitation.
- **Rehabilitation doctor** – Manages medical issues arising over time and issues such as returning to driving and providing reports for employers, Centrelink, lawyers and insurance. Liaises with your general practitioner (GP) and other specialists in the multidisciplinary team about rehabilitation planning and care over time.
- **Social worker** – Provides support with family relationships, managing stress, practical issues, and navigating the hospital. This may mean exploring financial support, alternative decision making and housing needs.
- **Speech pathologist** – Helps with communication skills, including understanding speech, forming sounds and words, social interactions, reading and writing. Also may support you to eat and drink safely.
- **Other health professionals** – Doctors, nurses and other hospital staff will continue to play an important role in your recovery and rehabilitation. Other staff in the BIRP team might include diversional and recreational therapists, support workers and allied health assistants.

Where are the brain injury rehabilitation programs (BIRPs)?



Specialised Brain Injury Rehabilitation Services in NSW

Metropolitan paediatric BIRP

- 1 John Hunter Kids, Newcastle
- 2 Sydney Children’s Hospital Network, Westmead
- 3 Sydney Children’s Hospital Network, Randwick

Metropolitan adult BIRP

- 4 Westmead
- 5 Royal Rehab, Ryde
- 6 Liverpool

Rural BIRP

- 7 Northern, Ballina
- 8 Mid North Coast, Coffs Harbour and Port Macquarie
- 9 New England, Tamworth
- 10 Dubbo, Lourdes Hospital
- 11 Hunter, Newcastle
- 12 Southern Area, Goulburn
- 13 South West, Wagga Wagga and Albury
- 14 Illawarra, Port Kembla and Nowra
- 15 Mid Western, Bathurst

Making important decisions

Important decisions may need to be made while you are still unconscious, confused or early in your recovery when your brain is not working as usual. These decisions may be about treatment, applying for leave from work, financial matters and family.

In this case, a person who has had a close and continuing relationship can make decisions. This person may be known as the ‘person responsible’. The person responsible is usually identified early after the admission to hospital. This person doesn’t have to be your next of kin.

The Guardianship Tribunal Act 1987 (Section 33A) provides information about who can be a person responsible, how to make a formal appointment and what to do if decisions are challenged.

Financial and insurance issues

If the brain injury was caused by a motor vehicle or work accident, then you may meet criteria to claim compensation.

You need to report the accident and submit a claim. The rules vary for different types of insurance and compensation schemes.

BIRP staff members can also work with you and others to determine if scheme entitlements can add value to your recovery and return home. Examples include income protection or accessing superannuation for financial support while not working due to medical reasons.

You may also benefit from talking with a qualified solicitor. Health staff cannot recommend specific solicitors, but they can support you to find and understand the information.

Discharge planning

When planning discharge, you may need to apply to specific accident or disability schemes for equipment, personal support, mobility and other services to achieve your recovery goals. The therapy team will work with you to make applications as early as possible so everything you need is available at the right time. You may need to apply for the National Disability Insurance Scheme. This may involve additional meetings and requests for information.

Where can I go for help?

The following organisations may be able to provide you or your family/carer additional information or professional help:

- Aboriginal Legal Aid – (02) 6640 1400 or www.alsnswact.org.au
- Australian Government Translating and Interpreting Service – 131 450 (available 24 hours a day, every day)
- Brain Injury Australia – www.braininjuryaustralia.org.au
- Carers NSW – www.carersnsw.org.au

- CTP Insurers NSW State Insurance Regulatory Authority (SIRA) – www.sira.nsw.gov.au/claiming-compensation
- Department of Human Services (Centrelink, Medicare, child support) – www.humanservices.gov.au
- Insurance and Care (icare) – www.icare.nsw.gov.au
- Law Society of NSW Solicitor Referral Service – (02) 9926 0300 or email ereferral@lawsociety.com.au
- NDIS (National Disability Insurance Scheme) – www.ndis.gov.au
- NSW Civil and Administrative Tribunal (NCAT) Guardianship Division – www.ncat.nsw.gov.au

Feedback

The ACI developed this brochure in consultation with people who experienced a brain injury, their families and carers.

If you would like the opportunity to provide feedback, we invite you to complete this short survey: <https://www.surveymonkey.com/r/BrainInjury>

Glossary

Word/ abbreviation	Meaning	Description
Acute	In need of urgent care	Early and immediate need for care or treatment for a new condition
BIRP	Brain Injury Rehabilitation Program	Specialised services for people with traumatic (acquired) brain injury across NSW.
Cognition	Mental processing of information	Knowledge, attention, memory, judgment, reasoning, problem solving, decision making, comprehension and language.
Coma	State of unconsciousness	In this state a person cannot be woken up and does not respond normally to noise or pain.
Functional	Ability to perform tasks	The ability to perform normal activities in our day-to day lives, such as independent living skills (e.g. bathing, dressing, shopping and housework).
GCS	Glasgow Coma Scale	A measure of how much a person can respond to different sensations (like light, pain, and instruction).
ICU	Intensive care unit	An area of a hospital dedicated to looking after patients with life-threatening illnesses or injuries.
PTA	Post traumatic amnesia	A period of confusion and poor memory. The longer this lasts, the more severe the injury.
Scans	CT, MRI, PET	Different types of pictures taken of the body. They cannot always show all of the damage that has occurred.
TBI	Traumatic brain injury	An injury to the brain that is often caused by an accident, such as a blow to the head or a fall

Quote reference: Agency for Clinical Innovation (ACI). Consumer engagement – NSW Brain Injury Rehabilitation Program Model of Care Review. Sydney: ACI; 2016. Available at: https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0007/306781/Consumer_Engagement-BIRP-MOC-report.pdf