



Living with Brain Injury

Westmead Brain Injury
Rehabilitation Service
Outreach Team

What does brain injury refer to?

Brain injury may be acquired through trauma to the head (e.g., as incurred in road accidents, falls, sporting accidents, violent assault, near drowning and gunshot wounds) or through non-traumatic causes such as strokes, substance abuse, disease, medical misadventure and haemorrhage. Other terms such as "head injury" may be used to refer to "brain injury" but this is misleading because it confuses the true location, potential cause and nature of the injury.

Injury resulting from any of the preceding causes can be described as "acquired brain injury".

Brain injury is the main cause of disability incurred by young people aged 16–30 years.

Who sustains a brain injury?

Each year an estimated 10,000 people will incur traumatic brain injury in New South Wales.

- + Brain injury is disproportionately concentrated in the young, particularly young males. While people aged 17 to 25 years constitute 15% of the population, they account for 40% of brain injuries.
- + Brain injury is the main cause of disability incurred by young people aged 16-30 years.
- + The ratio of males to females incurring brain injuries is 3:1.
- + More than 3 times as many people have serious lifetime disability from brain injury than from paraplegia and quadriplegia combined.
- + While the annual number of people admitted to hospital with a severe brain injury is constant, the cumulative effect of people being discharged back into the community is growing.
- + 70% of severe brain injuries are sustained in road accidents.¹

1. Source: Cuff Consultants, Brain injury Program for New South Wales: GIO's Commitment Under Transcover, GIO May 1987.

What are the prospects for recovery?

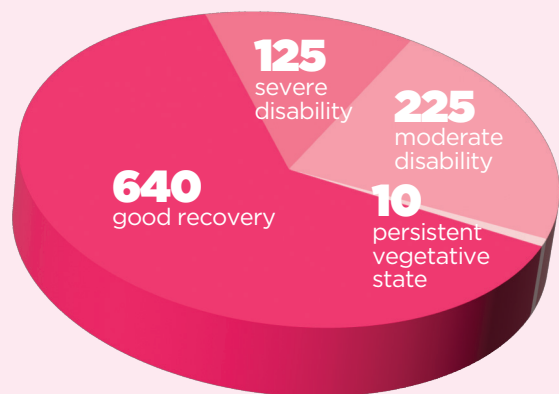
The brain can make significant recovery after an injury. Through a process of natural recovery and treatment the person with a brain injury may gradually regain abilities lost at the time of the injury.

The person who has had a brain injury may have to re-learn how to walk or to speak. People who were initially confused about where they were, or who did not recognise or remember family or friends, may start to regain their orientation and memories.

This period of recovery can continue for up to 12 months or longer after the injury. After that time, if people still have disabilities, it is likely that they will be permanent.

For each 1,000 persons who survive a severe brain injury, 125 will have a severe disability; 10 will be in a persistent vegetative state; 225 will have a moderate disability; and, 640 will experience a good recovery but possibly with some ongoing cognitive and/or behavioural problems.

For each 1000 persons



There is a great range in the severity of brain injury. It ranges from the mild concussive effects of, for example, being knocked out momentarily in the football field with no discernible ill effects, through to the person who may be in a persistent vegetative state for months as a result of an injury acquired in a motor vehicle accident.



What happens to the persons with a brain injury during hospitalisation, rehabilitation and beyond?

After rehabilitation many people with an acquired brain injury will face the challenge of resuming their lives. Many will require support to do so.

Community services may be unfamiliar to them and will provide a very different service to the hospital or the brain injury rehabilitation program.

To effectively, and sensitively, respond to the support needs of the person with a disability resulting from brain injury requires an understanding of what the person has been through prior to returning home to the community.

By the time a person who has had a brain injury seeks disability support services from the Department of Community Services s/he may have already had extensive contact with a range of health and allied professionals and carers in the hospital and rehabilitation systems.

This is important to understand because the expectations of the person with a brain injury have been shaped by these experiences. The person with a brain injury may still be dealing with the trauma of the injury, and consequent disability. Many people will also have had to cope with the experience of hospitalisation and rehabilitation.

When a person has acquired a brain injury, s/he will probably be admitted to a casualty/emergency department of a major hospital. If the person is simply concussed, s/he may be held for neurological observation and then discharged.

If the injury is serious, surgery may be required and the person will be transferred to a medical ward.

Some people who have acquired severe brain injury, may not benefit from rehabilitation and will require intensive full-time nursing care. In such cases the person may be discharged directly from the hospital into nursing home care.

Some people recover quickly and may be discharged home from the ward while others will require rehabilitation, and will be transferred from the hospital to a Rehabilitation Unit.

The period of rehabilitation may vary in both intensity and duration and be provided on both an in-patient and/or an out-patient basis.

For those people who require treatment, the process of rehabilitation can impose an emotional strain. Through this period the person with a brain injury and their family/carers will deal with various specialists, doctors, nurses, therapists, hospital social workers and other rehabilitation staff. Also, depending on the level of disability resulting from the brain injury, the person may experience frustration or anxiety in adjusting to new circumstances, new environments and new carers/service providers.

Furthermore, the person who has had a brain injury and their family/carer may require assistance to make informed decisions about the support required to maximise independent living.

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What are the disabilities and problems that may result from a brain injury?

There are a range of possible outcomes for people sustaining a brain injury, and it is hard to predict what these will be in the early months.

Sometimes the damage will be minimal and will cause little or no difficulty in returning to normal living. Unfortunately, some people may be left with some very serious difficulties which will require a long period of rehabilitation and adjustment.

In general, people who sustain brain injury may experience permanent disabilities in each of three functional areas:

- a) the physical (or motor-sensory);
- b) the cognitive (or intellectual); and
- c) the behavioural (or personality).

Cognitive and behavioural problems can be "hidden disabilities" that are not readily apparent and which are often most disabling for the person with a brain injury because of their effect on people around them.

The different types of problems people may face are:

Physical Problems

The most common physical disabilities are visual impairments, balance problems and paralysis/spasticity.

- + Only 25% of people with severe brain injury will have a permanent physical disability as most people make a complete physical recovery.
- + Some people may be unable to walk - others may walk only with difficulty.
- + Some may have difficulty in performing the activities of daily living e.g.: dressing, toileting, feeding, bathing, writing, doing their jobs.
- + Some people may have the use of only one side of their body, or have weakness on one side of the body.
- + Some people may be partially or completely paralysed.
- + Others may experience problems with motor control, loss of co-ordination, poor balance and low stamina.

Cognitive Disabilities

Problems with memory, resulting in:

- + impaired new learning
- + forgetfulness
- + more effort being required to remember everyday things, e.g. a telephone number.

Problems with attention and concentration resulting in:

- + reduced attention span
- + poor concentration
- + high distractibility

Problems with thinking resulting in:

- + difficulty with complex ideas
- + rigidity or "perseveration"
- + concreteness

Problems with planning and organising resulting in:

- + poor planning skills
- + a disorganised approach to problem solving
- + poor self-monitoring
- + failure to learn from mistakes

Problems with speed of information processing resulting in:

- + slow thinking and information processing
- + difficulties in shifting from one idea to another
- + Personality Changes

Changes in drive/motivation making the person:

- + lethargic or inert
- + or leaving the person with a lack of initiative or energy which
- + makes it difficult to begin the process of rehabilitation and training. This may be perceived by others as laziness.

Changes in self-control making the person:

- + uninhibited, or
- + experience a low tolerance for frustration

Changes in emotional state making the person:

- + unrealistically happy or optimistic
- + exhibit a "flattened affect"
- + inappropriately emotional or "labile"

Changes in personal insight making the person:

- + deny the effects of the injury
- + have unrealistic expectations
- + have poor appreciation of their own behaviour
- + unable to monitor, evaluate or regulate their own behaviour

Changes in perceptions of relationships to others making the person:

- + self-centred
- + demanding on others
- + less sensitive to others

Medical Problems

Generally there are few medical problems which persist after rehabilitation. People who have had a brain injury are usually well and healthy, although epilepsy is a problem for some people who have had a brain injury.

Communication Problems

The most commonly occurring speech problems which may follow a brain injury are:

- + Slurred speech as a result of impaired control over the muscles used during speaking.
- + Difficulty in finding words and organising ideas.

There may also be more subtle changes to speech which may cause communication difficulties, for example:

- + Inappropriate behaviours may occur during conversation including
- + talking too much or being unable to stay on the topic.
- + Some people with a brain injury may find that their speech becomes
- + jumbled when they are tired, stressed and/or excited.

Parents may have to reorganise their lives considerably to provide care and support

What are the implications for parent carers?

Where young people return to live with their families, after having lived independently, parents may have to reorganise their lives considerably to provide care/support. Parents not only have to readjust to living again with their son or daughter, they must learn to cope with that person's brain injury. Understandably, tensions may emerge and cause conflict.

What are the implications for spouses or partners?

In a relationship where one partner has had a brain injury, with consequent severe disabilities, the uninjured partner may carry most of the responsibility for keeping the relationship together.

There may be many role changes within the relationship because of the needs of the person who has had a brain injury for care and/or support.

Partners of a person who has had a brain injury may find that their partner is no longer the "same person" and has become a frustrated, difficult, dependent adult needing supervision, support and/or care.

There may also be problems in resuming and maintaining a normal sexual relationship because of physical and/or personality changes.

Some partnerships may falter and possibly break down under the impact of all these stresses.

What are the implications for the children of a person with a brain injury?

There will be major changes for any parent who has had a brain injury. In particular, it will be difficult for the sons or daughters of the person with a brain injury to adapt to the changes that the brain injury may cause. It is even more difficult for younger children of a person with a brain injury.

People who have had a brain injury may act in a socially inappropriate manner because of cognitive and behavioural changes. This may place their children in a position where they may be required to monitor and correct the behaviour of their parent.

Children may react in a number of ways in response to the behaviour of a person who has had a brain injury. Sometimes, children may respond by developing behaviour disorders, thereby compounding the long term problems for the family.

Sometimes a conflict situation may develop where children are in conflict with the parent who has had a brain injury, which may place the uninjured partner in the position of acting as a referee to hold the family together.

In cases where the person who has had a brain injury is violent and aggressive children may be at risk of a parent who "lashes out".

Adolescents may too embarrassed to bring their friends home, or fall into the habit of avoiding the parent who has had a brain injury because they do not know how to deal with possibly aggressive or irritating behaviour.



The adolescent with a brain injury

Normally, adolescence is a time when a person's self image, social skills and social relationships are consolidated and developed. This presents an enormous challenge for a person with a brain injury who may have a poor self image, and may be disadvantaged in dealing with these challenges by his/her cognitive and psycho-social impairments resulting from the brain injury.

What about children with a brain injury?

The situation facing children and adolescents with a brain injury is different than that for adults. Brain injury in adults may result in a significant loss of acquired skills and independence, changes in personality and altered relationships.

Children and adolescents with a brain injury may lose not only existing skills, but potential skills, as the brain injury alters the course of their development.

In very young children, the effects of the brain injury may not become apparent until later in their lives.

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Younger children with a brain injury

Children with a brain injury are unlikely to have the maturity and sophistication to understand what has happened to them with the majority of children with a brain injury cared for at home by their families.

The small child with a brain injury is likely to:

- + be unable to explain or express how s/he feels
- + may not be able to control irritability
- + be restless and aggressive experience learning difficulties
- + fall behind his/her peers, e.g.. at school or in sports have tantrums have difficulties understanding what has occurred
- + The brain injured child may find him/herself socially isolated as other children may not tolerate cognitive disabilities and demanding behaviour.

As children usually remain at home with their families until they are adults, there is an acute need for families with a brain injured child to have access to long term support, respite care services and counselling, to ensure that the family unit will cope with undertaking the work of long term care of their brain injured child.

The family will also need extensive help and support as the child becomes older and progresses through puberty, as adolescence may be more difficult and stressful than with the average child.

What is the difference between a person with a brain injury and a person with an intellectual or other disability?

Historically, the Department of Community Services has provided direct and indirect services for people with an intellectual disability, their families and their carers.

Although people who have had a brain injury may have similar needs to people with an intellectual and other disabilities there are some major differences.

- + Adults with an acquired brain injury have usually had what could be termed a normal social and intellectual development.
- + This means at the time they sustained the brain injury they typically have a store of memories and experiences from childhood, adolescence and early adulthood in which disability has played no role.
- + Their self identity and expectations of life after an injury are still strongly shaped by their social and intellectual development before the brain injury.
- + There is often little or no change in the IQ scores that people can achieve post-injury because they can still draw on their past memories and skills.
- + However, people's level of adaptive functioning (problem solving, organisation, personal management) is often significantly impaired.
- + The person who has had brain injury will have aspects of their self identity, behaviours and expectations based on pre-injury experience interspersed with their acquired disabilities.



What kinds of services might be needed by people who have had a brain injury?

The person who has had a brain injury and their family/carers may require a range of services to maximise the ability of the person to participate in community life. Services that might be required include:

- + Living skills training;
- + Behaviour management programs to deal with behaviour that might be aggressive, difficult, annoying and/or inappropriate;
- + Counselling to help the person with the brain injury and their family/carers deal with the emotional and psychosocial impact of the injury and resulting disabilities;
- + Sexual counselling;
- + Personal care for people with physical disabilities;
- + Respite care;
- + Supervision and/or support for people with cognitive disabilities;
- + Further education;
- + Vocational training and placement;
- + Supported employment;
- + Appropriate and meaningful leisure, recreational and cultural activities;
- + Opportunities to develop recreational interests;
- + Domiciliary support, such as meals on wheels, cleaning, home maintenance;
- + Home modification, aids and equipment;
- + Accommodation and support;
- + Opportunities to engage in social activities that are appropriate to the nature and level of disabilities, and the lifestyle of the person and his/her family.



Because of the relatively young age of the majority of people who have had a brain injury, it must be anticipated that support services may be required for a long time, perhaps some 40 to 50 or more years. For people who have had a brain injury and are living with their parents, there will come a time when others must assume the primary care-giving roles that may have been fulfilled by ageing parents.



What are some of the legal issues that affect people with a brain injury?

After acquiring a brain injury some people may be unable to manage their own affairs.

As a result they may require an advocate to give instructions to their solicitors' and/or for alternative arrangements to be made for the management of their financial affairs.

The Protective Commissioner undertakes this role for many people who have had a brain injury.

Alternatively' if the person is a person in need of a guardian the Guardianship Board may appoint a Guardian to assist the person, and/or appoint a financial manager.

Unfortunately, disputes sometimes arise amongst family members' spouses or partners, and the person with a brain injury in relation to important decisions that affect their lives. (For example, where the person should live or how finances are to be managed.)

In such cases some form of family arbitration might be required and in extreme circumstances, legal action may be necessary with some person or agency being appointed to assist the person with a disability to manage his/her affairs and make decisions and choices about their lives. The Guardianship Tribunal of NSW can often play a major role in resolving such disputes.

For further information on these matters contact:
The Guardianship Tribunal of NSW

Psycho/social changes following a traumatic brain injury

Recovery and adjusting to the changes due to traumatic brain injury may mean that the person may have to re-think about their goals in life.

Many people with a traumatic brain injury never fully recover to their former selves even after fairly minor injuries. Accepting the changes in themselves and their lives is an important step in being able to get on with living.

In order to do this they may need to grieve for the losses they have suffered. Feelings of grief may come and go and may form a very important part of their recovery.

Although people with a traumatic brain injury are usually unaware of the more specific ways in which their injury has affected their thinking, they are often aware that something has changed in their lives which they cannot specify.

The emotional reactions to this include loss of self-esteem, loss of selfconfidence, anxiety or depression.

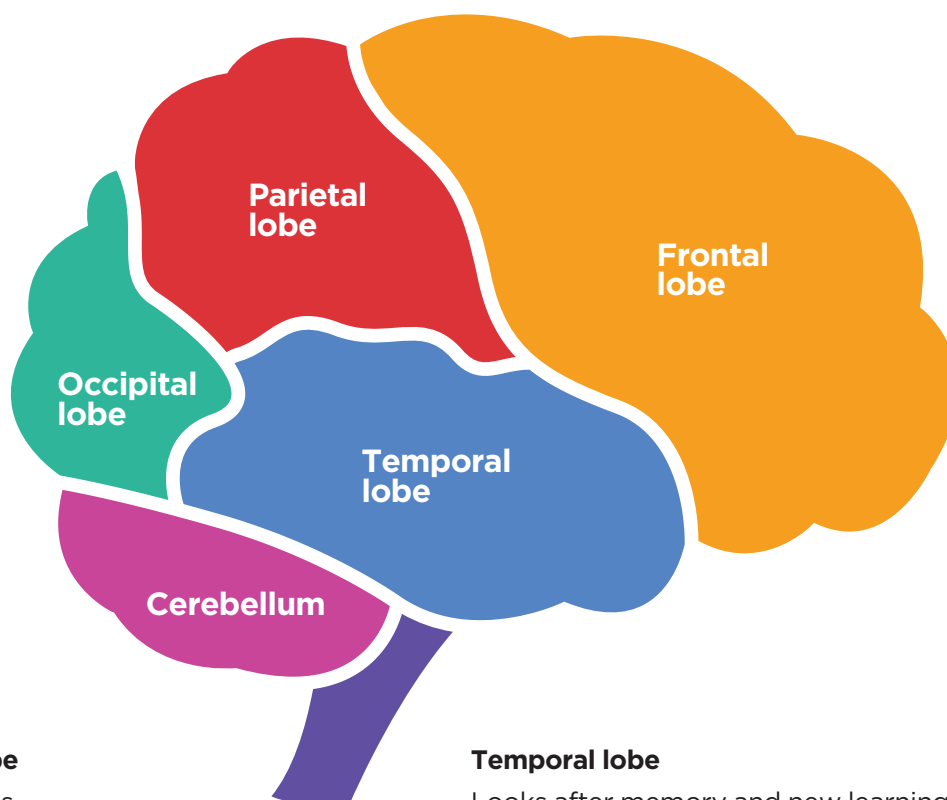
Some common feelings experienced by someone who has suffered a traumatic brain injury include...

Shock.	They are devastated by what has happened.
Depression.	A feeling of not wanting to go on with anything.
Anxiety.	Not feeling confident about being able to do things.
Anger.	Unable to even begin to describe the feelings.
Blame.	They want revenge on someone for what has happened to them.
Guilt.	Especially if they were somehow at fault or someone else was fatally wounded.
Loss of Independence.	Accepting assistance from others. Having lost confidence in their ability to do things by themselves.
Frustration.	Not being able to do things as they previously did.
Worthlessness.	Not feeling useful anymore. Feeling like they do not fit in or belong.
Denial.	Believing that they will be back to 'normal' soon.
Isolated.	Former friends not wanting to spend time with you anymore.

No one understands what it is like.

Our amazing brain.

Each cerebral hemisphere has four lobes.
Each does different things but they all work together.



Frontal lobe

- Makes plans
- Learns from mistakes
- Works out how to do things
- Adapts to new situations
- Controls emotions and impulses
- Controls activity level
- Controls expressive language
- Controls voluntary movement
- Helps us 'get along' with other people.

Occipital lobe

- Receives visual information
- Interprets colour, shape, distance

Temporal lobe

- Looks after memory and new learning
- Controls how things are ordered
- Receives auditory messages
- Understands spoken language, rhythm, intonation

Parietal lobe

- Monitors sensation and body position
- Controls reading
- Recognises faces
- Understands time
- Judges what objects are



Acknowledgements

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