

Acquired brain injury

The facts

The practical guide to understanding and responding to
acquired brain injury and challenging behaviours

Fifth edition
(2016)





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The facts is produced by Synapse.

Synapse is dedicated to improving the quality of life of people living with and affected by acquired brain injury, or people whose behaviour challenges our understanding.

Visual difficulties:

Visit synapse.org.au to view the online version which can be enlarged on screen.

Disclaimer:

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About brain injury

Almost everything we do, say and think is controlled by our brain, so when our brain is injured it has the potential to affect every aspect of life.

This resource has been prepared to inform and assist those who have experienced a brain injury, their family, and supports – as well as being a resource for medical professionals.

It has been designed to not only give an overview of the types and immediate impacts of brain injury, but also practical information and strategies on how injury affects broad areas of life.

While this resource features a wide range of acquired brain injuries and degenerative neurological disorders, much of the content is directed at acquired injuries. The strategies and information given in this resource may be useful in responding to both acquired injuries and disorders.

If you would like to speak to someone about this information in this resource.

To find support call, Synapse Options on 1800 673 074. Alternatively, visit synapse.org.au.

About acquired brain injury (and neurocognitive disorders)

The term brain injury includes a number of conditions and brain disorders that typically result in a level of neurocognitive impairment, and are distinct from intellectual disability.

Acquired brain injury (ABI) generally refers to injuries sustained after birth, such as through stroke, hypoxic injury (near drowning, attempted suicide, etc.) and traumatic brain injury (TBI) (Motor vehicle accidents, falls, sporting injuries, assault etc.).

Injury to the brain also occurs through degenerative disorders (Alzheimer's disease, Parkinson's disease; multiple sclerosis etc.), brain tumours, infections or brain diseases (meningitis, encephalitis, etc.). Degenerative brain disorders can have similar physical and cognitive impacts to ABI; however, the different characteristics of these conditions require specialist support.

Some injuries sustained during pregnancy, such as Foetal Alcohol

Spectrum Disorder (FASD), have also been classified as an ABI.

Brain injury is common in Australia, with around one in 45 Australians (432,700 people) acquiring a brain disorder (AIHW, 2007). The Queensland Government acknowledges that one in 12 are affected in some way by brain injury. Brain injuries are often called the hidden disability because, although people can experience significant changes in how they think, feel and relate to others, there may be no outward physical signs of injury. Problems can be easily ignored or misunderstood by others. The impacts of brain injury are also experienced by family and friends, particularly when the injury has resulted in personality or behaviour change.

Synapse will often refer to the term 'brain injury' as a collective representation to inclusive of both acquired injuries and neurological disorders.



Effects of a brain injury

The long-term effects of a brain injury or disorder are different for each person, and will vary depending on the type of condition, the nature and location of the injury, and other factors. For example, while disorders such as Parkinson's disease and multiple sclerosis typically impact the body's ability to control movement, other brain injuries may have a greater impact on cognition, or personality and behaviour may be affected more. The impacts of brain injury can cause:

Physical effects:

- movement disorders and paralysis
- dizziness and balance problems
- epilepsy and seizures
- eyesight, hearing and speech problems
- loss of taste and smell
- headaches
- chronic pain
- fatigue and sleep disorders
- hormonal changes.

Cognitive effects:

- memory problems
- difficulty solving problems
- poor concentration and attention
- reduced ability to organise and plan
- lack of initiative and motivation
- lack of insight and awareness, and poor judgement.

Personality and behaviour change:

- irritability, anger and easily stressed
- depression
- slowed responses and poor social skills
- impulsive behaviour and/or a lack of emotional control
- disinhibition.

Secondary effects – the interaction of impacts can result in additional secondary changes such as:

- changes to living arrangements
- reduced or changed social networks
- different vocational capabilities
- altered relationships and family dynamics.

Understanding the brain

The brain controls and coordinates everything we do: movements, feelings, thoughts, breathing and bodily functions.

The brain is made up of billions of nerve cells that communicate through electrical and chemical activity. It weighs around 1.3 kg and is cushioned within the skull by cerebrospinal fluid that circulates around the brain through a series of cavities called ventricles.

The brain makes up only two per cent of the body's weight, but uses 20 per cent of the oxygen supply and blood flow. Brain cells are quite fragile and need protection from trauma, pressure, infection, poisoning or lack of oxygen. They begin to die if they do not receive oxygen after three to five minutes.

The brain is divided into a number of parts, which have specific functions and are designed to work together.

Hemispheres and lobes of the brain

The largest part of the brain is divided into two halves, with the left half controlling the right side of the body and the right half controlling the left side of the body.

These hemispheres will be more dominant for certain activities. For example, the left hemisphere is mainly involved with speech, language, reading and writing, while the right hemisphere is predominantly focused on visual perception, and interpreting nonverbal information. Each hemisphere is divided into four lobes:

Frontal lobes are involved with problem-solving, planning, making judgements, abstract thinking and regulating emotions and impulses. Marked changes in personality and social skills can occur from damage to this area.

Temporal lobes are involved in receiving and processing sounds, visually recognising objects, and memory and learning. The temporal lobes are also involved in personality, emotions and sexual behaviour.

Parietal lobes are involved in monitoring sensation and body position, understanding time, recognising objects, reading and judging the position of objects in the environment.

Occipital lobes receive and interpret visual information from our senses including colour, size, shape and distance.

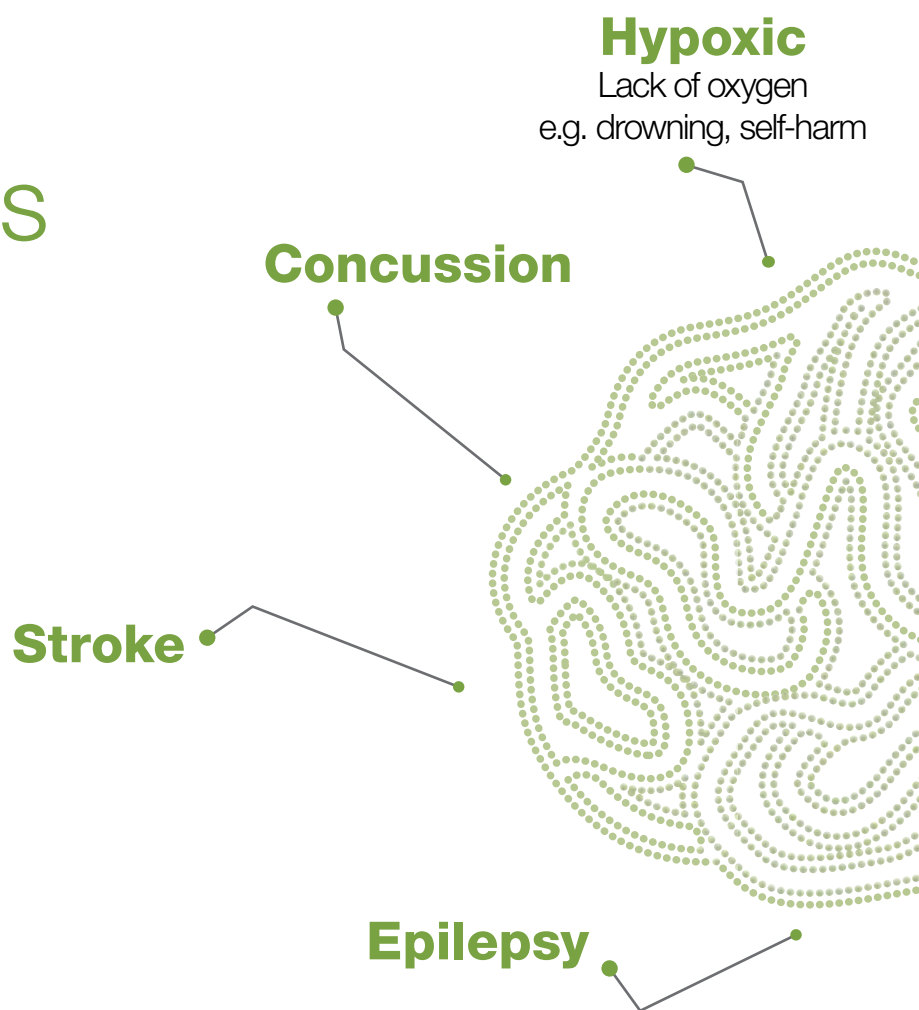
The cerebellum is located at the back and below the main hemispheres of the brain. It controls balance and the muscle coordination needed for large body movements. It processes information about how fast, how hard, how far and in what direction body parts are moving.

The brain stem stem connects the brain to the spinal cord and regulates basic activities such as wakefulness, breathing, swallowing, eye movement, body temperature and heart activity.

This brief introduction to the brain reveals not only why the brain is so vulnerable to injury, but also why the effects of a brain injury can be so varied. Each part of the brain deals with different aspects of what we think, feel and do; so injury to specific areas causes many different effects. The brain can be injured as a result of many things; a car accident, stroke, alcohol or drug abuse, tumours, poisoning, infection, disease, near drowning, haemorrhage, AIDS, and disorders such as Parkinson's disease, multiple sclerosis, and Alzheimer's disease.

The good news is that the brain does have a limited ability to heal itself and there are many rehabilitation strategies to compensate for lost skills and abilities. Read more in the rehabilitation and recovery section.

Types of brain injuries and disorders



Traumatic brain injury (TBI)

Traumatic brain injury has been defined as ‘an injury to the brain resulting from an externally applied mechanical force that affects the brain and leads to loss of consciousness or coma’ (Kay and Lezak, 1990).

TBI is caused by either a blow to the head or by the head being forced to move rapidly forwards or backwards. Brain tissue may be torn, stretched, penetrated, bruised or become swollen. Oxygen may not be able to get through to the brain cells and there may be bleeding.

Common causes include motor vehicle accidents, assault, falls, sporting accidents, domestic violence, and babies being shaken. The effects can be temporary or permanent, and range from mild injury, such as being momentarily stunned while playing football, to a very severe injury that may cause prolonged loss of consciousness.

Apart from the injury to the brain caused by the initial trauma, there are secondary effects that can arise from bleeding, bruising, lack of oxygen and increased pressure within the skull.

Hypoxic/anoxic brain injury (lack of oxygen)

Brain injury can occur when there is a reduction in (hypoxic) or complete lack of (anoxic) oxygen supply to the brain. Oxygen is crucial to the brain as it is used to metabolise glucose, which provides energy for all body cells. Brain cells are sensitive to the effects of restricted oxygen supply and can die within minutes of oxygen restriction. The immediate outcome of severe oxygen restriction is often coma and in very severe cases brain death.

Causes include stroke, near drowning, heart attack, drug overdose, strangulation, severe asthma, accidents involving anaesthesia, and carbon monoxide inhalation and poisoning. Hypoxia can also occur as a secondary injury following a TBI (e.g. When there is serious blood loss resulting in low blood pressure, or as a result of brain swelling that restricts oxygen supply to areas of the brain).

Recovery is similar to that of other types of brain injury, but because a hypoxic injury usually results in widespread injury to the brain outcomes are likely to be lower than other brain injuries.

Degenerative

e.g. Alzheimer's disease, Parkinson's disease, multiple sclerosis

Brain tumour

Traumatic brain injury

e.g. motor vehicle accidents, falls, assault

Infection or disease

e.g. meningitis, encephalitis

Degenerative conditions

There are a number degenerative conditions which involve brain impairment. The more commonly known of these are multiple sclerosis, Parkinson's disease and Alzheimer's disease.

In multiple sclerosis, nerve cells die when the Myelin is removed. Myelin is a fatty coating that acts in a similar way to the plastic insulation on electrical wiring. The exact cause is unknown, and there is no cure, although treatments exist that can reduce the symptoms.

Parkinson's disease results from the loss of cells in various parts of the brain, including an area that creates dopamine. Loss of dopamine causes neurons to fire without normal control, leaving people less able to direct or control their movement. The exact cause of Parkinson's disease is unknown, and the single biggest risk factor is advancing age. The effects include slowness of movement, rigidity, tremors and balance problems.

Alzheimer's disease is the most common type of dementia, accounting for around 50 per cent to 75 per cent of dementia cases worldwide (AIHW, 2012). The causes are poorly understood, but genes play a major role and there is no cure. Plaques and tangles in the brain usually develop later in life and lead to problems with short-term memory, disorientation, mood swings and behavioural issues. The average life expectancy is three to nine years after diagnosis.

More information can be found in our fact sheets at synapse.org.au

Brain tumours

Brain tumours can restrict blood supply to other cells or may squash cells through exerting physical pressure upon them. Infectious substances may cause cell death through exerting pressure if the brain swells (encephalitis) or the tissue surrounding the brain swells (meningitis), or may kill cells through direct infection. Viral infections may result in a widespread injury that can appear as fatigue disorders such as chronic fatigue syndrome.

References: AIHW (2012) Australian Institute of Health and Welfare 2012. Dementia in Australia. Cat. no. AGE 70. Canberra: AIHW.

AIHW (2007). Australian Institute of Health and Welfare. Disability in Australia: Acquired brain injury, Bulletin 55, Canberra: AIHW.

Kay, T., and Lezak, M. D. (1990). The nature of head injury. In D. W. Corthell (Ed.), Traumatic brain injury and vocational rehabilitation (pp. 21-65). Menomonee, WI: University of Wisconsin Stout, Research and Training Center.



Children and brain injury: an introduction

One of the most important differences between children and adults who acquire a brain injury is that a child's brain is still developing.

After a brain injury, rehabilitation for adults primarily focuses on relearning lost skills. However, a child may be yet to learn many skills, so extra support is needed to ensure development progresses as normally as possible.

Predicting the degree of recovery

Predicting how much recovery will occur after a brain injury is always difficult, regardless of the cause. It becomes even more so for children as specific problems may only become apparent at certain stages of development. It is important to provide plenty of support to prevent the child lagging behind their peers in key areas.

It was thought that younger children made a greater recovery due to neural plasticity – the ability of the developing brain to reorganise itself. Unfortunately, research suggests this isn't the case. Children are more vulnerable after a brain injury and will take longer to recover (Catroppa et al., 2008).

In general, it appears that the earlier a brain injury occurs, the more impact it will have for the child. Recovery appears to be an easier process when basic functional

skills have already been developed. However, a child's age only has a limited impact on recovery, and the key factors are still the severity and type of brain injury, how supportive the family is, and rehabilitation and support at school.

Effects of a brain injury

Sensory and motor skills: a child might either lose some previously acquired skills, or have difficulty learning new skills such as holding a pen, drawing, using a keyboard, constructing and manipulating objects, using cutlery, getting dressed, recognising objects and a variety of other hand-eye coordination activities. Other problems may involve mobility, balance and coordination or swallowing and speech difficulties. Professionals such as physiotherapists, occupational therapists and speech pathologists play an important role in the assessment and rehabilitation of sensory and motor disorders.

Cognitive abilities: a brain injury may lead to a general decline in a number of intellectual abilities. However, similar to adults, a child may be within the normal range on measures of intellectual functioning and yet display significant problems in specific areas of attention, memory, language, visuospatial and executive functioning.

Language and communication: many children experience receptive problems which involve difficulty processing different parts of spoken or written information. Comprehension problems occur when a child cannot understand what he or she is reading or what another person is saying. Spoken or written language expression may be affected in terms of pronunciation, fluency, grammar, intelligibility or the meaning and retrieval of words.

Social, behavioural and emotional issues: a child can experience difficulties relating to peers and siblings and have difficulty joining group activities. They can demand a lot of attention from parents or teachers, and have difficulty following rules and instructions. Behavioural problems include: depressed or anxious mood, hyperactivity, distractibility, impulsivity, poor judgement, reduced control of anger and frustration, mood swings, aggression, sleep disturbance and poor motivation. There are various rehabilitation strategies to help children manage their emotions and behaviour. These should be introduced as early as possible.

Brain injury and your child's development

A brain injury can disrupt normal development in terms of language and speech, learning, memory, behaviour, movement, balance and coordination. Children with a brain injury will often make good progress, even if it is limited to some extent by the injury. Support and assistance tailored to each child's needs will ensure they develop to their fullest ability. This is especially true at school where there can be a tendency to underestimate the degree of support needed within the education system.

Balancing risk & independence

One of the important things parents do is to help young people learn to manage and judge risk. It is important to encourage independence and allow a manageable element of risk, but a child's brain injury can cause problems with anticipating danger, judging risk, or showing self-control. Research shows that important factors in protecting young people from high-risk activities include a strong connection

with caring families and school communities, coupled with personal skills that enable young people to develop self-esteem and confidence. It is also helpful to have a stable family structure, open lines of communication, a proactive approach to solving problems and a good relationship with an adult outside the family – someone who believes in the young person.

Challenging behaviours

Challenging behaviours are a normal part of growing up as children test their boundaries. While the effects of a brain injury can further complicate this, the appropriate adult response to this behaviour is the same:

- The best basis for helping children is a loving, caring relationship, so it is important to see children as separate from their behaviour and use language such as: 'I love you, but I don't like what you're doing'.
- Structure and routine become even more important after brain injury. Specific rules and structures need to be set up for particular situations and rehearsed each time a similar situation comes up.
- Children will be encouraged to behave well when praised or rewarded. Challenging behaviour should not be rewarded. Instead, adults can help children to learn from experience by talking about what he or she did right or wrong, and how there might be other ways of responding.
- Children will also learn to get along with others and handle difficulties by watching how adults behave.
- Most importantly, young people with a brain injury may need very concrete, detailed and explicit instructions and rules about what to do in particular situations.

For more information, view our parents' guide at synapse.org.au

Reference: Catroppa, C., Anderson, V. A., Morse, S. A., Haritou, F., and Rosenfeld, J. V. (2008). Outcome and Predictors of Functional Recovery 5 Years Following Pediatric Traumatic Brain Injury (TBI). *Journal of Pediatric Psychology*, 33(7), 707-718. doi:10.1093/jpepsy/jsn006



Stroke

A stroke is an interruption of blood supply to part of the brain. If arteries become blocked, bleed or break, then the brain tissue that was being nourished deteriorates.

When this lack of blood supply occurs to the heart it is called a heart attack. When it occurs in the brain it is called a stroke.

Types of stroke

Embolism is where an object, most commonly a blood clot, blocks an artery. These clots can occur in other parts of the body then break up and travel to the brain where they lodge in the brain's smaller blood vessels.

Thrombosis is where there is a gradual closure of a blood vessel. In a stroke, this is most commonly fatty lipids called plaques building up on the walls of blood vessels and restricting blood flow. As a result symptoms usually develop slowly but may be rapid in some cases.

Haemorrhage is severe bleeding. There are two kinds that can cause a stroke. An intracerebral haemorrhage is caused by a ruptured artery leaking blood directly into the brain. A subarachnoid haemorrhage occurs on the surface of the brain and the blood fills the space around the brain and creates pressure.

Effects of stroke

The after-effects of a stroke vary widely for each stroke victim as different parts of the brain are responsible for thought processes, comprehension, movement and our senses. The extent of blood shortage also determines the effect of the stroke. A stroke may result in paralysis, loss of feeling, communication difficulties, visual problems and many other issues depending on which part of the brain is affected.

Treatment

Surgery, drugs, acute hospital care and rehabilitation are all accepted stroke treatments depending on the type of stroke.

An example of surgery is a carotid endarterectomy to remove plaque if a neck artery is blocked. Aspirin is a common drug used for thinning the blood. Other medications aim to dissolve clots that lead to stroke. New techniques continue to arise, such as cerebral angioplasty where balloons, stents and coils are used to dilate small intracranial arteries.





Recovery

Generally speaking, the brain does not regenerate if brain tissue dies after an embolism or thrombosis. The individual may regain some function after the pressure caused by the bleeding (haemorrhage) has decreased.

Recovery after a stroke depends on a number of factors including the:

- type and severity of the stroke
- part of the brain involved
- extent and nature of the damage
- existing medical problems
- type of treatment and rehabilitation.

Recovery usually involves a lot of relearning of activities such as walking and talking. This learning can be complicated by the fact that many people have trouble concentrating after a stroke.

Infections

Infections, such as meningitis and encephalitis, can injure the brain and even lead to death very quickly, so urgent medical attention is critical.

Meningitis is an inflammation of the protective membranes that cover the brain and spinal cord, leading to high fever, headaches, sensitivity to light, confusion, and occasionally seizures. Vaccination of young children is strongly recommended as a preventative measure. The most common causes of meningitis are viruses, bacteria, fungi, and protozoa.

Encephalitis is a swelling of the brain caused by viruses or bacteria. This can occur through insect bites, contaminated food, or other existing infections and diseases. Symptoms include an unsteady walk, sleepiness, confusion, fever, headache, light sensitivity, seizures, paralysis and impaired cognition.

Epilepsy

Epilepsy involves recurring brief episodes of abnormal electrical activity in the brain leading to either uncontrolled convulsions and unconsciousness, or just a momentary loss of awareness. The exact cause is unknown, but the majority of recurring seizures can be prevented by medications. While epilepsy is a brain disorder itself, it can also be caused by other disorders such as a TBI or stroke.

More information on injury on stroke can be found in our fact sheets at synapse.org.au

In the hospital

It is important to become familiar with the hospital's departments, wards and key staff providing treatment for acquired brain injury.

Patients presenting at hospital with a brain injury are typically admitted to the neurosurgical unit under the care of a neurosurgeon. A number of specialists may attend patients with multiple injuries. The specialist in charge can vary depending on the needs of the patient. For example, in cases of bone injury, an orthopaedic surgeon will be in charge, but the patient will have access to a range of specialists according to their needs. A registered nurse (RN) is always available and assigned to patients.

Understanding medical information

Understanding medical terminology can be difficult, especially during times of stress. It is important for people to ask questions in order to understand what is happening. People may prefer to direct such questions to a person with whom they feel comfortable, such as a member of the nursing staff, a doctor or an allied health professional. We have included a glossary of terms at the back of this resource.

It is common for hospitals to hold meetings with family members and various members of staff involved in the patient's care. Family members can request a meeting through the social worker if it has not been offered. These meetings provide a good opportunity for relatives to direct questions to specific professionals. It may be helpful for those attending a meeting to write down the most important points or questions they wish to raise ahead of time.

Advocacy

Families are entitled to ensure that their family member's best interests are being served. Most hospitals provide support for families to obtain information and make decisions about a patient's care. The person providing this support is often a social worker, who will advocate for the patient on the family's behalf.

Informing the patient

The focus of family members at this time is typically the wellbeing of their loved one, and they may be reluctant to convey potentially upsetting information to the injured person. Conversations about the person's condition, or another person's death, require sensitivity, and may be distressing for families. It is advisable to discuss any concerns with the appropriate hospital staff who will provide guidance in this matter. It is usually preferable to tell patients any traumatic news (although they may forget) and at times, their reaction may be different to what is expected as a result of the brain injury.

Adjusting to the experience

For family members and close friends, this may be one of the most stressful and emotional times in their life. People must look after their own emotional and physical health if they are to care for the patient and other family members. Support groups may be available at the hospital.

Contact Synapse for more information and support
1800 673 074.

Coping strategies

The following ideas are designed to help friends and relatives come to terms with the traumatic experience of having someone sustain a brain injury:

- acknowledge personal reactions to stressful experiences
- reduce sources of stress where possible
- accept support: whether it be talking things over or getting help with the housework
- talk with other people about your feelings and experiences as this can help you process what has happened
- be aware that other family members may deal with the situation differently
- maintain a sense of normality and make a routine for structure in your life.



Brain injury: treatment & diagnosis

Initial treatment of a brain injury is often in the emergency department with a priority on an initial diagnosis, stabilising the patient's condition, and appropriate treatment.

Stabilising a patient can include breathing assistance, such as using a ventilator and maintaining blood circulation. Secondary problems, such as blood clotting, bleeding and brain swelling, and oxygen supply to the brain will also be treated.

Tests & diagnosis

Once stabilised, a range of tests will usually be conducted to determine the cause and extent of the brain injury, which can be established with x-rays, computerised axial tomography (CT), magnetic resonance imaging (MRI), and other tests.

The CT brain scan provides a series of x-rays at different levels of the brain and can be used to determine whether surgery is needed.

Depending on the results of the scan, the patient might be transferred to an operating room for surgery, intensive care unit (ICU) or a general surgical/medical ward. An MRI provides a detailed picture of the brain without using x-rays.

Surgery

Approximately half of all severe brain injuries will need surgery to remove or repair hematomas or contusions. These are often emergency procedures. In other cases, as with some brain tumours, more time is available for surgery.

Prior to surgery a doctor will, when possible, seek informed consent from the patient. Informed consent means understanding the costs, benefits and possible adverse outcomes of surgery.

There are many tests done prior to surgery – not all of them relate to the brain as the doctor will ensure your other organs are capable of surviving surgery. Patients can be anxious the night prior to surgery and have trouble sleeping. Medication can be prescribed to ensure a good night's sleep.

Intensive care unit

Patients may be placed in an intensive care unit ICU if special drugs or assistance with breathing

is needed. The patient is attached to a range of tubes and machines, which can be disturbing for visitors to view. They are often heavily sedated and may be unconscious. Pads may cover the eyes to keep them closed and to prevent them from drying out. If an operation was required, the patient's hair may have been partly shaved. If the patient is unconscious, it is generally accepted that visitors should behave as if the person is conscious and talk to them. Typically, patients do not remember anything of their stay in the ICU.

Glasgow coma scale

CRITERIA	POINTS	
Open eyes	Spontaneously	4
	To speech	3
	To pain	2
	None	1
Best verbal response	Oriented	5
	Confused	4
	Inappropriate	3
	Incomprehensible	2
	None	1
Best motor response	Obeys commands	6
	Localises pain	5
	Withdraws to pain	4
	Flexion to pain	3
	Extension to pain	2
	None	1
A total score of 13 to 15 is classed as mild severity. A total score of 9 to 12 is classed as moderate severity. A total score of 3 to 8 is classed as severe severity.		



Brain swelling

Sometimes when the brain is injured, swelling occurs and fluids accumulate within the brain space. Because the skull restricts the brain, this swelling can create a dangerous degree of intracranial pressure (ICP) that can be relieved through medication, catheters or surgery.

Spinal injuries

In cases where spinal injury is even suspected the patient may be placed in a hard collar and receive special nursing care. It is important to remember that hard collars are used as a precaution if there is any possibility of spinal injury – it does not mean that the patient definitely has a spinal injury.

Coma

Coma is a loss of consciousness in which patients typically do not open their eyes, do not speak and cannot follow instructions. In the case of a mild brain injury, the loss of consciousness, or coma, may last for one or two minutes, while coma after a severe injury can continue for days and, in some cases, even longer. Patients may also be put into an induced coma if it will help with the recovery process.

Glasgow coma scale

A measure called the Glasgow Coma Scale (GCS) (Teasdale and Jennett, 1974) is used to monitor the level of

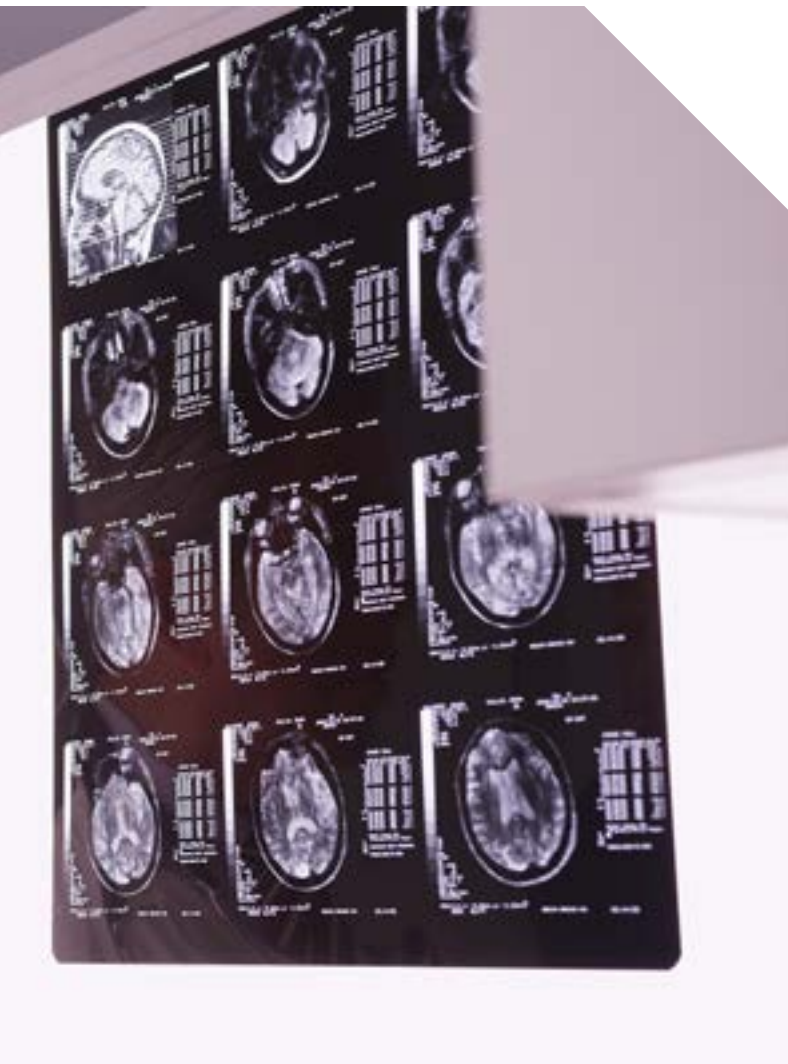
coma and the patient's emergence from coma. It rates the patient according to response to stimulation, eye opening and ability to speak. A fully conscious person has a score of 15, a person in profound coma has a score of three. Usually a shorter duration of coma and lower depth of coma (i.e. higher GCS score) is associated with a greater degree of recovery from the injury.

Post-traumatic amnesia

An individual coming out of a coma does not just wake up, but will go through a gradual process of regaining consciousness. This may last for hours, days or weeks. The patient will be unable to remember recent events or even things that happened minutes ago in some cases. Individuals in PTA can be fully awake but are confused about the time, day of the week, where they are, what is happening, and sometimes who they are. They may be fearful, aggressive, disinhibited, agitated and restless. If physically able, they may wander. Excessive stimulation during this time can compound the person's confusion and distress.

In conjunction with the GCS, length of PTA is frequently used as a guide to the severity of brain injury.

Reference: Teasdale, G., and Jennett, B. (1974). Assessment of coma and impaired consciousness. A practical scale *The Lancet*, 304(7872), 81-84. doi: 10.1016/S0140-6736(74)91639-0



Who are all these hospital professionals?

There are many professionals who may form part of the medical team. Specific nurses are usually assigned to a patient and are responsible for the immediate care of the patient.

A more senior member of the nursing staff usually coordinates the overall management of the ward including patient care, staff and support services. Medical specialists are involved in a patient's care depending on the type and extent of the injuries. Some specialists you may encounter include:

Intensive care physician: a doctor who specialises in the management of patients who require the complex support available in an ICU.

Registrar: a senior doctor who directs the hospital unit team and patient management. The registrar may also assist the specialist/consultant in caring for the patient.

Consultant: also known as visiting medical officer or VMO. A senior doctor subcontracted by the hospital to provide oversight and mentorship for registrars and residents.

Neurosurgeon: a surgeon who is a specialist in the management of disorders of the nervous system, brain and spine.

Neurologist: a medical specialist who has a high level of expertise in diagnosis and treatment of disorders of the brain, brain stem and cranial nerves.

Neuropsychologist: a psychologist who is trained in understanding how the brain works and how it affects behaviour, memory, learning and personality.

Occupational therapist: a therapist who has the expertise to improve or maintain independent functioning in all aspects of daily living.

Physiotherapist: a therapist who deals with the physical problems caused by the brain injury in order to maximise physical functioning.

Social worker: a social worker provides a wide range of social services including support, information, referral and counselling to patients and families.

Post traumatic amnesia

LENGTH OF PTA	SEVERITY
Less than five minutes	Very mild injury
Between five and 60 minutes	Mild injury
Between one and 24 hours	Moderate injury
Greater than 24 hours	Severe injury
Greater than seven days	Very severe injury

Brain injury diagnostic tests & scans

Some of these tests may be done very soon after admission to hospital as the doctors need to rapidly assess the danger of the brain injury worsening.

Neurologic tests fall into two groups: tests that examine the structure of the brain and those examining the function of the brain. The first group includes the CT scan and MRI, the second group includes the EEG, SPECT scan, PET scan, and evoked studies. These tests are commonly used after a TBI but could also apply for other types of brain disorders as well.

MRI, CT and MRA

The MRI and CT scan (also known as CAT—computerised axial tomography) scan the brain in cross sections. MRI does this with magnetic fields; the CT scan uses x-rays. The MRI has a higher degree of resolution than the CT scan so trauma seen by MRI may go unseen by CT scan. The x-rays used in CT scans are better at detecting fresh blood, while the MRI scan is better at detecting the remnants of old haemorrhaged blood, or damaged but intact nerve tissue. CT scans may be done frequently after the injury to keep an eye on the amount of brain injury.

The MRA (magnetic resonance angiogram) is a specialised form of MRI which detects blood vessels instead of brain tissue and can be used to check for bleeding or for the health of blood vessels. MRA produces extremely detailed pictures without the need for x-rays. The quality is not the same as normal arteriography, but the patient is spared the risks of catheterisation and allergic reactions to the dye. The MRA procedure is painless, and the magnetic field is not known to cause any tissue damage. Magnetic resonance spectroscopy (MRS) is

an imaging method of detecting and measuring activity at the cellular level. It provides chemical information and is used in conjunction with MRI which gives three-dimensional information and has great potential in the area of acquired brain injury.

Eelectroencephalogram

The EEG records the tiny, ever changing electrical signals coming from the brain using electrodes placed on the scalp. Slowing of electrical activity in some areas of the brain, while the person is awake, may indicate a lesion. Widespread slowing may indicate a diffused disturbance of brain function. Waves of electrical discharges indicate an irritable area of the cerebral cortex.

If allowed to spread, these spikes can produce a seizure. A quantitative EEG is capable of creating a map of the brain's electrical activity throughout the day. Comparison with a typical EEG makes it possible to localise areas of slowing of electrical activity. Alone, a EEG is insufficient to diagnose brain injury but can help to confirm other tests.

PET scan

PET measures concentrations of positron-emitting radioisotopes within brain tissue. The brain uses glucose for energy so glucose molecules are given a radioactive 'tag' and then breathed in by the patient. The person places their head under a large Geiger counter that is able to detect areas of the brain that are not using enough glucose.

Combined MRI & PET

The combined MRI/PET scan first appeared in the clinical setting in 2007 (Herrmann et al., 2013), and is still being developed. It is still in the prototype stage, but allows for the simultaneous measurement of anatomy, functionality and biochemistry. The technology allows for a faster, more accurate picture of the metabolic differences between normal and diseased tissue and reduces the patient's exposure to radiation. It is primarily used for oncology patients but also has application for neuroimaging.

Although the scans are conducted separately, combining them in one machine ensures that the images overlap perfectly. This gives doctors a better picture of the state of brain tissue following an injury, or the progression of a degenerative condition such as Alzheimer's disease.

SPECT scan

The SPECT scan, like PET, acquires information about the concentration of radio-nuclides introduced to the patient's body. The radioactive chemical does not enter the brain itself but stays in the bloodstream. It allows examination of the brain's blood supply which is normally reduced to damaged areas. Its advantage over PET scans is availability and cost.

Reference: Herrmann, K.A., Kohan, A.A., Gaeta, M.C. et al. (2013). *Curr Radiol Rep.* 1: 161. doi:10.1007/s40134-013-0021-0



Evoked potentials

Every time we hear, see, touch or smell, our brain generates an electrical signal. These signals, or evoked potentials, are generated by the nervous system in response to stimuli. Evoked potentials can be recorded by placing wires on different parts of the scalp for different senses. They can be useful for diagnosis and detection of neurological damage.

Lumbar puncture

A lumbar puncture is a diagnostic test where cerebrospinal fluid is extracted for examination, and pressure of the spinal column is measured. In relation to ABI, it can look for primary or metastatic brain or spinal cord neoplasm or cerebral haemorrhage.

Intracranial pressure monitor

Swelling of the brain is a potentially very serious issue immediately after a TBI so doctors often insert an intracranial pressure monitor into the skull to make sure there is no increased pressure that could worsen the injury.

What is neurosurgery?

Neurosurgeons specialise in treatment and surgery of the nervous system and surrounding structures.

The overall goal of neurosurgery is to maintain blood flow and oxygen to all parts of the brain, thus minimising the damage and increasing the prospect of survival and recovery.

Neurosurgeons operate on the brain, skull, scalp and spinal column. One of the most important roles the neurosurgeon performs is in the prevention of further damage to the brain. This is accomplished in several ways. When the brain is injured, the brain swells, causing parts of the brain to compress within the skull.

This compression decreases the blood flow and oxygen to parts of the brain, which causes more swelling.

One of the goals of the neurosurgeon is to break or diminish this cascade of damage to the brain. This can be done by removing any blood clots which are pressing on the brain and surgically repairing damaged blood vessels to stop any further bleeding. This gives the brain more room, increases blood flow, and helps stem the cycle of compression and swelling. In severe cases, portions of

the brain damaged beyond recovery may be removed to increase chances of recovery for the healthy areas.

The neurosurgeon is also responsible for the insertion of intracranial pressure monitoring devices, which measure the pressure and alert the medical team, allowing them to intervene when dangerous levels are reached. A ventricular drain may be used to drain off excess fluids or surgical intervention may be necessary.



Recovery from a brain injury

After acquiring a brain injury, the degree of expected recovery expected becomes an important issue.

Recovery is usually rapid at first with improvements occurring as swelling and bruising of the brain subside. Improvements continue as damaged cells heal; however, healing can be slow.

Stages of recovery

The brain does have some ability to heal itself, and as gains are made in our understanding of the brain, treatment options are also advancing. With appropriate support and rehabilitation, improvements can be made in lost physical and cognitive function.

There are three broad stages of recovery following an ABI.

1. The acute medical stage involves intensive medical treatment that may be needed for survival and preventing further complications.
2. The rehabilitation stage involves intensive therapy aimed at helping the natural process of recovery and reducing the likelihood of long-term disability. Emphasis is placed on the person regaining previous skills and learning strategies to overcome or compensate for ongoing problems.
3. Later, community re-entry, or tertiary rehabilitation, focuses on the issues of everyday living and returning to previous community activities such as work, study and leisure. It aims to help the person and family find ways to adapt to, and compensate for any long-term problems or disabilities.

The most rapid improvement is usually seen in the first six months as swelling and bruising of the brain subside. Recovery tends to slow down around two years after the injury. However, this varies across individuals and many people with brain injury report continued improvements. Generally, a slow rate of initial improvement is associated with a greater chance of permanent disability.

Managing recovery

Family members may need to make important decisions. This will require them to be clear headed and well informed. It can be useful to keep a diary for recording medical, social and financial information.

Medical information may include:

- names of the doctors and areas of responsibility/titles
- dates and times of assessments
- key medical terms
- diagnosis and test results.

Social information may include:

- person's achievements
- visitors' messages
- milestones (physical and cognitive recovery).

Financial information is necessary for any future compensation claims. It is important to keep all receipts associated with caring for the injured person, along with a diary showing the time people have devoted to the personal care and rehabilitation of the injured person.

Why predictions of recovery are difficult

Predictions of recovery are difficult in the months following a brain injury, with the person and their family often frustrated by lack of knowledge about the future.

This uncertainty is common along the spectrum of brain injury, and the long-term effects of the injury may not be evident for some time. With a severe injury, doctors can make their best estimates, yet these are only ever a guide, and the degree of recovery may not be known for months, or even years, after the injury.

Why aren't there accurate predictions?

Physical injuries do not give an accurate picture of the degree of brain injury sustained. The victim of a serious car accident may have numerous fractures, yet there can be less brain trauma than someone who fell over in the bath tub. The CT and MRI scans used to detect brain injury are good at detecting bleeding in the brain, yet fail to accurately show trauma at the microscopic level. Brain trauma can sever the connections between brain neurons over areas of the brain yet this will not show in many tests.

Importance of rehabilitation

Long-term outcomes may not be evident until the completion of a program of formal rehabilitation, which can continue for up to two years after the injury. Rehabilitation is crucial for optimising recovery following brain injury, and the level of engagement of the injured person and their family in the rehabilitation process influences the long-term outcome. Rehabilitation may commence while the injured person is still in hospital, and typically continues as an outpatient service once they have returned home. It should be noted that discharge from rehabilitation does not mean that recovery has finished. Equipped with the tools and strategies learned through rehabilitation, many people continue with their own recovery long after formal supports have finished. More information about rehabilitation and long-term recovery is discussed in the following sections.

Factors influencing long-term outcome

Personal factors make a significant difference to the degree of recovery expected. For example, people who did well in the educational system and those with very determined, motivated personalities usually perform very well in rehabilitation. Recovery typically slows down at some point; however, it need not stop when formal rehabilitation finishes.

The ability of a person to cope with these effects is influenced by many factors including:

- personal assets and limitations before the injury
- the nature and severity of the injury
- the person's reaction to the injury
- the support of significant others.

Of these four factors, it is the person's reaction to his or her situation that is recognised as the key factor in relation to future enjoyment and success in life. Self-awareness, motivation, goal setting, coping strategies (use of memory aids, etc.) and management of emotions are important factors which influence long-term outcome following an ABI.



Emotional recovery

A brain injury can disrupt almost every aspect of life, leading to emotional turmoil that also affects the whole family.



When a person sustains a brain injury, or a similar type of brain disorder, the focus is very much on regaining lost physical, cognitive and social functioning. However, there is also an emotional response to brain injury for the injured person and their family. Emotional recovery means feeling happy about your life and yourself again, and plays a role in overall outcome. Physical recovery can often be quicker than emotional recovery, which can take many years.

A sense of shock and loss are common after brain injury. The person with the injury may see lost friendships, independence, abilities, career and opportunities. Family members and partners can also experience loss—some say it is like losing a loved one due to personality changes, but being unable to say goodbye. Grief can have a serious impact upon a person's recovery, but there is no one definitive method for dealing with grief. People mourn in their own personal way and eventually begin to heal. It can be

helpful to understand some of the emotional responses that can occur after a brain injury. There are a variety of models of grief which are equally relevant to brain injury survivors and their loved ones. Dr Elizabeth Kübler-Ross (1969) described a sequential stage, based model that includes:

- denial (this isn't happening to me!)
- anger (why is this happening to me?)
- bargaining (I promise I'll be a better person if...)
- depression (I don't care anymore)
- acceptance (I'm ready for whatever comes).

Kübler-Ross originally applied these stages to any form of catastrophic loss—a person may not experience them in this order, or may not experience certain stages at all. Others saw the stage models of grief as overly simplistic, and proposed instead more dynamic process models (see Bowlby, 1980; Parkes, 1998). Bowlby's process model includes:

- shock – numbness and refusal to believe in the reality of the loss. The shock is greatest when the loss is not expected
- yearning and searching – effort is devoted to trying to undo the loss despite some awareness that it may not be possible. People may continue to search for signs that the loss has returned (e.g. the person's memory is getting better)
- disorganisation and despair – as it becomes clear that the loss will not return, people can experience a sense of hopelessness and despair
- adaptation or reorganisation – energy is spent establishing a new way of life with potential for satisfaction and achieving new goals.

References: Kübler-Ross, E. (1969) *On Death and Dying*, Routledge, ISBN 0-415-04015-9

Bowlby, J. (1980). *Attachment and loss: Vol. 3. Loss: Sadness and depression*. New York: Basic Books.

Parkes, C. M. (1998). *Bereavement: studies of grief in adult life* (3rd ed.). London: Penguin.

What is rehabilitation?

Rehabilitation refers to a variety of therapies and support services available to people following the acute phase of recovery, once a person is medically stable. Rehabilitation therapies usually commence in hospital, and often continue after returning home, up to two years post injury.

A brain injury can affect almost every aspect of a person's life, including mobility, thinking and emotional processes, personality and behaviour, relationships, vocational abilities, and leisure activities. A good rehabilitation program is vital to optimise recovery following brain injury, and will be tailored to the specific needs of the individual.

A neuropsychological test will explain the ways the brain injury is affecting

the injured person, and is used to guide the rehabilitation process, and assess areas of impairment. People work with a variety of health professionals to regain lost function, adapt to the injury, and set goals for the future. Depending on the nature of a person's injuries, they may undertake therapies to improve physical or cognitive function, speech therapy, anger or behaviour management, and later occupational therapy and vocational rehabilitation may be appropriate.

Support coordinator may help to coordinate care and people may also have the opportunity to see a social worker and/or a counsellor during this time. It is important for the injured person and the family to be optimistic yet realistic about recovery, and to understand what is possible.



Neuropsychological assessments

A neuropsychological assessment is a comprehensive evaluation usually done at some stage during rehabilitation after a brain injury. The neuropsychologist will usually look at case histories, hospital records and talk to family members to learn about the person's functioning before the brain injury.

Ideally, a neuropsychological assessment should explain how damage in the brain affects the way a person thinks, acts and deals with life post-injury.

The ultimate goal of a neuropsychological assessment is to fully maximise the survivor's recovery and participation in family, work and the community. It is very useful in guiding the rehabilitation process, and evaluates many areas of functioning such as:

- perceptual, sensory and motor functions

- concentration, attention and memory
- emotions, personality and behaviour
- language
- problem-solving
- planning and organisation
- intelligence
- study skills.

Benefits of a neuropsychological assessment

A neuropsychological assessment not only guides the rehabilitation process, but helps the person and their family to better understand the impact of the brain injury. The neuropsychologist will usually meet with the family to discuss the findings. Taking notes or recording the meeting is highly recommended. A written report is usually provided covering the case history, current issues, tests conducted, observations, assessment results

and recommendations. The neuropsychologist should explain abilities that remain unchanged including expected problem areas and the impact these will have on day-to-day life for the injured person and the family, noting for example: 'damage to the frontal lobes of the brain will cause difficulties in planning and organising. The family will need to provide structure, prompts and reminders.'

Obtaining a neuropsychological assessment

These tests can be quite expensive. If an assessment was not done during rehabilitation, then often universities offering programs in neuropsychology provide evaluations at low cost or sliding scale as part of their student training.

Contact Synapse for information on Neuropsychologists or testing centres near you.

Rehabilitation tips

Although the degree of recovery is largely determined by the nature and extent of the injury, the level of engagement in rehabilitation also significantly affects recovery outcomes.

There are many things people can do to maximise recovery throughout the rehabilitation process and beyond. Here are some tips on how to make the most of rehabilitation following brain injury:

Determination

People with a brain injury often say rehabilitation is the biggest challenge of their lives. While life may never return to 'normal', people can influence their recovery through hard work and persistence. Determination is helpful for people engaged in rehabilitation, but it is important not to overdo things as fatigue sets in easily. A steady and consistent approach to rehabilitation makes a big difference in the long run.

Resilience and positive attitude

The ways people react to hardship can have a significant impact on recovery and wellbeing after brain injury. Resilience, or the ability to 'bounce back' after trauma and adversity is an important quality for individuals and families managing brain injury. Resilience has been defined as 'the human ability to adapt in the face of tragedy, trauma, adversity, hardship and ongoing life stressors' (Newman, 2005, p.227). Others take the concept of resilience further, seeing it as a "bouncing forward" (Walsh, 2012), or rising above traumatic experiences-strengthened as a result of adversity, and living well despite it (Boss, 2006). According to Pauline Boss resilience means "flexibility, the opposite of brittleness; and movement, the opposite of paralysis" (p. 27).

People react to a catastrophe in many ways. Some people may find it impossible to see beyond their

challenges, but others are able to notice some positive factors, like how hard they have worked, or how strong the family has been. Indeed, research has shown that many people experience positive psychological growth following brain injury (Evans, 2011). This is not to say people are happy about the injury, but experiences like pride in themselves, strengthened relationship bonds, and a new appreciation for life have been reported (Collicut McGrath and Linley, 2006). Although people may still feel overwhelmed at times, and have bad days, the ability to experience some positives and enjoyment amongst the challenges can lessen distress and enhance wellbeing.

Many families use humour to sustain them through difficult times. There is nothing funny about a brain injury, but finding reasons to smile each day is a factor in health and staying positive. Research shows that our attitudes and beliefs have a strong influence to our wellbeing. Some of the qualities associated with resilience have been noted as having hope for the future; the ability to be independent, proactive and get things done, having close relationships, the ability to solve problems; and the ability to enjoy laughter and respond to humour despite tragic situations (Rees, 2012). A good rehabilitation program will enhance resilience by identifying individual and family strengths, and resources; acknowledging the latent potential for recovery and healing after trauma.

Making meaning out of what happened

For many, it is important to work through the grief and shock about how brain injury has changed their

lives so dramatically. It is common to feel bitter, resentful, or as if it is punishment. In some cases, finding a 'reason' for the brain injury can help during rehabilitation. For example, a person may never work again but discovers greater happiness in volunteer work that is helping others. Others become involved in brain injury support groups, online forums and writing stories about life with a brain injury—they make sense of their injury by seeing how they can help others in a similar situation.

Structure and routine

We all need structure in our lives, such as when to eat, rest, sleep and work. After a brain injury, this need for structure and routine is extremely important—it allows the brain to rest and save its energy for rehabilitation. A good strategy for keeping to routines is to set up a weekly timetable for meal times, rest periods, rehabilitation tasks and



exercise. Having this information on a big poster or whiteboard will provide gentle memory prompts and encouragement if memory or motivation problems exist. It will also help to alleviate boredom and depression, which are common. It is very important for people with a brain injury not to overdo things, so quiet rest periods should be part of any schedule.

Diet, exercise and sleep

Diet, exercise and sleep are very important during recovery, and should be built into each week's routine. Having meals at regular times and maintaining a healthy diet is vital. Regular exercise is good for health and maintaining a positive attitude. Suitable activities can be scheduled into a weekly routine. Doctors and rehabilitation teams can advise on suitable exercise where needed.

Good sleep and regular rest periods will prevent a person's brain from being over-taxed which can result in feeling tired for days afterwards. It is recommended to go to bed at the same time each night, and avoid tea or coffee late in the day. While a short nap in the early afternoon can be good for health, too much sleep in the middle of the day can disturb a good night's sleep.

Family involvement

Research has shown improved outcomes for people with a brain injury when their families engage in the rehabilitation process (Braga et al., 2005). Although the focus of rehabilitation is usually on the injured person, a good rehabilitation team understands the importance of family, and will include and support the whole family (McIntyre and Kendall, 2013). It is during this formal rehabilitation stage that knowledge can be passed on to family members about how to provide support beyond the formal period of therapy. If behavioural problems emerge, family members can ask for a plan to use at home in order to respond appropriately.

It is important to have a realistic discharge plan before leaving rehabilitation. Once home, it is necessary to establish a routine and consistently apply the discharge plan. It is important that the family member being cared for has control over aspects of their life they can safely manage.

Challenging behaviours

Once the formal rehabilitation has finished and a person returns home, behavioural issues that were not present at the time of rehabilitation can emerge. It is important for the family to identify the issues as early as possible, and create a positive behaviour support plan for the whole family to apply consistently.

*Contact Synapse for information and referral to behavioural specialists
1800 673 074.*

Support groups

Support groups can play a vital role for the person with a brain injury, their carers and family. It is a chance to identify with others who have similar problems, to feel understood, and to discuss ways of managing new challenges. Online support groups are an option for connecting people who live in remote areas or are unable to travel.

*Discover Synapse Reconnections social support
1800 673 074.*

Maintain friendships

It is beneficial to stay in touch with friends during the rehabilitation and recovery stage. This can be worked into a schedule and might be as simple as a quick phone call or email. This is often a good option as meeting a friend for coffee during the early recovery phase can be exhausting. It might be necessary to let friends know what kind of support is needed (For example, allow time for the person with the brain injury to answer and understand that they will tire quickly).

Reduce the chances of another brain injury

The brain is particularly vulnerable after injury, so an important aspect of rehabilitation is minimising the chances of a second brain injury. Rehabilitation specialists will usually recommend a person does not drink alcohol for at least a year after a brain injury, and often say it is best to permanently refrain from drinking alcohol. For the elderly, it is important to minimise falling risks around the house. For children, helmets must always be worn for risky activities such as cycling.

Whatever works for you

Some people manage catastrophic events well, surviving with much less effect than others—the key to an excellent recovery from brain injury will often be due to all of these areas mentioned. As stated by Professor Stephen Hawking: 'disability need not be an obstacle to success.'

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The post-rehabilitation slump

Survivors of a brain injury often make excellent recoveries through a positive attitude, hard work and professional and family support. But once the rehabilitation is over there can be a sudden slump, leaving the survivor with depression or despair.

The primary reason for the post-rehab slump is psychological. During rehabilitation, a person's energies are focused on recovery goals, and progress can clearly be seen. As this process tapers off post-rehab people can become disheartened about their residual impairments, and the absence of something to work towards can leave people feeling despondent. In some cases, people may be disappointed with their recovery, perhaps having hoped they would regain pre-injury functioning. It is important that people understand that life can continue to improve beyond formal rehabilitation, albeit with ongoing challenges.

Who is this stranger?

The life changes experienced by people after brain injury can be extremely difficult to accept. Physical and cognitive impairments, changed relationships and family roles, altered friendship networks, and limits on employment opportunities and leisure activities can all mean that people no longer feel like themselves. Some describe the new self as a stranger living in their skin, and knowing that this will not change can be hard to accept. The brain injury itself can add to the disappointment as anger, depression and the ability to tolerate stress are often much harder to handle post injury.

Accepting the new self

With help, a person with brain injury can learn to accept that life as they knew it is unlikely to return. It is time, instead, to build a new life, taking into consideration what is and isn't possible. A desire to work again and stay socially active may well be possible if the person is flexible about how this can be achieved. For example, working again might mean changing careers or volunteering. A person might not go out to socialise often, but invite friends to visit instead. Accepting a new self can be seen as the final, and often hardest stage of recovery. Coming to terms with this new identity and even learning to appreciate it is a very difficult step. For some people, being able to re-frame their experience into a more positive light can be helpful. For example, cognitive impairments can be viewed in a different way to acknowledge emergent strengths. An inability to work can be seen as an opportunity to develop hobbies, such as art or gardening. A lack of energy can be experienced as having more time to 'smell the roses'. Wrestling with depression gives an insight into the pain and suffering of others. Other survivors have made sense of their experience by seeing how they can help others. They may attend or even initiate a support group where they can share their

hard-won lessons with others, or write of their experiences. For those who can work, an option is casual work supporting others with a brain injury. For others, a spiritual approach or commitment to self-improvement may be the key. Each difficulty can be seen as an opportunity for self-growth and further development, not just as a disability. People often find gradual improvement in some areas for years after their injury when they use this approach. Some even come to appreciate how a brain injury has made them a more thoughtful, stronger person because of the many challenges they have faced and worked through.

What can the family do?

Families can help their loved one by putting strategies in place to avoid or lessen the post-rehabilitation slump. They can work together to develop new goals and activities before the end of formal rehabilitation. Counsellors are available to help people with brain injury accept their new identity. As one survivor put it: 'for survival, we must let go of what was, in order to become what we will be.'

Contact Synapse for more
information and support
1800 673 074.

Steps to independence:

Tips for families supporting a loved one after brain injury.



Resuming an independent lifestyle safely after a brain injury is an important goal, and should be approached in stages based on individual needs and abilities.

For some people with severe cognitive impairments, achieving complete independence may be an unrealistic goal. Determining when it is safe to let go after brain injury can be challenging for carers and families. All too frequently, families expect that discharge from a hospital or completion of a rehabilitation program indicates the injured person is 'well' or 'cured', but most people will experience some ongoing problems. There is a delicate balance between protecting someone with a brain injury from potential harm and promoting independence, and opportunities to learn.

The role of the family

It is helpful for family members to witness first-hand how the injured person's impairments impact their ability to perform certain tasks. It also prepares the family to assume their role as the support system once rehabilitation is completed. People with a brain injury function best within a structured environment. It is important for everyone with

whom the individual interacts to be aware of compensation strategies used for deficits, as well as the need to consistently reinforce those strategies. Ideally, people with brain injury should not use stimulants or depressive agents due to the exaggerated effect these substances have on the injured brain. It is much easier to monitor and prevent the use of addictive substances than to deal with them after they have become a problem. Additionally, family members should consider the need for guardianship and familiarise themselves with these protective tools.

Neuropsychological assessment

The neuropsychological assessment is a task-oriented assessment of cognitive functioning and the key piece of information that will help determine the extent of assistance a person may need to function in society. Many people with brain injury can experience a range of impacts which increase their vulnerability and inhibit independence and social integration. These include a reduced ability to exercise good judgement, poor reasoning and problem-solving, socially inappropriate behaviours, an inability to organise and structure time, control impulsiveness and

follow through with tasks. It is important that these types of problems are identified through an assessment, and strategies put in place to manage these.

If a neuropsychological evaluation was not completed as a part of your rehabilitation program, school systems, vocational rehabilitation agencies and other state-supported programs may be a good place to start looking for ways to obtain this information.

Watch for increased awareness

Sometimes as a result of brain injury, people can lack awareness about their impairments and may be prone to taking unnecessary risks. Over time awareness may improve, and while this can be a positive sign, it can be emotionally challenging as people realise the impacts of their injury. A lack of awareness can be a buffer to emotional distress, and families must be alert to any changes. If not managed effectively, increased awareness can lead to self-harm, disruption of cooperation and/or increased demands for independence.

Identification

With each step towards independence, it becomes more important to have proper identification at all times. In the event of seizures, ensure that the individual has information in the form of a bracelet, necklace and/or wallet card that accesses medical instructions. If there is a risk of getting lost, then maps or a record of the person's address should be carried at all times.

Contact Synapse for more information 1800 673 074.

Dignity of risk

Sometimes it can be helpful to support the person in an activity where there is concern about safety. Denial, whether organic denial or lack of awareness of one's deficits, can be a persistent problem. Sometimes it is useful to take risks to reach a goal. For example, an individual with balance problems who wants to ride a bike again can begin on a stationary bike. If they are able to get on and off safely, they could then progress to a two-wheel bicycle using protective equipment, such as elbow pads and helmets in safe areas with footpaths and grass.

Holistic independence

Promoting independence among people with a brain injury is complex, and may take many years to achieve. It is helpful to gradually establish some 'safe' activities for the injured person to manage independently, such as a program at a local gym where there are staff trained to monitor and provide assistance. Recreational activities are also good for re-establishing community involvement. Whatever activities a family member decides to participate in, ensure that those in charge are aware of their impairments and the extent of assistance needed to participate effectively.

Gradual re-entry can provide a measure of safety and protection that can move the injured person from dependence to interdependence and,

for many, complete independence. Focusing on what a person does well is an enriching experience for all family members. When letting go is a safety issue, it often is best to err on the side of caution rather than relinquish too much control too early. It is important to keep in mind that independence is not a virtue and dependence is not a vice. Finding the appropriate balance between control by the family and gradual relinquishing of control are the stepping stones to greater independence, with many families finding the journey can be a satisfying partnership.

The focus of rehabilitation typically emphasises regaining lost function; however, there are many other factors to be considered when working towards independence after brain injury. Consensus and clarity around goals and strategies in relation to independence should be reached between service providers, families and the injured person. An important aspect of goal development activities involves the social relevance of the identified goals – where a person lives, how they will be occupied, how they will relate to others, how they perceive their quality of life. People with a disability must have some interest in interacting with those who can provide assistance to them in promoting independence. When this interest does not exist, it must be established. Promoting

independence wisely can increase the injured person's safety, create opportunities to exercise choice, and enhance self-esteem.

In recent years, changes in disability policy have seen shifts away from long-term residential care to community living. Although this constitutes a positive change for people with a disability, community re-integration is complex, and high quality community living arrangements are not always available. Community knowledge about complex disabilities such as brain injury is poor, which can hamper successful community re-integration. More work needs to be done to prepare communities to understand and integrate well with people who have sustained a brain injury. The major area of difficulty here relates to the accommodation of behaviours that are considered anti-social or 'disruptive'. Obviously interventions designed to support people to learn more acceptable ways to interact are of benefit, but this is not always achievable, and a greater understanding for the general community is needed. Great modifications have been made to create a world that accommodates people with a wide range of disabilities. This needs to be extended to all.



Hope after brain injury

No one can truly understand the devastating impact a brain injury can have without experiencing it personally. Many face despair and depression in the early days, as the extent to which their lives have changed becomes clear. However, there is always hope.

In the past, it was commonly believed that recovery occurred mainly in the first six months, and tapered off, or plateaued, at around two years after the injury. This could be very discouraging for people to think recovery was limited to two years. However, the idea that recovery reaches a plateau at some point has been questioned. Many people report continued improvements and even significant breakthroughs many years later. It is important to find a comfortable balance between working hard on recovery and accepting limitations. Hope and determination are helpful qualities for people adjusting to brain injury. The following tips may be helpful in making the most out of rehabilitation and recovery:

- Keep working on things you know you're good at, but also deliberately target problem areas.
- Keep a diary so you can look back and see how far you've come.
- Pace yourself – find the balance between putting in effort and taking care of yourself. If you're wiped out for days you are doing too much.
- Pick the times of day where you have the most energy.
- Make sure you have a suitable environment when you need to take a break, away from noise, disruptions, and bright light.
- Cry when needed, and tell people if you feel overwhelmed. Know when to ask for support from health

professionals, family or friends.

- Remember you are not alone, many people have gone through the experience of brain injury, and emerged as stronger people for the experience. Consider a peer support group if you think it would be helpful for you.

Contact Synapse for more information 1800 673 074.

Most people who have experienced brain injury report that they have slowly managed to piece their lives back together, finding meaning, growth and enjoyment in life again. Recovery from brain injury doesn't necessarily mean people will be the same as they were before the injury. Rehabilitation will help regain as much lost function as possible. This idea of getting back to 'normal' can be a good motivator for people to work hard on their recovery. But for some people, particularly when the injury is severe, changes can be permanent. Recovery can involve learning how to integrate the injury into one's life, and finding new ways of doing things. It's important to get involved in activities which bring meaning and purpose to life.

Neuroplasticity and brain injury rehabilitation

Research in the field of neuroplasticity is cause for optimism for people with brain injury and their families (Chauvin, McIntyre and Blackett,

2013). Modern neuroimaging techniques have shown, contrary to previous understandings of the adult brain, as 'fixed,' that the brain is malleable (or plastic), and changes over time in response to experiences. In his ground-breaking book, *The brain that changes itself*, Norman Doidge (2010) explained how it is possible for the injured brain to reorganise itself, substituting injured parts for non-injured parts, and that dead brain cells can sometimes be replaced. Importantly, it was shown that neuroplasticity can be intentionally directed through targeted activities which can affect physical and cognitive functioning, and mental health.

Knowledge about how best to work with neuroplasticity in the context of brain injury rehabilitation is still in its infancy, and it is not yet clear which activities are optimal for improving which impairments. However, researchers are beginning to understand how to influence neuroplasticity for brain injury recovery. Research to date suggest that brain injury interventions need to include a range of physical and cognitive therapies, and be intensive and frequent (Kolb et al., 2011). New and innovative techniques and therapies are currently being developed that aim to harness the mechanisms of neuroplasticity to enhance recovery or maximise the surviving brain tissue (Young and Tolentino, 2011).

References: Chauvin, A., McIntyre, M., and Blackett, G. (2013). Neuroplasticity and Mindfulness in Brain Injury Rehabilitation: Cause for great optimism. In H. Muenchberger, E. Kendall, and J. Wright (Eds.), *Health and Healing after Traumatic Brain Injury: Understanding the power of family, friends, community, and other support systems*. (pp. 21-36). Westport, CT: Praeger.

Doidge, N. (2010). *The brain that changes itself: Stories of personal triumph from the frontiers of brain science*. Melbourne: Scribe Publications.

Kolb, B., Muhammad, A., and Gibb, R. (2011). Searching for factors underlying cerebral plasticity in the normal and injured brain. *Journal of Communication Disorders*, 44 (5), 503-514.

Young, J. A., and Tolentino, M. (2011). Neuroplasticity and its applications for rehabilitation. *American Journal of Therapeutics*, 18 (1), 70-80.

Family guide to a low-cost rehabilitation program.

Your family member is discharged from hospital and you are ready to continue their rehabilitation. The steps listed below may serve as a guide if you wish to develop a program using free or low-cost resources which exist in your community.

Step 1: Obtain detailed objective information

The injured person: As the cognitive and behavioural consequences of brain injury have been shown to be particularly disabling, information about the person's current level of functioning in these areas is essential if a realistic program is to be developed. Specific information is needed on factors such as how much can be learnt, what is the best way to learn, what activities are most likely to present problems, what limitations there may be perceptually, and how the environment be set up to maximise abilities. The rehabilitation program must also take physical limitations into account. In addition to general information about the person's medical status and physical abilities, thorough evaluation of both visual and auditory systems should be completed. Management of medical needs must be an integral part of the rehabilitation program. Adaptive equipment such as a wheelchair, braces, and communication devices, must be appropriate to the person's current needs and in good repair.

The support system: family members must realistically determine how much time, money and emotional energy they can feasibly commit, and for how long. This includes consideration of who will provide transportation to activities, supervision in both the home and the community, and what materials will be needed. An organised program requires the effort of more than one person - unless it is undertaken in extremely small and manageable steps.

Community resources: This is definitely the time to start ringing around. A wide range of community services are available in most communities and are appropriate for people who have sustained brain injuries. Most of these agencies do not advertise; many are not aware of the special needs of those who sustain brain injuries and how their agency's services might be utilised by this population. Think outside the box and don't be afraid to approach these community services for assistance.

Step 2: Develop and implement your program

Now you are ready to set specific rehabilitation goals. Since you are designing your own program, you are free to include only those activities which you feel will be helpful to the injured person and for which you have the time, resources and energy to follow through. Certain problems occur often enough that the broad areas which must be addressed can be identified even though specific activities must be decided by family members. Among these common areas, and in chronological order of importance, are:

Survival skills goals: Those activities which have the highest survival value (daily routines such as showering, grooming, toileting, dressing, sleeping and eating) should receive concentrated attention in the initial phase. Goals should address the mechanics of completing the task as well as the amount of time required. Goals in this area have been accomplished when the person is able to awaken on their own, independently complete morning hygiene routines, and prepare and clean up after eating, dress appropriately to go into the community.

Basic cognitive goals: Concentration and attention can be particularly challenging for people who have sustained a brain injury, and this can negatively impact community-based activities. Initial cognitive retraining activities should probably be conducted within the home setting. Appropriate activities might include working on craft projects from books in the public library, playing simple board or card games, or playing simple video games. Since pre-injury information and skills are frequently relatively intact, the injured person may be able to play games that were learned pre-injury (such as checkers or poker) without having to learn new rules. At this stage, the ability to learn is not being addressed, only the ability to attend and concentrate.

While such activities may initially require a quiet distraction-free environment, the amount and type of distractors should be increased as attention and concentration improve. The amount of consecutive time devoted to such activities can also be gradually increased until the person is able to continue at the task for a realistic amount of time.

Basic behavioural goals: When the person is able, at least at minimal levels, to attend and concentrate, to learn, and to remember, behavioural contracts can be used to reduce the frequency and severity of specific targeted behaviour problems, such as verbal aggression, perseveration, or social skill issues. Information about behaviour management strategies can be obtained from your brain injury association.

It is critical that not all the points are negative, for example, designed to stop certain behaviours. You must balance behaviours to be stopped with those you wish to see started so that the person is not left with a behaviour void. Your behaviour management program should utilise appropriate rewards to encourage the person to behave in more positive ways.

At this point in time (if you are not already doing so), you should begin to give honest, objective feedback to the injured person on specific maladaptive behaviours and your reactions to them. Although such direct oral feedback is not customarily given in most social settings, the injured person may not understand why he/she fails to make friends unless provided with such information.

Social/recreational goals: One of the most frequent complaints voiced by people with a brain injury is the lack of friends and social opportunities. The reasons for this are varied, but physical limitations, behavioural issues, decreased cognitive capacity and poor social skills are often major culprits. In many cases, the person may lack insight into the nature, range, severity or even the existence of impairments following the brain injury and may seem generally unable or unwilling to modify his/her behaviour. This could be the case even in the face of interpersonal cues which are not at all subtle. Once the person's behaviour is positively altered in the home setting, community recreation activities are often introduced in the rehabilitation program. Your local brain injury association should have a list of recreation programs set up for people with disabilities. Don't be limited by disability programs; however, if you feel able, reach out to other recreation programs in your community – try your hand at opening their eyes to inclusive by including your family and loved one in their group. This can take time and education sessions; however, may be more advantageous in the long term.

Academic goals: Some people with a brain injury may be able to successfully enrol in academic programs once their basic cognitive and behavioural impairments have been remediated or despite remaining deficits. The line between rehabilitation and education begins to blur at this point, especially when the courses or subject areas had not been attempted prior to the injury. If you are considering including a formal academic component, you should determine whether the person can keep track of class times, take notes, study for an examination, and learn the information presented. Also to be considered is having to deal with transportation to the campus, locating a specific classroom or dealing with distractions in the classroom. Speak with the campus's disability service. Most will have one and they can generally offer services such as notetaking, recorded lectures and one-on-one tutorials to assist.

Vocational goals: some people with brain injuries may recover sufficiently to return to their pre-injury employment, perhaps with modified hours or duties, particularly in the short term. Others may find they are able to work, but in a different field, and vocational retraining may be necessary. People who are unable to resume paid employment may be able to contribute to their communities in volunteer positions. If, and, when re-employment is a realistic goal,

disability employment services (DES) providers can assist people to find and maintain employment, and in turn, help employers put practices in place to support employees.

Step 3: Monitor progress and update as needed

As the program progresses, you should find that the person's cognitive and physical endurance, performance speed, and skills are steadily improving while the demands on your time are steadily decreasing. You must be able to fade yourself from the picture at appropriate times, even when you are not completely sure the person can perform the activity without your help. As the person's skills improve, you must make certain that your expectations rise so they are commensurate with new abilities. When indicated, set goals at higher levels. The myth of the plateau (which suggests that people who sustain brain injuries reach a certain point in their recovery and then stop making progress despite the best rehabilitation efforts, must also be challenged as your program progresses). When progress appears to be levelling off, it may be useful to think of that time as a period of consolidation of newly-acquired skills, a time for the repeated practice that is required to integrate the new information and skills with the old until they become as routine as possible.

At some point in time, the injured person and/or family members decide that they no longer wish to pursue rehabilitation. This occurs on rare occasions because all goals have been met. Usually other factors such as extremely slow progress, the wish to pursue other activities, or burnout, account for this decision. The fact that a structured rehabilitation program is no longer in place, does not necessarily mean that the injured person will stop acquiring or refining skills, or that deterioration will occur, although both are certainly possible. The long-term success of your program may be contingent upon continued effort on the part of all family members, especially the injured person. Many thanks to Judith Falconer, Phd For permission in adapting this article from her website.

For more information on community rehabilitation contact Synapse





Steps to a healthier brain

The healthy brain program is an initiative of the brain foundation aiming to assist Australians with keeping their brains healthy into old age. Exercise and challenge your brain.

Like our body the brain needs exercise. Practising skills leads to better performance whereas unused parts of the brain stop working. Ongoing mental stimulation provides some protection against mental decline. Challenge the brain by trying things you don't already do – such as studying a new language. Challenging creates new pathways that appear to become alternate routes when neurones die off in middle and old age. Keeping the brain active also protects individual neurons from injury and old age. Just remember, if you have a brain injury, take on tasks that are realistic. If you have trouble with judgement, you may need to discuss it with others first.

So how can you exercise and challenge your brain to reap the benefits? Exercising the brain is doing anything that makes you think, such as 'what did I do last Saturday?'.

Some possibilities are:

- avoid using calculators
- swap TV for mind games or a book
- play games that involve memory (bridge) or thinking ahead (chess)
- take up a new hobby

Nourish your brain with a healthy diet

Like any high-performance machine, the brain needs top quality fuel – a well-balanced, low cholesterol, low saturated (animal-fat) diet. Timing is significant as studies have demonstrated the importance of a good breakfast. Not all fats are bad for you in the right quantities. Unsaturated fat and protein are especially important for developing brains. Fish, a rich source of both, is sometimes called brain food. The body converts long strings of amino acids in protein to individual amino acids that the brain converts to the specific proteins it needs. Your brain needs vitamins and minerals that only come from a balanced diet. In particular research suggests the antioxidant vitamins E and C protect the brain.

Avoid excess food

Reducing calories can help slow age-related brain changes. If you must smoke or drink caffeine and alcohol, do so in moderation.

Glucose is the fuel needed to keep the cells alive and functioning. When your concentration wanes in the late morning or afternoon, eating a snack containing sugar, such as fruit, can solve the problem.

As a general rule, good nutrition for the body is good nutrition for the brain.

Enjoy physical activity

Exercise daily, if possible, by setting exercise priorities and sticking to them. Regular exercise reduces depression and reduces cardiovascular risk factors, even a simple walk can calm the mind and increase feelings of wellbeing. Some exercise states may produce euphoria, but even 12 minute bouts of exercise (to 85 per cent maximum heart rate) release serotonin, dopamine, and noradrenaline that can act like antidepressant medications.

Exercise that increases heart rate and blood flow is also good for the brain as it creates new pathways and blood vessels. See an exercise physiologist/rehabilitation specialist.

Exercise in the evening after a stressful day. Take exercise opportunities like using stairs instead of elevators.

Make “safety first” a priority

Take common-sense safety precautions including wearing seatbelts and sports safety helmets as appropriate. Remember that if you have an existing brain injury you are much more susceptible to acquiring another one.

Manage anxiety, stress and depression

Anxiety increases heart rate and blood pressure which can lead to stroke. Acute stress such as the “fight or flight reaction” is normal and short-lived. There is increasing evidence that stress actually damages the brain. The hormones linked to stress can have a negative impact on the body and increase the risk of numerous health problems, including:

- anxiety
- depression
- digestive problems
- headaches
- heart disease
- sleep problems
- weight gain
- memory and concentration impairment.

There are many strategies which can enhance relaxation, and decrease stress and anxiety, such as:

- using relaxation techniques, such as actively tensing then relaxing individual muscle groups
- practicing meditation can be beneficial for some people
- exercise to channel internal stress into external action
- mentally letting go of things outside your control
- ensuring a balance of work and recreation
- time out for yourself
- visiting your general practitioner, and letting them know if you are having difficulty.

The importance of sleep

During deep sleep, the brain repairs itself and boosts the immune system. During rapid eye movement (REM) sleep, the brain consolidates information learned during

the previous day. Poor sleep leads to fatigue, immune suppression, lack of memory, concentration and mood disorders. Optimal learning cannot take place against a background of poor sleep.

What can you do if you can't get to sleep?

The most common causes of difficulty are not being able to shut off the anxieties and worries of the day and preparing for tomorrow's problems. As well as the relaxation strategies above, it can be useful to have sleep preparation routines in place:

- Don't take one last look at email messages
- No phone calls or activities after 9 pm
- Don't go to bed until you feel sleepy
- Don't have caffeine after noon.

Check your blood pressure, diabetes and cholesterol

If you have diabetes and high cholesterol, you have four times the risk of stroke. If you have diabetes, you have twice the risk of stroke. Experiencing many mini-strokes can lead to dementia in later life.

Avoid alcohol and other drugs if possible

Alcohol and other drugs affect the central nervous system and can impair a person's ability to think clearly, and control emotions and behaviour. These abilities are often impaired by a brain injury, so when people with a brain injury use drugs and alcohol, they are likely to experience even greater problems with alertness, memory, problem-solving and controlling their behaviour and emotions.

For more information visit synapse.org.au



Complimentary therapies

People often turn to complimentary therapies and alternative medicines to assist with some of the issues created by a brain injury.

In addition to the traditional rehabilitation therapies discussed earlier, some people have found benefit in some complimentary therapies, such as meditation/mindfulness, craniosacral therapy, massage, acupuncture, biofield therapies, hyperbaric oxygen treatment and naturopathic medicines. Anecdotally, some people have found these types of approaches helpful with some of the more intractable impacts of brain injury such as chronic pain, sleeplessness, and mental health issues like anxiety and depression.

Complimentary therapies should never be used as an alternative to conventional treatment, and care should be taken when using therapies that have not been proven to be safe or effective. Always check with your health care professional, particularly in the case of alternative medicines, as there may be adverse reactions with prescribed medication. People may try alternative medicine for various reasons, including:

- prescribed medications have no effect
- the side effects of prescribed medication outweigh the benefits
- an aversion to drugs and preference for more natural remedies.

Many treatments once classed as alternative are now mainstream (e.g. putting mouldy bread on wounds eventually led to the discovery of the antibiotic penicillin). However, this does not necessarily mean that all alternative medicines work. Of course, not all prescription medications work either, but the research should give a clear indication of how likely it is to work or have side effects.

Do alternative medicines work?

This is a common and, at times, fiery debate. Prescription medicines have undergone a rigorous process to determine if they will work, how likely they are to work and what the side effects will be. In contrast, alternative medicines tend to rely more on anecdotal evidence and claims that are tested to a much lesser degree, if at all. Generally, if an alternative medicine works, eventually the active compound will be found, isolated, tested then produced by pharmaceutical companies. However, there may be potentially effective alternative medicines for which evidence is lacking, simply because the therapy is new and the evidence base is yet to be established.

Potential pitfalls

It is important to advise the therapist of any existing medications and conditions in case of contraindications (a situation where a medicine or therapy is known to react adversely with a condition or another medicine). Some therapies may be harmful if performed under certain circumstances (e.g. massage when you have high blood pressure or ingesting certain herbs while pregnant). It is therefore important to choose a therapist who is accredited in their field – as they will understand the particular contraindications to their therapy. Some alternative medicines may interact quite badly with prescription medicines. A good example of this is St John's wort (*Hypericum Perforatum*), a common and widely used herbal antidepressant. It can have severe interactions with a wide range of prescription medications, including antidepressants and the contraceptive pill, and its usage

should be discussed with your doctor.

Do your research

As with prescription medications, do your research. Complimentary therapies are not always regulated by the same legislative controls, and there may not be minimum standards of qualification required for the practitioners. Do your own research on the topic (Google Scholar can be quite useful here) and look for published research (in literary journals) rather than generic web pages.

Evidence-based practice

This approach asks four questions about the data supporting each medicine, practice, procedure, or therapy to help decide if they are trustworthy.

Validity – is the supporting evidence unbiased, performed by qualified researchers and published in a well-respected journal? For example claims on the internet that bee stings improve memory could be doubtful.

Importance – (significant difference/benefit) - do the results outweigh the risks? E.g. The bee sting medicine was “studied” in only two patients, caused an allergic reaction in one, improved attention span for only 30 minutes in the second person but, both were in pain.

Applicability – is the treatment performed easily, available to most people, medically possible, and cost-effective? For example is it convenient for a person to carry bees around to sting them three times a day?

Purpose – does it do what it should, and for most people? For example, the bee sting approach should be tested across a broad demographic.

Pets as therapy

Man's best friend, the dog, has been portrayed in our culture as a loyal companion.

The inclusion of pets into hospital and rehabilitation environments has long been considered therapeutic, and pets continue to be an important part of life, long after rehabilitation has ended. This is true for people with a brain injury, and the wider community. A pet can offer acceptance, love and motivation through the most difficult parts of rehabilitation and recovery after a brain injury. Pets are very good companions and have shown to reduce feelings of loneliness, which can be useful after brain injury if friendships have not been maintained. Pets can respond with feedback that can help reduce inappropriate behaviours, and interest in a pet may redirect egocentricity that often accompanies brain injury. Apart from companionship, pets can be trained much like the more familiar seeing eye dogs to perform tasks and assist persons with disabilities in many ways. The responsibility for pet care can enhance cognitive functioning in ways that are more subtle and more enjoyable than traditional therapies. Fun activities often stimulate individuals with low motivation in ways that are not often achieved by sitting in front of the television for hours, for example.

Selecting a pet can be turned into a cognitive exercise of planning. Selecting a pet should be fun, not fraught with discord. It is important to consider all options. For example, a sophisticated set up of aquariums with pumps and filters may be too complex for some.

Pets must be cared for, otherwise they fail to thrive. The needs of the pet can be motivating for a person who may otherwise resist or refuse to actively engage with others. Naturally, a responsible adult should intervene if the pet's health or wellbeing is adversely affected. When limitations arising from the brain injury are barriers to independently caring for a pet, talk with the individual about strategies that will enable more independence and determine what duties will be managed by whom so responsibilities can be monitored.

Almost everyone loves animals. This often enhances social skills building when encountering others in the park, neighbourhoods and other places people congregate with pets.

Individuals with severe brain injury and other impairing conditions often have little control over their lives. Owning

a pet can provide an opportunity for controlling at least one facet of their lives. Pets always have time for sharing with their owners and their loyalty is indisputable.

Pet therapy is a well-established routine in many hospitals, nursing homes and rehabilitation centres. The presence of pets appears to be a benefit in all stages of recovery, rehabilitation and even end-stage illnesses.

The comforting and calming effect of stroking a furry animal often elicits more relaxing facial expressions and postures in persons even thought to be in minimally-responsive states.

Non-verbal individuals generally respond with contented smiles when pets are introduced into their environment. Almost all people with disabilities can take some responsibility for the care of an animal, even if it is no more than a daily stroking or play session.

Dogs are frequently trained to assist individuals with brain injury, particularly those with mobility impairments. Customised saddlebags can be placed on the dog and used for carrying personal items, wallet, daily journal and other items needed by those using wheelchairs or other assisting devices that increase mobility. Henry David Thoreau writes: 'it often happens that a man is more humanely related to a cat or dog than to any human being'. Pets are indeed wonderful companions and can frequently impact positively even to those for whom other therapies, exercises and/or future promise for continuing recovery hold little interest.



Impact of brain injury

All brain injuries are different and people may be affected to a varying degree by any number of these problems depending on the severity of their injury and the area of the brain.

Brain injury involves a broad range of consequences depending on injury severity and location, like pre-injury factors, and available support and resources. People with TBI typically experience a range of physical, cognitive, emotional, psychological, behavioural, and social impacts.

The main effects of brain injury can be grouped into four areas:

- physical – affecting how the body works
- cognitive – affecting how the person thinks, learns and remembers
- emotional, psychological and behavioural – affecting how the person feels and acts
- social and relationship changes – friendship networks and community involvement.

Physical effects

Fatigue and sleep disorders

Excessive tiredness will affect everyone on the spectrum of mild to severe brain injury. Regular tasks such as getting dressed or walking can require far more effort. It is important to allow for rest periods at regular intervals during the day, and to avoid doing too many activities at once. Sleep problems are common after brain injury, which can be debilitating given people already feel fatigued as a result of the injury. Sleep problems can also exacerbate irritation and make it harder to concentrate.

Mobility and balance

Movement can become very slow and balance can be affected. Indeed, having a brain injury can sometimes feel like 'living life in the slow lane'.

Some people may need a wheelchair or other mobility aids, because their poor balance and coordination means they cannot walk without support. The fact that they use a wheelchair does not necessarily mean that the person cannot stand or walk for short distances.

Spasticity and chronic pain

A person's limbs may be stiff or weak, and the range of movement limited. Often one side of the body is affected more than the other, depending on the area of brain that is damaged. This is known as hemiplegia. Spasticity may cause pain or discomfort. If this occurs, it is advisable to seek help from a doctor who may be able to prescribe drugs to reduce muscle spasms.

Weakness or paralysis often affects one side of the body more than the other. This could mean that help is needed during personal care and when getting dressed or undressed. Muscle weakness may affect continence, and continence aids may be needed.

It is common to feel pain after brain injury, which can contribute to fatigue and irritation. Chronic pain, usually in the form of headaches, is experienced by at least 50 per cent of people with TBI (Lahz and Bryant, 1996).

Ataxia

Ataxia is the irregular, uncontrolled movement or tremors affecting the coordination of movements. The person's hands may be shaky or clumsy, and handwriting may be difficult or impossible.

Sensory impairment

The sensation of touch on the skin may be reduced, lost or exaggerated.

It may also be difficult for the person to know where their limbs are positioned without looking at them. Eyesight may be affected and this may not be correctable with glasses. Sensory impairments can also lead to odd postures or walking patterns, and a person's taste or sense of smell may be impaired or lost in either the short or long term.

Difficulties with speech

Slow, indistinct or rapid speech is common after a brain injury. It may be hard to understand the person's speech at first, but the listener can learn to 'tune in'. Some people may repeat what they have said many times over: this is known as perseveration. Others might lose the ability to speak altogether. It is important to remember that an inability to express thoughts does not mean that a person has lost their intelligence.

Reference: Lahz, S., and Bryant, R. A. (1996). Incidence of chronic pain following traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 77(9), 889-891. doi: 10.1016/S0003-9993(96)90275-0



Epilepsy

Brain injury can make a person prone to epileptic seizures or 'fits'. Many people who have had a seizure after a brain injury are given a drug for a number of years to reduce the chance of it recurring. The drug may have an overall 'dampening' effect on the person's level of arousal, and therefore on the performance of everyday tasks. Remember the added effect that this could have if the person already has excessive fatigue. It is important to remember that a person who suffers from seizures may not be allowed to drive and should contact the relevant authorities for advice.

Hormonal imbalances

Brain injury may cause damage to the hypothalamus and/or pituitary gland, which are small structures at the base of the brain responsible for regulating the body's hormones. Damage to these areas can lead to insufficient or increased release of one or more hormones, which causes disruption of the body's ability to maintain a stable internal environment (homeostasis). If damage to the pituitary gland leads to a reduction in hormone production the resulting condition is known as hypopituitarism. Another hormonal condition which can be caused by brain injury is neurogenic diabetes

insipidus, which is usually a short-term problem in the acute stage after injury, but can occasionally persist in the long term.

Cognitive effects

Memory

Problems with memory, particularly short-term memory, are common after brain injury. Some people may be unable to remember faces or names, what they have read or what has been said to them. New learning may be affected, while previously learned skills may still be intact.

Reduced attention and concentration span

Problems with attention and concentration are very common and can also impact on memory problems. Completing tasks can be a problem and the task may be abandoned before reaching the end. The person may initially appear eager to start a task, but then lose interest very quickly.

Slower information processing

People can take longer to think things through or work out what has been said to them. 'Information overload' can be quickly reached, and can cause frustration and anger.

Reduced problem-solving ability

It may be difficult for the injured person to work out what to do if they encounter an unexpected problem.

Repetition or 'perseveration'

The person may be unable to move on to another topic in the same conversation, and they may return to the same topic repeatedly. They may also repeat the same action, appearing unable to break the cycle.

Reasoning, judgement and insight

Impaired reasoning may affect a person's ability to think logically, to understand rules, or follow discussions. The person may easily become argumentative due to a lack of understanding. Impaired judgement can cause difficulties in accurately perceiving and interpreting one's own and other people's behaviour and feelings. Putting oneself 'in someone else's shoes' can be almost impossible. Lack of insight means the person may have an unrealistic view of themselves and others, and may not appreciate that they have certain problems. This may lead to unattainable goals being set, which then leads to failure and frustration.

Motivation

Reduced initiation and problems with motivation are common after brain injury, and can often be mistaken for laziness. These problems may also be a symptom of depression.

Aphasia (language loss)

Aphasia may be 'receptive' (difficulty making sense of what is said or read) or 'expressive' (difficulty finding the right words to say or write), or both. This can be very frustrating for the person and for others, and patience is needed on both sides. It is important to remember that just because a person cannot express themselves, does not mean they do not need or want to be heard.

Impaired visual-perceptual skills

A person may have difficulty making sense out of ordinary pictures and shapes, finding the way around a building, or drawing or constructing objects. These problems can be particularly frustrating for a person who is quite competent in their language and social skills. Occasionally, people may fail to respond to stimuli coming from one side of their visual field, or may ignore a particular side of their body, for example when shaving or dressing. This condition is known as visual neglect.



Emotional and behavioural effects

Personality changes

Although physical impairments can pose barriers to work and social inclusion, what people report as most disabling are the personality, cognitive and behavioural changes, which can result in an altered sense of self. Personality change can be experienced by the injured person or their family and friends. For the injured person, there can be so many changes from their pre-injury lives that they no longer feel like themselves. A person with brain injury may feel as though they have lost their identity and become another person. In other cases, a person with brain injury may be unaware of these differences, yet to their family and friends they seem like a stranger. It is common for a person to lose confidence following a brain injury. Plenty of encouragement and reassurance from friends and family can assist people to restore their sense of self.

Mood swings

The person may have a tendency to laugh or cry very easily, and to move from one emotional state to another quite suddenly. Depression and sense of loss are common. Depression may be caused by injury to the areas of the brain that control emotion, but can also be associated with the person gaining an insight into the other effects of their injury. After brain injury, many things that are precious to the individual may be lost forever and there may be much sadness, anger, guilt and confusion, surrounding this.

Negative emotions

It is understandable for a person to feel a range of negative emotions after a brain injury. Life has been changed forever, and the future can look frightening. Feelings of anxiety, frustration and anger are common, and are complicated by the fact that the injury itself can make it difficult for a person to control the way they feel and behave. Without effective help and support these feelings can become overwhelming, and depression can result. With the right supports and strategies, these negative feelings can be managed and overcome. Family and friends need to be aware that, as upsetting as it is, spontaneous and uncontrollable outbursts are at times the only way a person with brain injury can deal with their frustration. While it is important to understand the reason behind this behaviour, aggression should not be tolerated. A positive behaviour plan is one way families can help a loved one overcome the negative emotions and behaviour associated with their injury.

Disinhibition and impulsivity

In some cases, there may be a loss of control over social behaviour, so that the person may behave in an over-familiar manner or may make inappropriate sexual advances. A person with brain injury can have offensive outbursts or behave inappropriately in social situations. This can be difficult for family members, particularly if they feel judged or misunderstood by others. Impaired awareness can also lead to impulsivity, where people may be less able to understand the consequences of their actions.

Professional support is important to provide strategies for the injured person and their families to manage these behaviours.

Social and relationship changes

The interaction of the impacts of brain injury can mean changes in people's relationships, friendship networks, and employment circumstances. Personality and behaviour changes, including anger and poor impulse control, typically cause conflict in existing relationships, and hinder the formation of new relationships. Friendship networks tend to diminish so social isolation is common. Although in some cases injury symptoms are easily observed, in others they are less obvious, adding to the feeling of being misunderstood by others. Ongoing challenges relating to community integration and psychological adjustment make everyday life following brain injury more complex (Fuchs, Crawford, and Milders, 2003; McCabe et al., 2007). Problems with working memory, attention and concentration, and executive function often mean people are unable to resume pre-injury employment. Barriers to employment, and diminished social and financial resources create further stress and burden for people with TBI. The presence of family support is vital to managing these symptoms and side effects.

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Attention and concentration after a brain injury

A brain injury can affect our attention or concentration abilities, leading to problems with work, study and everyday living.

The injured person may not immediately recognise that their ability to concentrate is any different, and there may be no physical signs to suggest a problem exists. This can lead to misunderstandings when people think an inability to concentrate is due to lack of intelligence or motivation. This problem is of particular concern with children who return to the classroom after acquiring a brain injury, who may be seen as disinterested or lazy students. People who have sustained a brain injury may:

- become easily distracted and have trouble keeping track of what is being said or done
- have difficulty doing more than one task at a time
- experience information overload, and be slower at taking in and making sense of information.

The effects of these difficulties on people's everyday lives can inhibit their ability to learn and remember information, and cause them to feel frustrated with themselves and other people. People may be easily overwhelmed and confused, which can exacerbate problems related to fatigue, headaches and dizziness.

Causes of lack of concentration

When a person has trouble concentrating after a brain injury, the likely cause is injury to the relevant areas of the brain. A region of the brain called the lateral intraparietal

cortex controls attention by filtering out what is and is not important at any given time. This region then stimulates the medial temporal area which influences the processing of visual information, determining what visual information is attended to. If damaged, the ability to maintain visual attention is affected. There is also evidence that the cerebellum, at the back of the brain, has an influence upon attention and concentration as its core role of coordinating muscle activity.

Concentration can be impeded by several other factors, including:

- fatigue and tiredness, particularly from sleep disorders
- pain and other physical sensations, particularly headaches and including joint, muscle and organ pain
- illness, including short-term infections or long-term disease
- hunger
- dietary inadequacy, particularly B-group vitamins and iron
- legal or recreational drugs and environmental toxins such as carbon monoxide
- mental health conditions, particularly depression and mania
- extremes of mood, including fear.

Strategies to improve attention and concentration

It is important to realise that what is happening is influenced by the brain injury. For those who are supporting someone with a brain injury, provide reassurance when necessary. Strategies can be generated from past experience, with an awareness for what is currently working, or what has worked in the past. Be aware that what has worked in the past may no longer work due to the effects of the brain injury. Identify specific situations where particular strategies may be effective. The following strategies may be helpful after a brain injury:

- reduce all possible distractions in the environment
- take regular rest breaks, lie down or go for a walk
- meditation, deep breathing and other strategies for physical and mental relaxation, such as having a coffee break or talking to friends
- plan how to approach a task with a simple step-by-step approach
- break significant tasks down into small and achievable steps
- write information down using notes, and keep them in specific places
- use a voice recorder to tape messages that can be regularly played back
- use a white board to help organise, plan and store information
- use 'association' techniques, e.g. putting medication on the table with every meal
- get into a regular daily routine which has a structure
- aim for variety within an everyday routine
- schedule demanding tasks when levels of energy and alertness are greatest, often early morning
- eat a healthy diet and sleep well
- use self-talk to monitor thoughts and actions
- use a timer, electronic organiser or smart device and set goals to steadily improve duration of concentration in small steps.



Personal accounts of brain injury

A stroke three years ago has knocked me out of almost everything.

I am unable to work and described by the doctors as permanently disabled. I still haven't resolved many of the issues resulting from it all.

I still experience disorientation and confusion, with memory impairments, and I have troubles with concentration and fatigue. I've searched for some way of describing how I feel. The closest I've come to is to say that it is like having malaria without the fever. My eyes feel a long way behind my face; I have headaches a lot, and often have trouble finding my balance. Complicated

conversations and noise are particularly uncomfortable, and I find it very difficult to stay upright for any length of time, so tend to find my bed fairly quickly...

We can learn from the experience of others. Visit Synapse.org.au to read personal stories by people with acquired brain injuries, as well as their carers and family members.



Managing fatigue after a brain injury

Fatigue is a common and very disabling symptom experienced by people with a brain injury.

It may be a continual sense of mental fatigue or it can happen when a person is trying to do too much and the brain is overloaded, often resulting in mind-numbing fatigue that can last for several days. Brain injury can be likened to a highway when one of three lanes is closed down. If traffic is light, there will be no difference but once the traffic reaches a critical point, the cars barely move and it can take ages for the traffic jam to clear. It is important to avoid fatigue as much as possible, as any other problems are worsened as well, such as:

- vision problems
- slurred speech
- difficulty finding words
- poor concentration
- cramps or weak muscles
- poor coordination or balance.

Fatigue can occur for no apparent reason or after physical activity, but is quite likely to occur from too much mental activity. Examples include planning the week's errands, organising a work schedule or simply reading.

Fatigue can be managed with good planning and rest periods, but carers and family members must realise that fatigue is a very real problem.

Symptoms of fatigue

The following symptoms may all suggest fatigue:

- withdrawal, short answers, dull tone of voice
- loss of appetite
- shortness of breath
- slower movement and speech
- irritability, anxiety, crying episodes
- increased forgetfulness
- lack of motivation and interest.

What are the triggers of fatigue?

It can be helpful to identify what triggers fatigue and what factors make the symptoms worse. Long conversations, noisy shopping centres, movies with complicated plots, or talking with two or more people at once cause fatigue. In some cases, fatigue could be a side effect of certain medications, in which case it is recommended to consult with a doctor.

It is important for a person with brain injury to recognise the first signs of fatigue, and to immediately stop and rest. Ignoring these signs can lead to several days of extreme tiredness due to brain overload. A useful strategy is to make notes on how long it takes to do certain activities before fatigue sets in. For example, a person who is getting tired after 30 minutes of reading should only read for 20 minutes in the future.

Managing fatigue

Contingency plans: fatigue can occur at the least convenient times – on public transport or during a meeting. Coping strategies can be developed ahead of time. This may involve the injured person working out a plan with family, or consulting their rehab team, occupational therapist or physiotherapist to help with suggestions.

Assess best hours: it is best to organise routines around the times when people function best, and avoid driving when tired.

Assess your environment: an uncluttered environment that is easy to move around and work in will save energy. It is useful to think about how and where items are stored, whether bench heights are suitable or how easy it is to navigate entrances. Even furnishing and lights can affect fatigue. For example, people can feel tired when exposed to fluorescent or dim lighting.

Schedule rest periods: regular rest periods should be built into daily or weekly schedules. The best rest is to do nothing at all. A short nap can be restful, oversleeping can affect normal sleep cycles.

Use aids: mechanical aids such as wheelchairs should be used to conserve energy, as was the case with one man who spared his legs the extra effort of walking from his house to the car, then from the car to the church, before walking his daughter, the bride, down the aisle.

Break it down: activities are more manageable when broken down into a series of smaller tasks. This provides opportunities to rest in between. Sensible shortcuts should also be encouraged.

Set priorities: it is important for people to focus on what needs to be done and then decide what to let go.

Medication highs and lows: medication can affect how people feel at different times of the day. Activities should be planned accordingly.

Weather: hot weather can also increase fatigue and should be taken into consideration when planning activities.

Seek support: health professionals are available for advice. For example, an occupational therapist might visit a person to see how they can reduce the effort it takes to perform everyday activities around the home.

Contact Synapse for more information on health professionals 1800 673 074.

Healthy lifestyle

As with virtually every aspect of brain injury, fatigue will be less of a problem when following a healthy lifestyle that includes:

- plenty of sleep
- staying as active as possible
- avoiding or limiting alcohol
- a healthy diet and maintaining a healthy weight
- using strategies for reducing stress
- spending time in nature
- maintaining contact with friends and family.

Managing lack of motivation

Task analysis is one possible strategy to combat adynamia, or lack of motivation.

Tasks are broken into individual sequenced steps and formed into a checklist. Each step is then ticked as it is completed. In this way beginning, completing and following through on a task is much easier.

This reduces fatigue as it minimises the need to plan, organise, decide, prioritise, remember and put things in sequence. These are only some of the cognitive issues required to say, cook an omelette. The person with adynamia can be exhausted by these tasks before they've even opened the kitchen door. Task analysis re-establishes the routines in our activities of daily living. With the use of checklists and lots of practice it can eventually make a great improvement in terms of drive and motivation.

The ingredients for rebuilding these automatic habits are the three Ps: plan, practice and promotional attitude.

The result is rehabilitation, or removing obstacles to independence, and systematic achievement of incremental goals in desirable life areas. Once you have goals in place, try building your motivation by:

- telling people about the goal to confirm personal commitment
- monitoring progress towards the goal by noting signs of improvement
- developing a system of external rewards to reinforce personal effort
- developing a routine which allocates time towards the goal
- identifying people to provide support and encouragement.

Sleeping disorders after a brain injury

Sleeping disorders are a common experience after brain injury.

Lack of sleep has a negative effect on our cognition, mood, energy levels and appetite. The average person needs around eight hours of sleep a night or will suffer from decreased concentration, energy and many other problems. These effects are multiplied many times by a TBI, stroke and other types of brain disorder. Unfortunately sleep disorders such as insomnia are common after brain injury, both as a direct result of the injury and as a secondary result of pain, stress, anxiety and/or depression. (Singh, Morse, Tkachenko, and Kothare, 2016). People's sleep and wakefulness cycles often become disturbed and irrespective of the severity (Mathias and Alvaro, 2012). Research suggests that between 30 per cent to 70 per cent of people with a TBI will experience some form of sleep disturbance (Ouellet, et al., 2006).

For some, the problem can be too much sleep, but for most the sleep disorder results in difficulty sleeping at night. There can be problems with the timing of sleep, followed by feelings of drowsiness during the day. After a brain injury, many find it not only difficult to sleep, but they are very easily awakened, sometimes dozens of times a night. Sleep will usually be very light, so the smallest noise brings the person instantly awake. On top of this, they may find themselves unable to sleep at all around 3 am, despite being desperately tired.

Causes

Research suggests a major cause of sleep disturbance following brain injury relates to disruption to the normal release of specific quantities of certain neurotransmitters in the

brain during sleep which causes 'sleep fragmentation' due to waking up so often. Reduced evening melatonin production, due to traumatic brain damage, may cause disruption of circadian regulation of sleep and wakefulness (Baumann 2012).

There can be a variety of other causes disrupting sleep. Discomfort from headache, neck pain or back pain will always make it hard to get to sleep. Depression is a common feature after a brain injury and survivors may find they fall asleep easily but wake up several hours before dawn, unable to sleep again. It is common for people to feel anxious and focus on negative thoughts. This, and an inability to handle stress, makes falling asleep more difficult.

Sleeping your way to recovery

Sleep plays its part in not only helping the brain to recover, but in physical healing as well. There are often damaged muscles in a TBI. During active sleep, the brain stem secretes hormones that in effect paralyse our muscles to prevent twitching. This can play a role in helping muscles to heal, but poor sleep will hinder the process.

Medication and sleep

There are medications that can help with sleep problems. Some medications are designed to promote sleep but they are typically avoided by physicians who treat brain injury. Many physicians use small doses of antidepressant medications with their head-injured patients and have found them to be very effective. Sometimes this medication works too well and people sleep for 12 to 15 hours for the first two or three days. This is

normal as the brain tries to 'catch up' on the sleep that it has missed. However, some people report side effects such as difficulty waking up in the mornings. Doctors need to know about any side effects. Sometimes sleep medication becomes less effective over time. A doctor can readjust the medication as needed.

Practical steps for healthy sleep

Routine is vital for sound sleep. It may sound extreme, but going to bed at exactly the same time every night, even on the weekend, allows a person's body to adjust to that pattern. Ideally this would not be varied by more than 15 minutes.

Caffeine and nicotine should be avoided. These stimulants have a negative effect on the brain, and for some people it may increase the likelihood of seizures.

Exercising late in the evening is stimulating and should be avoided.

Bedrooms need to be very dark because light plays such a critical role in sleep patterns. A comfortable temperature and quiet surroundings are also important.

Some find that afternoon naps are essential due to the cognitive fatigue from a brain injury. However, afternoon naps can disrupt night time sleeping so it is important to experiment. Rest without sleep may be the best option if night time sleep is disrupted.

Cognitive behavioural therapy is helpful when stress, anxiety and negative thoughts prevent good sleeping patterns.

Contact Synapse for more information about psychologists 1800 673 074.

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Balance problems and dizziness after a brain injury

Dizziness and balance problems are common after a brain injury, and can result in problems with movement even when there is no loss of function in the limbs themselves.

Our sense of balance comes from the interaction of three systems in our body – eyesight, the vestibular system (inner ear), and proprioception (the brain's ability to sense where parts of our body are spatially).

Problems with balance can stem from damage to any parts of these systems, and a brain injury can affect all three. For example, the trauma of a TBI can damage the inner ear, while a stroke could affect parts of the brain responsible for our sense of balance.

Other possible causes include:

- infection or trauma to the inner ear
- low blood pressure
- medication side effects.

Diagnosis of dizziness or balance problems

Due to this complexity, diagnosis usually involves a thorough medical examination, which may start with a doctor and could go on to involve physiotherapists, neurologists, neurosurgeons and optometrists. Tests may include a CT scan, MRI scan or EEG reading.

It is helpful to have a detailed list of all symptoms for the doctor or rehabilitation team. This includes what the person was doing at the time the symptoms appeared, what was happening, and the time of day. A list of medications is also important.

Treatment options

Treatment depends on the nature of the balance disorder, and if a specific cause can be identified. If the specific cause is treatable, then that is the best option. Some conditions can be improved with dietary changes such as reducing salt, caffeine, nicotine or alcohol.

Another treatment option is vestibular rehabilitation balance retraining exercises that are sometimes combined with electrical stimulation or biofeedback to train the muscles more effectively.

Physical aids are sometimes used along with therapy, such as braces, splints or moulded shoe inserts.

Other treatments involving training the brain can include training an individual to rely more heavily on visual cues if proprioception can no longer be completely trusted.

Invasive surgical procedures that may be used can include correction of joint or limb contraction, shortening or lengthening limbs or, in some cases, severing proprioceptive nerves to prevent contradictory feedback.

None of these techniques, as useful and effective as they can be, should happen in isolation. Environmental modifications, such as the addition of handrails in the home or the use of a walking stick or frame, and safety education, are also desirable.

Coping strategies for people with brain injury experiencing balance problems

If a person is waiting to access treatment, or if it is taking time to work, there are ways to improve quality of life while suffering from a TBI or other type of brain disorder affecting balance:

- avoid alcohol and drugs
- get out of bed slowly and allow time to adjust to changed body posture
- stop the moment dizziness starts and sit or lie down until it passes
- avoid or slow down movements that unbalance you
- sleep without a pillow to keep your neck and backbone perfectly straight
- cut down on salt as this can increase the sensation of vertigo
- pinpoint times or conditions when dizziness is worse, avoid those conditions and schedule activities to avoid those times.



Coping with memory problems after a brain injury

Memory problems are very common after a brain injury, especially issues with short-term memory.

Typical situations include forgetting people's names, losing a train of thought, getting lost at the shops, repeating or forgetting past conversations, misplacing objects and difficulty learning new skills. Common everyday experiences become a nightmare of confusion without strategies to manage or compensate for the effects of memory impairment. Memory problems can occur with most brain disorders, but are particularly common with TBI as trauma makes it quite likely the parts of the brain responsible for memory are injured by bony protrusions inside the skull.

Lifestyle changes to improve memory

There is no 'wonder treatment' for memory problems; however, there are many effective strategies that compensate for short-term memory impairments. As with any cognitive issues, memory works better when people are able to:

- avoid fatigue from pushing themselves too hard
- sleep well
- manage stress and anxiety
- avoid alcohol, eat a healthy diet and exercise regularly.

Organise the environment

The aim is to arrange surroundings so that less reliance or demand is placed on a person's memory. Strategies for organising the environment include:

- keeping a notepad and pen beside the phone
- using a large notice board on the wall
- having a special place to keep objects which go missing
- labelling cupboards as a reminder of where things are kept
- tying objects to places, e.g. A pen to the phone or a key to a belt.

Short-term memory strategies

There are several strategies a person with brain injury can use to help overcome short-term memory loss:

- reduce distractions as an inability to pay attention makes memory problems worse

- learn in small, repeated chunks - it is easier to remember information when broken down into repetitive and manageable amounts
- people can remind themselves to 'pay attention' at times when they need to focus
- use mnemonics – techniques used to memorise information through acronyms, short poems, stories, images or memorable phrases. A typical example is the acronym KISS for 'keep it simple, stupid'.

External memory aids

External memory aids are extremely effective strategies to compensate for memory loss and include:

- a diary for storing and planning
- notebooks of all sizes for various place
- lists and checklists
- alarm clock, wristwatch alarm and timer on mobile phones
- calendar or wall chart
- voice recorder
- electronic organisers and smart devices
- pill reminder box
- Post-it notes
- a memory book for big events, personal experiences and names.

It is important to realise that not everyone will benefit in the same way from the same tips after a TBI. Experimenting with different aids is the best way to find out which are the most effective.

For more information, visit synapse.org.au (coping with memory problems after a brain injury)



Problems with organising

Many people have difficulty getting organised after a brain injury.

This part of the brain is very susceptible to injury. Some people with an ABI will find great difficulty with prioritising, sequencing, organising, initiating and completing tasks.

Improve your lifestyle

Factors such as anxiety, stress, multiple demands and fatigue can impede your ability to organise. The improvement of a person's emotional and physical well-being, therefore, will most likely have benefits for their mental alertness and ability to plan and prioritise. Important considerations for improving general wellbeing include:

- a balanced diet and appropriate supplements e.g. vitamins
- sufficient restful sleep

- regular exercise
- relaxation and stress-reduction strategies
- following prescribed medication guidelines and medical advice
- avoiding alcohol, cigarettes and drugs.

Structure

Structure allows people to put most of their lives on automatic pilot and reserve creativity, memory, and novelty for more important areas. After a brain injury, many find that they lose this structure to their day, particularly if they are not working. The solution is to have well defined tasks for the day and follow a timetable that enables a healthy

lifestyle. For example, sleep can be properly regulated by having set times for sleeping and waking. It is also important to set regular meal times and never to skip eating. A person with brain injury can work with family members to arrange a weekly plan for visiting friends, exercise and any rehabilitation tasks.

Setting goals

Everyone has goals they set out to achieve, often at a subconscious level. Goals keep people focused on a purpose and help them through difficult times when many others less motivated would give up. A person who wants to get the most out of life often has a number of goals at the same time. Goal setting



can improve negative mind states, and help to gain more control over life. It can be helpful to set these out in writing and approach them step-by-step. If formal rehabilitation has finished, a goal might be to continue rehabilitation independently. It is crucial for people to have an accurate idea of their strengths and weaknesses. Self-awareness can be affected as a result of brain injury, giving people an unrealistic idea of what they are capable of. Family and rehabilitation professionals can assist with helping to choose and reach goals.

One way to plan and organise a goal involves designing a goal schedule, which may include some of the following sections:

- goal
- task/steps
- time frame
- potential barriers
- benefits of achieving the goal.

It is important to realise the underlying emotions or needs behind a goal. For example, a person may want to return to work, but find that their cognitive impairments prevent this. Returning to work can help a person feel productive, part of a team and esteemed by peers. In this case volunteering for a community organisation may satisfy these underlying needs. Achieving goals is a step-by-step process. It may seem too daunting at first but families can provide support and assistance in a graduated way. The recovery process is more like a marathon than a sprint and can involve a network of family support. Everyone needs patience, a positive attitude and plenty of loving support for each other. Goals should be adjusted to fit particular learning styles and be as enjoyable as possible. For example, a person who doesn't like reading or writing shouldn't use written exercises or reading books to achieve goals. For those who do, keeping a journal is an excellent way to record progress, especially when it feels as though progress is slow. A journal can keep track of the 'three steps forwards, two back' style that can sometimes feature in recovery.

Memory aids

Memory is an important part of getting organised. When effectively used to store information, memory aids should enable a person to focus upon learning and recalling details for which a strategy cannot be used.

Bringing it all together

The suggestions above are compensatory strategies in that they make up for lost skills. The good news is that with commitment and patience these strategies are very effective.

Organising your environment

Get a daily planner, diary or electronic organiser and write things down in the order you are going to do them.

Get into the habit of checking your schedule at the beginning of every day or the night before. The aim is to arrange surroundings so that less reliance or demand is placed upon a person's memory.

Strategies for organising the environment include the following:

- using a note pad system beside the phone
- using a large notice board and making plans
- having a special place to keep objects which tend to go missing (e.g. sunglasses)
- labelling or colour-coding cupboards as a reminder of where things are kept
- tying objects to places, e.g. a pen to the phone or a key to a belt.

A 'things to do' list is a handy tool. Get a whiteboard and put it up somewhere in your house. Write on it the things that you have to do and then erase them as you complete them. Sometimes people will list 50 projects and none of them will get done. If you have this problem, create a list of five projects that you want to do and write them on the whiteboard. Don't add another project to the list until you have completed one of the five items. As you add one, you have to subtract one. You may want to limit it to only three projects if five is overwhelming.



Communication disorders after a brain injury

A brain injury can affect a person's ability to communicate through impairing hearing, the muscle movements of speech or the cognitive processes that turn our thoughts into words.

Communication problems vary, depending on an individual's personality, pre-injury abilities, and the severity of the brain damage. Typical effects may include:

- slow or slurred speech
- difficulty swallowing
- drooling or a nasal tone
- problems with finding the right words
- trouble with understanding others.

Communication problems can be a mixture of both receptive and expressive problems, regardless of whether the cause was a brain tumour, TBI, encephalitis or other type of brain disorder.

Receptive skills

Receptive skills involve receiving and understanding language. Typical signs of this are:

- poor recognition of vocabulary
- continually asking for things to be repeated
- difficulty with the speed, complexity or amount of spoken information
- not paying attention in conversations
- not understanding what is said
- difficulty remembering instructions.

Remember that hearing loss can also occur after a brain injury and have the same effects. The ideal is a hearing test by an audiologist before assessing receptive skills.

Expressive skills

The ability to form sentences, find the right words, and make the right sounds may appear unaffected and not be detected during rehabilitation, but subtle problems can emerge over time. These can include:

- non-stop rapid talking
- rambling explanations and switching to unrelated topics
- difficulty remembering certain words
- incorrect use of language
- interrupting others
- inappropriate comments and behaviour
- making up stories
- minimal responses when a detailed response is needed
- difficulty with abstract skills, e.g. humour, puns, metaphors
- poor spelling and difficulty learning new words
- repeating the same words (perseveration)
- trouble with long sentences.



How professionals can help

A speech pathologist can assess and treat communication problems, and provide advice to rehabilitation teams. They can help the individual with a brain injury to cope in given social situations by using therapy to restore lost skills, learn compensatory strategies, as well as use assistive technology, such as a hearing aids or augmentative communication devices.

How family and friends can help

The speech therapist will involve family to provide consistent support in any strategies taught. Family and friends should expect to be involved in rehabilitation after a TBI – it makes a big difference. Families might use

the following tips:

- acknowledge the injury and be supportive
- listen and allow time for finishing sentences or finding the word
- prompt the person to evaluate their speech and be aware of issues
- speak clearly and simply
- work with the person to see which techniques work well.

Approaches to avoid include:

- false reassurance
- finishing sentences for the person
- speaking excessively loudly or slowly
- using jargon or lengthy explanations.

Contact Synapse for details on speech therapists near you 1800 673 074.

Typical communication problems

Anomia means ‘can’t name’. Everyone has occasional trouble remembering a word, but it can be a severe problem after a brain injury. Sometimes a wrong word is chosen such as: ‘pass me the noon’ instead of ‘pass me the spoon’. A speech pathologist can provide techniques to help, such as circumlocution. For example, if a person has forgotten the word ‘telephone’, they might say: ‘you dial it to call people’ so that they are understood.

Dysarthria occurs when areas of the brain controlling muscles for speech are damaged. A speech pathologist can help with strengthening muscles, increasing movement of mouth and tongue, and breathing exercises. Common techniques focus on slow, clear speech with frequent pauses, as well as starting a topic with a single

word first, then checking that the other person has understood.

Apraxia occurs when the speech muscles can be unaffected, but the brain has trouble sending the signals to the muscles responsible for speech. For example, someone may repeatedly stumble on the word ‘yesterday’ when asked to repeat it, but then be able to say it in a statement. In mild cases therapy may involve saying individual sounds and thinking about how the lips and tongue should be placed, or speaking while clapping to improve timing. In severe cases, alternative systems such as gestures, facial expressions, written communication or pre-printed cards are used.



Sensory and perceptual skills

Sensory and perceptual problems can arise from damage to the right side of the brain or the parietal and occipital lobes of the brain.

These areas of the brain process the input from our senses. For example, when eating an apple our brain will report on the following:

- touch (round and smooth)
- sight (red)
- sound (crunchy)
- smell (fresh)
- taste (sweet and ripe).

Brain disorders such as TBI can disrupt our senses, and also our perception of what our senses tell us. Our sensory and perceptual systems include:

- auditory (sound)
- visual (colour, shape, size, depth and distance)
- tactile (touch relating to pain, pressure and temperature)

- olfactory (smells)
- gustatory (taste).

Visuospatial skills

While problems can occur with our sensory systems, visuo-spatial problems are often more noticeable. Possible issues include:

- drawing objects
- recognising objects (agnosia)
- telling left from right
- mathematics (dyscalculia)
- analysing and remembering visual information
- manipulating or constructing objects
- awareness of the body in space (e.g. climbing stairs)
- perception of the environment (e.g. following directions).



Neglect

A well-known problem is neglect, where the brain ignores one side of all it perceives – usually the left hand side. For example, a person may ignore food on the left side of a plate or fail to copy aspects on the left side of a picture.

Case study - Elsie: Elsie was a 52-year-old woman who had a stroke three years ago and since then had problems with side-swiping parked cars and posts on the left side of her car. Elsie visited her doctor to have her eyesight checked. She was referred to a neuropsychologist who diagnosed the problem as left-sided neglect. When asked how she managed to drive, Elsie said she stayed in the left lane and would know to steer right when she heard her tires going off the road.

Prosopagnosia (face blindness)

Prosopagnosia is a less common example of neglect. The ability to recognise faces is affected, or even lost completely. In extreme cases, there is an inability to distinguish one face from another or read facial expressions (aperceptive prosopagnosia). These people must rely on signifiers like the voice, hairstyle or clothing to identify others.

Case study – Lincoln: after a car accident, Lincoln could not even recognise a photo of himself. If separated from his family in a large crowd he was unable to find them again. One of the biggest problems he faced is that others could understand his ability to see and recognise objects, but not other faces.

Managing visuospatial problems

As shown with Elsie, neglect may be undiagnosed despite safety issues. A person with neglect may be unaware of their problems, or blame the problem on something else. It is important to identify problems like neglect during rehabilitation and then educate the person to increase their awareness of the impact of the problem in everyday living.

Retraining skills is one way to manage visuospatial problems until the person regains the required skill as far as possible. Retraining usually involves repetitive and intensive exercises for a specific skill or task, such as practice at drawing an object while receiving feedback. It tends to be more effective with specific skills.

Changing the environment or expectations involves modifying the environment to provide more support, or reduce the demands of a particular skill. For example, support could be fitting a handrail to make climbing stairs at home easier. Reducing the demands of a skill can be as simple as just shifting furniture at home so that walking around the house is easier. The person may also learn to adjust their expectations and educate other people about their difficulties.

Compensatory strategies are very important in rehabilitation – they compensate for what a person has trouble doing after a TBI or similar brain disorder. For example, Elise may be taught to turn her head or body to scan the environment properly due to her neglect of things on her left side.

A range of specialised equipment is available to fit into a person's home or assist with community access.

External prompts are things like colour stickers for object recognition, bright lights on the floor, musical or sound prompts, stencils or transparent paper for copying, hand rails and other safety devices.

A compensatory strategy for failing to recognise objects could involve the person relying more on other senses such as touch, hearing and smell by shutting their eyes.

The rehabilitation strategies described may be developed by a neuropsychologist, occupational therapist or physiotherapist. The eventual goal of any rehabilitation program is greater independence and the use of self-management strategies. However, family members, friends and support workers can still provide valuable support.



Visual disorders

Our vision is a sophisticated complex of subsystems involving the flow and processing of information to the brain.

A brain injury can disrupt this process, causing a person to experience neurological vision impairment. Individuals may experience problems focusing, have eye muscle coordination impairments, changes to their peripheral vision, and may require changes in eyeglass prescription. It is often the case that a person is straining without realising when they have difficulty processing visual information. This can lead to a general sense of fatigue.

The extent of any visual problem depends on the severity and location of the injury. Treatment is possible through rehabilitation and the management of symptoms. Vision can also improve as the injured brain heals

Causes

Trauma can cause damage to parts of the brain responsible for visual information processing. Even if the head does not hit anything, whiplash can cause damage.

Trauma may injure arteries, stretch nerves or damage the vertebral column. It can also create soft tissue damage that may cause eye muscle coordination problems and other symptoms.

Common visual problems

Dry eyes

This can result when nerves or muscles of the eyelids are affected. Symptoms are often relieved with the use of the correct eye drops. In bad cases, plugs placed in the tear ducts can solve the problem.

Hallucinations

Visual hallucinations may be 'formed' objects, such as a person or figure, or may be 'unformed' such as flashes of lights, stars or flickering distortions.

Double vision

This condition may cause confusion and disorientation. Individuals experiencing this condition are often given an eye patch to cover one eye although it reduces the field of vision and interferes with daily function. Double vision can often be prevented without an eye patch through the use of prisms and vision therapy.

Prisms are used to shift objects in the field of vision. They can correct problems between body image and perception of space.

Reading difficulties

These may arise from blurred or double vision, jerky eye movements, or visual field loss. Treatment can involve aids such as prisms or using a typoscope to focus on individual sentences. After an injury, it can be hard to focus on a page due to nerve damage that affects the eye's ability to refocus. Bifocal glasses can compensate. Eye movements can be impaired by ABI which may prevent smooth reading along the page. Therapists may be able to rebuild reading skills to reduce problems such as this.

Impaired visual memory

Memory is often impaired after stroke or head injury. In rare cases, very specific types of memory processing are impaired. A person may no longer be able to recognise faces, objects or letters.

Loss of visual field

This loss is a common visual effect of ABI. There are many kinds but the most common is loss of half of the field of vision in each eye.

People frequently bump into objects and easily trip or fall over objects. They may be afraid of leaving home and have difficulty reading. Therapy can help to detect objects on their 'blind side' and use constant scanning to compensate. Compensatory strategies are useful, such as always aligning oneself to objects or people so they are centred in the remaining visual field. Prisms and mirror devices are often helpful in cases of visual field loss. Tiny mirrors attached to glasses can expand visual field awareness. If there is some remaining vision, stimulatory exercises can be used to increase light sensitivity and regain some lost function.

Low vision

Following a brain injury, some people have a normal field of view but can't read print or watch television with conventional glasses because of low vision. Low vision aids include telescopic lenses for distance vision and a range of magnifying aids for reading and other fine tasks.

Photosensitivity

Light sensitivity varies from person to person. Some have no trouble but others find bright light painful. Solutions may include tinted eyewear or amber filters. Sometimes treatment for other problems will reduce photosensitivity.

Vision rehabilitation

After a brain injury some people experience a natural recovery, usually within six months. This recovery can be assisted with the use of prescription lenses. Some people will not recover naturally but may do so with vision therapy. Vision therapy can enhance the natural recovery process. A clinician skilled in both low vision and brain injury will understand the interaction of these problems and be able to make a plan to rehabilitate the visual system. After evaluation, examination and consultation, a clinician will determine how a person processes information after an injury and where that person's strengths and weaknesses lie. They provide treatment designed for each individual and frequently incorporate combinations of lenses, prisms, low vision aids, and vision therapy activities. The road to recovery needs the teamwork of many doctors and therapists with time and patience throughout the rehabilitative process.

Hearing problems after a brain injury

A brain injury can damage both mechanical and neurological processes and result in a variety of hearing difficulties.

The mechanical process of hearing is carried out by the ear itself which has three sections, the outer, middle, and inner ears.

The outer ear, consisting of the lobe and ear canal, protects the more fragile parts inside.

The middle ear begins with the eardrum – sound makes this thin membrane vibrate. The vibration is transferred via three small bones to the inner ear.

The inner ear has a tube called the cochlea which is wound tightly like a snail shell. From here the neurological process begins – the vibration is turned into electrical impulses and sent to various parts of the brain for processing.

The trauma involved in a TBI most commonly affects the mechanical process. An eardrum may rupture, any of the small bones could break or there could be bleeding or bruising of the middle ear.

Sometimes damage to the parietal or temporal lobes can disrupt the neurological process. Thankfully, many hearing difficulties are not permanent and can be reduced or eliminated with treatment.

Diagnosis of hearing problems

Accurate diagnosis and treatment are essential. The first step is to see a doctor for a referral to an audiologist or an ear, nose and throat specialist if needed. Some audiologists run specialist clinics to help manage particular conditions with specialist hearing aids or therapeutic noise generators.

Tinnitus

Tinnitus is experienced as noises which are commonly like a buzzing, hissing or ringing in the ears. It is usually caused by damage to the mechanical process of hearing. It can worsen with exposure to loud noises, excessive stress, caffeine, alcohol, nicotine, some illicit drugs and medications, and quinine found in tonic water.

Some audiologists run clinics to help manage tinnitus. Other treatments include tinnitus retraining therapy, cognitive behavioural therapy, and learning coping strategies.

Hearing aids can be adapted with a soft noise generator as long-term exposure to gentle sound can desensitise the ears very effectively. This 'white noise' contains every frequency audible to humans, and can be likened to the sound of distant surf or wind.

Hyperacusis (sensitivity)

Trauma to the inner ear can cause certain noises or pitches to become extremely loud or soft, causing many problems in situations, such as dining out, walking, washing the dishes, using a vacuum cleaner or listening to music. Often the problem is not diagnosed as the person has trouble convincing others that the problem exists. An audiology test will often show that hearing is 'normal', but it is the sensitivity or inability to handle rapid changes in volume that is the issue. There is no cure for hyperacusis, but there are many effective strategies to manage this

condition, including:

- ear plugs and ear muffs can help in some situations
- activities such as dining out or shopping should be scheduled for quieter off-peak times
- nicotine and caffeine are stimulants and should be avoided
- it is helpful to maintain good health through diet, sleep and exercise
- specially programed hearing aids can be used to desensitise ears through long-term exposure to gentle sound.

Meniere's syndrome

This syndrome is caused by excessive pressure in the chambers of the inner ear. Nerve-filled membranes stretch, which can cause hearing loss, ringing, vertigo, imbalance and a sensation of pressure in the ear.

It is incurable, but treatment can alleviate the symptoms with medication, such as diuretics or steroids, electrical stimulation or simply limiting movement. There are various surgical procedures that may decrease the pressure or remove/deaden the nerves responsible.

Auditory agnosia

This rare condition involves problems with recognising nonverbal sounds, but still being able to speak normally. It usually involves injury to the temporal-parietal parts of the brain and often resolves itself over time.

Practical tips for any hearing problems

There are practical steps a person can take to lessen many hearing problems, many of which will help with other aspects of a TBI and other brain disorders:

- avoid noisy stressful environments where possible
- talk with trusted friends or professionals about the problem
- exercise regularly
- listen to gentle music to cover constant noise caused by tinnitus
- sleep well
- eat well and reduce salt if you have fluid pressure in the ear
- stop using drugs such as coffee, cigarettes and alcohol.

Anosmia – loss of sense of smell

TBI often damages the part of our brain responsible for olfaction - our sense of smell.

Of the five senses, smell is often considered to rank fourth in importance for humans. Taste, considered the fifth sense, is mostly the smell of food in the mouth. The sense of smell originates from the olfactory nerves that sit at the base of the brain's frontal lobes, right behind the eyes and above the nose. After a brain injury, people may experience a loss of taste and smell that is called anosmia.

Why does it happen?

A trauma to the head can cause anosmia by injury to the olfactory nerve. This nerve sits between the frontal lobe and bony protrusions from the skull and is vulnerable to trauma. Damage to the brain via trauma, stroke, and many other ABI can also cause anosmia by damaging smell processing cells in the orbitofrontal or anterior temporal lobes, or by mechanical damage to nasal structures.

Will it go away?

If the sensory cortex has been bruised, a gradual recovery of sensation may be possible. One

study of 66 subjects showed that 36 per cent improved slightly, 45 per cent had no change, and 18 per cent worsened (Doty et al., 1997). The presence of odour distortions, however, (including phantom odours) decreased over time.

Weight loss or gain

Our sense of food flavour is a mixture of both smell and taste perception. Since the ability to taste and enjoy food and drink depends on our sense of smell, anosmia often leads to reduced appetite and weight loss. In some patients it leads to weight gain, because they eat food with a high salt and fat content to gain enjoyment.

Importance of testing

It is a good idea to have suspected anosmia tested. Treatment will most often depend on the cause of the anosmia. The cause may not be the brain injury itself – it may be due to pressure on nerves as a side-effect of the injury – or it may even be due to the effects of medications.

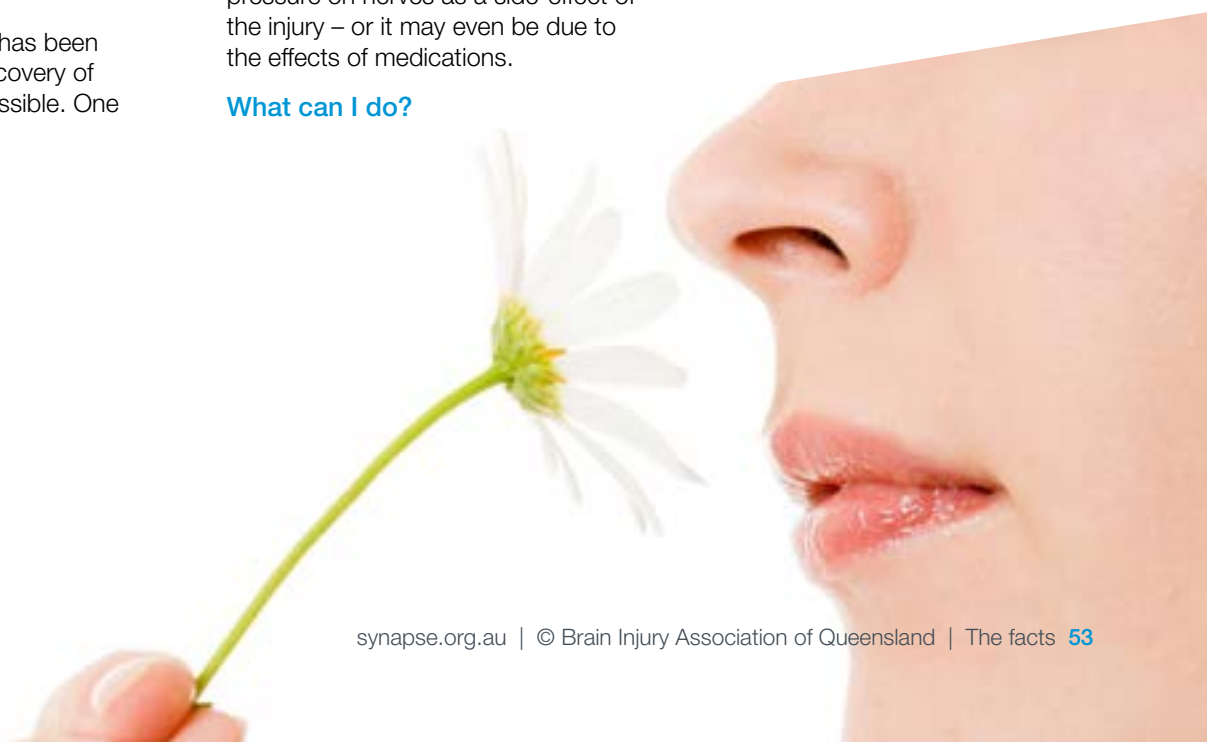
What can I do?

A person with anosmia can find ways to make eating fun again. The texture of different foods becomes very important, particularly when they are combined. For example, half-cooked vegetables can be mixed with cooked ones for a texture comparison. Hot meals can be eaten with a cold salad for different temperature experiences and spicy food will cause sensations on the tongue.

The object is to take some time to make meals interesting and fun, so they are still appealing to eat and you feel satisfied afterwards.

If a person has lost their sense of smell they may need to take added steps to become safety conscious. Installing extra smoke detectors is necessary if a person cannot smell smoke in their home. Similarly, electricity is a safer option if a person is unable to smell gas. It is also important to pay close attention to labels when using chemicals in case ventilation is needed.

Reference: Doty, R. L., Yousem, D. M., Pham, L. T., Kreshak, A. A., Geckle, R., and Lee, W. W. (1997). Olfactory Dysfunction in Patients With Head Trauma. *Archives of Neurology*, 54(9), 1131-1140. doi:10.1001/archneur.1997.00550210061014





Headaches and other pains

Pain is a frequent symptom after a brain injury, although its persistence is usually not related to the severity of injury.

In some cases, particularly with severe brain injury, surgical intervention may be required to relieve pressure upon nerves or within the skull. Appropriate clinical examination and diagnostic tests are needed to assess the form of treatment required.

Causes of headaches

The brain itself is not a source of pain. Headaches arise from problems with a number of different structures both inside and outside the head. Those inside the head can be the dura, the venous sinuses, blood vessels and cranial

nerves. Those outside the head can be the skin, muscles, nerves, arteries, joint capsules, cavities within the head, nerves and the periosteum.

A post-traumatic headache is only a symptom of an underlying disorder. Doctors need to know that a patient has experienced a brain injury in order to make the right diagnosis. A headache might be treated as a neurovascular or migraine headache, when the great majority are not primarily migraine-type problems. There are different types of injuries that may create the pain generators of headache and need to be identified as such.

Major types of headaches

The major types of headaches following trauma, include musculoskeletal headache, tension-type headache and neuralgic (e.g. migraine) headache. Other rare causes of headache include seizure disorders and pneumocephalus (air in the head).

Musculoskeletal headache is the most common type, and also the most overlooked. There can be musculoskeletal pain from the neck and structures in the head – a very common cause of this is whiplash injuries. These headaches often worsen with stooping, bending or exertion and may be associated with dizziness, sensitivity to light, sensitivity to sound and even imbalance. Manipulative therapy can be effective to assist in resetting bony structures. Other treatment may focus on strengthening weak spinal musculature, improvement of posture, anti-inflammatory medications and muscle relaxants, or the use of splints.

Cervical sympathetic nerve syndrome is, unfortunately, one instance in which headaches resulting from whiplash cannot be cured. This syndrome occurs when the cervical spinal column – the length of spinal column in the neck itself – is damaged. Symptoms can include (apart from a headache) uncontrollable spasms over the body, painful pins and needles all over the body, vertigo, facial pain, sinus congestion, fatigue and more. This condition has also been known as barre-lieou syndrome, after the doctors who independently discovered it. Although it is possible to treat this condition, if there is pressure upon the nerves but no actual damage, it is vital that treatment be within 72 hours of the injury or permanent damage is almost inevitable.

Tension headaches are reported by most people to feel like a diffuse vice-like pressure throughout the head. An attack can last from 30 minutes to a week. Tension-type headache may be chronic or episodic depending on frequency. There appear to be two types – one with migraine features fairly responsive to anti-migraine medications, the other without such features.

Neuralgic pain syndrome tends to occur when large nerves in the scalp are injured following trauma. This type of pain tends to be a shooting, stabbing type in the front and side of the head, sometimes with pain around or behind the eye.

Migraine headache can last from four hours to three days. They have perhaps the clearest diagnosis of any of the categories of headache, using the acronym 'pounding': pulsating headache for between four and seventy-two hours, unilateral (one-sided), nauseating and disabling. Treatment should include the reduction of triggers such as stress, foods that may elicit an allergic reaction, sleep inconsistency, and other allergies. Hormonal fluxes can also cause migraines, and hormone replacement therapy has been effective at controlling migraines in many cases. The most effective control is often awareness – people who are susceptible to migraines often have an 'aura' that signals the approach of a migraine, and may be able to prevent it by immediately stopping stressful activities and/or taking painkillers.

Appropriate medication could include tryptamines, ergotamine or corticosteroids. Relaxation training and biofeedback could also be considered. Newer techniques including the use of botulinum toxin injection into pericranial musculature can also be explored.

There are many other types of headaches that can be diagnosed with tests such as MRI scans of the brain, x-rays and MRA.

Other types of pain

Apart from headaches, there are numerous other sources of potential pain after a brain injury, such as abscesses, skin sores, cervical or spine injuries, fractures, heterotopic ossification (bony overgrowth), kidney stones, bladder infections, spasticity and constipation. There are two kinds of pain—acute and chronic. Acute pain is relatively short in duration. It has a readily seen cause and reduces with treatment. On the other hand, chronic pain lasts beyond the expected duration and it may continue beyond the physical healing of the body region involved.

Pain and rehabilitation

The difficulties a person with brain injury faces can be even greater when pain is involved. The pain may be so intense and bothersome that the person withdraws from work, family and social activities.

Pain may prevent individuals from attempting to return to everyday activities. This not only serves to lengthen significantly the time before returning to activities, but it also may contribute to hesitancy and reduced self-confidence when later attempting to resume activities.

In contrast to people with mild brain injury, people with moderate to severe brain injury may deny or minimise the effects of their impairment. For these people, pain may reduce both awareness of their impairments and their incentive to work on improving these impairments by causing them to focus too much on their pain.

Medication

Pain management in brain injury is often difficult as medications may work against recovery. Many painkillers work against the re-emergence of the person's mental and physical systems. Narcotics could also become a problem because of their potential for substance abuse and their negative side effects on the ability think clearly.

Anti-inflammatory agents are appropriate for musculoskeletal pain, though doctors must stay alert for possible gastric problems. Patients with brain injury and spinal cord injury tend to have high acid content in the stomach and are susceptible to stomach ulcers which can be increased by these agents.

Antidepressants can be effective in controlling some headache and nerve pain. These are not sedating except in high doses, and don't depress the respiratory cycle.

Epilepsy

Epilepsy is recurring brief episodes of abnormal electric activity in the brain leading to uncontrolled convulsions and unconsciousness, or just a momentary loss of awareness.

Epilepsy is a chronic condition produced by temporary changes in the electrical function of the brain, causing seizures which affect awareness, movement, or sensation. Its effects can be very similar to general seizures, but these usually occur due to causes other than abnormal electrical activity in the brain (e.g. stress, drugs, fever, low blood sugar or sodium).

Seizures can vary from a brief lapse of awareness to unconsciousness and jerking convulsions of the body. The majority of recurring seizures can be prevented by medications.

Diagnosis of epilepsy

One seizure alone is not enough for a diagnosis of epilepsy – it may be a once-off occurrence. In primary epilepsy, there is no discoverable abnormality in the brain and therefore no known cause. In secondary epilepsy, the seizures are caused by an abnormality in brain tissue which can be found by a CT or MRI scan. A brain injury can lead to secondary epilepsy.

Links between epilepsy and brain injury

Epilepsy has a close relationship with TBI and other brain disorders. It can cause neural damage by itself, and epilepsy is a risk factor for a TBI through a fall or violent convulsion. Epilepsy can also result from acquiring a brain injury.

Epilepsy caused by a brain injury does not usually start with a severe seizure. It may begin with absence seizures categorised by memory loss, attention problems or other subtle symptoms that may not be recognised as a seizure.

Treatment and management of epilepsy

The most common techniques for managing epilepsy include:

- taking medication on time
- avoiding alcohol, coffee and other stimulants
- sleeping well and minimising stress
- avoiding conditions that trigger seizures
- wearing a medic-alert bracelet
- ensure friends and family know all about epilepsy and managing a fit.

There is frequently an ‘aura’ before a seizure, which can include sensory hallucinations, dizziness or light-headedness, feelings of panic or déjà vu. On the other hand, there may be no warning at all. Recognising and acting upon pre-seizure sensations can be an important technique for preventing serious physical injury.

In some cases, there are triggers that may increase the chances of a seizure, including alcohol, caffeine, missing meals, infections, lack of sleep, flickering lights and missing medication.

There is no cure for epilepsy, but seizures are controllable with medication in the majority of cases. Different medications may be tried until the most effective treatment is found. Families and partners can play an important role by ensuring medication is taken when needed and obtaining first aid certificates to know how to provide first aid if a fit occurs.

In a small number of cases, people may benefit from a ketogenic diet – food that is high in fats and oils and low in carbohydrates to stress the body into burning fat for energy. It

is only used under strict medical supervision and when drugs are proving ineffective.

In severe cases that don't respond to medication, surgery might be used. It does not guarantee any benefit and there is the risk of brain injury.

First aid

See a doctor immediately or call an ambulance. A seizure may indicate a serious medical condition. If the seizure is severe, calling for an ambulance is the very first priority. If a person is alone, they need to call an ambulance as soon as they have recovered enough to be able to do so.

People should not be restrained during a fit. If possible, they should be rolled into the recovery position and their airway cleared, e.g. no vomit in the mouth. If a person could hurt themselves against nearby objects like chairs or tables, then these should be removed. It is important to ensure the person is still breathing, and to time the duration of the fits as the ambulance officers will want this information when they arrive.

When the fit has passed, the person will normally be quite groggy and tired when consciousness returns. They need to rest until they have recovered enough to get up.



Challenging and complex behaviours

Challenging and complex behaviours are common following a brain injury if there is damage to parts of the brain that control our impulses and regulate our emotions.

Behaviour that is considered acceptable is set by thousands of unwritten rules. Some examples include:

- how close to stand to others
- when it is okay to interrupt another person
- when and how to show emotions
- how to interpret and respond to non-verbal communication
- when and what parts of a person's body may be seen naked.

Behaviour that breaks these 'rules' can lead to social exclusion, restriction of access to community services, family breakdown and even prison.

What are complex and challenging behaviours?

A 'challenging behaviour' is one that we find hard to accept. It literally challenges our ability to understand why it is happening, usually because it is breaking those unwritten social rules.

A 'complex behaviour' is one that makes it difficult to initially see the reasons for the behaviour. These terms can be used interchangeably as they are usually strongly linked together in the context of a brain injury.

Examples of challenging and complex behaviours include:

- physical or verbal aggression
- self-injury
- property destruction
- disinhibited and impulsive behaviour
- hyper-sexuality
- impulsivity
- aggressive behaviour.

Why not just say 'bad behaviour'?

The problem is that when negative and judgmental words are used, our actions tend to follow suit and the behaviour will only deteriorate in response. Using terms like challenging behaviour makes us more objective in our thoughts and actions.

Case study: Sarah's behaviour changed dramatically after a brain injury. If her family sees Sarah as temperamental and willfully disruptive, these negative perceptions will seriously affect any efforts to understand the reasons behind the behaviour, and disrupt any plans made to encourage more appropriate behaviour.



What causes challenging behaviours?

A brain injury can affect those parts of the brain involved with emotions, the ability to control impulses, self-awareness and the ability to monitor and change behaviour. People learn these skills over many years as they grow and mature into adulthood. A brain injury often means a person needs to relearn many of these skills, and in some cases may be unable to do so if their self-awareness is affected severely.

Managing challenging behaviours – what can carers and families do about challenging behaviours?

It is important to have a good understanding of how brain injury affects behaviour in order to understand the 'message' behind each behaviour and develop positive responses.

Here are some basic tips that can help to reduce the chances of challenging behaviours, or develop positive responses to them:

- provide as much structure and routine as possible
- communication should be clear, direct and frequent
- talk about issues, including the behaviour and what to do about it
- be clear about which behaviours are acceptable or not
- have clear limits and rules – what is expected and what is appropriate
- give the person feedback and information about their behaviour
- be consistent in how you manage behaviour
- be positive – notice and encourage appropriate behaviour frequently
- take into account changes in thinking, understanding or memory
- use strategies that defuse behaviour and help a person calm down, such as talking it through, changing the topic or changing the task
- use redirection, distraction, and diversion to shift behaviour
- use humour to defuse things and reduce tension and stress
- get support for yourself and for the person with the brain injury.

Don't take challenging behaviours personally

People can become critical, argumentative or angry as a result of brain injury. Their behaviour should not be taken personally, although this can be difficult when it is upsetting. Carers need to remind themselves that the brain injury has affected the person's ability to manage their own behaviour. Focusing on positive responses to behaviour will reduce the powerlessness many feel when just reacting to challenging behaviours instead of responding.

Stress management for carers and family members

It is normal for carers and family members to feel upset and angry. Where possible, it is important to stay calm while responding to (or ignoring) the behaviour, but talk later with other family members.

Carers need to restore energy with regular breaks and relaxation, as well as stay in contact with friends. Where possible, they should keep up with personal interests and hobbies. Learning as much as possible about brain injuries will help carers understand the difficulties that the person with the brain injury might be having.

It is important to seek support from friends, support groups and health professionals to talk about ways to manage behaviour and how to cope as a carer.

Contact Synapse for more information and support 1800 673 074.

Is there a 'cure' for behaviour problems?

There are no easy solutions or fixes for challenging behaviours as they are caused by many complex factors (including the brain injury) which may not change. However, the good news is that even when a person has limited self-awareness, family members can often influence behaviours by responding positively and consistently with positive behaviour support.



Problems with anger

Anger is a common emotional response after a brain injury and can be directly related to impairments caused by the injury.

A brain injury can damage areas of the brain involved in control and regulation of emotions, particularly the frontal lobe and limbic system. Other effects of a brain injury can lead to irritability, agitation, lowered tolerance and impulsivity, which also increase the likelihood of angry outbursts. Anger issues are commonly associated with a TBI but occur with other types of brain injury as well.

Anger and self-awareness

There is usually an ‘on-off’ quality to the anger – an explosive angry outburst one minute, but calm again shortly after. This can be very difficult for family members and partners to cope with. In some cases, a brain injury can impact self-awareness. The person may not acknowledge they have trouble with anger, and may blame others for provoking them. It may take carefully phrased feedback and plenty of time for the person to gradually realise that anger management is an issue.

Triggers for anger

When a person has sufficient self-awareness to realise that they need to manage their anger, the first step is to recognise the triggers.

Common triggers for anger include:

- lack of structure or unexpected events
- perceived lack of control
- being confronted with a task the person is no longer capable of doing
- fatigue or confusion
- impulsivity
- confusion and overstimulation, e.g. crowds, lots of noise and activity
- other people’s behaviour, e.g. insensitive comments
- unrealistic self-expectations
- barriers to goals or routines, e.g. queues
- build-up of stress or frustration.

Recognising these triggers is an important step, as the person can either avoid those situations, or prepare for them mentally and begin to use their anger management strategies.

Recognise the signs of anger

It is important to become aware of personal thoughts, behaviours and physical states associated with anger, such as increased heart rate, sweating, muscles tightness or raised voice. After a brain injury, it can be difficult to recognise these signs and avoid unpleasant situations or prepare for them.



Coping strategies

Coping strategies for managing anger are a skill learned over many years as we mature. A brain injury can mean having to relearn these skills. Depending on an individual's level of self-awareness, learning ability and cognitive skill, assistance from family members or a carer may be needed.

It is useful to keep a record of events, triggers and associated levels of anger. This can assist with finding coping strategies that suit.

The 'back off, calm down and try again' technique is a technique from the brain injury association of Washington. It suggests a person:

- leave the situation when early warning signs of anger appear
- move to a safe place and calm down
- review the situation and prepare for return
- if needed, talk through the situation with others after returning.

The 'stop – think' technique is similar. When a person feels anger rising, they need to stop and think before reacting to the situation. This may require assistance from others to create a cue to signal that the person is getting frustrated. Decisions need to be made about how to respond to frustration, such as walking away, finding a better way to communicate or taking time out.

Recommended strategies for people with brain injury to manage anger:

- distract themselves from stressful situations, e.g. carry a magazine
- explain to another person how they can be of help to solve the problem
- leave the situation where possible if they feel they are losing their temper
- phone a friend or a crisis centre to talk about the situation
- make changes to routines, e.g. avoid peak hour traffic
- speak with a doctor, psychologist or rehab specialists for advice.

Recommended strategies for family and carers

It is important not to take anger personally and recognise that the individual has an impaired ability to control anger. Below are some tips for families and carers coping with anger:

Validation and understanding – try to understand why the individual is angry, listen to them and acknowledge their feelings. Try and find a way to assist the person with finding a solution to the problem.

Maintain structure – changes in structure or surprises in routine can result in agitation and frustration. Make sure the person has advance notice on changes to routines, is clear about what is happening and why the changes are occurring.

Distraction

Distraction involves changing the discussion topic, activity or setting. Once the person has been distracted, it can help to change the activity to one that is calming and enjoyable.

Self-removal and safety

Carers and family members need to think about their own safety. If the person being cared for is upset and this escalates, they may need to leave if it is safe to do so. They should tell the person what they plan to do with phrases such as: 'you're getting upset. We are leaving for a few minutes so you can calm down. We will return when your anger is under control'. If the person is being verbally abusive, it is best to ignore the behaviour by reducing eye contact and verbal interaction. Also make sure that the environment is safe from potential weapons or dangerous objects that could be thrown or used to damage property.

Impaired self-awareness and brain injury

Lack of self-awareness is a common outcome for people with injury to the frontal lobes which is common after a traumatic brain injury.

Impaired self-awareness is a lack of insight in assessing one's abilities and limitations, and the resulting implications. There are various degrees of impaired self-awareness after a TBI. For example, someone may know they have a problem, but has trouble detecting when it occurs and how to respond. In other cases, a person may refuse to acknowledge there is a problem at all, and believe that family members are lying or exaggerating the problems.

Lack of self-awareness can lead to unrealistic goals, such as returning to work despite a severe brain injury. Rehabilitation can be difficult as a person is unlikely to apply themselves or be cooperative if they don't believe a problem exists.

In some cases, insight can develop over time if the person encounters numerous setbacks. Periods of despair at not being able to regain skills and abilities can lead to an improvement in self-awareness.

Any techniques used to help increase self-awareness will depend on why there is a problem with insight in the first place. The main causes are:

- an inability to assess and monitor one's performance and abilities
- concentration and memory problems are reducing insight
- an inability to set goals and put strategies into action.

Techniques for increasing self-awareness

In a rehabilitation setting, common techniques include (Fleming and Ownsworth 2006):

- selecting key tasks and



- environments to highlight difficulties
- providing clear feedback and structured learning opportunities
- promoting habit formation through procedural learning
- specifically training for application outside the learning environment
- involving clients in group therapy
- educating family and enhancing social environment supports.

Families can provide effective support by asking the rehabilitation team to provide a consistent response to any problems arising from a lack of self-awareness. Some practical tips include:

- provide non-judgemental feedback on their performance
- provide positive feedback as well as pointing out issues
- encourage them to analyse their own performance
- link rehabilitation to personal goals (e.g. returning to work)

- minimise potential risks, such as driving and cooking
- avoid arguments.

Self-awareness and challenging behaviours

The inability to self-monitor and self-correct behaviour can lead to challenging behaviours after a TBI. These can be very frustrating for partners and family members if the person denies there is a problem, can't recognise when it occurs or doesn't have strategies to monitor their behaviour. Where possible, the family should work with the rehabilitation team to respond consistently to challenging behaviour.

Contact Synapse for more information and support
1800 673 074.

Reference: Fleming, J. M., and Ownsworth, T. (2006). A review of awareness interventions in brain injury rehabilitation. *Neuropsychological Rehabilitation*, 16(4), 474-500. doi:10.1080/09602010500505518

Self-centredness

In some cases, survivors of a brain injury can appear to become very self-centred and display egocentricity that is more normally associated with a young child.

They lose the ability to see the world from another person's perspective and have little or no self-awareness about how their behaviour is impacting on others.

'Gavin used to be a thoughtful and considerate husband and father. We've made so many sacrifices since his hospital discharge but he says we have not been supportive. No matter what I'm doing he expects me to drop everything to do the smallest tasks and responds with outbursts the moment he doesn't get his way.'

'before her stroke, Belinda was a great listener. But now she never takes an interest in my life any more, and gets frustrated when the kids want her attention.'

'I gave up my job to look after Andrew full time. This has been so exhausting that I've arranged respite one night a fortnight to have coffee with friends for an afternoon. Every time he sulks and complains that I don't really care about him.'

This inability to see another's point of view can be very destructive as the family often cannot understand how a previously caring person now lives completely for themselves and has no insight into how they are affecting the family.

Why does it happen?

Although we take it for granted, the ability to view the world from someone else's point of view is a very complex cognitive skill. This is just one of many sophisticated mental skills that occur in the frontal lobes of the brain. Unfortunately, this is a very common area to be affected in a TBI and other brain disorders. This

is why self-centredness frequently goes hand-in-hand with lack of self-awareness, anger, depression, fatigue and reduced social skills. Although this can test the most resilient of families, understanding the effects of brain injury and using strategies to reduce these effects will benefit everyone involved.

Impact on the family

Families are usually overjoyed when a loved one survives the initial trauma of acquiring a brain injury. After discharge, a relieved family will go to great lengths to help with the continuing rehabilitation process, usually making many sacrifices in time, money and effort on the road to recovery.

Family members can grow resentful over time if a person with a brain injury has trouble feeling or expressing gratitude for the sacrifices they have made. Friends can be even less likely to tolerate self-centredness, leaving family as the only social network available.

In some cases, the person may be able to portray a cheerful caring seemingly unchanged personality around their old friends, but immediately revert to their self-centred behaviour when only the family is around. This is particularly difficult as these friends may not believe the family when they talk about the difficulties of the new personality they are facing.

What the family can do

Often the hardest part for a family is accepting that self-centredness is unlikely to go away. Some say that understanding that the TBI

has caused the self-centredness eventually brings them to a point where they can accept the changes and enact strategies to manage the situations that arise.

Sometimes the family unwittingly contributes to the problem. In the early days after the injury, families may spoil the patient and do everything for them. If the family member is self-centred they will obviously lap up the attention, become dependent and expect to be the centre of everyone's world even more. Families need to be very firm in setting boundaries, and realise that they must look after their own needs as well as their loved one's needs.

It is important to understand that a person with brain injury is often not capable of being concerned about the rights and needs of their family.

In some cases, a person will not only be self-centred but very skilled at manipulating their family emotionally. If their demands aren't met, they try various strategies to get what they want such as threats, pleading, criticising the lack of compassion or sullen silences. Family members are often surprised that their loved one's skills in manipulation are so effective when their overall social skills have dropped significantly. In this case, it is vital for the family to have agreed-on boundaries for acceptable behaviour, refuse to be drawn into arguments and always be assertive.

Brain injury support groups can bring about some level of self-awareness as a result of seeing similar behaviours in others.

Another way to increase a person's awareness of their own self-centredness can be through therapeutic sessions with a neuropsychologist. If an assessment indicates the person could benefit from therapy, the neuropsychologist will gradually gain the person's trust and begin exploring and challenging their beliefs and behaviours. With time this can gradually increase a person's awareness and insight into how their behaviour impacts on others.

Impulsive behaviour

Injury to the frontal lobes after a traumatic brain injury can affect the area of the brain that normally controls our impulses.



This inability to control urges can lead to impulsive and inappropriate social behaviour. For example, a previously shy person may become quite extroverted and talkative. In a more severe case, a normally reserved person might make crude or sexually inappropriate comments to strangers.

When others don't understand how brain injury can cause impulsive behaviour, it often leads to rejection and criticism. Social isolation often results, as existing relationships break down and there is an inability to form new ones.

Apart from a TBI involving the frontal lobes, impulsivity can also result from a brain injury caused by alcohol and other drugs, dementia, other types of brain disorders and mood disorders.

Common features of impulsivity

- acting without thinking
- inability to save money or regulate finances
- irritability and temper outbursts
- too familiar with strangers and sharing very personal details
- asking personal questions that

cause discomfort

- yelling out answers before questions have been completed
- intruding or interrupting conversations
- unable to wait patiently for their turn
- sexual promiscuity.

Lack of insight

Another common outcome from a TBI is lack of awareness, so the person may deny their behaviour is impulsive, fail to see the consequences of their actions, or understand how someone else is feeling.

How is impulsivity treated?

Treatment varies depending on the underlying cause – usually there will be several techniques used. The most common treatment is medication, with other options including behavioural therapy, parent training and school-based interventions for children. Doctors and rehabilitation specialists will advise on whether or not medication may be helpful.

Strategies for partners and family

members

The more families know about impulsivity and TBI, the easier it is to respond positively when needed, whereas reacting negatively will only add to the problem.

As with so many aspects of a brain injury, impulsivity often arises when the person is confused or fearful, so predictable daily schedules and routines will help greatly.

Encourage self-monitoring techniques

A person with brain injury can monitor themselves by asking the following:

- do I really want to do this, am I ready?
- what are the pros and cons of doing or saying this?
- what will the outcome be?

A person should be encouraged to develop their listening and social skills again. Family and friends can role-play how to listen, introduce new topics, and how to politely interrupt two other people talking.

If the person engages in attention seeking behaviour such as yelling or interrupting, a positive response is to let them know that their behaviour is not a good way to get attention and offer an alternative strategy.

When people look for the message behind an impulsive behaviour, they will often see that it is caused by confusion and fear.

It is important to remember that the impulsivity is at fault, not the person. Generally, there is no intention to speak or act in ways that annoy or hurt people's feelings. Separating the person from the behaviour can go a long way to coping with the situation.

For more information about positive behaviour support visit synapse.org.au or call 1800 673 074.

Sexual changes

Acquired brain injury can have a number of consequences for an individual's sexual functioning. Talking about sex can be embarrassing, but it is important for the person with brain injury and their loved ones to discuss the various issues.

Impulsivity, disinhibition and lack of awareness may lead to rehabilitation staff receiving unwanted sexual attention from the brain injury survivor. The medical team, family and friends need to have a common response to inappropriate sexual behaviour that will assist the person to regain control over sexual impulses. This behaviour can particularly be a problem for males from their late teens to mid-twenties when their sexual urges are strongest. Some of this behaviour may include fantasising, lewd verbal responses, disrobing and/or masturbating in public, impulsiveness and touching others.

Understanding from the family

Families and partners can have trouble understanding these sexual changes and can react negatively. A good understanding should be gained of how impulsivity, disinhibition and lack of awareness have caused sexual changes.

The brain injury survivor must be

encouraged to take control over aspects of their life, when there is a reasonable expectation for responsible behaviour. When sexual behaviour is inappropriate, steps need to be taken to learn better ways for managing or compensating for the lapses in social skills. All members of the family should work to become comfortable in discussing sexual issues, and assist in implementing behavioural modification techniques to manage behaviours.

Common changes

Sexual changes are common after a brain injury. Although we are all sexual in nature, there is a great deal of stigma to sexual behaviour in the wrong place or time.

Some of the more common changes include:

- loss of libido or sexual drive
- hyper-sexuality (increased desire for sex)
- inability to achieve or maintain erection

- inability to orgasm
- premature ejaculation
- pain and discomfort during sex
- sexual disinhibition, e.g. talking excessively about sex or inappropriate touching
- reduced sexual responsiveness or desire for intimacy.

Such changes may be a direct result of damage occurring to particular brain structures underlying sexual functioning. Other biological causes of sexual dysfunction may include damage to genital organs, muscles and bones, spinal cord and peripheral nerve damage, medical conditions, hormonal disturbance and side effects of medication and drugs. Psychological and psychosocial changes can also have an impact on sexual function.

Some reasons for changes in sexual function:

- low motivation
- medication

Case study

Jill's husband, Paul, experienced a number of personality changes after his brain injury. In particular, Paul's behaviour was childlike and immature, and he became overly dependent upon Jill.

In many ways Jill felt like she had become Paul's mother rather than his wife, friend and lover. The impact upon their sexual relationship was significant. Jill read some information about the effects of brain injury, organised some regular respite care and learned some behaviour management strategies for encouraging Paul to be more independent. As a result of Jill's increased understanding, some lifestyle changes and new skills, she and Paul now spend more quality time together and their sexual relationship has improved.

Another important issue is the increased vulnerability that people may experience due to cognitive impairment and

emotional distress. In particular, the person may not sense when they are at risk, know how to cope with unwanted sexual advances or understand the consequences of their actions.

Family members and friends need to be aware of these issues and discuss any concerns with a professional. Some people may not feel that it is possible to discuss these issues directly with the person with a brain injury. In such cases, a friend or another family member may be a more appropriate person to recommend self-protection strategies or remind the person about general safety issues.

- diabetes or hypertension (high blood pressure) can reduce libido
- depression
- stress and anxiety
- emotional reactions, e.g. anger, embarrassment, shame and fear of rejection
- personality changes
- cognitive problems, e.g. distractibility, perceptual disorders and memory problems
- problems with communication e.g. aphasia or missing social cues
- a loss of self-confidence regarding personal attractiveness
- poor social skills and impaired self-control
- social avoidance and isolation
- relationship breakdown.

Assessment

Seeking professional advice can be an embarrassing and sensitive issue for many people as sex is usually a very personal and private aspect of life. People are often more likely to discuss sexual problems with their doctor during a visit for other health reasons. Assessment of sexual problems can be a vital first step in learning to manage or discover treatment options. Assessment may involve an interview, questionnaires, physical examination, and neurological and medical tests. In addition to a doctor, psychologists and psychiatrists may be involved in the assessment and treatment of sexual problems.

Management of sexual changes

Partners and family members' reactions

Partners and family members play a significant role in influencing the injured person's adjustment to physical and psychosocial changes that affect their sex life. Partners and family members may consider the following forms of coping:

- developing greater understanding by seeking information on how to support the injured person
- learning different techniques and compensatory strategies, e.g. different ways of giving and receiving pleasure with the person
- altering expectations and negotiating about how often, how long and the type of sexual activity the person can achieve

- being assertive and sensitively communicating personal views
- making changes to lifestyle and routines that improve quality time together.

Children's social and sexual functioning

ABI can also affect children's social and sexual functioning whereby development may be arrested or they appear to revert to a previous level of development. In less common situations, a child may develop physical and behavioural changes earlier than their peers. This is often referred to as 'precocious puberty'. Families and schools may vary greatly in their approaches to educating children about sexual issues and behavioural management. Parents and teachers can access community resources, such as family planning, sexual health clinics and professionals specialising in ABI for support.

Masturbation

A family member may need to be told that masturbation is an appropriate way to deal with sexual urges, but in the privacy of their own room. It is important to establish ground rules to protect the rights and privacy of others, so when, where and how need to be discussed.

In some cases, a partner or spouse may continue in a caring role but no longer wish to maintain a sexual relationship. In this case, it needs to be stated clearly and consistently that masturbation will be the only option to sexual urges.

Treatment for sexual problems

Professionals can help individuals cope with a variety of physical and psychosocial changes. Following assessment, specific treatment of sexual problems may involve education, learning new skills and behavioural techniques, physical rehabilitation, aids and medical treatment. Specific forms of treatment may include psychological support, medical and surgical approaches.

Psychological support

A psychologist or social worker can provide sexual and marital counselling to couples to enhance their understanding of sexual changes, communication skills, problem-solving, conflict resolution

and caring behaviours. Professionals may also provide literature, audio-visual aids and advice on sexual positions, techniques and aids. A psychiatrist may prescribe medication for either psychological or physical problems.

Medical and surgical approaches

The medical management of sexual problems is usually most applicable for musculoskeletal, neurochemical and vascular disorders. Some examples include hormonal replacement, new medication such as anti-spasticity drugs or a change of current medication, neurosurgical and orthopaedic procedures.

Where to get help

- your doctor
- neurologist
- Synapse 1800 673 074
- Brainlink 1800 677 579
- Brain Foundation 1300 886 660
- Open minds 07 3891 3711

Things to remember

Brain disorders such as traumatic brain injury can alter the way a person experiences and expresses their sexuality. Common problems can include reduced sex drive, difficulties with sexual functioning (such as erectile problems) and behaving sexually at inappropriate times.

Talking about sex can be embarrassing, but it is important for the person with brain injury and their loved ones to discuss the various issues and seek professional advice.

Mental health: Stress, anxiety and brain injury

Stress is part of everyday life and a natural reaction to change and adjustment with a major life change.

Stress occurs in response to ongoing daily challenges, such as traffic, noise or inconsiderate people. The body responds to stress with the 'flight or fight' response in the central and peripheral nervous system. This involves a series of chemical changes that prepare people for a stressful event.

Imagine the body's reaction to the sound of a loud siren late at night outside a person's home. During this stressful event, the body becomes mobilised into action via the brain's messages. Changes may include increased heart rate and blood pressure, sweating, dilated pupils and extra sensitive senses, such as hearing and vision.

While the 'flight or fight' response

is vital for survival, if this occurs too often to the body as a result of chronic stress, there can be negative effects, such as reduced protection from disease and infection, hypertension, heart, liver and kidney conditions and psychological disorders.

Stress is much worse with a brain injury

In the vast majority of cases, people find it much harder to deal with stress after a TBI or similar brain disorder. Coping with stress uses many different cognitive functions of the brains, such as recognising the symptoms, identifying causes, formulating a coping strategy, maintaining control of emotions appropriately and remembering these techniques. A

brain injury can dramatically affect each of these areas resulting in diminished ability to cope with the normal stresses of everyday life. Family members can find this hard to understand and believe a person is simply whingeing, being over-emotional or immature.

A brain injury has been likened to having a couple of lanes closed down on a six lane highway. While the traffic is light there is little disruption to the normal flow. But once the traffic reaches a critical point, those closed down lanes suddenly result in traffic at a standstill backing up for kilometres. The same applies for a person with a brain disorder such as a TBI – they can often handle a light load of stress, conversation, noise or workload, but at a critical point they can no longer cope and the stress sets in.

Understanding and managing stress

The first step a person can take to reduce stress is to become aware of the major sources of stress that exist in their life. It can be useful to keep a stress awareness diary for a few weeks that lists the date, time, event, severity, symptoms and coping strategies used to ease the situation. The second step is to categorise different stressful situations as follows:

- controllable/uncontrollable
- important/unimportant

This can help a person stand back from their situation in order to view it more clearly and objectively.

Four skills for managing

Four skills of managing have been identified as: awareness, acceptance, coping and action skills. Some skills may be more useful in certain situations. Each skill may be explained better using a situation which people are often faced with after a brain injury. To illustrate these skills, let us use the example of a person who is stressed because they have an appointment for a neuropsychological assessment.

Awareness skills

Awareness is about getting a clearer understanding of the situation and how it affects the person.

Example: finding out what a neuropsychological assessment involves and the purpose of the assessment.

Acceptance skills

Acceptance is about acknowledging the stress and being realistic about how it affects a person's lifestyle with regard to those aspects that are controllable/uncontrollable or important/unimportant.

Example: recognising that the

assessment needs to be conducted and that it will probably be quite tiring and demanding. The person may not be able to control when and how long the assessment is but they can manage their thoughts and reactions to the assessment.

Panic attacks

Panic attacks occur when the body reacts as if it is in immense danger in a situation where most people would not be afraid.

These can develop into a panic disorder, where the attacks are intense and frequent. If untreated, a panic disorder can be a debilitating condition, which severely restricts quality of life.

Panic attacks can occur at any time, repeatedly and without warning.

Symptoms of a panic attack

The symptoms of a panic attack include elevated anxiety, heart palpitations, hyperventilation, muscle pain, dizziness and sweating. There is often a fear of totally losing control or dying.

These physical symptoms are just extreme versions of our body's normal responses to danger. Adrenaline causes the heart to beat faster, and the breathing rate to increase in order to supply major muscles with more oxygen. Blood is diverted away from non-essential areas, including the stomach, brain and hands, often causing digestive problems, dizziness

and tingling or numbness in the hands. Pupils dilate for more acute vision and this can cause difficulty with bright lights or distortion of vision. Sometimes it may appear that the walls are closing in, or inanimate objects may even appear to move.

It is common to think the symptoms are due to a major health problem, such as a heart attack, brain tumour or mental illness. This fear causes more adrenaline to be released and can lead to a worsening cycle.

Panic attacks and associated disorders

Panic attacks can be accompanied by other conditions such as depression, or they can give rise to the development of phobias. For example, a panic attack in the supermarket or an elevator can lead to avoiding those situations due to linking the anxiety with them, so they are avoided in future. Some people's lives become very restricted in this way.

Panic attacks can develop into an anxiety disorder such as obsessive compulsive disorder (OCD) where repetitive activities are used to prevent anxiety from occurring.

Treatment for panic attacks

There are various treatments for panic attacks, with research showing cognitive behavioural therapy to be the most effective. It is common to combine several treatment options:

Cognitive behavioural therapy (CBT)

While not always effective for those with a cognitive deficit, CBT shows a person how to identify their anxiety and then change anxiety-generating thoughts. The premise is that it is not the events that cause anxiety, but more what we think about them.

Medication such as anti-anxiety drugs can provide short-term relief but can also have side effects. It is important that other strategies are used as well, including counselling and learning more about the condition.

Complementary therapies such as the use of herbs, vitamins and homeopathy can be effective for some people.

Diet and exercise are essential for emotional wellbeing. Exercise often stops the 'keyed up' feelings associated with anxiety. Caffeine in coffee, tea and chocolate can increase panic attacks for some people.

Relaxation techniques and meditation can be useful to reduce stress or provide relief during an attack.

Don't fight panic. When experiencing a panic attack remember the following:

- symptoms are just an exaggeration of normal reactions
- the feelings are frightening but not dangerous
- face the symptoms, don't run from them
- don't make things worse with scary thoughts about where it might lead
- allow time to pass and for the fear to fade away.

Or use one or all of the following positive statements:

'this feeling isn't comfortable or pleasant, but I can accept it.'

'I can be anxious and still deal with the situation.'

'I'll just let my body do its thing - this will pass.'

'this anxiety won't hurt me, even if it doesn't feel good.'

Coping skills

Coping skills are about preparing to cope with stressful situations by learning various strategies.

Identify what changes a person can make to control the situation and reduce stress levels.

Example: using self-talk to develop a constructive outlook towards the assessment.

Action skills

Action skills are about actively making changes to counteract or reduce the level of stress.

Example: following through with

the anxiety management plan and monitoring stress levels. After the assessment, the person can find a relaxing and enjoyable activity to wind down.

There are some coping strategies for managing stressful situations which include:

- progressive muscle relaxation
- slow breathing
- visualisation.

For more information visit synapse.org.au



Depression after a brain injury

Depression is a common experience following a brain injury.

Depression is a mood state, during which a person may feel 'low', 'down', 'negative' and generally unhappy about themselves, the world and their future. In most cases, depression is a reaction to difficult circumstances, but it can also be a direct result of brain injury.

Apart from negative thoughts and emotions, common signs can include:

- reduced attention to physical appearance
- withdrawal and loss of interest in formerly enjoyed activities
- sleep disturbance, appetite changes and tiredness
- a gradual decline in ability to perform everyday tasks

- decline in ability to cope with every day stress
- increased irritability, anger, frustration and agitation.

Some of these are common effects of a brain injury, so it can be difficult to pinpoint depression as the cause. It is important that family and friends are aware of the symptoms of depression once detected, depression is both manageable and can be treatable with the support of family, carers and professionals.

Most people will feel periods of despair following a brain injury; however, when it begins to seriously interfere with progress and functioning, treatment should be sought.

Possible causes of depression

Depression can occur at any stage following an ABI, from the acute hospital stage to many years post-injury. In the early stages of recovery, it can be a sign the person is developing awareness of their brain injury's effect – a promising sign for the rehabilitation process as the person can identify and work on areas needing attention.

Depression following a TBI or similar brain disorder is also related to other factors including:

- social isolation
- sleep difficulties
- difficulties in maintaining employment and relationships



- injury to the parts of the brain responsible for emotions
- history of mental illness or substance abuse
- some medications can increase the symptoms of depression.

Diagnosis of clinical depression

Professional help and treatment is advisable when depression becomes a serious problem. Doctors can provide referral to specialists who treat clinical depression. It is often the case that the earlier it is diagnosed, the easier it is to treat.

For more information about clinical depression, visit synapse.org.au

Coping strategies for depression

- adequate sleep
- listen to music
- socialise with friends
- avoid alcohol and other drugs
- work on a personal project or hobby
- walking or other exercise
- scheduling activities and making short-term plans
- eat a healthy diet
- write in a diary daily: five things you are grateful for
- use positive self-talk – ‘I can cope; I can manage this’.

Thought-challenging

This useful technique involves replacing upsetting thoughts with constructive explanations or more rational thoughts. A diary to monitor and assess negative thoughts will help the awareness of thinking patterns. This can include places and events, the thoughts that arose and the feelings and actions that resulted.

Peer support

The importance of social contact for the maintenance of good mental health should never be underestimated. Social contact, and in particular peer support, can be an immense help to someone with depression.

Contact Synapse for a referral to local peer support groups for brain injury or depression 1800 673 074.

How friends and family can help

- take time to listen and ask questions
- never minimise the issue by using phrases such as: ‘get over it’ or ‘it’s not that bad’
- help to schedule in activities for each day
- reinforce any positive coping skills e.g. talking, exercising
- give encouragement after any tasks are completed
- encourage them to seek help from a counsellor or psychologist.

Suicide, depression and brain injury

People with an acquired brain injury may be at risk of suicide at some stage of their recovery process.

An ABI can cause a sudden and lasting change in a person's thinking, how they react to certain situations, their work and how they relate to others. People who have experienced a brain injury might have increased stress, greater difficulty with relationships, difficulty managing their own emotions, but fewer skills for dealing with these problems.

Even though the person may seem the same as they were before, they may feel a disturbing sense of change in who they are. They may also be more impulsive and may find it hard to consider other perspectives or think differently about things. Without appropriate support, they may find themselves feeling isolated and helpless.

It is important to realise that because of these and other factors, people with an ABI might experience feelings of depression and may be at greater risk of suicide. For people who think about ending their lives, suicide may represent an answer to what they feel is an otherwise unsolvable problem.

The choice may appear preferable to circumstances, such as enduring emotional distress or disability, which the person may fear more than death.

It is particularly important for family members, friends and those who care about the person to know the danger signs, know ways of being helpful and know where turn to for advice or referral. Be aware of any signs of suicide risk. If suicidal thoughts are present, it is important to encourage the person to seek help from a doctor or psychologist.

Contact Synapse for more information and support 1800 673 074.

If the situation is critical, call 000

Recognising the first signs

A suicide attempt is rarely made following a sudden or impulsive decision. Rather, it is more common for individuals to shift between the stages on a continuum which range from the initial thoughts about suicide to committing suicide. The stages may be bi-directional (i.e. a person may move forwards, return to an earlier stage or no longer consider suicide as an option):

- planning
- organising means
- suicide attempt (intentional or sub-intentional)
- commit suicide.

Some may engage in self-harming behaviour which has the potential to lead to death that the actual goal is not to die. It is important to be alert to cues that someone may be considering suicide.

Things to look out for are:

- if they make statements like 'it would have been better if I had died'
- making threats about committing suicide
- if they become very withdrawn or depressed
- suddenly becoming cheerful after a long period of depression (this can indicate a decision to use suicide as a solution)
- having a plan for suicide, and the means to achieve it are very strong warning signs and must be taken very seriously
- if the person with brain injury has tried to commit suicide before, be particularly aware of cues and try to assist them to seek professional help.

There are various factors which indicate a higher risk of suicide occurring. The brain injury survivor may have access to lethal means and the development of a specific plan. Drug abuse, engaging in extreme behaviour and catastrophic reactions to relatively mild stress can also increase the risk factor. In some cases, a final crisis may act as a precipitating event. All suicidal comments need to be addressed, but having a plan and the means to achieve it is a sign that professional help needs to be sought as a matter of urgency.

If the situation is critical, call 000

How you might help

A person who is considering suicide desperately needs to know that others care. Some suggestions on providing support include:

- sometimes just being with a person is helpful, even if not talking
- contact others who may be able to provide support
- listen to what they are saying about themselves and their life

- avoid saying things like: 'you should be grateful you are alive' or 'you'll get over it'
- tell them you are always willing to talk and that there are others who care as well
- encourage them to stay in touch with friends or make new ones
- make sure they are in touch with a local doctor.

Interventions for individuals at high risk:

- crisis intervention (levels may include immediate support e.g. telephone counselling, referral to a psychiatrist, closely monitoring the person or moving the person to a less stressful environment)
- medical/psychiatric treatment (including medication)
- hospitalisation
- psychological therapy
- mental health case management
- linking into support systems (e.g. family and community organisations).

Specific crisis intervention strategies

The general aim is to lower the level of lethality or very high risk of suicide by working to: a) increase the individual's psychological sense of possible choices and b) to increase his/her sense of being emotionally supported.

Strategies may include the following:

- establishing rapport (e.g. 'I'm listening and I want to support you')
- explore the person's perception of the crisis
- focus on the immediate past (e.g. a recent significant event or problem) and immediate future
- develop options and a plan of action. increase the options available to the person and the number of people available to help (professionals and family members)
- arrange removal of the potential means of suicide where possible
- encourage the person to develop a plan which includes

resources and support in the immediate future. Write down the steps of a personal safety plan to be carried around by the person (e.g. in their wallet)

- try to increase the person's investment in the future by involving them in small and meaningful activities (e.g. tasks around the house and garden)
- monitor their emotional state and establish a follow-up plan
- try to involve appropriate people in the person's natural support system.

Effective communication

It is recommended that people offering support to a distressed individual avoid using the following techniques:

- false reassurance e.g. 'everything will be fine, don't worry'
- inappropriate use of facts e.g. 'you'll recover from your brain injury within a year'
- confrontation e.g. 'it is time for you to accept that you will never walk again'
- minimising a person's feelings e.g. 'come now, it is not that bad'
- probing or intrusive questioning e.g. 'why do you think your girlfriend left you?'

A combination of the following techniques can be used to convey support:

- active listening (nodding and minimal responses such as 'okay', 'sure')
- meaningful eye contact and supportive body language
- reflection of feeling (e.g. 'you sound really upset', 'I can see that you are frustrated')
- reflection of content (e.g. 'it sounds like you want your family to give you more space')
- paraphrasing and summarising (e.g. 'at the moment you are feeling overwhelmed')
- asking permission (e.g. 'I want to help you - can I come and sit near you?').

Support for the supporter

Working with, or being close to someone who is at high risk of committing suicide can be extremely stressful. It is very important that people receive their own support and take care of their own emotional wellbeing. Support for the person working with the distressed individual may come in the form of debriefing from other professionals. Relatives and friends may also benefit from seeking professional help in order to express their feelings and receive advice.

If you are considering suicide

If you are the person who has acquired a brain injury and you are considering suicide, you should know that:

- you are not alone
- most people think about suicide at one time or another. Thinking about suicide does not mean that things can't get better
- there may be physical issues caused by your brain injury, and these physical issues may be causing you to feel as bad as you do. It is important to get professional

or medical advice to help you deal with some of those physical problems

- the crisis will pass
- sometimes problems seem unbearable, but there are always things you or others can do. If you have a brain injury, it might be particularly hard to see your way through some problems. That is why it is essential that you talk about your problems with someone who can help
- others do care
- There are always people willing to help you work out your problems. Don't be afraid to ask for help. Let family members, friends, your local doctor or other professionals know how you feel.

There are 24 hour services available. You can call Lifeline to speak with a telephone counsellor, on 13 11 14, go to your local hospital emergency department or call the brain injury association in your state.



Brain injury and mental illness (dual diagnosis)

Some people may find themselves coping with the effects of both brain injury and mental illness.

Brain injury is a known risk factor for developing a mental illness, while some people with brain injury will have a pre-existing mental illness. Either way, dealing with both can cause additional stress for the person and their family after a brain injury. Common forms of mental illness include depression, anxiety, and obsessive or compulsive behaviour.

A person experiencing brain injury and mental illness might receive a dual diagnosis, although accessing services that support both can be difficult to find. These are normally provided for brain injury or mental illness – not both. Living with a brain injury and mental illness, lead to a very poor quality of life. For some, there can be a further complication of alcohol and/or other drugs dependence, and sometimes contact with the criminal justice system.

What does 'dual diagnosis' mean?

'Dual diagnosis' is used when someone is affected by two different conditions at one time. It can also be called co-morbidity, co-existing disorders or dual-disability.

The terms used may depend on the country and professional background of a person; for example, a psychiatrist or health professional may commonly use the terms co-morbidity or dual diagnosis, whereas someone from a disability organisation may use the term 'dual-disability'.

To be diagnosed as a disorder, the condition needs to be of such severity that it interferes with a person's cognitive, emotional or social abilities. Some of the most common mental health disorders are:

- clinical depression
- schizophrenia
- bipolar disorder
- anxiety disorder
- personality disorder
- social anxiety disorder
- substance abuse disorder.

The link between mental illness and brain injury

It is not uncommon for a person with brain injury to also have a mental illness. Australian statistics show that around 42 per cent of people with brain injury will experience both. A mental illness may have been present prior to brain injury, or a person might develop the illness in part as a result of the brain injury.

Factors affecting the risk of developing a mental illness after injury include; feelings of grief and loss, the ability to adjust to disability, pre-injury personality traits and strengths, coping skills and the level of social support.

It can also occur in the other direction. People with a mental health disorder are at an increased risk of brain injury when changes in cognitive abilities include reaction time, alertness and increased risk of self-harm.

Dual diagnosis issues

The effects of brain injury and mental illness can look very similar, so misdiagnosis is possible if there are no clear medical records.

Problems associated with a person's brain injury can be heightened by the presence of a mental illness. A mental illness in itself can affect skills in memory, attention and planning.

The brain injury itself can cause symptoms similar to syndromes such as psychosis and dementia, which can increase the chance of misdiagnosis.

If untreated, a mental illness can affect the rehabilitation process due to a negative mindset, low motivation and unhelpful coping mechanisms. A mental health disorder can increase risks associated with a brain injury, including social isolation, family breakdown, unemployment, aggression and risk of exploitation.

Treatment and support

Dual diagnosis situations require additional support and a holistic approach, which may include medication, psychological therapy, and programs focusing on retraining social and living skills.

The first step is to get an appropriate assessment by a qualified specialist, such as a neuropsychologist or

psychiatrist. There should be a care plan upon discharge outlining supports and services in the community to prevent relapse. Case management should be provided to coordinate any mental health and brain injury services.

It is not uncommon for people with a dual diagnosis to access support – mental health services will say they need a brain injury service, but the brain injury services say they should go to a mental health service. One option is to seek the support of an advocate to resolve this lack of support for dual diagnosis situations.

How can family help?

Signs that a mental illness may be developing following brain injury, include:

- a gradual decline in the ability to perform everyday tasks
- decline in the ability to cope with everyday stress
- increased behavioural issues e.g. Anger, frustration, agitation
- exaggeration of the effects of the ABI.

Seek advice from an appropriate professional or service for a suspected mental illness. Read about mental illness and brain disorders such as TBI.

Contact Synapse for more information and support 1800 673 074.

Steps needed to plug gaps in service provision

At the policy level, no government agency takes responsibility for this group of people. This plays out at the service level where people with a dual diagnosis are bounced back and forth between the disability, mental health and homelessness sectors. The following recommendation would go a long way to plugging the gaps in service provision:

- dual diagnosis recognised by governments at the policy level
- psychiatric and disability groups in partnership with a focus on the client
- training on dual diagnosis is required within mental health services
- neuropsychiatric services within mental health services
- crisis teams experienced in dual diagnosis
- screening for brain injury within the criminal justice system
- a 24-hour dual diagnosis crisis team is needed.

Reference: AIHW Dec 2007 – Disability in Australia: acquired brain injury (based on ABS 2003 Survey of Disability, Ageing and Carers).

Alcohol and other drugs after a brain injury

Alcohol and other drugs affect a person's ability to think clearly and control emotions and behaviour, so they can interact badly with the effects of a brain injury.

People who already had a dependence on alcohol or other drugs prior to a brain injury are likely to have an even higher dependency afterwards.

Others may find drug use becoming a problem for the first time as they struggle with the many changes faced after acquiring a TBI or other type of brain disorder.

Potential issues with alcohol and other drugs include:

- negative interactions with prescribed medications
- higher risk of brain injury from overdose and alcohol poisoning
- worsening of cognitive problems (e.g. memory, concentration)
- reduced social skills
- increased depression, anger and emotional ups and downs
- impulsivity and risk-taking behaviour
- problems with physical coordination
- increased challenging behaviours.

Can people drink alcohol after a brain injury?

Studies suggest that even 'normal' amounts of alcohol for people with a mild brain injury can have a negative outcome. Most rehabilitation specialists recommend that people abstain from alcohol for at least two years while the brain is recovering, if not permanently.

If a person does eventually resume

use of alcohol or other drugs, a major problem can be self-awareness – there may be an inability to assess accurately whether social skills, coordination, behaviour and cognitive abilities suffer with drug use. Honest feedback from family and close friends can help. Doctors and brain injury specialists are available for further support.

Dealing with dependency

After a brain injury, someone may have an alcohol or drug dependency for a number of reasons. They may have already had a dependency before acquiring the brain injury. The dependency may have arisen from trying to cope with depression and frustration during the recovery process. Personality changes arising from impulsivity may mean the controls are lifted on what was once a safe usage.

If possible, discuss the dangers of continued drinking or drug use after a brain injury. See if the person is willing to work with you on the issue. If they are still in a rehabilitation program, advise the team and work with them to:

- encourage the person to take responsibility for their own behaviour
- provide consistent feedback
- help them work through any issues causing the dependency.

Routines and an active lifestyle

When people can no longer work after a brain injury, it is often the boredom, lack of social isolation and unstructured days which contribute to a dependency on alcohol or other drugs. A preventative measure is to ensure a weekly routine is developed that has enough enjoyable activities and social interaction to provide meaningful structure to each week.

Discuss the issues

Families can offer support by discussing what to do when friends offer alcohol, tobacco or other drugs. Positive discussions about how to cope with stress and other problems is helpful, along with suggestions on how to have fun without drinking, smoking or taking drugs.

Families can remove the temptation by making sure there is no alcohol or prescription medications in the house. Having one doctor who takes responsibility for all medications will prevent a family member from misusing prescription medications.

Ask for help

Support is available for those who are concerned that drinking or using drugs is causing problems for someone they care about.

Contact Synapse for referral to services that assist with drug dependency problems in the context of a brain injury 1800 673 074.

Information for families and carers

When someone sustains a brain injury, their family can be 'the most powerful and enduring influence' on their lives (Frain, et al., 2007). Families often play a vital role in the lifelong support of people following brain injury. Families can be a vital source of ongoing emotional support and encouragement, as well as fulfilling a multitude of functions which are beneficial to the injured person and society. Families are an essential part of the care and rehabilitation and process, and family engagement in rehab improves outcomes for people with brain injury. Families can also be the primary source of financial and accommodation support, particularly in the early stages. Many families wish to care for their loved one at home and, for many people who sustain a brain injury, returning to the family home is the most desirable outcome at the completion of inpatient care. Families also provide important assistance with social and community re-integration. Social support has been identified as a significant contributor to wellbeing for people following brain injury, and families are usually the most significant provider of this support (Sady et al., 2010).

The impact of brain injury on families and relationships

The impact of a brain injury has been likened to throwing a pebble in a pond – the influences reach out to partners, friends, family, carers, work colleagues and the wider community. When some-one sustains a brain injury the impacts are felt by the whole family. Indeed, research has shown that families can experience

as great or greater distress than the injured person, and are at high risk for emotional and social difficulties (Kreutzer et al., 2016). The sudden disruption in life continuity and family relationships can profoundly impact on the ability of the family to adjust. Different issues may arise according to the stages of the recovery process, and each stage will bring its own challenges, hopes, joys and needs. Changes in relationships, stresses associated with personality and behaviour changes in the injured person, loss of income, and diminished social networks all create stress. Old coping methods may remain helpful for some, but others will find new methods need to be developed. Resentment, anger, despair, grief and numbness may be emotions encountered.

The hospital and rehabilitation stages

It is natural for family members to put themselves last when a family member is in hospital, particularly in life-threatening situations. It is important for families to think about their own needs at this time and accept offers of help. Friends often step in to help in practical ways such as taking care of children and daily household tasks, or they might become coordinators and communicate on a carer's behalf.

During the rehabilitation stage, the injured person is medically safe and has been moved to a rehabilitation centre. At this point, families can start to relax and restore order to their world. They may need friends to be patient as the trauma can lead to feelings of exhaustion. Families may be preoccupied by their own concerns. They may find greater comfort in being with other families in

the rehabilitation unit who are going through similar experiences, than with old friends.

The return back home

When the person with a brain injury moves back into family life and begins to renegotiate his or her social world, the family will begin to redefine their world as well. Families can expect a period of readjustment when a person with brain injury returns home. In many cases, parents will find themselves looking after a son or daughter who is used to living independently. For the person with the injury this can represent a significant loss of independence and self-reliance.

Living with family is often the only viable option for people with brain injury. This can be challenging for families, and may precipitate family crises and relationship breakdowns. Financial hardship can contribute to the challenges families encounter. Brain injury can have a significant impact on the financial circumstances of the entire family, not just the injured person. Homes may need extensive and costly modifications where physical impairments are present. Finances may also be diminished if the injured person was the main income earner, or if carer responsibilities inhibit participation in employment.

Friendship needs will change again. Depending on the severity of the injury, primary carers may find it difficult to leave a loved one and go out. They may want a friend or two to visit, but even that may feel like it is too much because of the extra work that now goes on in their world. Some friends may be uncomfortable with what has happened, and with the difference they observe in the

person with the brain injury – and perhaps the carer. A good way to address any fears or discomfort is to educate friends about the injury. It helps to seek out support groups and other families who are in similar situations.

In the long term

The family: brain injury can mean significant changes for all family members, and changed relationships and family roles can be difficult to adjust to. Future plans may be put on hold, family finances may be reduced, and there may be personality and behavioural changes in the injured person which fundamentally alter the family. For a variety of reasons, it is common for friends of the family to distance themselves over time.

Partners: partners of people with brain injuries will often take on extra responsibilities: becoming the sole wage earner, running the house, making most of the decisions and providing support to the person with the injury. A couple's financial situation can change due to medical bills and loss of income, and changes in their sexual relationship can occur. Maintaining a relationship under this kind of pressure can be a challenge.

Children: a child may have to come to terms with why their parent has changed so dramatically after coming home from hospital – why their parent needs care, walks or talks differently, doesn't remember things, and may get easily upset. Children may display increased acting out behaviours, emotional problems, or relationship difficulties. Negative parenting performance, such as yelling, ignoring or being impatient by both injured and uninjured parents is commonly reported. Many families report substantial breakdowns in relationships between children and their injured parent when it is the father who is injured. Most non-injured parents report substantial depression, which correlated significantly with negative behaviour in children.

Friends: a very common statement made by people with a brain injury is: 'you find out who your real friends are'. Unfortunately, friends can disappear at a time when the person most needs their support. It is also common for people who have



spent a long time in hospital to feel that they have missed out on a lot of experiences with their friends and that they now have trouble relating to them and sharing their interests. Supportive friends learn to adjust their expectations of the person with the injury and seek new activities for spending time together, e.g. watching a game of sport instead of going to a nightclub. Alternatively, the person may wish to meet other people with a brain injury by joining a specialised group rehabilitation program or a less structured brain injury social group.

Family resilience following brain injury

Families have the capacity to greatly influence how a person adapts to life after a brain injury and may be their greatest resource. If families respond with resilience and a positive outlook, then it is easier for their loved one to adapt to their new reality. However, the sudden onset of change brought about by brain injury is a challenge, not only for the person with the injury, but for all those within a person's inner circle. The emotional, behavioural and personality changes resulting from injury can be as stressful for the family as they are

for the person with brain injury. In addition, families are often trying to manage with decreased financial resources and may be grappling with changing roles, particularly when partners or parents become carers. Resilient families are better able to cope with the stressors of brain injury and adapt positively. The key processes involved in family resilience have been identified as belief systems (family appraisal of the event including meaning-making, positive outlook, and transcendence or spirituality), organisational patterns (including flexibility, connectedness/cohesion, social and economic resources), and communication/problem-solving (including clarity, emotional expression and collaborative problem-solving) (Walsh, 2012). Families often report that they have coped with brain injury because they had 'no choice.' With the right supports, families can draw on their unique strengths to develop resilience and cope with adversity. As Ronald E. Osborn said: 'undertake something that is difficult; it will do you good. Unless you try to do something beyond what you have already mastered, you never grow.'



Coping with grief and ambiguous loss

Coping with grief and loss for families following brain injury is complex. Although the injured person is physically present they may be psychologically absent, and appear to be a stranger to family and friends. This type of loss where there is no resolution has been called ambiguous loss (Boss, 1999; 2006). The fact that their loved one survived makes it very difficult for families to grieve for the person they used to be, which can prolong the grieving process (Kreutzer, et al.,

2016). This type of loss is confusing and people can find themselves frozen in grief. It is important to acknowledge this loss, and seek support and assistance when needed. Brain injury support services are increasingly acknowledging the need to support the entire family unit following brain injury. Family support which acknowledges the presence of ambiguous loss and focuses on family strengths and resilience, rather than deficits and problems are desirable. Guiding families to find meaning and growth in their new realities can increase tolerance to ambiguity, and allow families to live well despite ambiguous loss (Kreutzer et al., 2016).

Grief is an ongoing process in which people may move forwards, backwards or miss different stages. Jeffrey Kreutzer and colleagues (2016) have outlined how Pauline Boss's ambiguous loss model (Boss, 2006) can provide a set of guidelines for family therapists to assist families managing ambiguous loss after brain injury, including:

- **finding meaning:** people are able to find meaning in their circumstances through a variety of mechanisms, such as looking at the issue from many perspectives, framing their circumstances as sacrifice for greater good or love, religion and spirituality, helping others, recognising positives, perceiving suffering as part of life.
- **adjusting mastery:** downward: acceptance that family relationships are not perfect. Learning to accept the 'new person' and adjust to the fact that the 'old person' and 'old family' may not return. Upward: increase sense of mastery over their

circumstances by applying coping strategies.

- **reconstructing identity:** recognising the changes in the lives of all family members, and being flexible about changed roles and relationships.
- **normalising ambivalence:** help people, particularly carers, to recognise that having a combination of positive and negative feelings at the same time is normal in this situation.
- **revising attachment:** moving from despair to protest, developing memorial ceremonies and farewell rituals, let go of expecting closure.
- **discovering hope:** cultivate hope by helping family members to recognise the progress made, and their achievements to date, focus on the positive aspects of their lives, set goals for the future.

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Major issues for couples

Both men and women with brain injuries find the loss of autonomy and independence is their biggest problem, and both mention personality changes and memory impairments as significant.

Among married couples, wives identify the personality changes and cognitive impairments in their husband with a brain injury as primary problems. Husbands, by contrast, place loss of autonomy and mood swings in wives with a brain injury at the top of their lists. Families in which husbands had sustained brain injuries place higher importance on job loss and income change than do families in which wives were injured. Women with

brain injuries and non-disabled wives value support groups and other emotional support methods as coping strategies, whereas the men stressed problem-focused and goal-orientated strategies. People with a brain injury who experience higher ratings of cognitive and social dysfunction are more likely to be depressed and anxious. Non-injured spouses also show increased anxiety and depression, with wives more affected than husbands.



The impact of caring for someone with brain injury

Caring for a person with a disability can be one of the most difficult challenges that can confront a family, especially for those providing direct care.

Primary carers of people with brain injury commonly experience social isolation, the inability to continue working, and anxiety and depression. Carers often feel that their life is not their own. Some feel that due to the demands of the caring role they have very little time alone to pursue their own interests and social life. Carers may find they have to take on sole responsibility for household and financial matters, where they had been able to rely on their partner's support prior to the injury. Following the injury, the workload increases while at the same time there is reduced support to help the carer cope.

There are many types of brain injury, but the difficulties faced by carers remain the same. Carers may have difficulties accessing therapy for intensive rehabilitation for

their loved one. Over time, carers often become their own advocates and even act as case-managers to ensure that their loved one receives the care they need.

Personality and behavioural changes

Families may be confronted by many changes in the injured person's personality and behaviour such as:

- egocentric behaviour
- disinhibition around others and poor social skills
- emotional outbursts
- increased anger and frustration
- reduced stress tolerance
- an apparent lack of gratitude
- depression and/or anxiety



- impulsivity and financial irresponsibility
- increased or decreased libido
- alcohol and drug abuse.

When self-awareness has been affected, this places further stress on family as the family member disagrees that they are acting inappropriately and responds angrily to feedback.

Lack of understanding outside the family

People who are somewhat distanced from the person with the injury often have little understanding of what they are going through. The person with the injury may be able to act normally for short periods in front of visitors or in public, so that many won't believe the difficult home situation as described by the family. Rather than offer support, friends or members of the extended family may make judgements about how a person cares for their relative.

Common reactions for carers

All carers respond to the demands of caring for their loved one in their own way. It is common for carers to feel overwhelmed, confused and shocked. There are no right or wrong feelings. These feelings are a natural and normal reaction to caring.

Guilt can be a common feeling for carers. They may feel responsible for the brain injury occurring or feel guilty about negative feelings in relation to the carer role. They may feel guilt over losing their temper or being embarrassed by the person being cared for. Even taking a break from caring or placing the injured person in residential care can produce this feeling.

Anger can arise in carers when they become frustrated with the challenges of the caring role, particularly if they feel unsupported by other family members.

Resentment can arise from lack of support when friends cease contact, support services don't provide enough help, and the focus always is on the injured person.

Fear and anxiety about the future are common. Uncertainty about how much the injured person will recover, whether the family will cope, and financial and legal outcomes, such as a compensation claim can be very stressful.

Grief is experienced by many families. Personality changes often result in feeling that they have lost their loved one, but being unable to say 'goodbye'. Caring duties can be so overwhelming that there is also the loss of one's former lifestyle when life starts to revolve purely around the person with the brain injury.

Stress may bring physical symptoms such as headaches, difficulty sleeping, fatigue, anxiety and frequent illness. Carers may also find themselves feeling out of touch with reality, forgetful, not looking after themselves, crying easily and not eating properly.

It is important for carers to also look after themselves and seek support.

Grief and loss for carers

The demands on carers are high, and losses can include the personality changes in their loved one, friends becoming distant, loss of career opportunities, less freedom or personal time and loss of financial security. It can be difficult for carers to find the time for their own personal grief. The demands of caring can mean little 'me' time for carers, and they may feel guilty about focussing on themselves when their loved one has gone through so much.

Ultimately, it is important for carers to retain a sense of normality in their daily routine regardless of the extreme stress they may be under. People need to remember that they are experiencing normal reactions to abnormal and traumatic life events. Each person's reaction is unique and it is important to allow for delayed reactions or reactions that are different to your own.

Self-care strategies for carers

Carers need to maintain their health and wellbeing to ensure they retain the capacity to care for another person.

Maintaining your health and wellbeing provides the energy and capacity to endure the challenges that you may face in your role. Good health and wellbeing mean that you can provide the best care to your loved one. Some of the most important tips for carers include:

- ask for help when you need it
- take time for yourself (e.g. respite services)
- exercise, eat healthily and sleep well
- relax regularly
- keep up social contacts
- attend a carer's group for support
- access all available services and funding
- acknowledge and deal with difficult feelings and emotions.

Respite care

Long-term carers find that taking time out for themselves is vital for survival. It can be provided at home or in a variety of other settings, for just a few hours or even a week to allow a holiday. Make sure you have a regular schedule of breaks using respite care. Families may hesitate to allow a stranger to provide care for their family member; however, there are good quality services that can offer vital support. This can make an enormous difference to helping you care more effectively.

Stress

The cumulative effects of stress can build over time and not be noticed until problems emerge. Apart from exercise, diet and regular sleep, there are plenty of useful strategies for managing stress, including:

- problem-solving major issues

- investigating and altering irrational beliefs
- meditation
- counselling.

Regaining control of your life

In the aftermath of a brain injury, a family tends to put life on hold and focus everything on the person with the brain injury. In the long term, families often find that this dynamic doesn't change, and the whole family can begin to suffer. Carers need to establish a balance in life that allows enough self-care to be effective over the long term. While respite care is an important part of this, good time management and being able to return to normal activities is essential. It is important for carers to make time for their own interests and hobbies, otherwise they can fall into the trap of becoming 'super carer' and find themselves working, looking after the rest of the family, and caring for their injured family member all by themselves indefinitely.

Depression and difficult feelings

Guilt, anger, resentment, fear, stress, anxiety, depression and grief are some of the emotions that can be encountered while caring for someone with a brain injury. With time, the worst of these feelings will go. It is normal for carers to feel as if they are 'going crazy' at times. It is better to accept these feelings rather than try to suppress or deny them. Talking with someone who understands, whether it is a family member, friend, counsellor or support group, is important. Depression is always a potential concern for carers. Professional help should be sought if it becomes a serious issue.

Self-advocacy

At some point, carers may find themselves unhappy with the level of support from a particular hospital, health professional or welfare association, and may find they need to advocate on behalf of the injured person. Carers have the right to expect appropriate support or treatment. There are grievance procedures and appeal processes in most cases.

Contact Synapse for information and support with advocacy 1800 673 074.

Support groups

Support groups allow carers to meet others in a similar position, have a break, find information and get support from others who understand their situation. Sharing ideas, feelings and concerns can help carers feel less isolated. Sometimes friends won't understand a carer's situation, but a support group will. Online brain injury support groups may be an option for those who do not have a group in their local area.

Maintain your friendships

Carers need to maintain an identity of their own separate from the caring role, and stay connected to the world outside of caring. They need to be aware that some friends may tire of hearing about problems associated with caring, and that it is normal to feel resentful towards those who are not as supportive as expected. It is advisable to seek support from other carers rather than relying on friends who may not have the same level of understanding.

Plan for the future

Where possible, it is better to act than react. Carers can alleviate many of their anxieties by thinking through potential problems and putting plans in place to solve them. For example, a carer might plan ahead in case they are no longer able to perform their primary care role. It is also possible to plan for future emergencies and events. This will bring peace of mind to the carer and ensure the best possible care for the person with a brain injury. Planning ahead will also ensure minimised stress for others should the carer be unable to provide care.

Domestic violence

Challenging behaviours after a brain injury can sometimes lead to domestic violence within a family.

In the majority of cases, challenging behaviours after a brain injury do not lead to domestic violence, but it is always important to develop a positive behaviour support plan when anger management is an issue.

The frontal lobe is responsible for controlling our more basic impulses and emotions such as anger. Frontal lobe damage, which is common in the case of TBI, can result in angry outbursts with minimal provocation, and with little warning. Self-awareness can be affected, so a person may feel justified in saying others were responsible for provoking their anger.

Domestic violence is never acceptable

Around the world, domestic violence is also called intimate partner violence (IPV), spousal abuse, and woman abuse. Violence within the home is never acceptable no matter what it is called. Choosing to ignore angry outbursts and not set limits can lead to a cycle of violence developing. A pattern of family abuse should never be tolerated. While allowances need to be made for changes brought on by a brain injury, actual violence requires an immediate and consistent response. This will prevent a pattern of family abuse from establishing in the home.

Positive behaviour support

There are a wide variety of strategies available for families within the positive behaviour support approach to minimise the chances of domestic violence occurring:

- establish consistent routines
- remain calm and respond positively during an anger outburst
- involve the injured person in discussing behavioural issues

- recognise and manage the triggers for aggressive behaviour
- give positive feedback for appropriate behaviour
- make agreements about behaviour and set limits
- give clear feedback on aggressive behaviour
- ignore the behaviour when appropriate to do so
- have a safety plan.

Obtain specialist help

Behaviour specialists are available if rehabilitation has already finished. There are many strategies available such as working on communications skills, anger management, and relaxation techniques to control aggressive behaviour within a positive behaviour support plan.

Have a family meeting whereby all members are trained to treat aggressive behaviour consistently within a positive behaviour support plan.

Personal support

Joining a local support group is a great way for carers to connect with families who are in similar situations.

Safety plans

Carers need to remove themselves from a potentially violent situation the moment they no longer feel safe, and may use language such as: 'you're getting upset, we are leaving for a few minutes so you can calm down. I will return when your anger is under control.' It is important to maintain a safe environment by removing potential weapons or dangerous objects that could be thrown or used to damage property. An easy-to-access list of emergency phone numbers should also be part of any safety plan.



The last resort?

Brain injury is never an excuse for domestic violence. If violence still occurs despite professional support and a positive behaviour support plan, the next option is to either to contact police and report the abuse, or request a restraining order.

Contact Synapse for information about available support advice legal, emergency accommodation and restraining orders, as well as appropriate support for the person with the brain injury 1800 673 074.

Accommodation options

The effects of a brain injury can be diverse, so a wide range of accommodation options are needed.

Exploring accommodation and support options is recommended once rehabilitation begins. Appropriate options are often scarce so it pays to look ahead and plan early. Points to consider include:

- level and type of support needed
- funding available to the person
- the family's social support network
- capacity of the family to care for the injured person in the home or nearby
- services available in the area
- local amenities in the area that the person with brain injury might like to engage with (e.g. local parks; cafes, restaurants, movie cinemas, shopping centres, chemists). Living close to places of interest will allow them to engage with these places more regularly (i.e. less time spent travelling means more support hours available to engage in the things they enjoy).

Accommodation options need to be flexible, thus enabling people to move to more independent living as life skills are re-mastered. Below is a list of accommodation from high support through to more independent living options.

Nursing homes

While nursing homes have long been a 'last resort' for young people with high-care needs, they are not suitable. There are a number of organisations working towards moving young people back into the community, though it is important to keep in mind that this transition can take time due to a lack of suitable housing options in the community.

Slow stream rehabilitation facilities

A small number of government-funded facilities, which specialise in brain injury, are available for people with high-care needs; however, there are long waiting lists. These facilities are intended as a transitional facility from hospital to home, for people who might benefit from ongoing intensive rehabilitation but cannot remain in hospital, as they are medically stable. It is important to think about the discharge destination early, so that the transition from the facility to home is smooth and timely. Unfortunately, these facilities are usually in capital cities so family members may have to travel long distances to visit.

Supported accommodation (also known as group homes).

Supported accommodation is a residence, usually a three-five-bedroom house in the community, where support workers provide the required amount of support and supervision. This can vary from around-the-clock care to a few visits each week. With a National Disability Insurance Scheme (NDIS) or national injury insurance scheme (NIIS) funding package, individuals can choose to (a) hire their own support staff, or (b) share the cost of support staff between their housemates (this option will be cheaper but everyone must agree on the support agency and workers chosen). The NDIS is progressively rolling out in sites across Australia (full roll-out expected by the end of 2019). The NIIS is unique to Queensland and began staged roll-out on 1 July 2016. Roll-out in New South Wales and other states is also well underway. For more information about the NDIS and NIIS, phone the enquiry lines: 1800 800 110 (NDIS) / 1300 302 568 (NIIS). Alternatively, you can call Synapse first on 1800 673 074.

Non-government agencies like Synapse receive funding to set up brain injury-specific supported accommodation. Supported accommodation is also provided by other government and non-government organisations, though their housing may not be brain injury-specific (i.e. the person's housemates could have other forms of disability).

Supported accommodation works for some people but not for everyone. People with acquired disabilities, such as brain injury or multiple sclerosis, often have partners and/or school age children; therefore, their needs may not be met by group homes. There are not enough supported accommodation dwellings available to meet the expected need, so it is important to plan early if this housing type is a potential option.

Contact Synapse for more information
1800 673 074.

Living with friends or family

The injured person and their friends/families may choose this option, because they would prefer to be supported by, or provide care support to their loved one personally, or because they find the available alternatives inappropriate or expensive.

For friends/families, getting plenty of support is crucial in taking on this potentially demanding role. Access as much respite care as possible to get regular breaks. Check on the government funding if you take on a caring role.

A creative alternative chosen by some families is to build a detached dwelling so that their loved one can live semi-independently, but have ready access to support. This could be a long-term option or provide a temporary, transitional solution for the person to gradually return to their own home. Another option is for the person with the brain injury to buy or rent an apartment nearby so that it is easy for friends or family to visit or assist as needed.

Hostels

Hostels are rarely appropriate for people with brain injury, but can be suitable for people who are more independent. They are typically a large house divided into small bedrooms, often with on-site managers who provide differing levels of supervision. Assistance may include help with meals, supervision of challenging behaviours, laundry services and medication supervision. Hostels are not suitable for people with high-care needs, such as those who require nursing assistance (e.g. toileting, personal care). Instead, many hostels cater for people with a mental illness and have psychiatric support specialists visiting on a regular basis.

Own home with support

Most people with brain injury prefer to live in their own home with support. However, the need for home modifications (e.g. ramps at entry, accessible bathroom, toilet, accessible kitchen) can be costly, and access to enough funding for the required support hours is difficult.

People who are eligible for a NDIS or NIIS funding package will be able to include home modifications and support in their request for funding. However, available resources will ultimately determine what is funded. There are other services such as home-delivered meals and community nursing which can be useful. Synapse will also know of all the available funding options and community services that are available, and who to contact.

For more information about local services and funding options, contact Synapse 1800 673 074.



Young people in nursing homes

This is a serious social issue, which can and must be fixed.



Despite being unsuitable, aged care facilities are often the only option for thousands of young Australians with high-care needs. More than 7000 young people with a disability live in nursing homes, which are not suited to their needs (Winkler, 2015). Many of these people are socially isolated, have infrequent contact with family and friends, may be separated from their children, and have little choice and control over many aspects of their lives.

What is needed

Young people in nursing homes want a range of creative and innovative solutions to enable them to actively participate in the community and have a real choice about where they live. Groups such as young people in nursing homes national alliance and the Summer Foundation are driving awareness of the need for systemic change and an increase in the number of supported housing options to stem the flow into nursing homes.

Young people with a disability want the ability to make the fundamental

everyday choices most people take for granted: what to eat, when to eat it and what time to go to bed. They say they do not necessarily want to live in group homes with other people with disability, and would like to be part of the community, where they have ready access to community facilities and services.

The solution

In addition to building more housing, expanding the range of housing options is also needed to ensure that people with disability have real choice about where they live. Since 2008, the Summer Foundation has been working on the development of the next generation of housing and support for people with disability in Victoria who require access to 24-hour, on-call support. A similar model began several years ago as a Synapse initiative in Queensland.

The NDIS can play a key role in providing independence for young people with disability as it could provide the necessary funding to finance housing options.

The following quotes illustrate how moving from a nursing home to an environment that is more home-like has given these young people the ability to make everyday choices for themselves. These people participated in the 'my future my choice initiative' and were part of the summer foundation's evaluation of that same program:

'right now, you know, I love it. I can play music loudly and I can play my own music.'

'clean my own clothes. . . Just chuck them in the washing machine, put some powder in it, and psssh.'

'you can make your own mind up what you want for tea, what you want for lunch or whatever.'

'just being yourself, eat when you want to eat, just be who you want to be.'

'at first, it was unusual to go out the front door but now I've done it quite often and it's just... It's not so formal... You're free. I have a life.'

'it feels like home. I never could say I wanted to be in a nursing home. I could never call it 'home'.'

Reference: Winkler, D. (2015). Nursing homes are no place for young people with disabilities. The Conversation. Available from <http://theconversation.com/nursing-homes-are-no-place-for-young-people-with-disabilities-43847>

Returning to work

One of the main hopes and expectations people have when leaving hospital is that they will return to the work or study they were involved in prior to the brain injury.

For many people returning to pre-injury employment is an important milestone towards regaining a sense of identity and purpose. However, it is very common after a brain injury to have unrealistic expectations about one's capabilities in this regard. People often feel they are ready to go back against the advice of family and health professionals. This can be due to a lack of awareness, or denial in relation to impairments. Returning to work too early can result in fatigue and overwhelm, which can be disappointing, and feel like a step backwards.

If a neuropsychological assessment took place during rehabilitation, this should provide some indications about the areas of difficulty that will need to be addressed in returning to work. For some people, returning to pre-injury employment may never be feasible, and options for retraining into a different vocation may need to be considered.

The ability to hold a job is one of the most potent measures of community integration. The single most important factor in predicting return to work is active participation in rehabilitation and in the therapeutic community. The second best predictor is the injured person's self-awareness. The ability to manage emotions is also a significant factor in employability.

Potential barriers

Some of the barriers in returning to work are:

- an individual's desire to work being greater than their actual readiness
- accessing support, e.g. being linked with the right employment support agency
- cognitive impairment

- a lack of opportunities for people to demonstrate capabilities
- poor control over emotions
- fatigue and other physical problems, e.g. dizziness and headaches
- experiencing a loss of self-confidence after unsuccessful attempts
- loss of motivation.

Support

Employment support agencies and rehabilitation services often provide programs that may focus on the person returning to their previous position. However, this is not usually possible straight away. The results of different assessments can gather information about what a person is capable of to provide guidelines regarding employment potential. Sometimes a meeting can be organised for the person who was injured, family members, the employer and rehabilitation professionals to discuss a gradual return to work plan. A work trial may be organised to assess how well the person can cope with the demands of different tasks. On-the-job training provides the opportunity for people to relearn previously acquired skills or learn new skills.

Strategies for managing impairments

Understanding the different forms of recovery and adjustment becomes particularly important when people return to work after their injury. It can be helpful to consider which areas of impairment might benefit from which form of recovery and adjustment.

Remediation

This involves relearning skills with practice until a certain level has been achieved e.g. practising typing speed.

Substitution

Substitution requires maximising previous skills or learning a new skill to overcome a difficulty, e.g. using self-instruction to improve concentration skills.

Accommodation

Accommodation relates to the adjustment of goals and expectations in line with capabilities e.g. aiming for a position with less responsibility and a reduced work load.

Assimilation

Assimilation involves modifying the environment and expectations of other people e.g. introducing specialised equipment, supportive work environments and educating employers and colleagues about the nature of support required.

Some common recommendations for returning to work include having plenty of rest periods, a routine and structure to tasks, flexibility, reduced hours, supervision and support. Some individual characteristics that may influence level of achievement include self-awareness, motivation, determination and adaptability.

Volunteer work

People who are assessed as being unready for work may wish to pursue volunteer work (e.g. at a charity organisation) to improve their skills and experience, and gain greater awareness of their capabilities. However, for some people employment may not be a realistic option after brain injury.

Accepting this situation can be very distressing for people who have often spent most of their lives building a career. It is important that people are supported to pursue other avenues for achievement, satisfaction and productive use of their time.

Managing fatigue

Fatigue is a very common outcome after brain injury, and it can be a significant barrier to the resumption of work; particularly when intense concentration or fast-paced decision making are required. Survivors are often able to manage a workload if they are able to approach one task at a time, work in a quiet environment without distractions, and have a flexible schedule for rest breaks as needed. Employers may need assistance to ensure the right practices are in place to support those returning to work.

For more information visit synapse.org.au (information for employers).

Legal issues

After rehabilitation some people manage to return to their jobs, only to lose them soon after. There may be grounds for objecting to this on the basis of discrimination. In Australia, the Disability Discrimination Act 1992 specifies that people with a disability have equal opportunity to gain employment and that their disability should only be taken into consideration when it is fair to do so.

The act also states that employers should make reasonable adjustments to accommodate the needs of someone with a disability. This means the employer must examine the physical and organisational barriers that may prevent the employment, limit the performance or curtail the advancement of people with disability.

For more information visit synapse.org.au (discrimination in the workplace).

Information for employers

Some employers have the misconception that people who have disabilities are expensive to accommodate.

This is not necessarily true. Adapting the workplace and introducing changes are typically low cost and easy to implement. Simple modifications, such as a handrail or reducing background noise, can allow a person with a brain injury to manage their work environment better. When considering modifications for someone with a brain injury, it is important to remember that this process must be conducted on a case by case basis – with input from the individual. An abi may result in a combination of disabilities. The limitations resulting from each of these disabilities may need to be individually accommodated for.

Examples

A police officer who returned to work after surgery for a brain aneurysm had partial paralysis to his left side. This meant he could no longer use both hands for word processing. He transferred to a new position requiring computer research and was given a one-handed keyboard.

A therapist who developed short-term memory impairments had difficulty writing case notes from counselling sessions. Modification suggestions included: allowing the therapist to tape record sessions and replay them before dictating notes, scheduling 15 minutes at the end of each session to write up hand written notes, and booking in fewer counselling sessions per day.

A labourer working in a noisy factory had difficulty concentrating on job tasks. Modification suggestions included: erecting sound absorbing barriers around his work station, moving unnecessary equipment from the area to reduce traffic, and allowing the employee to wear a headset or ear plugs.

Excerpt from the information for employers of a person with ABI fact sheet at synapse.org.au





Returning to studies

Survivors of a brain injury who have done very well in their recovery may still face significant challenges in returning to their studies

A number of factors will make returning to studies difficult after a brain injury or similar brain disorder:

- short-term memory will make it very hard to learn new material
- attending school or another learning institution can be tiring. With a brain injury, people have limited energy and may feel energised in the morning, but fade early in the afternoon
- returning to study involves a social dimension that can be challenging for some following brain injury. Reduced capacity to make friends, and possible adverse reactions from others can be isolating.

Impaired concentration

An injured brain may never be restored to pre-injury capabilities, but performance can generally be improved. Difficulties are often experienced in the areas of attention and concentration. It will be necessary to gradually build up tolerance for concentrating on a daily basis, which can be a difficult process to manage. Keep periods of concentration short by allowing regular breaks. Start with ten minutes and build up gradually with a few extra minutes daily.

Lack of insight

Many students with an ABI have a lack of insight regarding their level of ability, and may be unable to recognise that their performance and capabilities are functioning at a reduced level. They may respond to negative feedback by believing that teachers are against them, or find other ways to convince themselves that their performance is still normal.

Lack of planning and organisational skills

Planning and organisational skills can be impaired to the extent that the student knows what he or she wants to do, but has difficulty getting started. Time and support to develop a step-by-step plan are required. People can be encouraged to identify the task, keep it simple, and address one task at a time. The following tips can assist with planning an organisation:

- write down all the steps required to complete the task
- arrange the list of steps in the order they are to be achieved
- treat steps as self-contained goals and tackle them one at a time
- as each step is completed, reinforce it as an achievement of success
- create a distinct break between each step
- review each preceding step before moving onto the next.

Short-term memory problems

Most brain injuries will result in

impairment of short-term memory and the ability to retain or process new information. Students might lose books and equipment, forget appointments and arrangements, ask the same questions again and again, or forget which classroom they are supposed to be in. Fortunately, there are ways to assist memory and it can be an exciting challenge to work out new avenues to compensate for problems. However, it is important that the students are aided but not rescued from their own failing memory.

Common memory aids include:

- a diary to note all class times, appointments and instructions
- a notebook to list common times and protocols
- a map of the school showing classrooms, toilets, offices, bus stop etc.
- clearly marked exercise books and equipment
- thong necklace for keys
- wristwatch with an alarm.

Students with poor memory will need to become familiar with using memory aids and will need constant reinforcement. Other helpful aids are clocks, calendars, blackboards, whiteboards, signs, notices, photos, post-it notes, or anything that provides a compensation to memory deficits.

Confusion

People without a brain injury usually

use their planning and organising skills to work their way through confusion. However, because brain injury can mean a reduction in these skills, it may be difficult for a student with brain injury to deal with confusion. Confusion typically arises due to:

- unrealistic self-expectations, e.g. the student may have a memory of achievement that is inconsistent with their impaired ability
- the student's inability to recognise that a disability exists
- others having too high an expectation of the student
- the student attempting to achieve too much at once
- interruptions, noise, clutter or visual distractions around the student
- too many instructions being given to the student at the one time
- students should make their teacher aware of these issues and see what changes can be made to minimise confusion.

Stress, frustration and anger

A common trigger for personal stress is the feeling of helplessness or being trapped in a situation over which we have no control. Disciplined or authoritarian environments can add to the student's belief that he or she is deprived of alternatives. The student should be able to choose from a number of options in dealing with these emotions.

The triggers for these emotions should be identified, and where possible, avoided. When this is not possible, relaxation, and for some people, meditation can be helpful. When high levels of anger or aggression arise, the student should have the opportunity to take timeout, having previously planned for this with teachers. This needs to be seen as a chance to restore balance and perspective, not as a punishment.

Impulsive behaviour

Impulsivity as another common

consequence of brain injury which can also cause problems in this context. Impulsive behaviours are not intended to be hostile, however they can be disruptive or inappropriate. Strategies should be discussed with teachers so that undesirable behaviour can be replaced with an agreed alternative. It is also helpful to agree on a signal that the teacher can give as a sign for the student to stop and think about what they are doing. It could be a word, or a sign (e.g. arm up in the air). In time, it will become an automatic process.

Allowances

All educational institutions now have policies that make allowances for people with disabilities in relation to time given for tests and assignments. These institutions are frequently unaware of the multiple impacts on a student's abilities, such as short-term memory difficulties, mental fatigue, lack of concentration, susceptibility to stress and lowered organisational ability. Students should contact their disabilities officer to make suitable arrangements for tests and assignments.

Schools and universities have resources available to help students with a disability learn new material. A student may need to provide information about their particular disability in order to gain access to these resources, as there can be limited awareness of brain injury in many organisations. A doctor or neuropsychologist can provide a letter to document that a person has a valid disability.

It is necessary for a student to explain the accommodations or special help they require, such as:

- extra time, assignments and examinations
- exams in a quiet room without distractions
- copies of class notes if concentration and attention are affected.

Some study strategies

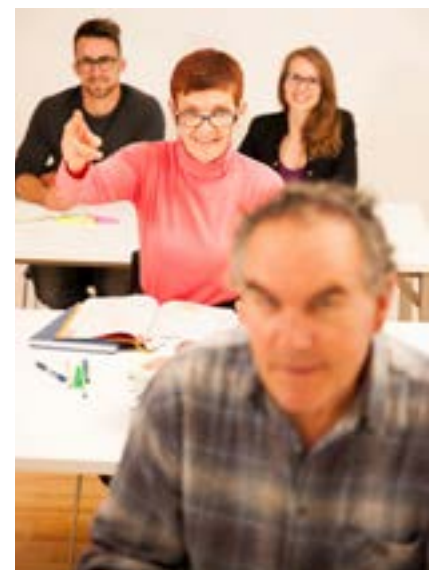
Having routines and strategies

in place is advisable for students managing the effects of brain injury. Students can try the following:

- have a balanced diet, good sleep and regular exercise
- avoid alcohol, cigarettes and other drugs
- structure the days and week with a daily planner, diary or electronic organiser
- use memory prompts, such as notepads, alarms, post-it notes, and a large notice board
- experiment with study times, most do better in mornings than evenings
- structure study times and stick to them no matter how you feel
- make use of study groups or a 'study buddy'.

Patience and endurance

There are many resources available on good study techniques which will be useful to students. Students with a brain injury may take longer to learn these strategies, but the same benefits are available as the skills are acquired. Most survivors say that learning compensatory strategies is one of the hardest challenges in their lives, but their determination and perseverance paid off, and has made them better people.





Advocacy

Advocacy relates to justice and the fundamental human rights, needs and interests of all. Advocacy may involve speaking up for someone with a disability, or self-advocacy where a person speaks for themselves.

Why is advocacy important?

Advocacy is important because people are important. Advocacy is particularly pertinent with regard to people with a disability, as people can be unable to speak up for themselves. Human rights of people with a disability can be eroded, leave people vulnerable to neglect or manipulation. Despite progress made by the disability rights movement there is still a long way to go to ensure a fair, equitable and inclusive society. Disability is generally poorly understood within the community, and people with a disability experience many barriers to accessing various buildings, services and community associations, which excludes, and limits participation.

When is advocacy needed?

A person needs advocacy when available supports and services are inadequate, or when:

- other people or organisations are not meeting their obligations to that person
- their rights are being ignored or violated
- they have a responsibility that is difficult to carry out
- they are misunderstood, or are having trouble understanding or communicating with others.

Advocacy within the hospital system

Families are entitled to ensure that their family member's best interests are being served. Most hospitals provide support for families to obtain information and make decisions about a patient's care. The person providing this support is often a social worker who will advocate for the patient on the family's behalf.

Finding an advocacy service

Many welfare organisations engage in systemic advocacy – influencing and changing the 'system' in general such as legislation, policy, practices and community attitudes to benefit people with a particular disability. Unfortunately, limited resources means that advocating for individual people or families is beyond the scope of most disability organisations.

Contact Synapse for information and support with advocacy 1800 673 074.

Self-advocacy

Given the lack of funding in the disability sector, the ability for self-advocacy is important. Self-advocacy pertains to the person with a disability, as well as family or friends who advocate on a person's behalf. Here are some basic steps for self-advocacy:

What is the issue? You may have more than one goal, but they will all need to be relevant to the main issue. Gather as much information about the issue as possible (this may be paperwork, notes, receipts, or other general documents). Ensure good record of everything are kept as you progress.

Develop a strategy through a list of steps needed to reach your goal. Remember to check off each goal as it is completed.

Who do you need to speak to?

Contact the organisation first to start a resolution process. The organisation must always be given a reasonable opportunity to resolve the issue. Read about the organisation's complaint or grievance process. Keep a full record of all contacts and discussions.

What do I say? What you say or write may influence how long the advocacy process takes. Focus on your goal and be specific. Make it clear that you are giving the organisation a chance to resolve the issue. Remain polite and calm no matter how upset you feel. Always ask questions if you are unsure about anything.

What if I need help? Sometimes you may need a professional to communicate your views e.g. a doctor may write a letter or speak with someone directly. Consider asking a family member or close friend to assist – they often know your situation well and are highly motivated.

How do I make contact? There are several different methods you can use to self-advocate; phone, email, letter, fax, or the media. Choose the method that best suits you, or the one you feel most comfortable with. Remember that the way you raise your issue will be different from place to place.

Important tips for effective advocacy

People who advocate for themselves or others will have a better chance of success by following these tips:

Keep emotional control. While passion and emotions may be high due to negative circumstances, hostility and over emotionality will not be helpful when attempting to negotiate. Logical and evidential information will always help to influence change more effectively than anger, tears or threats. If you become overwhelmed, state calmly that you would prefer to continue talking at another time and leave.

Pick your battles wisely. Decide which issues are most important and must be addressed first. You cannot fix everything at once. Other concerns should not be forgotten, but it is wiser to prioritise what can be solved, or must be fixed urgently, and only move on once resolved.

Know your rights, entitlements and responsibilities. Thoroughly read about the organisation's policy, legislation, best practice, service standards and objectives. An informed perspective will win you respect in negotiations and reduce any feelings of vulnerability or dependency on others.

Come with suggestions for resolution, not just complaints. This shows the organisation that resolution is possible. It is far more productive to be a willing part of the solution than to simply judge, point out fault, or criticise the efforts of others. Grievances may be justified, but anger and resentment rarely lead to a resolution.

Create a win-win situation and be prepared to compromise. Prioritise your needs and rights, but show equal consideration and awareness for the needs of others. This demonstrates you do not hold a selfish disregard or are dismissive of the impacts of these actions. A small gain is far better than no gain at all.

'Our son has a severe brain injury'

'The hospital says he must be moved to a nursing home now. That isn't the right place for him, but we aren't sure how to stop the hospital doing this.'

'I think Centrelink are going to take me off the pension. The doctor assessing me doesn't seem to be aware of mild brain injuries and their effects. He doesn't think it really affects my ability to work. I get so stressed about it; I have no idea how to fight this. I have trouble even filling out the normal forms, let alone complaining.'

'I've returned to work after the car accident, but I'm having trouble learning the new systems they've brought in. The boss says he won't pay for training, so I either shape up or get sacked. Can he do this? What are my rights?'





What to do when they don't believe you have a brain injury

Often someone with a brain injury has no outward physical signs of injury, and may have trouble convincing others that they do have a disability.

Brain injuries and disorders are often called invisible disabilities because a person may outwardly appear to be unaffected. This is particularly the case when there is no physical trauma associated with the injury such as brain tumours, mild stroke, near drowning, or drug-related injuries. Even when the injury is caused by trauma, such as a motor vehicle accident, the impacts may not be visible and the person can outwardly appear to be fully recovered. Even a so-called 'mild' traumatic brain injury can leave a person with life-long problems with memory, concentration, motivation, fatigue, stress, and depression. It is common for family, employers and friends to lack understanding of these problems when physical evidence is not apparent. Typical examples include:

- 'the insurance company says I'm fine and don't need rehabilitation'
- 'my girlfriend says I'm self-centred and don't care about her anymore'
- 'mum and dad think it's all in my head, that I'm making all this up'
- 'the boss thinks I'm being lazy and avoiding working too hard'.

When family members don't understand

Family members often have the most trouble understanding the invisible nature of a brain injury. Families may be confronted with a 'new' personality and behaviours in their injured loved one. The injury can mean the injured person may be depressed, angry, anxious, lacking motivation, unable to remember things and appearing not to listen. It can be difficult for families to understand that these things are part of the injury and often beyond the injured person's control. Family members commonly express frustration, and can even 'forget' that problems and behaviours are injury-related, and not intentionally difficult.

It is common for people recovering from brain injury to feel exhausted by their efforts to regain aspects of their former life, and a perceived lack of compassion from family members can be particularly discouraging. Conversely, the person with the brain injury may lack self-awareness, and not fully understand how difficult it can be for their family in the caring role.

Tips for helping others to understand

How does a person with brain injury convince others of their injury and its impact? It can be difficult to discuss the issue, particularly if family members resent having to cope with challenging behaviours caused by the injury. Discussions can break down into recriminations and the injury can be seen as an excuse for inappropriate behaviour.

People who have no experience of brain injury usually have little understanding about it, so it is important that families educate themselves about their loved one's injury. If the rehabilitation process is still occurring, it can help to have a professional discuss the situation in a family meeting, and look at strategies to ease tensions at home.

Contact Synapse for
information and support
1800 673 074.



Insurance, compensation and legal cases

Insurance companies and generic rehabilitation services are often unaware of the ongoing effects of a brain injury, and may not realise that complete recovery is unlikely. In some cases individuals need to take legal action to obtain the rehabilitation and support that their insurance guarantees. It is useful to keep all paperwork, correspondence, emails, and medical reports on file. Notes should be taken during meetings and phone calls to keep a permanent record. The more details a person has, the easier it will be to establish a case for insurance claims, compensation and any legal action. In the long term it may help to keep a diary to record any ongoing rehabilitation at home, along with issues being faced and any progress made.

Obtaining hard evidence of a brain injury

Some people might refuse to believe a brain injury exists unless there is firm medical proof. A moderate to severe brain injury often leaves scarring that will clearly show on MRI or cat scans. The brain does have a limited ability to heal itself; and in milder cases, a scan conducted years or even months after the injury may no longer show evidence, although cognitive problems can persist.

It is more difficult to provide hard evidence for a diffuse brain injury – this is where the damage occurs at a microscopic level throughout the brain, and will not show on scans despite the huge impact it can have on a person's life. In these cases, a neuropsychological assessment

is used to identify a brain injury, its effects, and the strategies needed for rehabilitation. Testing includes a variety of different methods for evaluating areas, such as attention span, memory, language, new learning, spatial perception, problem-solving, social judgement, motor abilities and sensory awareness.

These tests can be expensive. Universities offering programs in neuropsychology often provide evaluations at low cost or on a sliding scale as part of their student training.

*Contact Synapse for information and support
1800 673 074.*



Potential future medical problems

Carers and family members are in a unique position to notice medical problems that may emerge after leaving hospital

Families need to be alert to various problems and changes that may indicate the need for re-evaluation or follow-up treatment. Problems developing after the person is home and no longer involved in medical or rehabilitation settings may not be as readily recognised as a result of brain injury. Valuable treatment time can be lost if caregivers are unaware of some possible medical consequences of brain injury.

Heterotopic ossification (HO)

This is a secondary condition in which there is abnormal bone growth in selected joints, most commonly in the hips, shoulders, knees and elbows. It usually occurs within the first nine months of injury and is usually discovered by the physical therapist when limited or painful range of motion is seen. Medication can slow the growth of the excess bone. Heterotopic ossification, along with changes in musculoskeletal system problems, such as various forms of arthritis, osteoporosis, worsening spasticity (involuntary muscle stiffness) and dystonias (muscle problems causing movement disorders), are all warnings of future problems that must be addressed.

Hearing loss

Hearing problems can occur for a number of reasons, both mechanical and neurologic, particularly when the inner ear and/or temporal lobes have been damaged. All patients should have an otoscopic examination and hearing screening followed by behavioural testing. External bleeding in the ear canal, middle ear damage, cochlear injury, and/or temporal lobe lesions can cause auditory dysfunction.

Visual system changes

Vision and visual functioning often adversely affected by brain injury. Families, vigilant at the bedside, are often the first to notice changes in the eyes, such as redness, watering and other signs of a problem. A consultation is usually arranged with an ophthalmologist and with treatment, the problem can be controlled. Traditionally, the occupational therapist evaluates visual perceptual functioning and teaches methods for compensating for any perceptual impairments. In addition, it is important that visual processing and visuomotor ability be evaluated. Some of the more common visual systems problems include double vision, field cuts, sector losses, rapid eye movement and near-sightedness.

Neuroendocrine disorders

Research suggests that chronic neuroendocrine difficulties can occur in women some years post injury. Although these functions may have been monitored well in the acute phase of recovery, the participants report five or more years later that they were experiencing problems such as weight gain, thyroid disorders, changes in hair and skin texture and perceived body temperature changes.

The women additionally complained of chronic sleep disturbances, difficulty controlling blood pressure, a reduction in levels of immunity to infections and arthritic complaints. Indications are that damage in the hypothalamus, limbic system and pituitary may play a role in these disturbances.

Most people with a brain injury are expected to experience a normal life span, barring unforeseen circumstances. Families can play a crucial role by monitoring for any further medical problems arising post injury.

Thanks to the Brain Injury Association of America for permission to adapt this article from their site at biausa.org

Glossary

This glossary covers many of the basic terms used in the context of acquired brain injury, both in the hospital stage and during rehabilitation.

A

Acquired brain injury: this is any organic damage to the brain occurring after birth. ABI can have a number of causes including (but not limited to) trauma (TBI), stroke, degenerative diseases (like Alzheimer's), hypoxia and alcohol and other drugs.

ADHD: attention deficit hyperactivity disorder (sometimes ADD or attention deficit disorder) usually manifests in childhood or adolescence, and tends to linger through adulthood. Behaviours can include difficulty maintaining attention, hypersensitivity to stimuli, incessant talking, impulsivity, incessant movement, ignoring or tuning out, anxiety, frustration and irritability.

Adynamia: a lack of motivation after trauma to the frontal lobes. Characterised by difficulty initiating activities or completing tasks. Gives the appearance of lethargy.

Affect: your experience of an emotion, and the behaviour that arises from it.

Agnosia: a disorder of recognition from injury to higher order information processing cells, which can result in an inability to recognise or distinguish faces or objects.

Agraphia: inability to write that can arise from damage to areas of the brain responsible for cognitive or motor skills necessary to write.

Acalculia: a disorder characterised by an inability to comprehend or write numbers or perform arithmetic operations.

Alexia: inability to read due to brain damage causing cognitive or visual problems.

Alzheimer's disease: degenerative disorder of the brain with cognitive decline due to appearance of plaques followed by development of neurofibrillary tangles in the cells of the brain.

Ambiguous loss: the experience of loss which is ongoing, without resolution.

Amnesia: inability to remember learned information. ABI can cause retrograde amnesia (loss of recall of events right before the trauma) and/or anterograde amnesia (loss of recall of events for some period of time after the trauma). Another term for anterograde amnesia is post-traumatic amnesia (PTA).

Anosmia: loss of the sense of smell by either mechanical damage to the olfactory nerve or damage to areas in the anterior temporal or orbito-frontal lobes that process the sense of smell.

Anoxia: no oxygen in cells of the body. If prolonged, will cause cell death. Can be due to no oxygen reaching the blood, e.g. through strangulation or suffocation, or can be due to no blood reaching the cells, e.g. through the heart stopping or blood flow being stopped in one area by an embolism.

Aphasia: difficulty understanding or expressing language as a result of damage to the brain.

Apraxia: inability to voluntarily perform skilled movements.

Arterial line: a thin tube (catheter) inserted into an artery to allow direct measurement of the blood pressure, amounts of oxygen and carbon dioxide in the blood.

Asymptomatic: without symptoms. If someone is asymptomatic, they have no symptoms that are evident.

Ataxia: abnormal movements due to the loss of coordination of muscles.

Autism: developmental disorder of the brain that may lead to lack of social response, inability to cope with change, and ritualised behaviours.

Autonomic nervous system (ANS): this is the part of the peripheral nervous system that controls

functioning mostly below the level of consciousness, e.g. Heart rate, digestion, respiratory rate, salivation, perspiration, etc.

Axon: the long slender projection of a nerve cell that allows it to conduct electrical impulses and deliver them to other cells - allowing for communication.

B

Blood clot: a solidified localised collection of blood.

Brain stem: the lower extension of the brain where it extends to the spinal cord. Neurological functions located in the brain stem include those necessary for survival (breathing, heart rate) and for arousal (being awake and alert).

Burr hole: a 10-20mm surgical drill hole made through the skull.

C

CAT scan: computerised axial tomography, also known as computerised tomography or CT scan. A scanning technique that uses a rotating x-ray machine to record thin slices of your body.

Catheter: a tube which is inserted into any body part to withdraw or introduce fluids.

Cerebellum: the portion of the brain (located at the back) which helps coordinate movement. Damage may result in ataxia.

Cerebral: concerning the brain.

Cerebral angiogram: x-ray picture of the blood vessels inside the head. A drug is injected via the groin artery which outlines these cerebral vessels.

Cerebral cortex: the outer layer of the brain, responsible for cognitive processes including reasoning, mood, perception of stimuli and other thought processes.

Cerebrospinal fluid (CSF): liquid which fills the ventricles of the brain

and supplies the brain and spinal cord with nutrients.

Chronic: in medicine, this means lasting consistently for a long time. A 'chronic' condition lasts for three months or more. This is in contrast to acute (abrupt/sharp/ brief) and subacute (between acute and chronic).

Cognitive: the function of the mind by which we become aware of all aspects of perceiving, thinking and remembering.

Coma: the state of not being responsive or able to be aroused. Person does not open their eyes, follow commands or speak.

Concussion: disruption of brain function usually from a blunt impact to the head causing the brain to bounce inside the skull.

Contrecoup: bruising of the brain tissue on the side opposite to where the blow was struck.

Contusion: another name for a bruise, caused when blood vessels are damaged or broken often as a result of trauma.

Craniectomy: surgical removal of a section of the skull.

Craniotomy: the making of a surgical opening through the skull, by removing a segment of bone, which is usually replaced. This allows access to the brain and its coverings.

CSF: see cerebrospinal fluid.

CT scan: see cat scan.

Chronic traumatic encephalopathy (CTE): a progressive degenerative disease of the brain often found in athletes (e.g., boxers, football players) with a history of repetitive brain trauma, including symptomatic concussions as well as asymptomatic sub-concussive hits to the head (i.e., injuries without symptoms).

D

Dementia: includes, but is not limited to, Alzheimer's disease, dementia following head injury, Parkinson's disease, dementia following HIV, and substance-induced dementia. Dementia was formerly used in the DSM to define a disorder that presents with memory impairment and multiple cognitive deficits. See neurocognitive disorder.

Diagnostic statistical manual for mental health (DSM): this is the guide by which psychologists and neuropsychologists categorise and diagnose mental health disorders.

Diffuse axonal injury: this is widespread damage to the axons in the brain that deliver signals between cell bodies.

Diffuse brain injury: injury to cells in many areas of the brain rather than in one specific location.

Disinhibition: loss of control over impulses due to frontal lobe trauma.

Dysarthria: speech impairment resulting from damage to the nerves and areas of the brain that control the muscles used in forming words.

Dysautonomia: a malfunctioning of the autonomic nervous system, presenting primarily as ineffective temperature regulation, and ineffective regulation of heart rate and breathing.

Dysexecutive syndrome: impaired executive functioning, usually resulting from damage to the frontal lobes.

Dysphagia: difficulty with swallowing.

Dysphasia: see aphasia. Dysphasia is a milder form of aphasia.

Dyspraxia: see apraxia. Dyspraxia is a milder form of apraxia.

E

Echolalia: imitation of sounds or words without comprehension. This is a normal stage of language development in infants, but is

abnormal in adults.

EEG: EEG or electroencephalogram is a test used to record any changes in the electrical activity of the brain. An EEG is often used in the testing of epilepsy.

Embolism: blood clots are the clumps that result from coagulation of the blood (blood hardens from liquid to solid). A blood clot that forms in a blood vessel, or within the heart and remains there, is called a thrombus. A thrombus that travels to another location in the body is called an embolus. The disorder is called an embolism. For example, an embolus that occurs in the brain is called a cerebral embolism.

Embolus: see 'embolism'.

Emotional lability: repeated, rapid, abrupt shifts in emotion that are not related to external stimuli.

Epilepsy: a chronic condition caused by temporary changes in the electrical function of the brain, causing seizures that can affect awareness, movement and sensation.

Executive function: range of abilities to plan, monitor oneself, learn from experience and accomplish steps to reach a goal. Executive functions include attention, concentration, planning, initiation, and problem solving.

F

Focal brain injury: injury restricted to one region (as opposed to diffuse).

Frontal lobes: the region of the brain directly behind the forehead. Responsible for executive functions, a variety of higher cognitive functions, and motor control. Damage can cause changes to personality, dysexecutive syndrome, problems with spoken language, impaired social skills, and paralysis.

G

Glasgow coma scale (GCS): measures the degree of disturbed consciousness arising from trauma.

H

Haematoma: a collection of blood in an organ, space, or tissue, due to a break in the wall of a blood vessel.

Hard collar: stiff plastic collar worn to support the neck.

Hemianopia: blindness in the same sides of both eyes that can follow damage to the brain. This can cause an inability to see on the left or right side.

Hemiparesis: weakness, partial paralysis or loss of movement that only affects one side of the body.

Hemiplegia: paralysis of one side of the body. May be associated with spasticity – increased muscle tension and spasms.

Heterotopic ossification: abnormal deposits of bone in muscle.

Homeostasis: the ability of the body to maintain a stable internal environment, e.g. temperature, breathing, blood – sugar levels. Mainly controlled by the autonomic nervous system through the hypothalamus.

Hydrocephalus: enlargement of the ventricles due to an increase of fluid (CSF) on the brain. Often due to a blockage in the ventricles preventing them from draining into the nervous system. Can cause ABI.

Hypertension: abnormally high blood pressure.

Hypotension: abnormally low blood pressure.

Hypothalamus: small region of the brain at the top of the brain stem which regulates the autonomic nervous system.

Hypoxia: an insufficient supply of oxygen to cells of the body. May result in cell death if severe. Can be

through not enough oxygen reaching the blood, e.g. due to drowning or carbon monoxide poisoning, or not enough blood reaching the cells; or due to bleeding or constricted blood vessels such as a blood clot causing a stroke.

I

Intracranial pressure monitor: is a monitoring device to determine the pressure within the brain. It consists of a small tube (catheter) in contact with the pulsating brain or the fluid cavity within it. ICP is measured by means of a metal screw or a plastic catheter connected to an electronic measuring device.

Impulsivity: a tendency to rush into something without thinking or reflecting first.

Intracerebral haematoma: a blood clot in the brain.

M

Meninges: the three membranes that cover the central nervous system. From outermost to innermost: dura mater, arachnoid mater, pia mater.

Meningitis: an inflammation of the meninges.

Migraine: severe headache often associated with sensitivity to light or noise. May emerge after acquiring a brain injury.

Minimally-responsive state: a state of consciousness following a coma in which the patient appears to be awake but is unable to respond to their environment and can only make reflex movements. Previously known as persistent vegetative state or PVS.

Magnetic resonance imaging: enables detailed pictures of the brain to be acquired using a scanning machine. It uses a strong magnet rather than x-rays.

N

Neurons: nerve cells in the brain,

spinal cord, and peripheral ganglia that communicate via electrical signals. The cells most often comprise of a cell body, axon and dendrites.

Neuropsychologist: a psychologist with further studies in brain function, personality and behaviour.

Neurocognitive disorder: the DSM-5 has moved towards this as a new categorisation of disorders attributable to changes in brain structure, function, or chemistry. The core or primary deficit is cognitive, and the deficit represents a decline from a previously attained level of functioning. ABI, dementia, stroke and Parkinson's are now able to be defined as 'neurocognitive disorders'.

Neuroplasticity: the brain's ability to reorganise its structure, function and neural connections throughout life in response to experiences and stimuli.

O

Occipital lobes: region in the back of the brain which processes visual information. Damage to this lobe can cause visual deficits.

Oedema: increased fluid content in the brain causing swelling.

P

Parietal lobes: located in the middle and top of the brain. Responsible for visual attention and processing, spatial awareness, touch perception and manipulation, voluntary movements, and the integration of different senses. Damage can cause difficulty with identifying or naming objects, difficulty with writing or mathematics and difficulty with motor coordination or being aware of space and distance.

Peg tube: short for 'percutaneous endoscopic gastrostomy' tube. A tube inserted into the stomach through the abdominal wall to provide food or other nutrients when eating by mouth is not possible. Commonly

used for patients in a coma or PVS.

Perseveration: persistence of a response in a current task, which may have been appropriate for a former task. Perseverations may be verbal or motoric.

Persistent vegetative state: see minimally-responsive state (MRS).

Post-traumatic amnesia: this refers to the period following brain trauma when the victim is unable to effectively imprint and retain a stable, continuous memory of events. See also amnesia.

Premorbid: existing before the injury. This can refer to attitudes, interests, personality traits or medical conditions.

Proprioception: the sensory awareness of the position of body parts with or without movement.

R

Resilience: the human ability to adapt positively to significant adversity, trauma, and ongoing life stressors.

S

Seizure: an uncontrolled discharge of nerve cells, usually lasting only a few minutes. It may be associated with loss of consciousness, loss of bowel and bladder control, and tremors.

Sequelae: pathological condition occurring as a result of an illness or injury, typically chronic e.g. a loss in short-term memory following a brain injury.

Shunt: an apparatus designed to remove excessive fluid from the brain. A surgically placed tube which transfers fluid into the abdominal cavity, heart or large veins of the neck.

Spasticity: an involuntary increase in muscle tone (tension).

SPECT: single photon emission computed tomography. A diagnostic

scan that uses a small, safe amount of a radioactive drug to measure blood flow inside the brain. Not as sensitive as a PET scan, but more useful for examining seizure activity.

Subarachnoid: beneath the arachnoid mater. This is in-between the arachnoid and the pia mater, the inner two meninges covering the brain and spinal cord.

Subdural: below the dura, the outermost meninx. Most often in between the dura and the arachnoid layers.

Symptom: evidence of an illness or injury, e.g. anything that the patient experiences as a result of that illness or injury.

Synapse: neurons communicate with one- another via synapses. This is where the axon and dendrites of cells join together to facilitate communication and hence brain function.

T

Tachycardia: excessively rapid heartbeat. Usually refers to a heartbeat of greater than 100 beats per minute (BPM).

Temporal lobes: located at about the level of the ears. Responsible for interpreting and understanding sounds, categorisation of objects, some visual processing and short and long term memory. Damage can result in impaired memory, hearing and recognition of objects.

Thermoregulation: the maintenance of a stable body temperature. Thermoregulation can be impaired through damage to the brain stem, particularly the hypothalamus.

Thrombus: blood clots are the clumps that result from coagulation of the blood (blood hardens from liquid to solid). A blood clot that forms in a blood vessel or within the heart and remains there is called a thrombus. See also embolism.

Tracheostomy (Trachy): this is a breathing tube inserted through the middle of the neck just below the voice box. Through this tube an adequate air passage can be maintained. It may be necessary to leave the tube in the windpipe for a prolonged period.

V

Ventilator: this is a machine that does the breathing work for the unresponsive patient. It delivers moistened (humidified) air with the appropriate percentage of oxygen and at the appropriate rate and pressure.

Ventricles: cavities (spaces) inside the brain which contain cerebrospinal fluid.

About Synapse

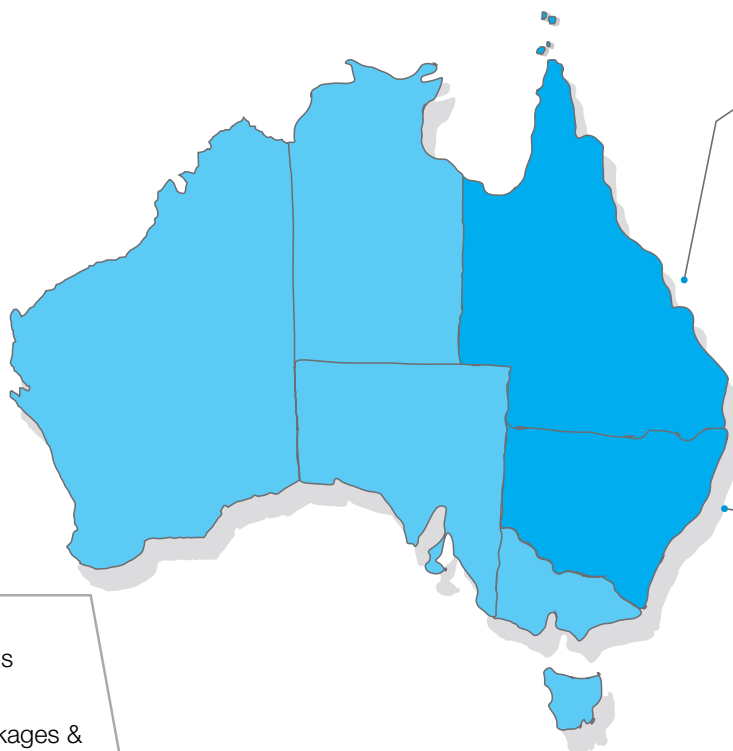
Synapse is dedicated to reconnecting the lives of those affected by brain injury.

Our vision is that those affected by a brain injury in Australia are able to lead a life of quality, based on their own decisions and choices.

We do this through excellence in services delivered with integrity, fairness, and a vision for what the future for people with brain injury could be.

Increasingly our information, linkages, and capacity services are supporting people across Australia.

- **Accommodation & Lifestyle Support**
- **Advocacy**
- **Brokerage**
- **Indigenous services**
- **National Disability Insurance Scheme Pre-Planning**
- **Support Services Coordination**
- **Information, Linkages & Capacity Building**
 - Synapse Options
 - Assessment and Planning
 - Reconnections program



Queensland

- Accommodation and Lifestyle support
- Assessment and Planning
- Indigenous services

New South Wales

- NDIS pre-planning
- Reconnections
- Support services coordination
- Brokerage

Nationwide

- Synapse Options
- Advocacy
- Information, Linkages & Capacity Building



Support Services Coordination

We can assist you with finding the right service providers to meet your formal support needs, help you maximise your informal supports, guide you to overcome barriers in your life and make meaningful connections in your local community.

The Support Services Coordination Program can also help with:

- sourcing information
- accessing services/support
- finding local service providers
- support in decision making regarding service providers
- establishing appropriate service providers to deliver supports defined in individual NDIS plans
- monitoring new support arrangements
- looking for housing
- setting up a Neuropsychological assessment
- connecting with peer support groups
- connecting with capacity building supports tailored for people affected by a neurocognitive disability, including brain injury
- budgeting and ongoing management of your NDIS funds

Currently available in New South Wales – we will be bringing the service into new areas as the NDIS expands.



Call the team on
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