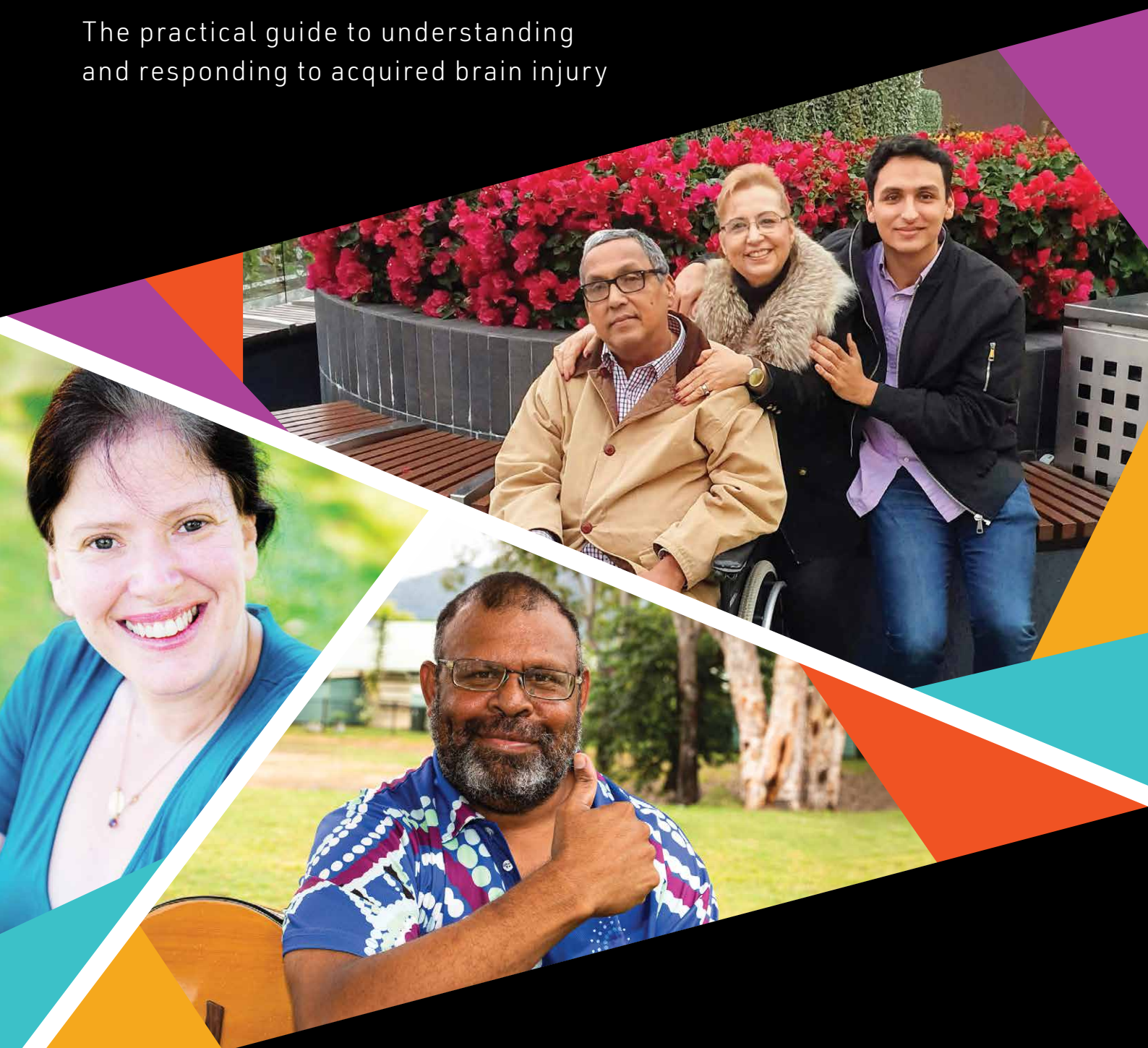


ACQUIRED BRAIN INJURY

The Facts

The practical guide to understanding
and responding to acquired brain injury



Sixth edition (2021)

SYNAPSE
AUSTRALIA'S BRAIN INJURY ORGANISATION

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Synapse respectfully acknowledges the traditional custodians of the lands, sea and waterways on which Synapse provides its services. We pay our respects to the Elders, past, present and future, and commit to working together.

Aboriginal and/or Torres Strait Islander readers are advised that this publication may contain images of deceased persons.



SECTION 1

Brain Injury Basics

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

The brain is a very complex organ comprised of many different parts. The term 'brain injury' relates to conditions and disorders that result in impairment to the brain and its functions. There are a wide range of causes and the long-term effects differ for each person.

What is Brain Injury?

Brain injury includes a number of conditions and disorders that result in impairment to the brain and its functions. When we use the term 'brain injury' it is intended to cover both acquired brain injuries and degenerative brain disorders.

About 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 various other factors. The impacts of brain injury are also experienced by family and friends, particularly when the injury has resulted in personality or behaviour changes.

Brain injuries are often called an 'invisible 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 disability. As a result, the problems caused by brain injury can be easily ignored or misunderstood by others, even health professionals.

Causes of brain injury

Acquired brain injury (ABI) generally refers to injuries sustained after birth. These include incidents that result in an interruption of blood or oxygen supply to the brain or traumatic external force to the head. Injuries sustained by infants in the womb such as Foetal Alcohol Spectrum Disorder (FASD) can also be considered an ABI.

Brain injury also occurs through degenerative brain disorders such as Alzheimer's disease and Parkinson's disease. Brain tumours, infections or brain diseases like Meningitis and Encephalitis can also result in brain injury. Degenerative disorders can have similar impacts to ABI, but their different characteristics may need specialist support.

Causes of brain injury and brain disorders include:

- Traumatic brain injury
- Concussion
- Stroke
- Degenerative conditions
- Hypoxia/Anoxia (lack of oxygen)
- Brain tumours
- Infection or disease
- Foetal Alcohol Spectrum Disorder (FASD)
- Assault
- Domestic violence.



Did you know?

In Australia, approximately **1 in 45 adults have a brain injury**, with approximately half of those being the result of traumatic injury (Pozzato, Tate, Rosenkoetter, & Cameron, 2019)



Effects of 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 degenerative disorders typically impact the body's ability to control movement, other brain injuries may have an impact on cognition, personality and behaviour.

COGNITIVE EFFECTS

- Memory problems
- Difficulty problem-solving
- Poor concentration and attention
- Reduced ability to organise and plan
- Lack of initiative and motivation
- Lack of insight and awareness, and poor judgement

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

BEHAVIOURAL EFFECTS

- Irritability and anger
- Slowed responses
- Poor social skills
- Impulsive behaviour and/or a lack of emotional control
- Disinhibition

PSYCHOLOGICAL EFFECTS

- Stress
- Depression
- Panic attacks
- Anxiety

SECONDARY EFFECTS

The interaction of impacts can result in additional secondary changes to a person's life such as:

- Changes to living arrangements
- Reduced or changed social networks
- Changes in ability to work or study
- Altered relationships and family dynamics

Understanding the Brain

The brain controls and coordinates everything we do - our movements, feelings, thoughts, and bodily functions.

About the brain

The brain is made up of billions of nerve cells that communicate through electrical and chemical activity. Weighing around 1.5 kg the brain is cushioned within the skull by cerebrospinal fluid which circulates around the brain through a series of cavities called ventricles.

The brain makes up only two percent of the body's weight but uses 20% 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 many parts, which have specific functions and work together.

Hemispheres of the brain

For much of the 20th Century, it was believed that the two hemispheres of the brain were highly specialised and responsible for everything from which hand you prefer to write with to your personality. You have probably heard people talking about how the left-brain is all about language and logic, and the right brain is creative and visual. Although there is a small amount of truth to this, the reality is far more complicated. The two hemispheres work seamlessly together perceiving, processing, and integrating information.

THE RIGHT HEMISPHERE

In many people (but certainly not all people) the right hemisphere is more involved in the following activities: controlling parts of the left half of the body; perceiving and processing visuospatial information; recognising the emotional aspects of speech and some other emotional cues from others; some kinds of emotional regulation; finding your way through familiar surroundings; some aspects of self-awareness; and some aspects of metaphor and humour.

THE LEFT HEMISPHERE

Likewise, in many people (but not all) the left hemisphere is more involved in: Controlling the right side of the body; speech production; understanding words; understanding sign language; following sequential directions; and focusing the attention.

Communication and collaboration between the two hemispheres is vital for all brain functions.

For example, although the left hemisphere processes information relating to the meaning of language, the right hemisphere adds important information about the emotional aspects of speech.

Lobes of the brain

Each hemisphere of the brain is divided into four lobes.

1. FRONTAL LOBES

The frontal lobes are involved in problem-solving, planning, making judgments, abstract thinking. They also regulate how we act upon our emotions and impulses. Changes in a person's personality and social skills can occur from damage to this area.

2. TEMPORAL LOBES

The temporal lobes play a role in auditory information processing, particularly the ability to hear and understand language. They are also concerned with memory, the emotions, the ability to enjoy music and to recognise and identify things we see, such as faces or objects.

3. PARIETAL LOBES

The parietal lobes are concerned with the perception of sensations, such as touch, pressure, temperature and pain. They deal with spatial awareness, such as our ability to find our way around a house, to drive a car and to reach for objects. They are also involved with the understanding of words and sentences, reading and writing and sometimes the ability to use numbers.

Further information:

For a dynamic view of the brain take a look at InformED's Brain Map
<http://www.opencolleges.edu.au/informed/learning-strategies/>



4. OCCIPITAL LOBES

The occipital lobes are mainly connected with vision but also with our ability to recognise what we see. Our ability to see objects accurately, identify colours and locate objects in the environment comes from the occipital lobes.

Other parts of the brain

The cerebellum

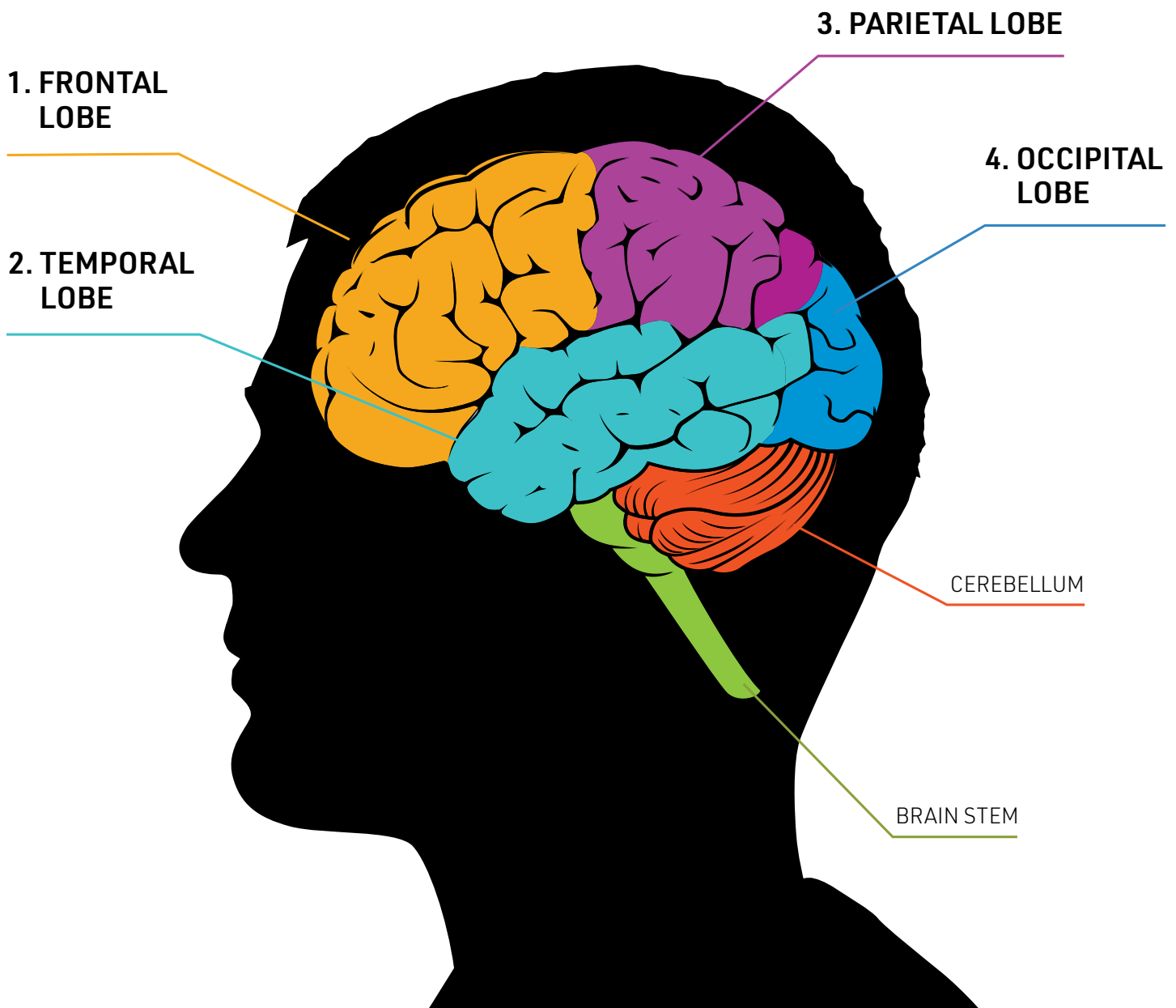
The cerebellum is involved in “doing” rather than “thinking” activities. It is located at the back and below the main hemispheres of the brain. It controls balance and the muscle coordination needed for large body movements. It lets a person know how fast, how hard, how far and in what direction his or her body parts are moving.

The brain stem

The brain stem connects the brain to the spinal cord and regulates basic activities. These include breathing, blood pressure, blood circulation, swallowing, appetite, body temperature and digestion, as well as the need for water, staying awake and sleeping.

The effects of brain injury

Each part of the brain deals with different aspects of what we think, feel and do, so injury to specific areas can cause many different problems to occur. The good news is that the brain does have some ability to heal itself. There are many rehabilitation strategies to compensate for the effects of brain injury.



Understanding the Nervous System

The nervous system is a complex system including the brain, spinal cord and nerves. It interprets and responds to information received through the senses.

The Nervous System

The brain communicates messages through a complex network of nerves that travel throughout our body. Together, the brain and nerves are known as the nervous system, while the spinal cord and the brain make up the central nervous system.

On their own, the nerves that run throughout our body are called the **peripheral nervous system (PNS)**. They relay information from our brain through our spinal cord to the body, and back again.

The **autonomic nervous system (ANS)** is part of the peripheral nervous system. It communicates messages from all the organs in our chest, abdomen and pelvis. For example, it manages our “fight and flight” responses, our “rest and digest” responses. It looks after the automatic activities of our heart and blood vessels and plays an important part in sexual response and bladder control.



Neurons - basic building blocks

The basic building blocks of the nervous system are nerve cells or neurons. We are born with about 100 billion neurons. Neurons are connected by synapses which carry electrical signals and chemical neurotransmitters.

Grey matter is formed when neurons cluster together on the outer part of the brain and inner part of the spinal cord.

White matter is found on the inner part of the brain and outer part of the spinal cord. It is made up of bundles of nerve fibres called axons, which are long thin extensions of neurons. Axons are covered by a white, fatty substance called myelin which insulates them, like the plastic coating of an electric wire. The axons then bundle together, like the individual telegraph wires in a cable, to form a nerve.

How it all works

The brain is in constant contact with all parts of the body, sending instructions and receiving feedback from the senses. The axons carry these messages as tiny electrical currents or nerve impulses.

Outgoing messages are sent from the brain along the motor pathways to activate the muscles of the body. The neurons that make up these pathways are called motor neurons.

Incoming messages sent from the senses back to the spinal cord and brain come along the sensory pathways. These are called sensory neurons.

How brain injury affects the nervous system

The various causes of brain injury can affect the way the nervous system functions by:

- affecting brain function itself
- affecting the brain's ability to communicate with the rest of the body
- affecting the ability of muscles to respond to the brain's orders (nerve impulses).



SECTION 2

Causes of Brain Injury

Brain injury has a wide range of causes and refers to any type of brain disorder or injury which is sustained rather than developmental.

Acquired brain injury (ABI) generally refers to injuries sustained after birth. These include incidents that result in an interruption of blood or oxygen supply to the brain, or a traumatic external force to the head, known as a Traumatic Brain Injury (TBI). Injuries sustained by infants in the womb such as Foetal Alcohol Spectrum Disorder (FASD) are also considered an ABI.

Brain injury also occurs through degenerative brain disorders such as Alzheimer's disease and Parkinson's disease. Brain tumours, stroke, and infections or diseases like Meningitis and Encephalitis can also result in brain injury.

Traumatic Brain Injury

Traumatic Brain Injury (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 including domestic violence, falls and sporting accidents. The effects can be temporary or permanent, and range from mild injuries, such as being momentarily stunned, to a very severe injury that may cause prolonged loss of consciousness.

As well as 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.

Types of TBI

CLOSED & OPEN HEAD INJURIES

A TBI can be described as being a closed or open brain injury:

- An open head injury results from the head hitting an object, or an object piercing the skull and brain tissue (open or penetrating head injury).
- A closed head injury occurs without the skull being broken or penetrated, so the brain has not been exposed. An example of a closed head injury is when the rapid movement of the head backward and forward causes the brain to slam against the inside of the skull.

FOCAL & DIFFUSE BRAIN INJURY

A TBI can be focal or diffuse, meaning damage may be isolated to one specific area of the brain, or widespread. Both types of injury can occur together.

Focal damage involves damage to specific areas of brain tissue. Focal injuries include:

- Contusions (bruised brain tissue), which often occur under the site of impact.

- Lacerations (torn brain tissue)
- Hematoma (a collection of blood inside or around the brain), which can be the result of hemorrhaging and can lead to increased pressure on the brain.

Diffuse damage involves damage to axons, the brain's microscopic communication pathways which extend from brain cells. Damage occurs when the axons are stretched or severed.

Secondary injury

A TBI often results in secondary injuries, which arise due to the brain's reaction to the first injury. These include brain swelling and hemorrhaging. Swelling puts pressure on brain tissue, which can restrict oxygen supply to other parts of the brain leading to cell death. Treatment is focused on controlling the secondary effects of a brain injury to prevent further damage.

Possible effects of TBI

The effects of a TBI and the degree of recovery that can be expected will depend on the location and severity of the injury. The success of the rehabilitation process will also determine the extent of the long-term effects.

Cognitive effects can include:

- memory problems
- fatigue and slowed responses
- difficulties with concentration and attention
- reduced ability to regulate emotions such as irritability, and anger
- inappropriate behaviour and poor social skills
- self-centredness, dependency and lack of insight
- poor problem-solving, initiative and motivation
- depression and anxiety
- impulsivity.

Physical effects can include:

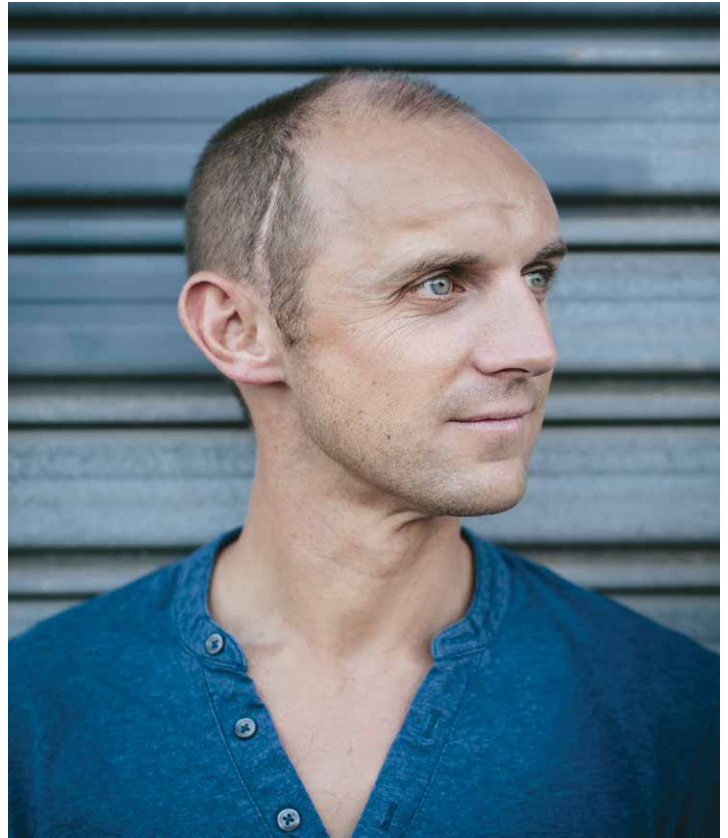
- loss of taste and smell
- dizziness and balance problems
- epilepsy and seizures
- fatigue
- headaches and chronic pain
- visual problems
- paralysis or movement disorders.

Diagnosing and assessing TBI

Initial diagnosis and treatment usually occur at the hospital emergency department. Once the person is assessed as not being in immediate medical danger, a neurological evaluation is performed. This evaluation is to rule out conditions requiring neurosurgery, such as hematomas, skull fractures, and high intracranial pressure.

Different imaging tests may be used in diagnosis, including:

- **Computed tomography (CT)** scans which provide a three-dimensional view of the brain to detect abnormalities.
- **Magnetic resonance imaging (MRI)** which uses electromagnetic radio waves to produce either 3-D or 2-D images of the brain.



- **X-rays** is a form of radiation used as a diagnostic tool that reveals damage to structures of the brain.
- **Inter-cranial pressure (ICP)** monitors implanted inside the skull to track changes in intracranial pressure.

Assessing the severity of a TBI

The severity can range from a mild brain injury (often called concussion) to severe or catastrophic brain injury.

Two reliable indicators of severity include:

- how long the person is in a coma and,
- the length of time in post-traumatic amnesia.

Another widely used indicator is the Glasgow Coma Scale (GCS). This scale measures a person's level of consciousness on a scale of 3-15, with 3 being the lowest level of consciousness. Scoring is based on verbal, motor and eye-opening reactions to stimuli. A score of 13 or above on the GCS is considered a mild brain injury or concussion, 9-12 as moderate and 8 or below severe.

Concussion/Mild TBI

Concussion

Concussion is the most common form of traumatic brain injury (TBI), affecting around 42 million people worldwide each year. It is the result of a physical blow or sudden jolt that forces the brain to move within the skull. The cerebrospinal fluid that usually protects the brain is not enough to stop it from hitting the skull and causing neuron damage.

Most people will make a quick and complete recovery after concussion. However, neurosurgeons and other brain experts stress that there is no such thing as a minor concussion. The effects can be significant, especially when a person suffers concussion a second time before they have had a chance to recover from the first injury. Contrary to popular belief, you don't have to lose consciousness (pass out) to have concussion and even mild forms should be taken seriously.

Effects

The effects of concussion are:

- a rapid (usually immediate) but temporary loss of normal brain function
- a change in mental state or level of consciousness, but not necessarily a loss of consciousness
- a wide range of signs and symptoms, including headache, confusion, nausea
- no obvious damage to the physical structure of the brain
- a gradual improvement of symptoms for most people, and prolonged symptoms for some.

Immediate signs of concussion to look for include:

- upper limb muscle rigidity or spontaneous movement
- loss of overall body tone
- loss of control of the neck ("rag doll effect")
- lack of co-ordination, such as stumbling, or an inability to walk a straight line
- a fit/seizure
- balance difficulty
- slow responses
- vacant stare or appearing dazed
- confusion
- disorientation - not sure of the time and place
- no memory of events immediately before or after the injury
- holding the head
- facial injury
- inability to speak coherently or slurred speech.

After the initial injury people describe the following symptoms:

- headache or a feeling of pressure in the head
- nausea or vomiting
- confusion or difficulty concentrating
- memory loss or difficulties
- poor attention & concentration
- dizziness or difficulty balancing
- tiredness and fatigue
- changes in vision, such as double or blurry vision, or 'seeing stars'
- ringing in the ears
- sensitivity to light
- loss of smell or taste
- trouble falling asleep
- intolerance of bright light & loud noise
- mood disturbances, including feeling sad, irritable, and frustrated
- sleep difficulty
- lethargic, low motivation
- slow reaction time.

Diagnosis

Because the damage caused by concussion is too small to show up on imaging tests like CT and MRI scans, a doctor will make a diagnosis based on neurological and cognitive examinations. CT or MRI scans can be used to detect bleeding on the brain.

Treatment

For most people, rest is all that is needed for recovery before slowly getting back to normal activities. It is important to avoid another concussion during recovery, and to seek medical attention straight away if you experience any of the following:

- headache gets worse or does not go away
- any sign of slurred speech, weakness, numbness, or decreased coordination
- significant nausea or repeated vomiting
- seizures
- loss of consciousness
- inability to wake up
- symptoms have worsened at any time
- symptoms have not gone away after 10–14 days
- previous concussions or other brain injuries.

Post-Concussive Syndrome

Some people will continue to have symptoms of concussion for weeks to months after the injury. These include:

- memory and concentration problems
- mood swings

- personality changes
- headache
- fatigue
- dizziness
- insomnia
- excessive drowsiness.

Second Impact Syndrome

There is a risk of second impact syndrome (SIS) when a person is concussed a second time while still recovering from a previous concussion, regardless of how mild the injuries are. Although rare, it can be fatal, which is why it is necessary to recover fully from concussion before taking part in activities or sports where there is a risk of injury.

Concussion and children

Young people are at a much greater risk of concussion than adults, with one in five children under the age of 10 affected. Boys between the age of 10 and 19 are the most likely to have sports-related concussion, with contact football carrying the biggest risk. Sport accounts for a quarter of all concussions, with around half of all concussion due to falls.

Chronic Traumatic Encephalopathy

Repeated, mild ABIs, such as concussions experienced by professional sports people like boxers and footballers, can be related to a neurodegenerative condition known as Chronic Traumatic Encephalopathy (CTE). This condition was recognised in boxers some decades ago, historically being referred to as 'punch-drunk syndrome' (Buckland et al., 2019). In Australia, cases are now being identified in players from professional sports such as Rugby, NRL and AFL. CTE can occur at any age and can present years after the repetitive contact stops.

The effects of CTE can include:

- Difficulties with balance and motor skills
- Depression
- Disturbances to memory
- Staggered gait
- Psychotic symptoms
- Significant behavioral changes such as aggression or depression
- Initial symptoms of Parkinson's disease (McKee et al. 2010)

It is currently understood that the only risk factor for CTE is repeated, traumatic brain injury (Buckland, 2019), and many repetitive knocks over a number of years – even ones that don't result in obvious concussion – puts players at a higher risk.

There are still gaps in the research. At the moment, a confirmed diagnosis can only be made at autopsy, as brain tissue samples are required (Concussion Legacy Foundation, n.d). However, as imaging and other testing technologies improve, it is hoped that other methods of diagnosing the condition will be developed.

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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 is damaged, causing brain injury.

Types of stroke

Ischemic stroke

An ischemic stroke occurs when the brain's blood vessels become narrowed or blocked, severely reducing the blood flow. Blocked or narrowed blood vessels are caused by fatty deposits that build up in blood vessels (also known as thrombosis), or by blood clots or other debris that travel through the bloodstream and lodge in the blood vessels in your brain (also known as an embolism).

Haemorrhagic stroke

Haemorrhagic stroke occurs when a blood vessel in or on the surface of the brain leaks or ruptures. When it happens in the brain it is referred to as an intracranial haemorrhage. When it happens on the surface of the brain it is referred to as a subarachnoid haemorrhage. Brain haemorrhages can result from many conditions that affect the blood vessels, including:

- Uncontrolled high blood pressure
- Overtreatment with blood thinners (anticoagulants)
- Bulges at weak spots in your blood vessel walls (aneurysms)
- Protein deposits in blood vessel walls that lead to weakness in the vessel wall (cerebral amyloid angiopathy)
- The rupture of an abnormal tangle of thin-walled blood vessels (arteriovenous malformation).

How to recognise a stroke

A stroke is not necessarily a major event, and may not always be recognisable as a stroke. It may present as someone stumbling or having a moment of blankness. It is vital to treat a stroke immediately and call an ambulance.



FAST

The FAST test is an easy way to recognise and remember the signs of stroke. Using the FAST test involves asking three simple questions:



Face

Check their face.
Has their mouth drooped?



Arms

Can they lift both arms?



Speech

Is their speech slurred? Do they understand you?



Time

Time is critical. If you see any of these signs **call an ambulance** straight away.

Effects of stroke

The effects of a stroke vary widely for each stroke patient depending on which part of the brain is affected. 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 generally result in:

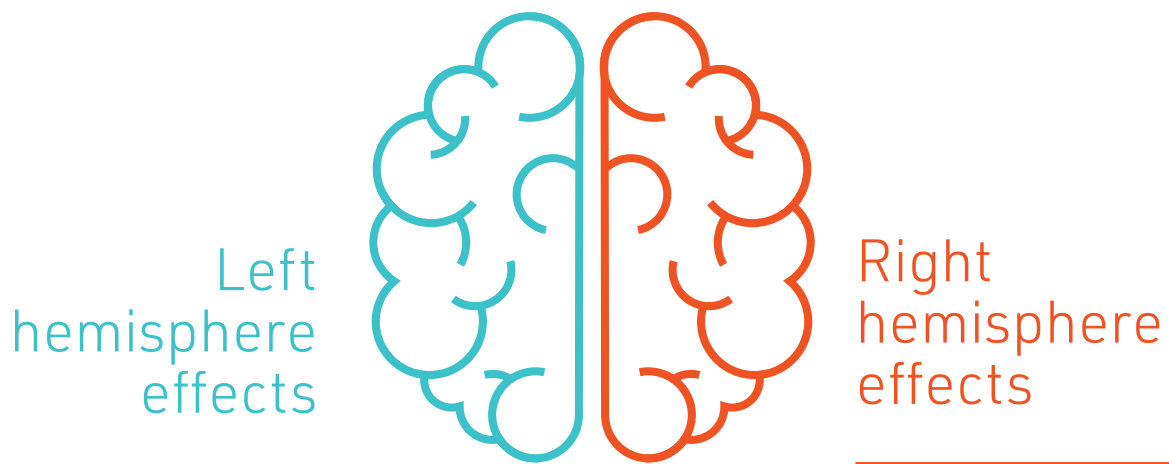
paralysis

loss of feeling

communication difficulties

visual problems

and many other issues depending on which part of the brain is affected:



A stroke in the left hemisphere of the brain may result in:

- some degree of paralysis on the body's right side
- lost or disturbed (hot or cold, acute or diminished pain) feeling on body's right side
- right field of vision deterioration
- loss of speech or comprehension (Aphasia), and other speech problems including Echolalia (exact repetition of a word or sentence just spoken by another person), perseveration (continual repetition of a word or phrase), inappropriate use of "yes" and "no" and inability to discriminate between left and right
- inability to name objects that can be recognised and used

A stroke in the right hemisphere of the brain may result in:

- Some paralysis on the body's left side
- lost or disturbed (hot or cold, acute or diminished pain) feeling on body's left side
- left field of vision deterioration
- difficulty expressing emotions
- inability to read facial expressions or voice tone in other people
- difficulty speaking, slurred speech or incessant and repetitive talking
- spatiotemporal difficulty with a tendency to get lost if left alone



Brain stem and cerebellum effects

Although the left and right hemispheres of the brain are usually affected, damage in the lower levels of the brain can also occur. The brain stem and cerebellum are involved in maintaining vital body systems, reflexes and balance.

A stroke in the brain stem can cause:

- unconsciousness
- inability to speak
- paralysis
- unstable pulse
- blood pressure fluctuations
- difficulty swallowing or breathing
- difficulty with eyeball movement.

A stroke in the cerebellum can cause:

- double vision
- dizziness and loss of balance
- lack of coordination in the hands
- slurred speech.

Treatment

Emergency treatment for stroke depends on whether it is an ischemic or haemorrhagic stroke.

Ischemic stroke

To treat an ischemic stroke, blood flow must be quickly restored. This can be done with:

Medication. An injection of a drug called alteplase, or Activase Therapy, has to be given within hours of when symptoms first started. This drug restores blood flow by dissolving the blood clot causing the stroke. Quick treatment not only improves the chances of survival, it may also reduce complications.

Endovascular procedures. Ischemic stroke can be treated by delivering medications directly into the blocked blood vessel, or by removing the clot with a stent retriever.

Hemorrhagic stroke

Emergency treatment of hemorrhagic stroke focuses on controlling the bleeding and reducing pressure in the brain caused by the excess fluid.

Treatment options include:

Medication. Drugs that counteract any anticoagulants or blood thinners that have been taken can be used. There are also drugs available to lower the pressure in the brain, lower the blood pressure, prevent spasms of the blood vessels, and prevent seizures.

Surgery. If the area of bleeding is large, surgery to remove the blood and relieve pressure on your brain may be required. Surgery may also be used to repair blood vessel problems associated with

Recovery and rehabilitation

Although the brain does not regenerate brain tissue that dies after an embolism or thrombosis, it will repair damaged tissue, and it will find ways to make new connections to replace those that have been lost. After a haemorrhage the brain may also regain some function after the pressure caused by bleeding has decreased.

Recovery after a stroke depends on many factors, including:

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

Recovery usually involves a lot of relearning of activities such as walking and talking. Relearning can be complicated as many people have trouble concentrating after a stroke. Attention can be affected markedly by a stroke in the front right side of the brain and can lead to slower rehabilitation as learning may be impaired.

Rehabilitation aims to:

- help you understand and adapt to your difficulties
- regain skills
- prevent secondary complications
- help you and your family to come to terms with the stroke.

Knowledge of rehabilitation following a stroke is growing steadily, as neurologists and neuropsychologists experiment with using mirrors or offset treadmills to retrain muscle groups and nerve pathways. As with any other form of brain injury, the key is understanding, persistence and a close relationship with the medical team.

Degenerative Conditions

There are a number of degenerative conditions that lead to brain injury.

Dementia

Dementia is a category of brain diseases that result in memory loss and deterioration of speech, motor skills and cognitive functioning as it progresses.

It is estimated that there are up to 459,000 Australians with dementia (AIHW, 2018), and impacting on a much greater number of family, friends and carers. Research shows that people who have acquired a brain injury are more likely to develop dementia in old age than the general population. Fortunately, there are a number of changes that can be made in our own lives to reduce our risk of dementia.

What is dementia?

Dementia is a broad term used to describe a range of symptoms, the most well-known of these being a gradual loss of a person's memory. Other symptoms can include gradual deterioration in speech, motor skills, thinking and planning, and the ability to carry out daily tasks. People with dementia can lose the ability to control their behaviour and may at times act socially inappropriate or unaware.

The disease is progressive, meaning that symptoms become worse over time. Towards the later stages of the disease, people require full-time care from family or staff, sometimes in residential aged care. Dementia is a terminal disease, and despite the best efforts of our medical researchers, there is currently no cure.

There are a number of different types of dementia, the most common being Alzheimer's disease, and others including vascular dementia (usually related to stroke), Parkinson's disease dementia, alcohol-related dementia, and Lewy Body Syndrome. While the risk of dementia increases with age, it is not a normal or natural part of ageing. Although rare, people in their 50s, 40s and even 30s can be diagnosed with 'younger onset' dementia.

How are dementia & brain injury related?

Research shows that people who have had a moderate to severe brain injury are more likely to develop dementia in later life. The pattern of changes seen in the brain following a moderate to severe brain injury can appear similar to those changes seen in Alzheimer's disease.

Reducing your risk of dementia

Researchers at the World Health Organisation (WHO) have found that a person is more likely to develop Alzheimer's disease if they have diabetes, high blood pressure or depression. A person is also at greater risk if they are obese, don't exercise regularly, if they smoke, or if they have low levels of education. Other types of dementia have other risk factors: for example, heavy drinkers are more likely to develop alcohol-related dementia.

Based on these risk factors, there are five important steps that we can take to reduce our risk of dementia:

- 1. Look after your heart** - Have your blood pressure, cholesterol, blood sugar levels and weight checked regularly by your doctor. Avoid smoking.
- 2. Be physically active** - At least 30 minutes of moderate-intensity exercise such as walking, dancing, swimming or cycling is recommended daily.
- 3. Mentally challenge your brain** - Learn a new skill, enrol in an educational course, read about interesting or novel topics, or have a regular, engaging hobby.
- 4. Follow a healthy diet** - Eat a variety of foods, including two serves of fruit and five serves of vegetables per day. Limit your alcohol consumption to no more than two standard drinks per day.
- 5. Enjoy a social activity** - Help to keep your brain active by organising regular social outings with friends and family, joining a community or volunteer group or having a regular social leisure activity.

Concerned about your memory?

If you are concerned about your memory or that of someone close to you, it is important to speak to a doctor. A doctor will be able to listen to your concerns and investigate a range of possible causes of memory difficulties. An early diagnosis of dementia ensures that a person has access to support, information and treatment options. It also gives people the opportunity to help plan their future care, including financial and lifestyle wishes. When visiting your doctor, it is helpful to write down your concerns before the appointment and consider bringing along a close friend or family member for support.

More information on how to maintain brain, heart and body health can be found at www.yourbrainmatters.org.au or call us on **1800 673 074**.

REFERENCES:

Australian Institute of Health and Welfare (2018). *Dementia in Australia*. AIHW: Canberra.
www.aihw.gov.au/reports/australias-health/dementia

Parkinson's Disease

Parkinson's disease (PD) affects a person's ability to control muscle movement.

It is a neurodegenerative condition that occurs when nerve cells die in certain parts of the brain and in particular, the substantia nigra where dopamine is created.

Motor symptoms

Dopamine is the chemical messenger responsible for the planning and smooth coordination of movement. When levels are low, the four main signs of Parkinson's disease start to appear:

- tremor - shaking that usually starts in the finger and thumb while a person is at rest
- body kinesia - movements become slower
- muscle rigidity and
- postural instability.

If a person experiences all four motor symptoms, then a diagnosis can be made.

Non-motor symptoms

There are also many non-motor symptoms that a person with Parkinson's might experience:

- anosmia - loss of sense of smell
- anxiety
- constipation
- brodyphrenia - slow thought
- depression - due to neurotransmitter imbalances
- fatigue
- festination of speech (involuntarily speaking faster)

- impotence
- micrographia (abnormally small handwriting)
- microphonia (abnormally weak voice)
- postural hypotension (low blood pressure upon standing up)
- sialorrhea (excessive salivation)
- sleep disturbance
- swallowing changes
- sweating.

Who is affected?

Around 100,000 Australians live with Parkinson's disease. It mainly affects older people but around one fifth of those affected have young onset Parkinson's and are between the age of 21 and 50.

Causes

There are two forms of Parkinson's disease, familial (a genetically inherited form), and sporadic or idiopathic (believed to develop from gene-environment interactions). The familial form accounts for approximately 10-15% of cases. There have been many studies looking at the role of various environmental toxins, however, the results have been inconsistent, indicating that the cause, as well as the symptoms, of PD are very individual.

Age remains the greatest risk factor, although the condition is in no way part of the normal ageing process.

Treatment

While there is no cure, there are several treatments available to control symptoms.

Medication: is used to raise the level of dopamine in the brain and help its uptake. Levodopa (L-Dopa) is the most common medication and it is usually taken with carbidopa. Other medications that are used include dopamine agonists, MAOB inhibitors, COMT inhibitors, anticholinergics, and amantadine (See the Mayo Clinic for details <https://www.mayoclinic.org/diseases-conditions/parkinsons-disease/diagnosis-treatment/drc-20376062>)

Deep brain stimulation (DBS): is an option when the disease affects a person's quality of life and medication alone does not work, or the side effects cannot be tolerated. DBS involves reversible surgery to help control stiffness, slowness and tremor. Electrodes are implanted

into the areas of the brain that control movement. They are programmed to send electrical pulses to the brain using a neurostimulator, which is also implanted during surgery.

Focused Ultrasound: is a non-surgical option using an MRI machine to target abnormal brain cells and destroy them without affecting healthy tissue. It is used to ease the motor symptoms of Parkinson's but can only be performed on one side of the body and is not reversible.

Treatments will differ depending on a person's symptoms and how they respond to medication. Because Parkinson's is a degenerative condition with symptoms getting worse over time, treatments will need to change accordingly. Therapies such as occupational, speech and physiotherapy can also be beneficial, along with exercising and staying active as much as possible.

Further information

Shake It Up Australia: <https://shakeitup.org.au>



Huntington's Disease

Huntington's disease (HD) is a rare neurodegenerative condition that affects movement, thought, emotions, and behaviour.

Huntington's disease is caused by the inheritance of an altered Huntingtin gene on chromosome 4. The altered gene causes an excessive build-up of the Huntingtin protein, which damages the neurons in certain parts of the brain, primarily the basal ganglia and the frontal cortex. These parts of the brain are responsible for motor movement control and coordination, cognition, personality and emotion.

HD is a slow, progressive condition that affects people differently. Usually, symptoms first appear when people are in their 30s and 40s, however, there have been cases of onset as early as childhood. There is no confirmed order for the onset of symptoms, and each person experiences the disease's progression differently. On average, life expectancy is between 10 and 30 years from the time symptoms appear.

A child born to a person with Huntington's has a 50% chance of inheriting the gene and developing the disease. If the child does not inherit the gene, she or he will not develop the disease, and will not pass it future generations.

Symptoms in adults

Huntington's disease affects people differently, but symptoms include:

- chorea – uncontrollable jerking movements that begin as twitches, usually in the finger and toes
- difficulty with coordination – leading to problems walking, swallowing and speaking
- difficulty planning, making decisions, insight and short-term memory changes in mood and personality – irritability and depression.

Treatment

While there is no cure, the physical and psychiatric symptoms of the disease are managed with medication, alongside physio, speech and occupational therapies.

Further information:

Huntington's Disease, Health Direct
www.healthdirect.gov.au/huntingtons-disease



Age-related Brain Injury

Ageing is a risk factor for acquiring a brain injury, particularly over the age of 65.

As we get older, our chance of developing dementia rises. So too does the likelihood of falls that result in brain injury. We might not be able to stop either from happening, but there are ways to reduce the risk and manage symptoms.

Age-related cognitive decline

The effect that ageing has on mental abilities is generally very mild. Working memory, attention skills and the ability to multitask can deteriorate over time without affecting a person's ability to live a normal, independent life.

Some people will experience Mild Cognitive Impairment (MCI), which is more pronounced than the normal signs of ageing but not severe enough to interfere with everyday tasks. MCI is divided into two categories:

- **Amnesic:** memory impairment is the main symptom
- **Non-amnesic:** a cognitive skill other than memory is the main symptom, e.g. attention, language, visual or spatial perception, complex thinking

Cognitive and physical assessments are used to diagnose MCI, as well as brain scans such as CT, MRI and PET.

MCI can be the start of dementia, and it affects thinking, emotions and behaviour in similar but less severe ways.

While some people with MCI will see improvement over time, others will stabilise and a proportion will go on to develop dementia.

Risk factors and how to avoid them

Although some people have younger-onset dementia, symptoms usually appear later in life, which means age is a big risk factor. Having an acquired brain injury also puts people in a higher risk category but it should be remembered that dementia is not inevitable or a natural part of ageing.

There are simple ways to reduce risk, like staying physically and mentally active, maintaining friendships and eating healthy food. Not smoking and having regular medical check-ups is also important to avoid an increased risk associated with high blood pressure and cholesterol, type 2 diabetes and obesity.



Traumatic Brain Injury due to falls

Getting older often means losing some of our physical strength, sense of balance and vision, all of which can put people at an extra risk of falling. Australian Health and Welfare studies show that head injury is the most common injury in people over 65 who are admitted to hospital after a fall (AIHW, 2019).

Slower reaction times, conditions like dementia and even dizziness due to medication can all play a part in increasing the risk of a traumatic brain injury due to falls.

Tips to reduce the risk of falls:

- stay active to improve physical strength and balance
- wear footwear that is safe and doesn't slip off easily
- make sure floor surfaces are safe, e.g. rugs cannot slip
- make walkways and stairs easier to see with lights.

REFERENCES:

AIHW: Pointer S 2019. *Trends in hospitalised injury due to falls in older people, 2007-08 to 2016-17*. Injury research and statistics series no. 126. Cat. no. INJCAT 206. Canberra: AIHW.

Anoxic and Hypoxic 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.

About anoxic and hypoxic brain injury

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:

- near drowning
- drug overdose
- strangulation
- severe asthma
- accidents involving anaesthesia
- carbon monoxide inhalation and poisoning
- stroke
- heart attack.

Hypoxia can also occur as a secondary injury following a traumatic brain injury, 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.

Types of anoxic/hypoxic brain injury

Anoxic anoxia occurs when inadequate oxygen is breathed in and absorbed by the body, e.g. altitude sickness or suffocation.

Anaemic anoxia is an inadequate oxygen supply due to a decrease in total haemoglobin or change in the haemoglobin's ability to carry oxygen

Stagnant hypoxia is inadequate oxygen supply to the brain due to the reduction of cerebral blood flow or pressure, e.g. stroke, heart attack

Toxic anoxia occurs when toxins or substances interfere with oxygen supply, e.g. carbon monoxide, cyanide, narcotics, alcohol.

Effects of anoxic and hypoxic brain injury

The overall effects of a hypoxic/anoxic brain injury vary depending upon the severity of damage. Areas of the brain particularly vulnerable to lack of oxygen include those responsible for coordination, movement and memory. A significant hypoxic brain injury can result in coma and possibly post-coma unresponsiveness.

Symptoms following a return to consciousness can include memory difficulties, abnormal movements, weakness in arms and legs, lack of coordination and visual problems. Movement disorders are quite common, including lack of coordination, spasticity (involuntary muscle tightness), tremors and an impaired ability to adjust the body's position.

As with other types of brain injury, people can develop challenging behaviours and emotional problems, such as depression, agitation or a reduced ability to tolerate stress and frustration.

Outcomes and recovery

Recovery is similar to that of other types of brain injury, but if a hypoxic injury results in widespread injury to the brain, the outcomes will be worse.

A holistic level of support is important, e.g. a physiotherapist and occupational therapist for movement disorders, speech pathologist for communication difficulties, and a neuropsychologist to assess for cognitive deficits. Support from a good team of specialists and family and friends will ensure the best recovery possible.

Brain Tumours and Brain Cancer

Brain tumours can affect brain function in a number of ways and to varying degrees, depending on where they grow and how severe they are.

An overview of brain tumours and brain cancer

There are more than 100 types of brain tumour, which are broadly categorised according to:

- where they originated
- whether they are cancerous or benign, and
- how fast or slow they grow and invade surrounding brain tissue.

They are graded on a scale of one to four (I to IV), from benign and slow growing (I) to the most malignant and aggressive (IV).

Primary brain tumours originate in the brain and can be cancerous or benign. It is very rare for these tumours to spread to another part of the body.

Secondary brain tumours are cancerous tumours that started as cancer in another part of the body and spread to the brain through metastasis. Some common examples are lung, breast and skin cancer.

Treatment

Surgery is used to remove brain tumours as long as it is considered safe to do so. Radiotherapy and chemotherapy can be used to try and destroy any sections left behind. If the tumour is in a position where surgery is life threatening or could cause too much damage, radiation is used as a treatment. Immunotherapy is a group of biological therapies that help the immune system detect and destroy cancerous cells. These therapies are not yet as widely used as surgery, radiation therapy or chemotherapy.

Symptoms

Growing tumours put pressure on the brain and can block the fluid surrounding it, which then builds up and creates swelling. This can lead to a wide variety of symptoms, even in the long-term. Treatments, while often alleviating symptoms, can also be among the causes. The most common symptoms are:

- headache
- nausea and vomiting
- cognitive difficulties (e.g. memory, planning, general attention)
- weakness
- impaired coordination (e.g. clumsiness, difficulty walking)

- seizures
- vision or hearing problems
- emotional and behavioural changes (e.g. mood swings, depression).

The type of tumour and its location will determine the effect it has on particular brain functions. For example, if the temporal lobe is affected, then memory, hearing and language might be impaired. If the tumour has an impact on the frontal lobe, decision-making, planning and movement can be affected.

Brain tumours and brain cancer in children

Children with brain cancer or benign tumours are treated differently to adults because of the effect treatment can have on their development. Surgery remains the first choice of treatment. Chemotherapy is usually chosen over radiotherapy as a follow up or replacement therapy because of the long-term effects radiation has on developing brains. For this reason, radiotherapy is not recommended for children under three years of age, and only given to older children when tumours don't respond to chemotherapy.

Children experience a similar wide range of symptoms, which vary according to age. They can include:

- vomiting
- headaches
- problems with balance, walking and coordination
- abnormal eye movement
- change in behaviour (e.g. lethargy)
- seizures
- abnormal head position (e.g. wry or stiff neck),

All the symptoms listed overlap with many medical conditions and are not necessarily an indication of brain tumours or brain cancer.

References and further information

Brain and other central nervous system cancers, Australian Institute of Health and Welfare:

<https://bit.ly/3kDrqK4>

Children's Brain Cancer, Cancer Australia, Australian Government: <https://childrenscancer.canceraustralia.gov.au/types-childrens-cancers/brain-and-cns-tumours/treatment>



Infections and Disease

Infections that cause swelling in the brain or the membrane that surrounds the brain and spinal cord (meninges) can result in acquired brain injury (ABI).

Encephalitis

Encephalitis refers to inflammation of the brain, usually caused by a virus and occasionally through bacteria, fungi or parasites. Another type of encephalitis known as autoimmune encephalitis occurs when a person's immune system mistakenly attacks the brain. Viruses common to infectious encephalitis include herpes, tick-borne and enteroviruses.

Symptoms of encephalitis can be similar to the flu and include headache, high temperature, light sensitivity, neck stiffness, difficulty with speech and movement, sensory changes and changes to behaviour.

The infection can damage and destroy nerve cells, causing injury to various parts of the brain and can result in:

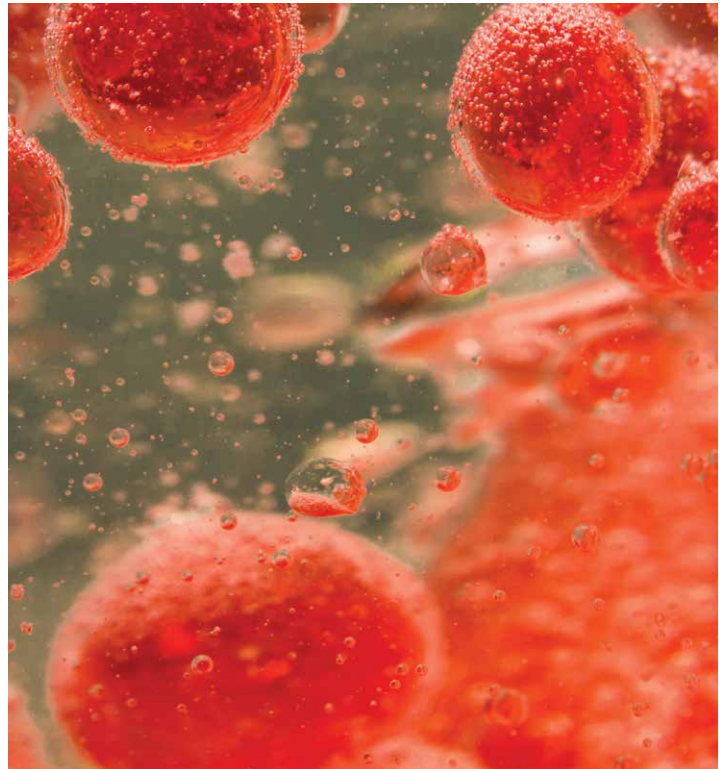
- difficulty with memory and concentration
- difficulty with balance and control of bodily function and movement
- difficulty with speech and language
- headaches and fatigue
- sensory changes
- epilepsy
- changes to mood and behaviour.

Meningitis

Meningitis refers to inflammation of the protective membrane that surrounds the brain and spinal cord (meninges). The cause of infection is usually a virus or bacteria, and occasionally fungi, parasites and protozoa. Physical head and spine injuries or medication can also cause meningitis.

Viral and bacterial meningitis both start with flu-like symptoms, but while most people recover easily from viral meningitis with rest and plenty of fluids, bacterial meningitis can be life-threatening and requires urgent medical attention. Symptoms include headaches, high temperature, light sensitivity, confusion and seizures.

There are many kinds of bacteria that potentially cause meningitis, some of which can be prevented through vaccines.



Types of bacteria include:

- meningococcal
- pneumococcal
- haemophilus influenza type b (Hib)
- streptococcal
- E.coli
- listeria
- salmonella
- tuberculosis.

The long-term effects of meningitis can include:

- problems with memory and concentration
- hearing loss
- blurred vision or blindness
- difficulty with speech
- difficulty with balance and coordination
- dizziness
- kidney damage.

Brain abscess

Brain abscesses can develop from infections elsewhere in the body or when bacteria or fungi enter the brain via physical injury or surgery.

They are an immune response to infections or foreign objects, whereby a capsule is formed around infectious pus to prevent it from spreading.

As an abscess develops, it can put pressure on surrounding brain tissue and damage or kill brain cells, causing brain injury. Scarring from surgery to drain and remove abscesses can also lead to localised brain injury.

The three ways infection can spread to the brain are:

- nearby infections (e.g. sinusitis, infected teeth, middle ear infection, infection of the bone behind the ear)
- infections in other parts of the body (e.g. heart, lung, skin, bowel and pelvic infections)
- infection in the brain via physical damage from foreign objects (e.g. bullet, shrapnel) or a wound that penetrates the brain, including surgery.

Brain abscesses are rare and the further likelihood of acquiring a brain injury even rarer. Long-term effects can include changes to brain function, personality and seizures. Although they can be life threatening, most people make a good recovery if treated early. Treatment is usually a combination of surgery and antibiotic or antifungal medication.



Hydrocephalus

Hydrocephalus occurs when the fluid that cushions the brain and spinal cords builds up inside cavities in the brain called ventricles. The ventricles expand, putting pressure on brain tissue and potentially causing brain injury.

Cerebrospinal fluid (CSF) normally protects the brain by acting as a shock absorber, providing nutrients, eliminating waste and regulating the amount of blood in the brain. It is constantly being replenished as it flows through the ventricles and is removed by being absorbed into the bloodstream.

Hydrocephalus can be genetic and present at birth (congenital) or develop after birth (acquired). Neural tube defect (NTD), or spina bifida, is one of several possible causes of congenital hydrocephalus. Acquired hydrocephalus also has many causes, including traumatic brain injury (TBI).

Hydrocephalus is further defined as non-communicating and communicating:

- **Non-communicating hydrocephalus** occurs when the flow of CSF is blocked by an obstruction as it travels along passages between ventricles. Possible causes include brain tumour, traumatic brain injury and infection (e.g. brain abscess, bacterial meningitis).
- **Communicating hydrocephalus** occurs when CSF cannot properly reabsorb into the bloodstream after it leaves the ventricles. The conditions Hydrocephalus Ex-Vacuo and Normal Pressure Hydrocephalus are examples of this.

The effects of hydrocephalus are varied according to the particular type, a person's age and stage of treatment. They can include:

- learning difficulty
- problems with coordination
- difficulty with speech and language
- visual problems
- seizures.

The main form of treatment is to implant a shunt to direct CSF to a part of the body where it can be absorbed in the bloodstream, including a valve to regulate pressure.

Early diagnosis and treatment is important to effectively control hydrocephalus.

Fetal Alcohol Spectrum Disorder (FASD)

Fetal Alcohol Spectrum Disorder (FASD) refers to a range of impairments that can develop in an individual due to exposure to alcohol in the womb.

Research suggests that early identification and intervention is linked to improved psychosocial and behavioural outcomes, although many people are not diagnosed until adulthood, if at all (National Organisation for Fetal Alcohol Spectrum Disorders, 2013).

FASD is not always seen at birth and often can be found in children, young people and adults who have not previously been diagnosed.

It can present as:

- structural impairments, such as a small head
- functional impairments – physical, cognitive, behavioural and learning difficulties
- birth defects such as heart and eye problems.

It is believed between 2% and 5% of infants in Australia may be affected. FASD can impact anyone, regardless of income or culture. However, in some marginalised Indigenous communities the prevalence may be as high as 12% (AMA, 2016).

If FASD is unmanaged, it can lead to secondary effects including:

- difficulty accessing education and gaining employment
- substance abuse
- mental illness
- lack of independence
- interaction with the justice system.

There is no safe limit of alcohol consumption for women during pregnancy.

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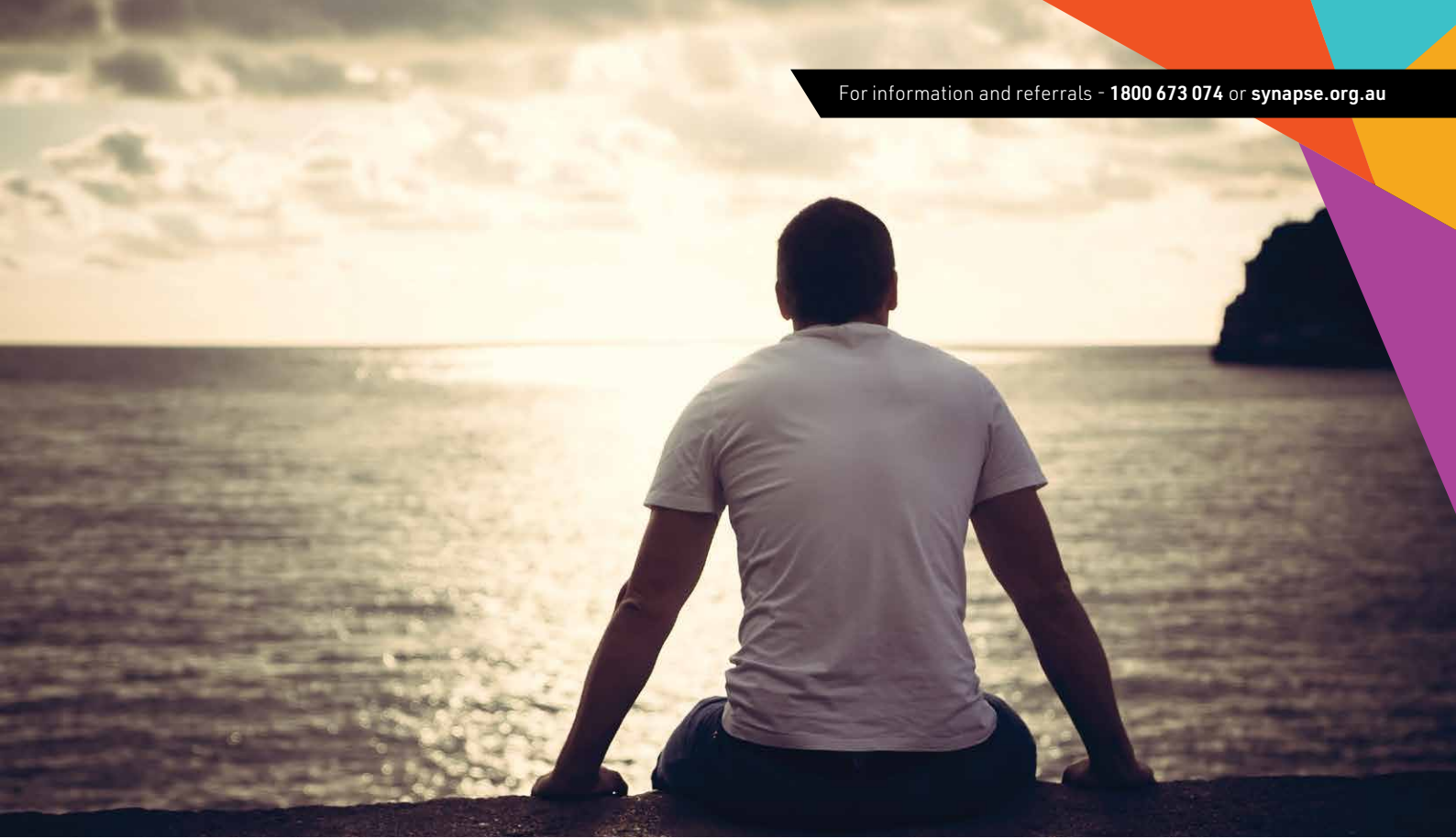
Australian Medical Association [AMA] (2016). *Position Statement Fetal Alcohol Spectrum Disorder (FASD)*.

Burns, L., Breen, C., Bower, C. et al. (2013). *Counting fetal alcohol spectrum disorder in Australia: the evidence and the challenges*. *Drug Alcohol Rev.* 2013 Sep 32 (5):461-7. Doi: 10.1111/dar.12047.

Further information:

FASD Hub Australia: www.fasdhub.org.au/fasd-information/understanding-fasd/what-is-fasd/





Assault

Physical assault is a major cause of traumatic brain injury (TBI), with young men between the ages of 20 and 24 being the most vulnerable.

Statistics show that males are twice as likely as females to be hospitalised with injuries from assault, and that those injuries are mostly to the head and neck area (AIHW 2018).

There is strong association between alcohol and violence. This link could be due to strong cultural associations between drinking and violence, expectations that drinking will lead to violence, alcohol being consumed in situations where violence is more likely to occur, and greater tolerance of violence when people have been drinking.

The brain is vulnerable to permanent damage in an assault, whether it is a blow to the head, punch, fall or strangulation and results in open or closed head injuries.

Brain tissue can be bruised or torn by a sharp blow, and may lead to haemorrhaging, contusions and haematoma. At the microscopic level the complex connections between neurons – the communication pathways – can be stretched or torn.

People can seek compensation for trauma related to violent attacks through the legal system. Going through the criminal justice system can be a very stressful time for a person who has been a victim of violence. It is important for a person to have the support of family and friends when needed. A person may be trying to cope with the feelings associated with the attack while managing the paperwork and legal requirements of going to court. Counselling and support groups for survivors of assault are available.

REFERENCES:

Australian Institute of Health and Welfare 2018. *Hospitalised assault injuries among men and boys*. Cat. No. INJCAT 196. Injury research and statistics series no. 116. Canberra: AIHW

Domestic and Family Violence (DFV)

There is a strong link between domestic violence and brain injury.

Brain injury can affect a person's ability to control emotions and behaviour. It is important that people have the support and structures in place to ensure that any lack of emotional regulation will not lead to violence against partners, family, and other household members.

In addition, victims of domestic or family violence have a high chance of acquiring traumatic brain injury due to physical blows, or hypoxic brain injury from strangulation.

In Australia, 1 in 6 women have experienced physical and/or sexual violence by a cohabiting partner since the age of 15 (AIHW, 2019).

Traumatic brain injuries often result in damage to the frontal lobe. This area of the brain is used in reasoning, problem solving and controlling our more basic impulses and emotions such as anger.

The loss of these skills through brain injury can make it hard for a person to control how they respond to anger and it can happen with little warning.

In many cases, brain injury affects social judgement and the ability to know what is appropriate in different situations. A lack of self-awareness can mean others are blamed for provoking the anger in the first place and violent actions are often forgotten due to memory loss.

Positive behaviour support

Behaviour support can help in a variety of ways including:

- establish consistent expectations and routines
- remain calm and respond positively during an anger outburst
- involve the injured person in discussing behavioural difficulties
- recognise and manage the triggers for aggressive behaviour
- give positive feedback for appropriate behaviour
- give clear feedback on aggressive behaviour
- have a safety plan.

Extra support

Behaviour specialists can help a person with brain injury learn better self-regulation using techniques to improve communication, anger management and relaxation. They can also teach family members how to treat aggressive behaviour in a consistent way within a positive behaviour plan.

Carers and family members need to maintain support systems so that they always have trusted people to talk to. Joining a local support group is a great way for carers to connect with families who are in similar situations.

Stay safe

Carers need to remove themselves from a potentially violent situation the moment they no longer feel safe.

Brain injury is never an excuse for domestic violence. If it still occurs despite professional support and a positive behaviour support plan, the next option is to either contact police and report the abuse, and/or apply to the court for a protection order (also called a Domestic Violence Order). You can ask the police to apply to the court for a protection order. Otherwise, you can apply directly to the court yourself, or ask a lawyer, community/welfare worker or others to apply for you. An easy-to-access list of emergency phone numbers should also be part of any safety plan.

REFERENCES:

AIHW (2018). [Australian Institute of Health and Welfare] *Family, domestic and sexual violence in Australia 2018*. Cat. no. FDV 2. Canberra: AIHW

Baldry, E., Clarence, M., Dowse, L., & Trollor, J. (2013). *Reducing vulnerability to harm in adults with cognitive disabilities in the Australian criminal justice system*. Journal of Policy and Practice in Intellectual Disabilities, 10(3), 222-229

For confidential information, counselling and support service contact **1800 RESPECT (1800 737732)**
www.1800respect.org.au



Alcohol and Other Drug Related Brain Injury

Alcohol is a poison, or neurotoxin, that can cause injury to the brain. This is known as Alcohol Related Brain Injury (ARBI). Other drugs - which fall into the category of stimulants, depressants or hallucinogens - can also lead to impairments. A person under the influence of alcohol or drugs is also at risk of Traumatic Brain Injury (TBI) due to accidents.

Alcohol related brain injury (ARBI)

Moderate to high levels of alcohol consumption over a long period of time, or excessive drinking over shorter periods, can lead to ARBI. In the short-term, it can reduce inhibitions and affect judgement, balance and coordination, increasing the risk of Traumatic Brain Injury (TBI) as a result of accidents.

A major reason for ARBI is thiamin (vitamin B1) deficiency. Thiamin, which is an essential nutrient for healthy brains, is not produced by the body and must be consumed in food or supplements. Alcohol interferes with the absorption of thiamin due to swelling of the stomach lining. If excessive alcohol consumption is also associated with a poor diet, which means thiamin can be lacking in the first place.

The effects of ARBI can result in:

- impaired judgment and self-awareness
- social isolation
- depression and mood disorders
- lack of motivation
- distractibility and concentration issues
- impulsivity and reckless behaviour.

There are various types of ARBI depending on where the brain injury occurs:

- **Cerebellar atrophy** – causes balance and coordination issues
- **Peripheral neuropathy** – leads to sensory issues with the hands, feet and legs
- **Hepatic encephalopathy** – can result from liver disease
- **Frontal lobe dysfunction** – affects cognition, behaviour and personality
- **Wernicke's encephalopathy** – can develop due to extreme thiamine deficiency
- **Korsakoff's amnesic syndrome** – also a result of extreme thiamine deficiency.

Other drug related brain injury

The toxic effect of drugs varies according to the type of drug and how much is taken. The consequences of drug misuse can be serious and include:

- seizures
- stroke
- heart attack
- hypoxic brain injury.

Psychoactive drugs can be divided into three general categories according to how they affect the central nervous system:

- Stimulants
- Depressants
- Hallucinogens.

Anytime you take more than one drug there is a risk of a drug interaction. These interactions can occur between prescription medications, recreational substances, over-the-counter medicines, vitamins, supplements, and herbal remedies. A few of these interactions can be very serious so it is important to understand the possible outcome before you take your medications. Discuss the possibility of interactions with your doctor or pharmacist, or visit websites such as NPS Medicine wise:

www.nps.org.au/consumers/understanding-drug-interactions

Stimulants stimulate the central nervous system, increasing alertness and physical activity. Stimulants include caffeine, nicotine, pseudoephedrine, methylphenidates, betel nut, amphetamines, cocaine, and Ecstasy.

Depressants depress the central nervous system. In a normal dose, they can lead to euphoria, relaxation, reduced coordination, disinhibition and lack of concentration. Larger doses may lead to nausea, unconsciousness and even death. Depressants include alcohol, cannabis, barbituates, benzodiazepines, opioids, some antihistamines, muscle relaxants, sedatives, some anticonvulsives, some antipsychotics, and alpha and beta blockers.



Inhalants are a range of chemical products that are inhaled to produce a high feeling. Many of these have a depressant effect and can be obtained from a variety of household products such as glue, aerosols and petrol. The long-term use of inhalants can cause brain damage and damage to the central nervous system as well as hearing loss, bone marrow, liver and kidney damage and depletion of blood-oxygen levels.

Combining different depressant medications is particularly dangerous

Mixing Benzodiazepines (prescription medications often used for sleep or anxiety), opioids (e.g., heroin, morphine, codeine, pethidine, oxycontin), and/or alcohol has been responsible for many deaths.

Hallucinogens affect a person's perceptions, sensations, thinking and emotions. Examples include LSD, mescaline and psilocybin. Psilocybin is found in certain mushrooms that are known as "magic mushrooms" or "golden tops".



SECTION 3

Effects of Brain Injury

The long-term effects of brain injury are different for each person but can be managed with relevant strategies and support.

Effects will vary based on the type of condition, the nature and location of the injury, and a variety of other factors. For example, while degenerative disorders typically impact the body's ability to control movement, other brain injuries may have an impact on the way a person thinks, their personality or their behaviour.

Understanding how different effects specifically impact a person allows for appropriate management strategies and support to be put in place.

Cognitive

The cognitive effects of brain injury include attention and concentration problems, memory problems and difficulty with motivation and making decisions.

This may mean that people with a brain injury become easily distracted, or experience information overload. They might also be slower at making sense of information. However, there are strategies that can help manage these effects and can improve concentration and attention.



Attention and Concentration Problems

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

Brain injury and concentration

People who have sustained a brain injury may not immediately recognise that their ability to concentrate has changed. There are often no physical signs to suggest a problem exists. This can lead to misunderstandings when others perceive an inability to concentrate as a lack of interest or motivation. This problem is of particular concern with children who return to the classroom after acquiring a brain injury.

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.

Concentration problems can inhibit the ability to learn and remember information, causing people to feel frustrated with themselves and others. They may be easily overwhelmed and confused, which can exacerbate problems related to fatigue, headaches and dizziness.

Causes of concentration problems

When a person experiences difficulties with concentration after a brain injury, the likely cause is injury to specific 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. 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 is coordinating muscle activity.

Concentration can be affected 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
- dietary inadequacy, particularly B-group vitamins and iron

- drugs, including medications, and environmental toxins such as carbon monoxide
- hunger
- mental illness, particularly depression and mania
- extremes of mood, including fear.

Strategies to improve attention and concentration

It is important to realise that concentration and attention problems are influenced by brain injury.

Strategies can be developed based on what has worked in the past but it's worth being aware that what has worked in the past may no longer work due to the changing effects of brain injury.

The following strategies may be useful:

- 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 to approach tasks with a simple step-by-step method
- break significant tasks down into small and achievable steps
- write information down using notes, and keep them in specific places
- use a voice recorder or as voice memo app on a smart phone to record 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, structured daily routine
- schedule demanding tasks when levels of energy and alertness are greatest
- eat a healthy diet and sleep well
- use a timer, electronic organiser or smart device and set goals to steadily improve duration of concentration in small steps.



Memory Problems and Memory Tips

Memory loss is very common after a brain injury – thankfully there are plenty of coping strategies available.

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.

Short-term memory loss

Memory problems can occur with most brain disorders and are particularly common with traumatic brain injury (TBI).

You should discuss any difficulties you are having with your GP, psychologist or psychiatrist, as there may be changes that can be made to your medications and other parts of your healthcare that can improve your memory. It may never be as good as it was before the injury, but there are many things that can be changed that can make a difference but there are many ways of coping and making life easier.

Changes to help improve memory

As with any cognitive challenge, memory works better when people:

- avoid fatigue
- sleep well
- manage stress and anxiety
- minimise alcohol, eat a healthy diet and exercise regularly

Memory tips to improve general wellbeing

Memory is very important in giving us a sense of identity. Memory problems can have major emotional effects, including feelings of loss, anger and increased levels of depression and anxiety. Some approaches to dealing with this include:

- Talking with your GP, psychologist or psychiatrist
- sharing your feelings with others who can provide relief and reassurance. (Contact Synapse to speak about support groups in your area).
- identifying activities you find enjoyable and relaxing - such as listening to music or exercising, and take the time to take part in them
- following strategies outlined overleaf – they can provide a measure of control which can relieve anxiety and depression.

Adapt the environment

One of the simplest ways to help people with memory problems is to adapt their environment to reduce their reliance on memory.

Some ideas include:

- keep a notepad by the phone to make a note of phone calls and messages
- put essential information on a noticeboard
- decide on a special place to keep important objects like keys, wallets or glasses and always put them back in the same place
- attach important items to yourself so they can't be mislaid e.g. using a neck cord for reading glasses
- label cupboards and storage containers as a reminder of where things are kept
- label perishable food with the date it was opened
- paint the toilet door as a distinctive colour so it is easier to find
- label doors as a reminder of which room is which.



Adopt short-term memory strategies

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

- reduce distractions - 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
- 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'.

Use external memory aids

External memory aids are extremely effective in helping with memory loss and include:

- a diary for storing and planning
- notebooks of all sizes for various places
- lists, wall charts and calendars
- alarm clock, wristwatch alarm and timers on mobile phones
- voice recorder
- electronic organisers and smart devices
- pill reminder box for medication, or speak to your pharmacist about getting your medications in a Webster pack.
- sticky-backed notes
- a memory book for big events, personal experiences and names
- cameras
- photo albums.

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

Follow a set routine

Having a daily and weekly routine helps reduce the demands on memory. Changes in routine are often necessary but they can be confusing for the person with brain injury. It is a good idea for family and carers to explain any changes in routine carefully and prepare the person with memory problems well in advance, giving plenty of spoken and written reminders.

Try the following reminder strategies in order to establish routines:

- make a note of regular activities in a diary or on a calendar
- make a chart of regular events, perhaps using pictures or photographs, on a notice board.



Perseveration (Repetition)

Perseveration is repetitive and continuous behavior, speech or thought that occurs due to changes in cognitive skills such as memory, attention, and mental flexibility.

About perseveration

Stress and anxiety can trigger perseveration, or at the very least make it worse. Brain injury is just one of a variety of conditions in which perseverative disorders can occur. Others include Alzheimer's disease, aphasia, schizophrenia and Parkinson's disease.

An example of perseveration is someone sandpapering a table until they've sanded through the wood, or a person who continues talking about a topic even when the conversation has moved on to other things. Another person might be asked to draw a cat then several other objects, but continue to draw a cat each time.

Treatment

Perseveration can be treated through behavioural and cognitive training in a structured environment, and possibly by group therapy or medication.

How others can help

When a person is perseverating they feel unable to stop. Others need to respond in a calm and supportive way as frustration will cause greater anxiety and make the situation worse.

Try redirecting the person by changing the topic of conversation, or asking them to try another activity. It is also helpful to direct a person from conversation to an activity and visa versa. This will help them to move on from the behaviour, speech or thoughts they are stuck on.

Managing symptoms

As with most aspects of a brain injury, staying healthy can help make the symptoms of perseveration easier to manage:

- sleep well
- exercise regularly
- avoid alcohol or limit your intake
- follow a healthy diet
- learn stress management techniques
- maintain contact with people you enjoying being with and who are supportive.

Problems with Organising

Many people have difficulty getting organised after a brain injury.

The parts of the brain that are responsible for organisation are easily affected by injuries. Most people with an ABI will initially find some difficulty with prioritising, sequencing, organising, starting, and completing tasks. How long these problems will last, and how much difficulty they cause, will depend on the severity and location of the injuries.

There are quite a few things that can be done to help someone get and stay organised. The suggestions below are strategies that can help make up for some of the skills impacted by a brain injury. The good news is that with commitment and patience these strategies can be very effective.

Staying as well as possible

Anxiety, stress, and fatigue can make it harder to plan, prioritise, and complete activities. Therefore, better emotional and physical wellbeing is likely to improve mental alertness and the ability to get and stay organised. Emotional and physical wellbeing can be improved by:

- following prescribed medication guidelines and medical advice
- a balanced diet and, if required, supplements such as vitamins (but always check with your doctor before using any dietary supplements)
- enough restful sleep
- relaxation and stress-reduction strategies (mindfulness practices can be particularly helpful)
- avoiding alcohol, tobacco, and other recreational drugs.

Structure

Structure allows people to put some 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. Having well defined tasks and a weekly timetable can make it easier to plan activities and stay organised. It can also make it easier to stay healthy. For example, having set times for sleeping and waking is a great way to get a good night's sleep, and makes it easier to build a daily schedule.

It can also help to have set regular mealtimes and to not skip meals. A person with brain injury can work with family members to arrange a weekly plan for visiting friends, exercise, any rehabilitation tasks, and time to engage in hobbies or other meaningful activities.

Setting goals

Setting goals and working toward them can provide a sense of purpose and meaning to our daily lives, can make us feel like we have some control over our future, can improve a negative mood, and can give us a sense of accomplishment. However, it is not unusual for someone with a brain injury to have difficulties in this area.

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 at this point. Returning to work can help a person feel productive, part of a team, and valued 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 give support and help in a gradual 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 different 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.

If formal rehabilitation has finished, a goal might be to continue rehabilitation independently. Other goals could be to make some new social connections or learn a new skill.

It is important for people to have an accurate idea of their strengths and weaknesses. Self-awareness can be affected by a brain injury, giving people an unrealistic idea of what they are capable of. Family and rehabilitation professionals can help choosing and reaching 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.

There are many smart phone apps and resources on the internet to help with goal setting and tracking.

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.

Organising your environment

Get a daily planner, diary, or a smart phone app 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 the surroundings so that less demand is placed upon a person's memory. Strategies for organising the environment include the following:

- keeping things needed every day in the same place
- putting phones and devices in the same place and charging when not in use
- using a large notice board/ white board and making plans
- having a special place to keep objects which tend to go missing (e.g. keys and sunglasses)
- For things that are used together, store them together (e.g. the tea, the tea pot, the teacups, and the sugar bowl next to the kettle)
- labelling or colour-coding cupboards, boxes, and drawers as a reminder of where things are kept
- tying objects to places (e.g. a key to a belt or a whiteboard pen to the whiteboard)
- Use alarms and timers to help keep track of time.

A '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 plan to do and then erase them as you complete them. Sometimes people will list 20 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 remove one. You may want to limit it to only three projects if five is overwhelming.

Decision-making and Brain Injury

Decision-making ranges from minor decisions, such as what to have for dinner, to major life-changing ones, such as changing careers. It involves many different cognitive functions working together:

LONG-TERM MEMORY ('how I have dealt with these situations in the past?')

WORKING MEMORY (holding information in mind and thinking things through)

EMOTION ('how important is this decision to me, and how will the possible outcomes make me feel?').

A brain injury or other brain disorder can disrupt the complex process of decision-making. People are affected in different ways and some find simple decisions almost impossible, while others become impulsive, making hasty decisions without thinking them through.

Poor judgement in relationships, with money, or in business, can have negative consequences for the individual and the people around them. We all have difficulty making decisions from time to time, but brain injury can make this much more frequent.

Decision-making and follow through

Some people may be able to decide on a plan of actions to take but will struggle following through with the plan. It is as if a person's intention, or goal, becomes neglected. This can sometimes be because the person becomes distracted by other tasks or activities. The person 'forgets' to do things, not because what they have planned to do has been completely forgotten. Rather, it is difficult to keep planned activities in mind (e.g. going to an appointment).

This is often called 'prospective remembering', as a person needs to be alert to all elements of their plans for the day. Psychologists describe this ability to keep a list of actions in mind as having a 'mental blackboard'. It is a very complex set of cognitive operations that is very easy to disrupt. All of us can find this ability impaired from things such as a poor night's sleep, stress, a head cold, last-minutes changes to tasks or priorities, or even just an additional task that need to be completed. It is not a surprise then, that for people with brain injury, items are easily rubbed off the mental

blackboard and temporarily forgotten, although the person may remember their planned intention when prompted.

Self-awareness (insight)

The cognitive problems that affect decision-making can also affect a person's ability to recognise their own difficulties. A person might appear to have poor judgement and may fail to achieve important tasks. This can be a challenge for family and friends and even become a source of conflict. However, it is important to keep in mind that the person may not be aware of these difficulties, or share the opinion of those judging it as a problem.

The first step is to help the person achieve a degree of self-awareness and gain an understanding of the problems they are experiencing. This may need sensitive feedback from family, friends or professionals, and requires that the individual has a desire to learn about possible solutions.

Rehabilitation

The first step in rehabilitation is to understand the problem. This is easier said than done because of the complex process involved in decision-making or problem solving. It may be best done with the help of a professional such as an occupational therapist or clinical psychologist.

For many, learning to manage impulsivity is an important step. This involves developing the habit of stopping to think, even just briefly, about what you are doing and what you have to do. This interrupts a person's tendency to act without thinking. The idea is that people become better at using 'self-talk' to regulate their own actions or behaviour.

External aids

External aids such as diaries, notebooks, wall charts and calendars are invaluable for people with memory impairment. Devices such as mobile phones, tablets and electronic watches can all be set to provide reminders and cues about specific tasks, or to check a daily planner. It isn't always easy for someone with memory difficulties to use these aids so the help of a relative, carer or occupational therapist may be needed.



Did you know?

A study by researchers in **Cambridge and Glasgow** showed that **Goal Management Training**, combined with text message reminders, helped people to remember tasks that had to be done regularly throughout the day.

Motivation and Initiation (Adynamia)

Some brain injuries can result in a loss of motivation and difficulty in getting started with activities.

Motivation, initiation and adynamia

Our ability to initiate activities and see them through to completion is an important skill for everyday life. This lack of motivation, also called adynamia, is common with injury to the frontal lobes that occurs after a traumatic brain injury (TBI). It is also one of the most debilitating parts of depression, and can last for months after the other symptoms of depression (e.g., low mood, sleeping changes, eating changes, apathy) have improved. It may be difficult to determine if the cause is the brain injury or depression, so discussing it with a psychologist or psychiatrist is a good idea.

Initiation is an important part of motivation - it is our ability to get started on a task and something we all take for granted. In some cases, a person with brain injury needs verbal reminders and prompts to begin an activity. Further reminders are often needed to see the task through to completion.

Difficulties with motivation can impact on many areas of life such as rehabilitation, learning coping skills, social functioning and a return to work or study.

Social isolation can be a common outcome due to impacts on motivation to participate in activities or contact friends and family.

Understanding adynamia

It is important for friends and family to have an understanding of what adynamia is - and isn't - in order to help. People experiencing adynamia as a result of brain injury are not lazy and can feel quite motivated. They might be clear about what they want to do and talk about their plans, yet not know how to actually start an activity.

Lack of initiation should not be confused with other aspects of TBI that appear similar, such as fatigue and depression. Fatigue easily sets in when people with brain injury push themselves too hard. Similarly, the feeling of apathy associated with depression is a common and understandable reaction to changes brought about through brain injury, yet is distinct from adynamia, but as mentioned above, adynamia can be a part of depression.

Managing adynamia - advice for carers

Break tasks down into easily managed steps and write a checklist. Tick these off when completed. This can be used to re-establish normal daily activities.



Structure and an uncluttered environment will help a person feel less overwhelmed after a brain injury. Provide a timetable of weekly events with built in rest periods as needed. Have lists of how to accomplish various tasks in a handy spot. Keep the environment free of distractions and noise as much as possible.

Prompts and positive reinforcement need to be given regularly. Give encouragement when the person initiates or sees activities through to completion. Where possible make activities fun so they seem less of a chore. Having to constantly give prompts may feel frustrating at times, but is an important part of helping a loved one manage adynamia.

Mental health needs must be considered. As motivation is closely associated with mood, appropriate treatment should be provided for depression, anxiety or any other psychological problems.

A healthy lifestyle is important for managing fatigue and general wellbeing. Encourage your loved one to:

- sleep well
- get regular exercise
- avoid alcohol or limit intake
- eat a healthy diet
- learn stress management techniques
- maintain contact with friends and family.

It is natural for families and partners to find it difficult when the lively person they once knew seems uninterested in activities or other people.

Physical

Managing Fatigue

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

What is fatigue?

Fatigue 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. This often results in mind-numbing fatigue that can last for several days.

Brain disorders such as traumatic brain injury (TBI) can be compared 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 it will make any other problems worse as well, such as:



Vision
problems



Slurred
speech



Difficulty
finding words



Poor
concentration



Cramps or weak
muscles



Poor coordination
or balance

Fatigue can often occur for no apparent reason or after physical activity, but is also quite likely to occur from too much mental activity such as planning the week's errands, organising a work schedule or simply reading. While it can be managed, with good planning and rest periods, 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. Some things that cause fatigue include long conversations, noisy shopping centres, movies with complicated plots or talking with two or more people at once. In some cases, fatigue could be a side effect of certain medications, in which case it is recommended to see your 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 may 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 to 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 dim lighting.

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

Use aids: mechanical aids such as wheelchairs should be used to conserve energy.

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 on 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 can do a home visit to see how they can reduce the effort it takes to perform everyday activities.

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.

Sleep Issues

Lack of sleep has a negative effect on our ability to think, mood, energy levels and appetite. The average person needs around eight hours sleep a night or will suffer from decreased concentration, energy and many other problems. These effects are multiplied many times by a traumatic brain injury, stroke and other types of brain disorder.

Brain injury and sleep disorders

Sleeping disorders can be a common occurrence after brain injury. The American Academy of Neurology reports that as many as 40 to 65 percent of people with mild traumatic brain injury experience insomnia.

This can be hard to detect because people with brain injuries often have a fatigue disorder as well. Some people have problems with getting too much sleep, although trouble sleeping at night is most common.

Causes

After a brain injury many find it not only difficult to sleep, but they are very easily awakened, sometimes dozens of times a night. They may then find themselves unable to sleep at all, despite being desperately tired. Sleep will usually be very light, so the smallest noise brings the person instantly awake.

Research suggests a major cause is disruption to the normal release of certain neurotransmitters in the brain during sleep which causes "sleep fragmentation" due to waking up so often.

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 common after a brain injury and people may find they fall asleep easily but wake up several hours before dawn and are unable to sleep again. Anxiety and stress are other factors for many. Recurrent thoughts whirring through the mind make it very hard to fall asleep.

Sleeping your way to recovery

Sleep plays a big part in not only helping the brain to recover from a brain injury, but in physical healing as well. In a traumatic brain injury, there are often muscles damaged. 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 you 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 2 or 3 days. This is normal as your brain is trying to "catch up" on the sleep that it has missed. However, some people report side effects such as finding it hard to wake up in the mornings. Talk to your doctor about any side effects.

Sometimes the medication may seem to stop doing its job after a month and may need readjustment by your doctor.

Practical steps to good snoozing

Routine is vital for sound sleep. Go to bed at a similar time every night, even on the weekend. Do not vary this by more than 15 minutes. That may sound extreme, but if you go to bed at the same time and get up at the same time each day, your body will adjust to that pattern.

Avoid caffeine and nicotine. These stimulants have a negative effect on the brain, and for some people it may increase the likelihood of seizures.

Don't get the body revved up with exercise late in the evening. Make sure your bedroom is at the right temperature and that the room is very dark. This can be very important because light plays a critical role in your sleep pattern. Make sure it's quiet as well. Talk to those you live with about your need for a quiet environment.

Some find that afternoon naps are essential due to the cognitive fatigue from a brain injury. However afternoon naps can disrupt your night time sleeping so it is important to experiment. It might be better to lie down and rest without allowing yourself to sleep.

When stress, anxiety and negative thoughts are involved, cognitive behavioural therapy can help.

Headaches

Headaches are a common and often persistent problem after acquiring a brain injury. Headaches can arise after damage to different structures both inside and outside the head.

Major types of headaches

These are the most common after a brain injury but please note that how headaches are named and classified changes from country to country.

Tension headaches often feel like a diffuse vice-like pressure throughout the head, lasting from 30 minutes to a week. They usually respond well to over-the-counter analgesics like ibuprofen, paracetamol and aspirin. A very common cause of headaches is due to the microscopic damage to nerve pathways in the brain after a traumatic brain injury and other types of brain disorder, resulting in what is often called a tension headache.

Migraines are moderate to severe headaches, recurrent and pulsating in nature and often only affecting one half of the head. Other symptoms may include vomiting and sensitivity to light, sound or smell. They can last from four hours to three days in length. Sometimes the person sees an 'aura' before the migraine starts and can avoid the onset. This can be achieved by avoiding activities that are triggering the migraine or taking appropriate medication.

Musculoskeletal headaches are common with traumatic brain injuries when there is injury to the neck and/or structures in the head. An example of this is a whip lash injury. These headaches often worsen with stooping, bending or exertion. They may be associated with dizziness, sensitivity to light, sensitivity to sound and even imbalance. These headaches often disappear when the underlying problem is resolved.

Cluster headaches are typically short (15 minutes to three hours) of severe pain that usually is located around one eye. Other symptoms include nasal congestion, tearing and a red eye.

Diagnosis

If you are experiencing headaches after a brain injury it is important to report these to your doctor. It could be the symptom of a condition needing urgent treatment or as a reaction to medication in which case a new medication should be tried.

Healthy habits to reduce headaches

Before you try medications, there are basic lifestyle changes to try which could cut the chances of headaches occurring:

- sleep well
- regular exercise
- avoid caffeine and nicotine
- avoid certain foods that can trigger headaches e.g. red wine, certain cheeses
- minimise use of pain medications, unless they are prescribed.

Treatment of headaches

Pain management in brain injury can be difficult as some medications may work against recovery. Certain medications can also become a problem because of their potential for substance abuse and their impact on the ability to think clearly. Often over-the-counter analgesics like ibuprofen, paracetamol and aspirin are used.

Non-steroidal anti-inflammatory drugs (NSAIDs) which include aspirin, ibuprofen (Nurofen), Voltaren, and other COX-2 inhibitors are appropriate for musculoskeletal pain. However, they can increase the risk of serious gastrointestinal complications (including ulcers) and may increase cardiovascular events in some people, so check with your doctors before taking them.

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

Most headaches following brain injury do not require surgical treatment. In some cases, particularly severe brain injury, surgical intervention may be required for conditions such as communicating hydrocephalus, carotid cavernous fistulas tension, pneumocephalus, brain abscesses and subdural hematomas. Appropriate clinical examination and diagnostic tests are needed to assess the form of treatment required.

Further information:

Migrain and Headache Australia
www.headacheaustralia.org.au



Epilepsy and Other Seizures

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

What is epilepsy?

Epilepsy is a family of disorders 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 as it may be a one-off occurrence, and 50% of people who have a seizure will never have another. In primary epilepsy, there is no abnormality seen in the brain and there is 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 traumatic brain injury and other brain disorders. It can cause neural damage by itself, and epilepsy is a risk factor for a traumatic brain injury 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 categorized 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:

- take medication on time
- sleep well and minimize stress
- avoid conditions that trigger seizures
- wear 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 on pre-seizure sensations can be an important technique for preventing serious physical injury.

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. They can also undertake first aid training to know how to provide first aid if a fit occurs.

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 an ambulance is the very first priority. If you are alone and have a severe seizure, it may take time to recover but call an ambulance as soon as possible.

Don't attempt to restrain the person during a fit. If possible, roll them into the recovery position and ensure the airway is clear e.g. no vomit in the mouth. Make sure there are no objects like chairs or tables nearby that they could hurt themselves against when fitting.

Ensure they are still breathing and 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. Make sure they rest until they have recovered enough to get up.

Further information:

Epilepsy Action of Australia: www.epilepsy.org.au

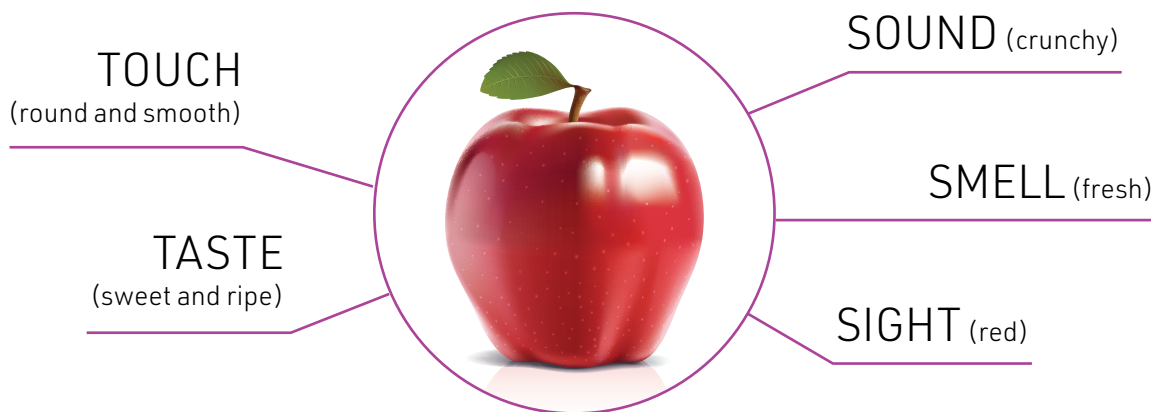
Sensory and Perceptual Problems

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

What causes sensory and perceptual problems?

Damage to the right side of the brain or the parietal and occipital lobes of the brain can cause sensory and perceptual problems. These areas of the brain process the input from our senses.

For example, when eating an apple our brain will report on the following:



Brain disorders such as traumatic brain injury (TBI) can disrupt our senses as well as 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, visuospatial 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.

Prosopagnosia (face blindness)

Prosopagnosia is a less common example of neglect. The ability to recognise faces is reduced, or even lost completely. In extreme cases, there is an inability to distinguish one face from another or read facial expressions (aperceptive prosopagnosia).

CASE STUDY

ELSIE

Elsie was a 52-year-old woman who had a stroke three years ago and since then had problems with sideswiping 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.



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 was that others could not understand his ability to see and recognise objects, but not other faces.

Managing visuospatial challenges

A person with neglect might be unaware of the issue, and hence it's important to identify during rehabilitation and provide them with education.

Retraining skills is one way to manage visuospatial problems and usually involves repetitive and intensive exercises for a specific skill or task (e.g. drawing an object while receiving feedback).

Changing the environment or expectations involves modifying the environment to provide more support or reducing the demands of a particular skill. Reducing the demands of a skill can be as simple as shifting furniture at home so that walking around the house is easier and support might be fitting a handrail to make climbing stairs easier.

Compensatory strategies and rehabilitation

Compensatory strategies are very important in rehabilitation as they are designed to improve areas of difficulty post brain injury. For example, Elsie 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
- handrails and other safety devices.

Recognising objects could involve the person shutting their eyes and relying more on other senses like touch, hearing and smell.

The rehabilitation strategies described may be developed by a neuropsychologist, occupational therapist or physiotherapist.

Balance Problems and Dizziness

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

What causes balance problems and dizziness after a brain injury?

Our sense of balance comes from the interaction of three systems in our body:

- eyesight
- the vestibular system (inner ear)
- 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, a traumatic brain injury (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 disorder

Due to this complexity, diagnosis usually involves a thorough medical examination. This may start with a GP and could also 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, as well as a list of medication.

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.

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.

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 can include the addition of handrails in the home or the use of a walking stick or frame, and safety education.

Strategies for 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 in the meantime:

- avoid alcohol and other drugs
- get out of bed slowly and allow time to adjust to a changed body posture
- stop the moment dizziness starts and sit or lie down until it passes
- avoid or slow down movements that unbalance you
- pinpoint times or conditions when dizziness is worse and then avoid those conditions or schedule activities to avoid those times.

Communication Disorders After a Brain Injury

A brain injury can affect a person's ability to communicate by impairing their hearing, speech and cognitive processing.



Communication problems vary depending on an individual's personality, their abilities before the injury, and the severity of the brain injury itself. Regardless of the type of injury, problems can affect both the ability to receive and express thoughts and ideas. Effects may include:

- problems finding the right words
- difficulty understanding others
- slow or slurred speech
- difficulty swallowing

Receptive skills

Receptive skills involve receiving and understanding language. Signs of receptive issues include:

- poor recognition of vocabulary
- continually asking for things to be repeated
- difficulty with the speed, complexity or amount of spoken information
- not being able to pay 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. It's important to have a hearing test first before assessing receptive skills.

Expressive skills

Expressive skills involve forming words and sentences clearly. Signs of expressive issues can be subtle and emerge over time. They 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
- confabulation
- 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.

Common communication disorders affecting people with brain injury

Anomia is a difficulty recalling or recognising the names of people and objects.

In some cases, a person will choose the wrong word, for example "pass me the noon" instead of "pass me the spoon". A speech pathologist can provide techniques to help. 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 is damage or lack of control of the muscles that control speech.

Dysarthria impacts control of the tongue, larynx, vocal cords, and surrounding muscles, making it difficult to form and pronounce words.

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 is when the brain has difficulty sending movement signals to the muscles responsible for speech.

Apraxia of speech will make it difficult for a person to say the words they want consistently and correctly. 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.

Confabulation is a symptom of memory disorders where a person subconsciously creates made-up stories to fill gaps in their memory.

The made-up stories brought about by confabulation can range from small and insignificant responses to extremely elaborate stories based in actual events or completely separate from reality.

Confabulation is not lying - the person is unaware their responses are inaccurate and will believe they are telling the truth.

How professionals can help

Speech pathologists and occupational therapists can assess and treat communication problems and provide advice to rehabilitation teams. They can help a person with a brain injury to manage and improve communication by using therapy to restore lost skills, teach compensatory strategies and employ the use of assistive technology such as hearing aids or augmentative communication devices.

How family and friends can help

Health professionals will involve family to provide consistent support for any strategies taught. Family and friends should expect to be involved in rehabilitation after a traumatic brain injury - it makes a big difference.

Families might use the following tips:

acknowledge the communication problems caused by brain 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.

Hearing Impairment After a Brain Injury

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

How hearing can be damaged

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

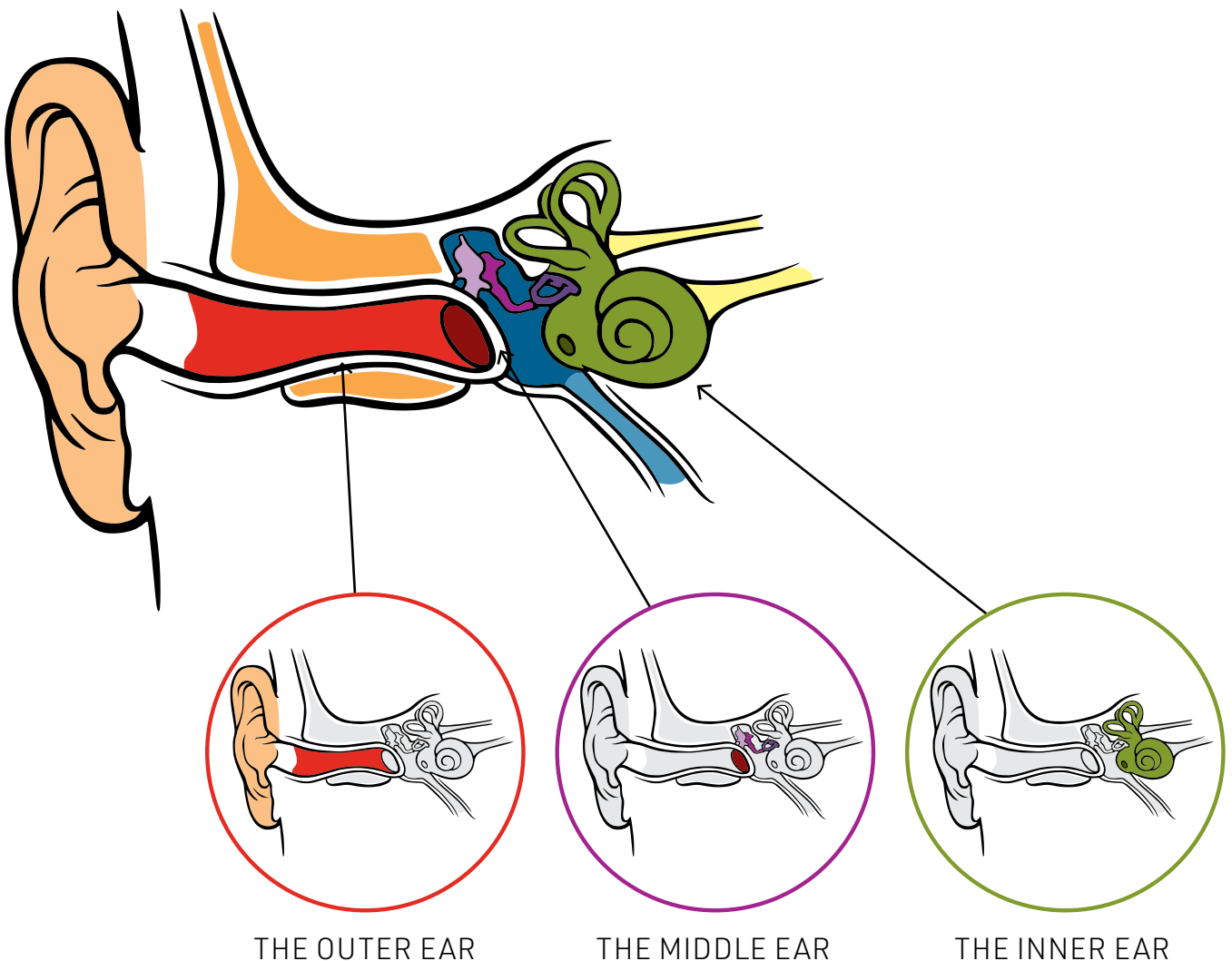
The outer ear, consisting of the lobe and ear canal, protects the more fragile parts inside.

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 traumatic brain injury (TBI) most commonly affects the mechanical process. An ear drum 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
- quinine found in tonic water.

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

Hearing aids can be adapted with a soft noise generator. This 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. This causes 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 programmed 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. This causes nerve-filled membranes to stretch, which can cause hearing loss, ringing, vertigo, imbalance and a sensation of pressure in the ear.

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

Auditory agnosia

This rare condition involves difficulty in recognising non-verbal sounds, but still being able to speak normally, because of injury to the temporal-parietal parts of the brain. It often resolves itself over time.

Practical tips for any hearing impairment

There are practical steps a person can take to lessen many hearing problems. Many of these steps will help with other aspects of a TBI and other brain disorders.

These include:

avoid noisy, stressful environments where possible

talk with trusted friends and 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.

Visual Disorders

Our vision is a complex system that processes what we see with our eyes and sends information to the brain. A brain injury can disrupt this complex process, causing a person to experience what is known as neurological vision impairment.

People with neurological vision impairment may experience problems focusing, eye muscle coordination impairments and changes to their peripheral vision. These difficulties can cause people to strain in order to process visual information, leading to an increasing sense of fatigue.

The extent of visual impairment will depend on the severity and location of the brain injury. Treatment is possible through rehabilitation and the management of symptoms with vision often improving as the brain heals.

Causes

Head trauma can cause damage to parts of the brain responsible for visual information processing. Even if the head does not hit anything directly, whiplash can cause damage. Trauma may injure arteries, stretch nerves or damage the spinal column. It can also create soft tissue damage that may cause eye muscle coordination problems and other symptoms.

Common visual impairments

LOSS OF VISUAL FIELD

The visual field is the full area that a person can see around them. Loss of visual field is a common problem after brain injury and limits the size of the visible area. This can impact a person's perception of space and movement causing them to easily trip or fall and impacting their ability to read. Treatment will include exercises to regain or compensate for visual field as well as the use of special eyeglasses and mirrors.

DEPTH PERCEPTION

The visual perception of depth and 3-dimensional structure is made possible by the slight differences in what is seen by each eye and the way the brain interprets these images. Problems can be a result of physical damage to the eyes themselves but following brain injury, is more commonly associated with dysfunction in the brain's ability to process visual signals. Depth perception is important for daily tasks involving movement such as climbing stairs, reaching for objects and driving a car.



EYE MOVEMENT

A combination of eye movement types including rapid response, slow pursuit, alignment and stabilisation allow us to perform a range of visual functions. These include maintaining a fixed view, tracking moving objects, focusing and balancing – all critical for daily tasks such as reading and driving. Brain injury may cause eye movement difficulties when parts of the brain responsible for controlling the nerves and muscles involved in eye movement are damaged.

LOW VISION

Low vision is a loss of sharpness and contrast, causing things to appear blurred or distorted. It primarily impacts a person's ability to read, use a computer, watch TV and recognise faces as well as impacting other aspects of daily life. Low vision cannot be treated by conventional eyeglasses, however, can be helped with special eyeglass lenses and magnifying aids.

LIGHT SENSITIVITY

Light sensitivity is an increased visual sensitivity or intolerance to light. Sources of light such as sunlight and bright interior lighting can cause significant discomfort, often making a person feel they need to squint or close their eyes. Light sensitivity after a brain injury can cause headaches and significant feelings of fatigue or tiredness. Treatment may include tinted eyeglass lenses to reduce the brightness and intensity of light.

DOUBLE VISION

This condition may cause a person to see two sets of a single object, resulting in confusion and disorientation. Individuals experiencing this condition are often given an eye patch to cover one eye, although this reduces the field of vision and interferes with daily function. Special eyeglasses and vision therapy can also be used.

Reading difficulties

Common reading problems related to vision can include losing place, skipping lines and difficulty moving to the next line. Reading ability can improve over time as a person recovers, but this will depend on both their age and the severity of their injuries.

Vision rehabilitation

After a brain injury some people experience a natural recovery from visual impairment, usually within six months. Those who don't recover naturally will benefit from vision therapy and the use of prescription glasses and other aids.

Vision therapy can enhance the natural recovery process. A clinician skilled in both visual impairment and brain injury will understand the interaction of these problems and make plans 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 can provide individual treatment options that will incorporate lenses, prisms, low vision aids, and vision therapy activities.

Loss of Sense of Smell (Anosmia)

Traumatic brain injury often damages the part of our brain responsible for our sense of smell.

Smell is considered the fourth most important sense and contributes greatly to the sense of taste. The sense of smell originates from the olfactory nerves which 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 smell and taste which is called anosmia.

Causes

Trauma to the head can cause anosmia. Damage to the brain from trauma, stroke, and other acquired brain injuries can also cause anosmia by damaging smell processing cells in other lobes of the brain or by physically damaging the nasal structures.

Recovery

Recovery from anosmia varies greatly and depends on both cause, severity of damage and treatments involved. For anosmia caused by direct damage to parts of the brain that control the senses, there may be gradual recovery as the brain heals itself and medications are administered as treatment. When anosmia is caused by swelling or bruising that puts pressure on the brain, there may be improvements as the swelling subsides or is treated with surgery.

Importance of testing

It is a good idea to have suspected anosmia tested. Treatment will most often depend upon 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 the effects of medications.

Weight loss or gain

Since the ability to taste and enjoy food and drink depends on our sense of smell, anosmia often impacts a person's eating habits. In some people it can lead to reduced appetite and weight loss. In others it can cause weight gain, as a result of eating foods higher in salt and fat content to feel satisfied.

Managing anosmia

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

When it comes to eating, a person with anosmia can find ways to make food interesting again. The texture and temperature 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 contrast. Hot meals can be eaten with a cold salad for different temperature experiences and spicy food will cause similar temperature sensations on the tongue.

Sexual Changes

Acquired brain injury (ABI) can have a number of consequences for an individual's sexual functioning.

Talking about sex can be embarrassing, but an ABI can impact on a person's sexual functioning. Although sexuality is part of being human, there is a great deal of stigma around displaying inappropriate sexual behaviour. It is important for the person with brain injury and their loved ones to discuss the various issues.

Understanding from the family

Families and partners can have trouble understanding how impulsivity, disinhibition and lack of awareness can lead to sexual changes and can react negatively.

As a result, there are times when a person with brain injury may display inappropriate sexual behaviour and will need support in modifying this behaviour. It is helpful if members of the family are able to become comfortable in discussing sexual issues and to work with their loved one and professionals in implementing behaviour modification techniques.

Impulsive behaviour

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. Behaviours may include fantasising, lewd verbal responses, disrobing and/or masturbating in public, impulsiveness and touching others.

Common changes

Sexual changes are common after a brain injury.

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.

These changes may be a direct result of damage which occurred 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

Some of the reasons for changes in sexual function include:

- low motivation
- medication
- 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

For many people sex is a personal and private aspect of life, and so seeking professional advice can be an embarrassing and sensitive issue. 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

PARTNER/SPOUSE REACTIONS

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

- developing greater understanding by seeking information on how to support the person with brain injury
- 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 that is agreed upon by both parties
- 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; 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 and it is wise to discuss this with your child's school. Parents and teachers can access community resources, such as family planning, sexual health clinics and professionals specialising in ABI for support.

MASTURBATION

Masturbation is a normal and healthy sexual activity for many people. However, the person with brain injury may need to be reminded that, while it is an appropriate way to deal with sexual urges, it is a private act.

It is important to establish ground rules to protect the rights and privacy of others, so boundaries around masturbation should be discussed e.g. when, where and how.

In some cases, a partner or spouse may continue in a caring role but no longer wish to maintain a sexual relationship in which case masturbation could be discussed as an option to deal with sexual urges.

Treatment for sexual changes

Professionals can help individuals cope with a variety of physical and psychosocial changes. Following assessment, specific treatment of sexual challenges 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 for 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.

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.

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.

CASE STUDY

Jill's husband, Paul, experienced a number of personality changes after his brain injury. In particular, Paul's behaviour was 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. She then organised 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.

Psychological

Stress, Anxiety and Brain Injury

While stress is part of everyday life and a natural reaction when major change occurs, its impact can be much greater following brain injury.

Stress occurs in response to daily challenges; everything from traffic and noise to relationship problems or money worries. The 'fight or flight' response is driven by the sympathetic nervous system, triggering a series of chemical changes which prepare our bodies for a stressful event. For example, if you think you hear someone breaking into your house late at night, it's likely your body will be mobilised into action - increased heart rate and blood pressure, sweating, dilated pupils and your senses greatly heightened.

While this response is useful in dangerous situations, if our 'fight or flight' response is triggered too often as a result of chronic stress, there can be negative effects, including reduced protection from disease and infection, hypertension, heart, liver and kidney conditions and psychological disorders.

Stress is much worse with a brain injury

Most people find it much harder to deal with stress after a traumatic brain injury or similar brain disorder. Coping with stress requires many different cognitive functions; recognising the symptoms, identifying causes, formulating a coping strategy, maintaining control of emotions appropriately and then remembering these techniques.

A brain injury can dramatically affect each of these areas, resulting in a much-lowered ability to cope with everyday stresses. For family members, this can be hard to understand and seem like whingeing, being over emotional or even being immature.



Understanding and managing stress

The first step to reducing stress is to become aware of the major sources that exist in your life. It can be useful to keep a stress awareness diary for a few weeks, listing 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

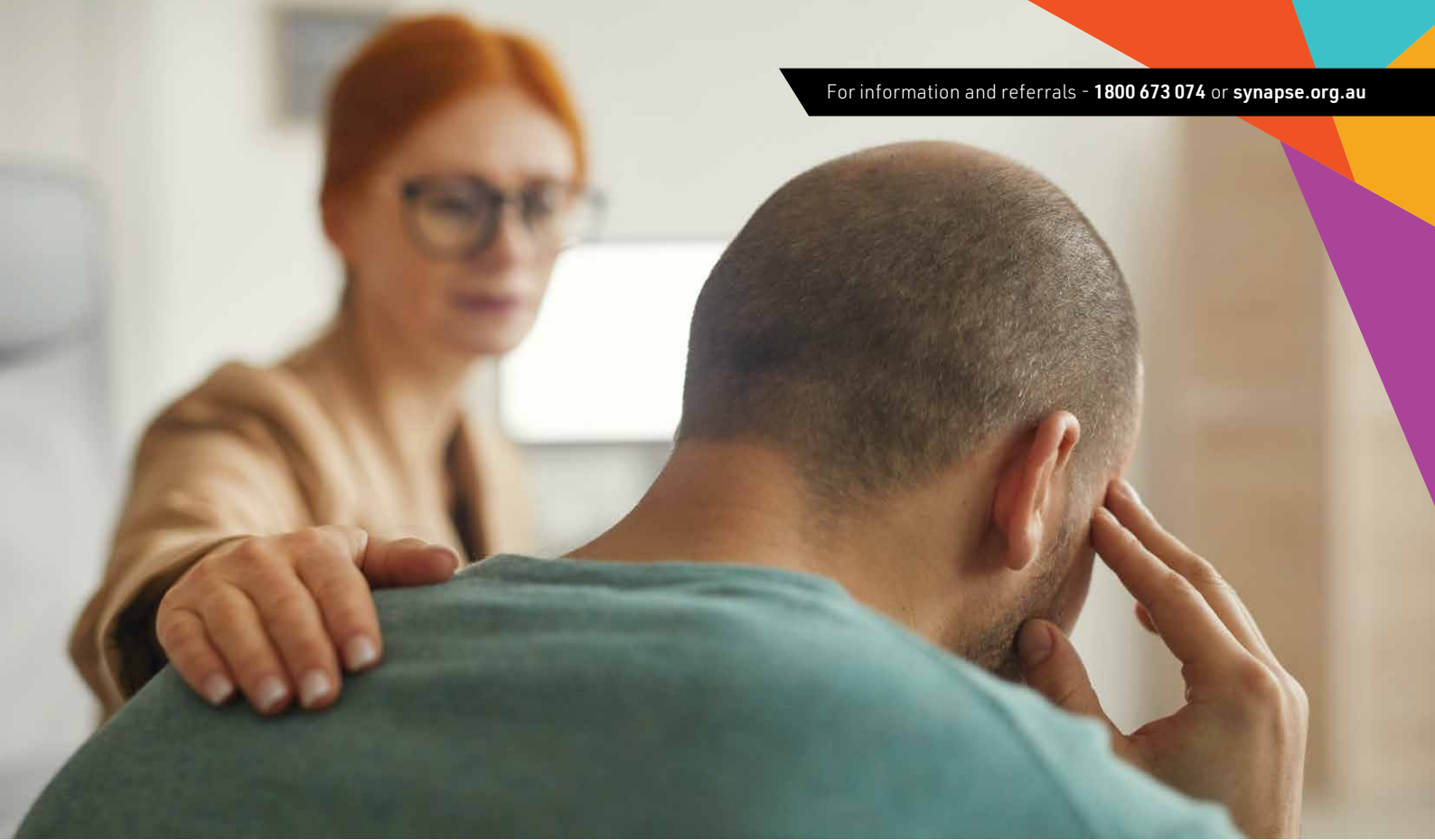
uncontrollable

important

unimportant

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

There are also four key skills involved in managing stress: awareness, acceptance, coping and action. To better understand their roles, we can use the example of a person who is stressed because they have an appointment for a neuropsychological assessment.



AWARENESS

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

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 it.

COPING

Preparing to cope with stressful situations by learning various coping strategies. Identify what changes you might be able to make to control the situation and reduce stress levels.

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

ACTION

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 other coping strategies for managing stressful situations which include:

progressive muscle relaxation – tensing up and then relaxing particular muscles, in sequence, for a number of seconds at a time

slow breathing – by breathing slower and more deeply from your stomach, you send a signal to your nervous system to calm down

visualisation – using mental imagery – either of how you would like the situation to play out, or of a relaxing environment such as being in nature – to achieve a more relaxed state of mind.

Panic Attacks

Panic attacks occur when the body reacts as if it is in grave danger in a situation where there is no imminent threat.



Symptoms of a panic attack

Panic attacks can occur at any time, repeatedly and without warning often leaving the individual feeling like they are dying. The symptoms of a panic attack include elevated anxiety, heart palpitations, hyperventilation, muscle pain, dizziness and sweating, often accompanied by a fear of totally losing control. These symptoms 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.

The physical symptoms of a panic attack are 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 anxiety disorders

Panic attacks are an anxiety disorder that can be accompanied by other conditions such as depression, or they can give rise to the development of phobias or panic disorder. For example, experiencing a panic attack in the supermarket may cause someone to associate the supermarket with anxiety, leading them to avoid going in the 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 and anxiety disorders

There are various treatments for panic attacks, with research showing cognitive behavioural therapy (CBT) 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 change anxiety-generating thoughts. The premise is that it is not the events that cause anxiety, but how we think about those events.

MEDICATION

Anti-anxiety drugs and similar medications can be very helpful, although they can have unwanted side effects for some people. They are best used with other strategies including counselling and learning more about the condition.

DIET AND EXERCISE

Good 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 anxiety for some people.

Managing anxiety - 10 strategies to try

1 Slow breathing.

When you're anxious, your breathing becomes faster and shallower. Try deliberately slowing down your breathing. Count to three as you breathe in slowly – then count to three as you breathe out slowly.

2 Progressive muscle relaxation.

Find a quiet location. Close your eyes and slowly tense and then relax each of your muscle groups from your toes to your head. Hold the tension for three seconds and then release quickly. This can help reduce the feelings of muscle tension that often comes with anxiety.

3 Stay in the present moment.

Anxiety can make your thoughts live in a terrible future that hasn't happened yet. Try to bring yourself back to where you are. Practising meditation can help.

4 Healthy lifestyle.

Keeping active, eating well, going out into nature, spending time with family and friends, reducing stress and doing the activities you enjoy are all effective in reducing anxiety and improving your wellbeing.

5 Take small acts of bravery.

Avoiding what makes you anxious provides some relief in the short term, but can make you more anxious in the long term. Try approaching something that makes you anxious – even in a small way. The way through anxiety is by learning that what you fear isn't likely to happen – and if it does, you'll be able to cope with it.

6 Challenge your self-talk.

How you think affects how you feel. Anxiety can make you overestimate the danger in a situation and underestimate your ability to handle it. Try to think of different interpretations to a situation that's making you anxious, rather than jumping to the worst-case scenario. Look at the facts for and against your thought being true.

7 Plan worry time.

It's hard to stop worrying entirely so set aside some time to indulge your worries. Even 10 minutes each evening to write them down or go over them in your head can help stop your worries from taking over at other times.

8 Get to know your anxiety.

Keep a diary of when it's at it's best – and worst. Find the patterns and plan your week – or day – to proactively manage your anxiety.

9 Learn from others.

Talking with others who also experience anxiety – or are going through something similar – can help you feel less alone. Visit our Online Forums to connect with others.

10 Be kind to yourself.

Remember that you are not your anxiety. You are not weak. You are not inferior. You have a mental health condition. It's called anxiety.

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Developing Mental Illness after Sustaining Brain Injury

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.

Australian statistics show that around 42 per cent of people with brain injury will experience a mental illness.

Experiencing feelings of grief and loss are normal, and there might be sadness around the loss of pre-injury personality traits and strengths, or the levels of social support received after injury. However, ongoing and lasting despair and lack of motivation might be indicative of disorders such as depression. It is best to seek professional assessment by a doctor.

Diagnosing mental illness

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

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

Dual diagnosis

'Dual diagnosis' is a term 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 effects of brain injury and mental illness can often look similar, so misdiagnosis and other complications are possible. The mental illness may be affecting skills in memory, attention and planning – areas also commonly impacted by brain injury.

An undiagnosed or untreated mental illness can negatively impact the brain injury rehabilitation process by worsening mindset, low motivation and unhelpful coping mechanisms. Untreated, it can increase risks such as 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. It can be difficult to source treatments for both, as they can be confused, but help is available. One option is to seek the support of an advocate to resolve this lack of support for dual diagnosis situations.

It is appropriate to undergo assessment by a qualified specialist, such as a neuropsychologist or psychiatrist. This will help to outline supports and services in the community.

How can family help?

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

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

Seek advice from an appropriate professional or service for a suspected mental illness.



Clinical Depression

Clinical depression is a serious disorder that impacts on a person physically, emotionally and even cognitively - slowing thought processes and reducing the ability to concentrate.

Normal sadness is caused by upsetting or disappointing circumstances, and resolves over time. Clinical depression is influenced far more by inherited body chemistry than circumstances. It is hard for people who have not experienced clinical depression to understand its impact and severity.

Diagnosis of clinical depression

A diagnosis is based on one of the following two elements being present for at least two weeks:

- depressed mood, or
- the absence of pleasure or the ability to experience it - anhedonia.

In addition, at least five of the following ten symptoms must also occur:

- feelings of overwhelming sadness, fear or lack of emotion
- decreased interest in daily activities
- changing appetite and marked weight gain or loss
- disturbed sleep patterns
- unintentional and purposeless movements
- fatigue, mental or physical, and loss of energy
- intense feelings of guilt, anxiety, hopelessness and worthlessness
- trouble concentrating, making decisions or remembering
- recurrent thoughts of death or suicide
- fear of being abandoned by those closest.

Treatment of clinical depression

There are two primary modes of treatment, typically used in conjunction - medication and psychotherapy.

Medication

Most antidepressants are believed to work by slowing the removal of certain chemicals from the brain. These chemicals are called neurotransmitters (such as serotonin and norepinephrine). Neurotransmitters are needed for normal brain function and are involved in the control of mood and in other responses and functions, such as eating, sleep, pain, and thinking.

Antidepressants help people with depression by making the natural neurotransmitter chemicals more available to the brain. By restoring the brain's chemical balance, antidepressants help relieve the symptoms of depression.

Psychotherapy

Therapy offers people the opportunity to identify the factors that contribute to their depression and to deal effectively with the psychological, behavioural, interpersonal and situational causes.

Skilled therapists aim to:

- pinpoint the problems that contribute to depression
- identify and assist with negative or distorted thinking patterns
- explore learned thoughts and behaviours that contribute
- help regain a sense of control and pleasure in life.

Suicide risk

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. Warning signs to look for include:

- statements like "It would have been better if I had died"
- making threats about committing suicide
- having a plan for suicide and the means to achieve it are very strong indicators of intent and must be taken very seriously.

All suicidal comments need to be taken seriously and 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.**

Further information

Beyond Blue

www.beyondblue.org.au - 1300 22 4636

Lifeline Australia

www.lifeline.org.au - 13 11 14 for 24/7 support.

Sane Australia

www.sane.org.au - 1800 18 7263



Brain Injury and Suicide Risks

People with an acquired brain injury may be at risk of suicide at some stage of their recovery process. It is very important for family members and friends to recognise the danger signs, know how to help and who to turn to for advice or referral.

Brain injury's impact on mental health

An acquired brain injury (ABI) can cause sudden and lasting changes in a person's thinking, how they react to certain situations, their work and how they relate to others. Brain injury can lead to an increase in stress, as well as difficulty in managing emotions and relationships. At the same time, brain injury adversely affects a person's ability to deal with these challenges.

People might appear the same but nevertheless feel a disturbing sense of change within. Brain injury can cause people to be more impulsive and have trouble considering other perspectives. Without appropriate support this can lead to feelings of isolation and helplessness.

These are among the factors that cause depression and increase the risk of suicide among people with brain injury. Without support, a person in this situation might see suicide as an answer to seemingly unsolvable problems, such as enduring emotional distress or disability.

Recognising the signs

A suicide attempt is not usually made following a sudden or impulsive decision. Rather, it is more common for individuals to shift between stages on a continuum. These range from initial suicidal thoughts (ideation), to planning how (intent), to following through on a suicidal act. A person may move back and forth across these stages, progressing forward in severity or returning to earlier stages where suicide is no longer considered

The broad stages include:

- planning
- organising means to attempt suicide
- attempting suicide (intentional or misadventure)
- suicidal act.

Initial signs to be aware of

- statements such as 'It would have been better if I had died'
- any threat about suicide
- behaviour that is very withdrawn or depressed
- a history of having attempted suicide in the past.

It is important to look for cues, particularly when a person has attempted suicide before, and assist the person to seek professional help.

Signs of increased risk

- evidence of a specific plan
- drug abuse or extreme behaviour
- catastrophic reactions to relatively mild stress
- a crisis that precipitates the event.

How others can help

A person who is considering suicide desperately needs to know that others care and that help is available. Sometimes just being with a person helps, even without talking. Simply listen to what the person is saying about themselves and their life. It's reassuring for the person to know that you care and are always willing to listen and talk with them.

Encouraging them to reach out is also important. Counselling services and GPs can be a first port of call to provide support, but the person may need your help to engage with them.

Intervention for people at risk of suicide

Crisis intervention can include immediate support via telephone counselling, referral to a psychiatrist or close monitoring. Medical and psychiatric treatment is an option, including the use of medication, hospitalisation and psychological therapy. In the long-term, it is important that people are linked to support systems such as mental health case management.



Crisis intervention strategies for very high risk of suicide

These strategies aim to increase a person's sense of choices available to them, and increase feelings of being emotionally supported:

- establish rapport, e.g. 'I'm listening and I want to support you'
- ask whether the person has considered suicide
- if yes, have they made a plan
- explore the person's perception of the crisis and what they can do right now to stay safe
- develop options and a plan of action e.g. going to GP to get a mental health care plan – increase the options available to the person and the number of people available to help (professionals and family members)
- suggest they call Lifeline Australia www.lifeline.org.au – 13 11 14 for 24/7 support.
- arrange removal of the potential means of suicide, if this is possible
- 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
- try to involve appropriate people in the person's natural support system
- if you are concerned for their welfare, call the **emergency services on 000.**

Effective communication techniques

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'
- 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?'

Avoid these techniques when offering support to people who are distressed they will make the person feel as if you are minimising their distress, and potentially stop the person from seeking support in the future.:

- 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's not that bad*'
- probing or intrusive questioning, e.g. '*why do you think your girlfriend left you?*'

If you are considering suicide

If you have an ABI and are considering suicide, you should know that you are not alone. Most people think about suicide at one time or another. Thinking about it does not mean things can't get better. There is a lot of help and support available.

Brain injury causes physical issues that can lead to depression. It is important to seek medical and professional advice to help deal with these physical problems. The crisis will pass even when it feels like it won't.

Don't be afraid to talk about your problems with someone who can help. Let family members, friends, your doctor or other professionals know how you feel.

If you are in need of immediate support, 24/7 support is available by calling Beyond Blue on **1300 22 4636** (or visit them online at beyondblue.org.au) or Lifeline on **131114**.

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. Relatives and friends may also benefit from seeking professional help to express their feelings and receive advice.

Organisations such as Lifeline www.lifeline.org.au or Suicide Call Back Service www.suicidecallbackservice.org.au, **1300 659 467** have resources for supporters.

Behavioural

Anger

Anger is a very common emotional response after a brain injury and can be directly related to impairments caused by the injury and difficulties with self-regulation.



Anger after a brain injury

A brain injury can damage areas of the brain involved in the 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 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
- 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. The person can then 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. These can include an increased heart rate, sweating, muscles tightness or raised voice.

Impulsive Behaviour

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

How does a brain injury cause impulsive behaviour?

The frontal lobe of the brain is responsible for executive functions, including controlling impulses. Damage to the frontal lobes and reduced ability to control impulses can be caused by trauma, alcohol and other drugs, dementia, other types of brain disorders, and mood disorders.

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 can result, as existing relationships break down and there is an inability to form new ones.

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. 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. Other options include behaviour 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 for them to respond positively when needed. 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.

Self-centredness

The ability to view the world from someone else's point of view is a complex cognitive skill that occurs in the frontal lobes of the brain. This is a commonly affected part of the brain, which can cause self-centered behaviour.

What is self-centered behaviour?

Some people with brain injury can appear to become very self-centred and display egocentricity more normally associated with a young child.

That is because 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.

”

“

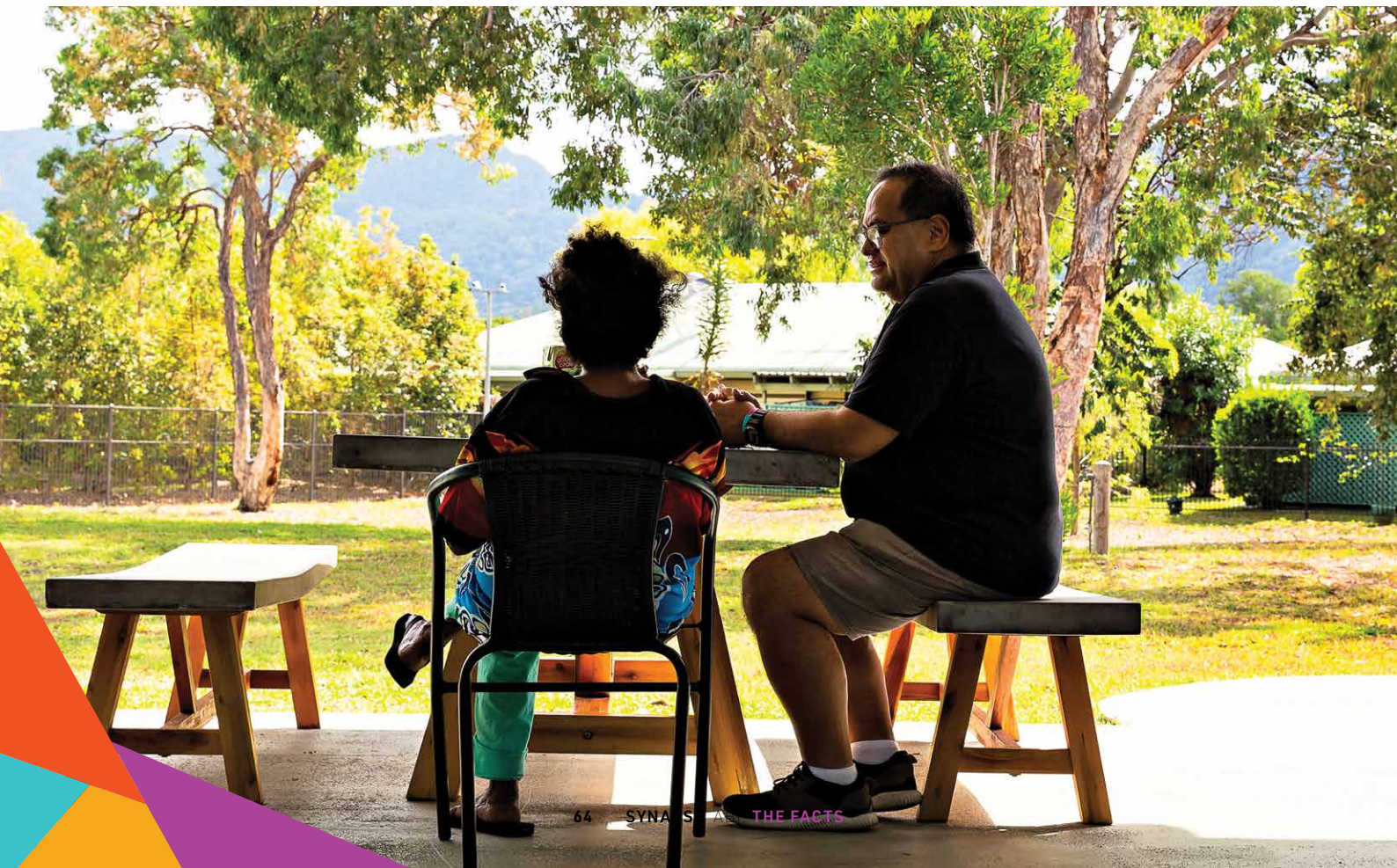
Before her stroke, Belinda was a great listener. But now she never takes an interest in my life anymore and gets frustrated when the kids want her attention.

”

“

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 complex cognitive skill. This is just one of many sophisticated mental skills that occur in the frontal lobes of the brain which are frequently damaged with brain injury. This is why self-centredness frequently goes hand-in-hand with lack of self-awareness, anger, depression, fatigue and reduced social skills.

Impact on the family

Families are usually overjoyed when a loved one survives the initial trauma of 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 and move away from the friendship, leaving family as the person's only social connections.

In some cases, the person may be able to portray a cheerful, caring unchanged personality around their old friends, but this is a very difficult task for the person, which uses a lot of cognitive and emotional energy, and it can't be maintained for very long. As a result, they 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 challenges they are facing in this regard.

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 brain injury has caused the self-centredness brings them to a point where they can accept the changes and find ways to manage the situations that arise.

Sometimes the family contributes to the problem without intending to. In the early days after the injury, it's common for families to try to do everything for their loved one. The person with a brain injury may be re-learning how they relate to others and how others relate to them. So they may learn that it is normal for the dependence, the attention, and being the priority in the household. If this



happens, families need to re-establish boundaries and ensure that they are taking care of themselves as well.

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; they are not intentionally being inconsiderate.

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 may try various strategies to get what they want. This can include 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 in this regard 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.

Impaired Awareness

Lack of self-awareness is a common outcome for people who sustain brain injuries with frontal lobe damage. Their inability to self-monitor and self-correct behaviour can lead to challenging behaviours.

Lack of self-awareness after a brain injury

Lack of self-awareness is a common outcome for people who sustain brain injuries with frontal lobe damage. It becomes difficult for a person to assess his or her own ability and limitations, depending on the degree of injury. They may not be able to recognise it, they may not know how to respond or they may refuse to acknowledge the problem exists. They may believe family members are lying or exaggerating the problems. This lack of self-awareness can also lead to unrealistic goals such as returning to work too quickly.

Increasing self-awareness

It is possible for a person to increase their level of self-awareness but can be challenging because they may not want to take part in rehabilitation for problems they don't believe exist.

Any techniques used to help increase self-awareness will depend on the specific challenges with insight.

The main causes are:

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

Common techniques in rehabilitation include:

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

- provide non-judgmental 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.

In some cases, insight can develop over time if a person experiences repeated setbacks. While upsetting, periods of disappointment at being unable to regain skills and abilities can lead to an improvement in self-awareness.

Self-awareness and challenging behaviours

The inability to self-monitor and self-correct behaviour can lead to challenging behaviours after a brain injury.

Partners and family members can feel frustrated if the person denies there is a problem. The person may not recognise when it occurs or have may trouble controlling their own behaviour. Where possible, the family should work with the rehabilitation team to respond consistently to challenging behaviour.

Domestic Violence

Challenging behaviours after a brain injury can sometimes lead to domestic violence within a family.

Why does this happen?

Traumatic brain injuries often result in damage to the frontal lobe. This area of the brain used in reasoning, problem solving and controlling our more basic impulses and emotions such as anger. An individual who has sustained a brain injury has often lost these skills which can result in difficulty controlling responses to feelings of anger. In some cases, this can lead to violent outbursts with minimal provocation and little warning.

Brain injury also affects social judgement and the ability to know what is appropriate in different situations.

Examples include:

- an adolescent who spits in his mother's face when told he can't go out
- a grandfather who screams constantly at a niece he used to adore
- a husband who hits his wife whenever he doesn't get his way.

Because brain injury also affects self-awareness, a person may feel justified in saying others were responsible for provoking their anger.

Management techniques

While allowances need to be made for changes brought on by a brain injury, actual violence requires an immediate and consistent response and should never be tolerated.

Family members should respond to inappropriate behaviours as soon as they emerge. This will prevent a pattern of family abuse becoming established in the home. Ignoring angry outbursts and not setting limits can lead to a cycle of violence developing.

Positive behaviour support

There are a variety of strategies available for families to minimise the chances of domestic violence occurring. The strategies within the positive behaviour support approach include:

- establish consistent rules
- 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.

Remember that because brain injury affects memory and self-awareness a person with brain injury may not remember past violent behaviour and their actions should not be taken personally. Try to find out what triggers the behaviour and avoid or minimise these in the future.

Families can respond to issues of anger and violence early by discussing and establishing 'family rules' before the person returns home.

Obtain specialist help

Behaviour specialists are available if rehabilitation has already finished. There are many strategies available such as:

- working on communication skills
- anger management
- relaxation techniques to control aggressive behaviour with a positive behaviour support plan.

Holding a family meeting whereby all members are trained to treat aggressive behaviour consistently within a positive behaviour support plan.

Personal support

It is important for carers and family members to have support networks around them; people to talk to and people who understand. Joining a local support group is a great way for carers to connect with families who are in similar situations. Synapse runs a number of support groups, both in person and online – check out www.synapse.org.au for details.

Safety plans

Carers need to remove themselves from a potentially violent situation the moment they no longer feel safe.

It is important to maintain a safe environment by removing potential weapons or dangerous objects. This includes 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 contact police and report the abuse or request a restraining order.

Contact Synapse on **1800 673 074** for information about available support and advice.

This includes information on legal, emergency accommodation, restraining orders and appropriate support for the person with a brain injury.



SECTION 4

In the Hospital

The time in the hospital can be an overwhelming experience, but there are things that you can do to minimise stress.

Knowing why things are happening, what to expect, and being familiar with treatment suggested can help family members to understand what is happening during this stage. There are staff in the hospital who are there to provide you with support and help you through this time.

At Hospital

A brain injury has an immediate effect on the family as they battle a wide range of emotions while coming to grips with the hospital system.

The initial hospitalisation, waiting for a prognosis and even things like understanding medical terminology can all add to stress. There are many places to find support at the hospital, both for the patient and family members.

Coping with stress in hospital

Support in hospital

In the Intensive Care Unit (ICU), a registered nurse is always available and assigned to patients. Most hospitals should have a social worker available who can assist with information and navigating the hospital system. There is going to be a lot of information for you to understand, at a time when your ability to process information and remember things is going to be limited by the stress. Make lots of notes, and be sure to ask staff to write things down, and to provide printed material that you can keep, and look back on later. Hospital staff (particularly the nursing staff) have seen many people go through this, so not only will they understand, they may have helpful suggestions or ideas.

Emotional reactions for the family

It is very stressful for families when a loved one acquires a brain injury of any kind. A period of shock or disbelief is common at first. Many report a sense of unreality and being on "automatic".



It is perfectly normal to feel a loss of control, panic, anxiety, fear, despair, distress, guilt, blame, anger, and/or absolutely nothing at all. It is also perfectly normal to feel all these things at once or swing between them. It is going to be hard for a while, so be kind to yourself. There is no 'right' way to react or to feel; there is nothing you 'should' be feeling or experiencing. Those around you are going through the same thing, but it is important to remember that how someone is acting may not be an accurate reflection of how they are feeling. If possible, forgive yourself and others for lapses in social skills or failing to live up to the standards you would normally expect.

Waiting for the prognosis - predicting the future

Predicting the level of recovery after a brain injury is difficult. Doctors are usually cautious about early prognosis. Family members and other visitors have the right to ask questions, express a point of view, and receive clear and timely information. Sometimes the answer may be "we don't know" and this may be the only honest answer available. Patience and persistence are required in the search for information.

Understanding medical information

Understanding medical terminology can be difficult, especially during times of stress. However, it is better to ask questions than not understand what is happening. If hospital staff use words you don't understand, ask them to explain things in a simpler way.

Some hospitals hold meetings with family members where you can ask questions. Write these down and record the answers. Common examples include:

- What are your treatment goals?
- What is being done to achieve these goals?
- Do you have any idea of how much recovery can be expected?
- What ongoing effects from the brain injury are expected?
- How can the family help at this point in time?
- Should we be doing anything now to prepare for discharge?

Coping strategies

This is a very stressful and emotional time for family members. Look after your own emotional and physical health so that you can provide support for the person with brain injury and each other in the weeks ahead. Commonly, the family feel they should be at the hospital as much as possible, but it's recommended to go home regularly and recharge your batteries as the recovery process can be long.



Tips for self-care include:

remember to eat well and get regular sleep

organise a rotating schedule for visits by family members

talk with others about your feelings and experiences and maybe join a support group

reduce other sources of stress in your life

accept support e.g. meals being cooked or help with housework

be aware others may deal with the situation very differently to you

maintain a sense of normality with routines and structure in your life

learn as much as you can about brain injury

call Synapse on **1800 673 074** to find out about available support.

Emotional Recovery

A brain injury in the family can disrupt almost every aspect of life, creating emotional turmoil that impacts on everything and everyone in some way or another.



When a person sustains a brain injury or similar type of brain disorder the focus is very much on regaining lost physical, cognitive and social functioning. But the emotional response to brain injury can be just as challenging.

Emotional recovery means feeling happy about your life and yourself again; while physical recovery can be relatively rapid, emotional recovery can take many years.

A sense of shock and loss is common after brain injury. The person with the injury may experience lost friendships, independence, abilities, career and opportunities. And family members and partners too can experience loss – where there are personality changes, some have said it is like losing a loved one but being unable to say goodbye.

Grief can have a serious impact upon a person's recovery but there is no one single method for dealing with it; people mourn in their own personal way and eventually begin to heal.

Dr Elizabeth Kübler-Ross (1969) described a the 5 stages of grief which 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 accept the situation as it is and will deal with it)

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.

Other models of grief include Bowlby's:

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.

While the journey to emotional recovery is often challenging, and impacted by the severity of injury, a combination of time, awareness, family support, and social networks can all influence the person's experience of grief.

Support and Advocacy

There are many places to find support in the hospital. We take a look at some of them.

Advocacy - in hospital

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.

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.

Synapse also runs support groups, both in person and online. Call **1800 673 074** to find out more.

Informing the patient

Conversations about the person with brain injury's condition (or another person's death) require sensitivity and may be distressing for families. The focus of family members at this time is typically the wellbeing of their loved one, and they may be worried about sharing upsetting information with them.



It is recommended families discuss any concerns with hospital staff who will provide guidance. It is usually preferable to tell patients any traumatic news although their reaction may be different than expected or they may forget quite quickly as a result of their injury.

Coma and Brain Injury

Coma is generally the result of damage or interference with particular structures of the brain, and its length and depth provide a strong indication of the severity of brain injury.

A coma means a person is in a state of unconsciousness. They do not show intentional response or movement, the eyes remain closed, and they cannot be awakened or obey commands during this state.

During a coma

The person may still show some level of response to touch, pain, and verbal commands, depending on the depth of coma they are experiencing. Family members often have trouble accepting their loved one is in a coma when there are basic responses.

A coma can be chemically induced to accelerate healing, protect the brain from secondary damage, or to relieve severe chronic pain during healing after a traumatic brain injury (TBI) or other kind of brain disorder.

Post-coma unresponsiveness (PCU)

Some coma patients may progress to a wakeful but unconscious state called post-coma unresponsiveness (previously called persistent vegetative state) where the cerebral cortex is not functioning. The person is unable to respond to stimuli in their environment, but they maintain a normal sleep-wake cycle and breathing.

People can remain in this state for a long time, and it can be difficult for family members to accept when there are seemingly conscious behaviours e.g. a patient's eyes may follow them around the room.

Coma scales – measuring comas

There are two scales commonly used to measure the depth and duration of a coma. The most common is the Glasgow Coma Scale (GCS) which scores actions and reactions in three specific areas including eye, verbal and motor response. The scores in each area are summed to give an overall score, ranging from 3 (deep coma) to 15 (fully awake). The Rancho Los Amigos Scale is another measure of coma, it has a single scale and assesses global functioning.

Treatment during a coma

During a coma the medical team provides treatment to prevent any further complications. A respirator may be used to assist breathing, and surgery may be required to stop any bleeding or swelling in the brain. There is constant monitoring of vital signs, such as blood pressure and pulse and levels of any prescribed medications.

Other therapies may be used to prevent problems upon awakening from coma. There is a risk of the patient losing their range of motion in their extremities, so the limbs will be moved regularly.

Changing the patient's position is also necessary on a regular basis to prevent pressure sores or skin ulcers, as the patient will not have the reflex actions that prevent these sores from occurring.

Are people aware during a coma?

It is difficult to know if there is any degree of awareness during a coma. As a patient emerges from coma, awareness of those around them increases. There have been cases where patients reported awareness of family members around them and could remember some of what was said. For this reason families and medical staff should be careful of what is said near the patient while in a coma.

How long will a coma last?

There is no reliable way to accurately tell how long a coma will last and there are currently no medications which will reliably shorten the duration of a coma. A coma is usually said to last no longer than four weeks, but post-coma unresponsiveness may last from months to years.

Post-traumatic amnesia (PTA)

Unlike the popular concept of coma shown in many movies, an individual coming out of a coma doesn't just wake up. There is usually a gradual process of regaining consciousness and when intentional movement or attempts to communicate are seen, the person is generally considered to have emerged from coma.

Following emergence from a coma, the patient enters another level of consciousness known as post-traumatic amnesia (PTA). Individuals in PTA are partially or fully awake, but are confused about the day and time, where they are, what is happening and sometimes who they are.

The duration of PTA can be used along with that of the coma to provide an indication of how severe the traumatic brain injury or other type of brain disorder is, and what the long-term outcomes are likely to be.

It is also possible for an injury or pressure to the frontal lobes to mimic the effects of PTA, so diagnostic scans may be used during PTA to ensure that the diagnosis is correct as well as to ensure that healing is progressing normally.

Diagnosis

The long-term effects of a brain injury may not be evident for some time.

This makes predictions of recovery difficult in the months following a brain injury. Health professionals look at several indicators to predict the level of a patient's recovery during the first few weeks and months after injury.

Tests and Scans

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

What the tests examine

Neurological 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.

The long-term effects of a brain injury may not be evident for some time. Those with a mild brain injury may be able to return to work but still have some cognitive challenges. Others may require higher levels of care or specialist housing.

MRI, CT and MRA

The MRI (Magnetic Resonance Imaging) and CT (Computed Tomography, also known as CAT - Computerized 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 hemorrhaged 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.

EEG

The Electroencephalogram (EEG) records the ever changing tiny 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 widespread 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 see areas of slowing of electrical activity.

PET scan

Positron emission tomography (PET scan) shows the size, shape, and function of the brain. A small amount of a radioactive material (called the tracer) is added to some glucose molecules, which is then injected into a vein or breathed in by the patient. The glucose tracer travels through the blood to the brain, giving off photons. The patient is placed in a photon detector, and by counting the photons being emitted, and calculating their positions, it is possible to tell how much blood is being supplied to, and used by, the various parts of the brain. This can help determine the location, extent, and type of damage, making it easier to make a diagnosis.

Combined MRI/PET scan

This allows for the simultaneous measurement of anatomy, functionality and biochemistry. 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

Single-photon emission computed tomography (SPECT), 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.

Evoked potentials

Every time we hear, see, touch or smell our brain generates an electrical signal. Evoked potentials are recorded by placing wires on different parts of the scalp for different senses.

Lumbar puncture

A lumbar puncture is a diagnostic test where cerebrospinal fluid is extracted for examination, and pressure of the spinal column is measured. It is used to test for brain and spinal cord cancers, cerebral haemorrhage, and infections including meningitis and encephalitis.

MRS & MRA

Magnetic resonance spectroscopy 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.

Magnetic resonance angiography produces extremely detailed pictures of body tissues and organs 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. The magnetic field is not known to cause any tissue damage.

Intracranial pressure monitor

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

Determining Brain Injury Severity

Several indicators are used to make predictions in determining brain injury severity.

How predictions are made

Doctors look at several indicators to predict the level of a patient's recovery during the first few weeks and months after injury:

- duration of coma
- severity of coma in the first few hours after the injury (as measured by the Glasgow Coma Score)
- duration of post-traumatic amnesia (PTA)
- location and size of contusions and haemorrhages in the brain and severity of injuries to other body systems sustained at the time of the brain injury.
- Individuals in PTA are partially or fully awake, but are confused about the day and time, where they are, what is happening, and possibly who they are. They are likely to have problems with memory.

Precise predictions are difficult with brain injury, but some generalisations can be made:

- the more severe the injury, the longer the recovery period, and the more impairment a survivor will have
- recovery from diffuse axonal injury takes longer than recovery from focal contusions
- recovery from TBI with hypoxic (lack of oxygen) injury (e.g. near drowning, strangulation or carbon monoxide poisoning) is less complete than without significant hypoxic injury
- the need for surgery does not necessarily indicate a worse outcome. For example, a patient requiring the removal of a blood clot may recover as completely as one who never needs surgery.

The length of time a patient spends in a coma correlates to both post-traumatic amnesia (PTA) and recovery times. PTA is the gradual process of regaining consciousness after coma:

- coma lasting seconds to minutes results in PTA that lasts hours to days; recovery occurs over days to weeks
- coma that lasts hours to days results in PTA lasting days to weeks; recovery occurs over months.
- coma lasting weeks results in PTA that lasts months; recovery occurs over months to years.

Length of PTA is frequently used as a guide to the severity of brain injury. A commonly used interpretation of the scale involves the following:

General Guide

Severity Category	Mild	Moderate	Severe	Very severe
Initial GCS	12-15	9-11	3-8	<1
Duration of PTA	< 24 hours	1-7 days	1-4 weeks	> 4 weeks

A general finding is that if the PTA stage lasts for more than one week ongoing cognitive problems can be expected.

It is important for the person and the family to be optimistic but realistic about recovery and to develop a better understanding of what is or isn't possible. Some families with a loved one in hospital have likened this to hoping for the best while preparing for the worst.

Why Predictions Are Difficult

Predictions of recovery are difficult in the months following a brain injury.

Why are predictions 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 will 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 should ideally commence while the injured person is still in hospital and continue 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.



Factors influencing long-term outcomes

Recovery will continue for years after the injury. Neurons can take up to 5 years to heal, and there is no reason to stop teaching the brain new ways to do tasks that have been effected by the injury. The rate of improvement, will slow down over time, but there is no need for it to stop.

Long-term outcomes are 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.

Treatment

Treatment options vary depending on individual patients and injuries.

Being familiar with treatments, terminology, and medical staff titles can help you understand what's going on. There are many professionals who form the medical team, and being familiar with these roles can help you understand their contribution to the recovery process.

About the Medical Professionals

There are many professionals who may form part of the medical team.

Medical staff

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 intensive care unit.

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.

Visiting Medical Officer: a visiting medical officer is a senior doctor subcontracted by the hospital to provide oversight and mentorship for registrars and residents. This role may also be called a VMO or consultant.

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.

Medical Director: a senior doctor responsible for a department or unit.

Ward Consultant: a doctor who is assigned to a particular ward to oversee the care of patients in the ward.

Resident: a junior doctor who will rotate through all the specialist areas of a hospital in order to gain experience and skills unique to these areas.

Other health professionals

As well as the above medical specialists, there are many professionals who may form part of the medical team for treating a stroke, traumatic brain injury and other brain disorders.

Below are brief explanations of those likely to be involved in acquired brain injury situations.

Nursing 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

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.

Orthotist: a specialist technician who develops and fits mechanical devices such as a brace, splint or body jacket.

Speech language pathologist: a specialist who assesses and treats communication and swallowing difficulties. Sometimes there may be damage to the voice and articulation mechanisms, such as the breathing, tongue and facial muscles.

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

Other professionals who may be involved in monitoring a person's condition or providing care at different stages of recovery include a dietician, ear nose and throat (ENT) specialist, ophthalmologist, psychiatrist, radiologist, recreational therapist and rehabilitation coordinator.

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

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.

Neurosurgery

A neurosurgeon specialises in treatment and surgery of the nervous system and surrounding structures.

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

Swelling will cause 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. A neurosurgeon can remove blood clots pressing on the brain and surgically repair damaged blood vessels to stop any further bleeding. In severe cases, portions of the brain damaged beyond recovery may be removed to increase the chances of recovery.

The neurosurgeon can also insert an intracranial pressure monitoring device. This alerts the medical team if swelling reaches dangerous levels. A ventricular drain may also be used to drain off excess fluids.



SECTION 5

Recovery and Rehabilitation

A good rehabilitation program is vital to optimise recovery following brain injury.

Recovery and rehabilitation is a long-term process and needs to be tailored to the specific needs of the individual. A rehabilitation program will involve a variety of therapies and support services once a person is medically stable. These therapies will ideally begin in the hospital, and often continue after returning home to ensure the best long-term outcomes.

Leaving Hospital

The return home from hospital after a brain injury is usually eagerly awaited by family members.

The rehabilitation team – your practitioners

A team of professionals are usually involved in your rehabilitation to assist with different parts of recovery including:

A **physiotherapist** may be involved in assessing and assisting with muscle strength, balance and mobility.

An **occupational therapist** helps with relearning practical tasks of everyday life such as dressing, washing and using cutlery.

A **speech language pathologist** works not only with communication difficulties but also with problems of swallowing.

A **social worker** may assist with counselling and advice about community support, financial issues and other services.

A **neuropsychologist** may assist with cognitive changes and problems controlling emotions.

The **rehabilitation doctor's** role is to integrate medical requirements and treatments with the other therapies.

Before leaving the hospital, check that you have the documents you will need, including medical certificates, and documents required for NDIS, NIS, and Centrelink. If you are unsure you can call Synapse on **1800 673 074**.

What to expect

The amount of changes a family has to make will depend on the degree of brain injury. For example, in the case of a severe traumatic brain injury, the family may be taking on a full time caring role and need a wide range of supports. With a mild brain injury, an almost complete recovery might be expected but the family may need to assist the person with ongoing rehabilitation at home for behavioural issues and cognitive changes such as memory problems.

Hospital discharge information

Upon discharge, the hospital should provide a wide range of information on topics such as:

- prescriptions and medications
- cognitive changes and how to respond appropriately
- symptoms of any complications that could need urgent treatment
- activities to avoid and for how long (e.g. work, driving, drinking alcohol)

Family members can contact the hospital to ask for any information that has not been provided. Usually the social worker is the best person to provide this information.

The first few days after discharge

For the first few days after discharge, make sure you:

- ensure someone stays with you for the first two days
- can easily contact emergency services if needed
- don't drink any alcohol
- rest as much as possible and don't rush into activities

Important symptoms to watch out for

Learn as much as you can about brain disorders. There are various symptoms that are normal after a brain injury. These include headaches, inability to concentrate, fatigue, depression, memory problems and poor sleep. These generally do not require medical treatment but if you have any concerns consult your doctor.

Having My Health Record set up, is one way to ensure that all your healthcare providers can access information about your injury, tests, diagnoses, treatments, and medications. You can control what information is included and who it can be shared with. For people with multiple healthcare providers it is an easy way to ensure that everyone has access to vital information about your care. For more information, go to www.myhealthrecord.gov.au.

However, there are symptoms that could indicate urgent treatment is needed. Examples of these include:

- any unconscious episodes
- vomiting
- increased disorientation or loss of balance
- loss of hearing in one or both ears
- changes in vision
- sudden difficulty understanding or speaking
- paralysis or weakness in the limbs
- bleeding from the ears, or clear fluid from ears or nose
- severe headaches not relieved by paracetamol.

Ongoing rehabilitation

The family plays a key role in ongoing rehabilitation once a person is discharged from hospital and formal rehabilitation has ended. The rehabilitation team should provide information about how family members can help long-term.

In some cases a person will return home after a brain injury with unrealistic expectations about how soon they can return to activities such as work and driving, if at all. The family may need to help the person slowly come to terms with their abilities and the length of time recovery can take, especially if self-awareness has been affected.

Fatigue is an extremely common problem after a brain injury. Overdoing activities can bring on extreme fatigue that lasts several days.

Challenging behaviours can emerge after the return home due to various cognitive changes. While this can be difficult for families, having consistent appropriate responses to these behaviours will make a significant difference. Most rehabilitation specialists recommend avoiding alcohol for at least two years, if not permanently, after a significant brain injury.

Support for family members

Family members may have to take on new roles and responsibilities as part of the changes needed to care for their loved one. For example, a person may have to take on the role of breadwinner or full time parenting for the first time, and children might be asked to help around the house more. Support is available for carers and their family.

Call us on **1800 673 074** to find out what's available.

Accommodation Options

The effects of a brain injury can be diverse, so a wide range of accommodation options are needed.

Planning ahead

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:

- the level and type of support needed
- the funding available to the person, including NDIS, NIS, and Centrelink
- the family's social support network
- the family's capacity to provide care in the home or nearby
- services available in the area
- local amenities in the area (e.g. parks, cafes, restaurants, cinemas, shopping centres, chemists)

Living close to places of interest allows people to engage with them regularly. Less time on travel means more support hours available to engage in the things people enjoy.

People need the flexibility to move to more independent living as they re-master life skills. Below is a list of accommodation from high support through to more independent living options.

Nursing homes

Nursing homes have long been a 'last resort' for young people with high-care needs, however, they are not suitable. There are a number of organisations working towards moving young people back into the community, including Synapse. 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 specialising in brain injury are available for people with high-care needs. These facilities provide a transition for people who might benefit from ongoing intensive rehabilitation but cannot remain in hospital because they are medically stable. It is important to think about accommodation well before discharge so that the transition home is smooth and timely. These facilities are usually located in capital cities and can have long waiting lists.

Supported accommodation (also known as specialist disability accommodation)

Supported accommodation is a residence 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 either hire their own support staff, or share the cost of support staff with housemates (this option will be cheaper but everyone must agree on the support agency and workers chosen).

For more information about the NDIS and NIIS, phone the enquiry lines: **1800 800 110** (NDIS) / **1300 302 568** (NIIS). Alternatively, you can call us first on **1800 673 074**.

Supported accommodation might not always 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.

Living with friends or family

A person with brain injury may choose to be supported by family and/or friends at home. Carers might take on the role because they want to provide personal care and support, or find that available alternatives are inappropriate or expensive.

Taking on the role of carer is demanding and requires support. Respite care is available so that carers can take regular breaks. Government funding is also available to provide carers with financial support.

A creative alternative chosen by some is to build a detached dwelling so that their family member can live semi-independently, while still having access to support. This is a long-term option for some, and a transition for others who will ultimately move into their own home. Another option is to buy or rent an apartment near family or friends to make it easier for them to visit and provide support.

Hostels

Hostels are rarely appropriate for people with brain injury, but can be suitable for people who are more independent. A hostel is 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 a support worker or nursing assistance. (e.g. toileting, personal care). Many hostels cater for people with a mental illness and have psychiatric support specialists visiting on a regular basis.

Your own home with support

Being supported to live at home can be an expensive option but one that most people prefer. In most cases a home will need to be modified to make it accessible and safe (e.g. building ramps to replace steps or installing handrails). People who choose to live at home will also need to access some level of care and support.

Those who are eligible for an NDIS or NIIS funding package will be able to include home modifications and support in their request for funding. There are a wide range of services available to help people stay in their homes including home-delivered meals, community nursing, support with daily living and community participation.

The Synapse Options team can provide you with information and assistance with accessing financial support and the services you need in order to stay at home.

Equipment and Lifestyle Aids

Equipment and lifestyle aids have a role to play in helping people regain some or all of their independence after a brain injury.

Lack of coordination, problems with movement and poor vision are just some of the effects of brain injury that can make everyday tasks like eating, dressing and getting in and out of bed difficult to do. Fortunately, there is an ever-growing list of lifestyle aids that are designed to compensate for these types of problems.

Occupational therapists, physiotherapists, and speech therapists are among the health professionals with expert knowledge about choosing the right aids. The list below is a general guide to what is available and how they can help.

Eating and drinking

Tables and chairs The first thing to think about is sitting safely and comfortably. It helps to have a chair with a contoured backrest and armrests for support that can be adjusted to the right height for the table. Tables with a cut out section help a person feel stable and to reach what they need easily.

Cutlery A wide range of modified cutlery is available. For problems with grip, built up handles work well and so do Velcro straps that wrap around the hand and the handle of cutlery. Cutlery might be lighter, heavier or shaped differently to help overcome the variety of challenges people have.

Plates and bowls It helps to have a plate guard that clips to a plate and provides an edge for people to push against. Suction cups on the bottom of plates and bowls are another modification that allows people to eat meals independently.

Cups and mugs are also modified in ways that make them easy and safe to use. A cup might have extra large handles on both sides, be insulated to prevent burns or have a lid and spout to help regulate the flow of liquid into the mouth.

Straws can have a one-way valve for people with difficulty sucking and swallowing.

Dressing and grooming

Clothes and shoes There are aids to help people dress themselves independently, whether it is doing up buttons or putting on stockings, socks or shoes. Some clothes are specially designed to be easy to get in and out of. Look for Velcro and elastic instead of zips and buttons, and think about t-shirts and other types of clothing that are easy to wear. Shoes often have Velcro or elastic laces instead of shoelaces so that they are easy to slip on and off.

Grooming aids Aids are used for everything from brushing hair to cutting toenails. Hairbrushes might have longer handles to help people reach, while heavier items like hairdryers can be mounted using suction caps. A universal cuff is a Velcro strap, which wraps around the hand and is used to place objects in a tubing pocket so there is no need to use fingers.

Adjustable beds and transfer equipment

It is important to choose a bed that meets an individual's support, comfort and function needs.

Beds can be electronically or manually adjusted to put people in positions that are beneficial and comfortable. For example, a knee break adjustment may be used to elevate the knees without elevating the feet and prevent the user sliding down the bed.

Height adjustment is often used to make it easier for carers to nurse someone, assist transfers and change the linen. There are many helpful accessories, such as built in massage, bed extensions and rails.

Companion beds are two beds that can be placed directly beside each other. Depending on the needs of the users, both or only one of the beds may be adjustable.

Adjustable beds need suitable mattresses that are flexible enough to bend with the movement of the bed. There is a choice of inner spring, latex or foam. If a person is likely to spend a lot of time in bed and is at risk of developing pressure ulcers, a pressure care mattress or overlay can help.

Transfer equipment is used to help people get in and out of bed or reposition themselves. These might include a bed stick, which acts like an anchor point for people to hold onto as they turn in bed, or a self-help pole, which is a triangle shaped handle that sits above a person's head and allows them to lift themselves up from the bed. Transfer equipment is also designed for carers, the most common being the slide sheet.



Recovery 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.

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. A steady and consistent approach to rehabilitation makes a big difference as it is important to avoid fatigue.

Acceptance

There will be times when it will seem impossible to see past the challenges you are facing. That's OK – that's a normal part of adjusting. Trying to deny the pain, fear, suffering, loss, grief, or pain you are experiencing will not make it go away, it will just make you feel bad for feeling bad. Accept that you are going to have bad moments, but also remember that these bad moments (like all emotions) will pass, and over time, they will happen less often and be less intense. Remember to give yourself, and your family, credit for all the things you have managed to do since the brain injury

happened. It is easy to underestimate how much we have adapted and how far we have come, so be sure to take note of it, and pat yourself on the back for it. It might help to tell others in your family that you can see how much they have changed, adapted, or learned new things.

Talk to someone

If you find that you cannot see any positives, it might be a good idea to see a psychologist. Talking to a psychologist can help a great deal. Make sure that the psychologist you see is registered with the Psychology Board of Australia (PsyBA) and listed with the Australian Health Practitioner Regulation Agency (AHPRA).

Go to your GP and ask for a referral and a Mental Health Care plan to let you claim a Medicare rebate. Alternative, the Australian Psychological Society have a web page to help you find registered psychologists in your area. go to www.psychology.org.au/Find-a-Psychologist



Resilience

Resilience can be helpful for individuals and families managing brain injury. A good rehabilitation program will enhance resilience by identifying individual and family strengths.

Some of the qualities associated with resilience are:

- having hope for the future
- having close relationships
- the ability to be independent, proactive and get things done
- the ability to solve problems
- the ability to enjoy laughter and respond to humour despite tragic situations (Rees, 2012)

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. It is common to feel bitter, resentful, or as if it is punishment. In some cases, finding a positive outcome from the brain injury can help during rehabilitation. For example, a person may never

work again but discovers happiness in volunteer work that is helping others. Others become involved in brain injury support groups and make sense of their injury by seeing how they can help others in a similar situation.

Structure and routine

There is a large amount of difference in how much structure we like in our lives, such as when to eat, rest, sleep and work. After a brain injury, however, structure and routine provides predictability that allows the brain to rest and save its energy for rehabilitation. Having meals at regular times and maintaining a healthy diet is vital. Having a weekly timetable for meal times, rest periods, rehabilitation tasks and exercise on a big poster or whiteboard will provide gentle memory prompts and encouragement if memory or motivation problems exist.

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 (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.



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.

Synapse runs support groups for people with brain injury and their families - both in person and online.



Maintain friendships

It is beneficial to stay in touch with friends during the rehabilitation and recovery stage. This can be scheduled and might be as simple as a quick phone call or email. It might be necessary to let friends know what kind of support is needed. For example, allow time for the person with brain injury to answer and understand that they will tire quickly.



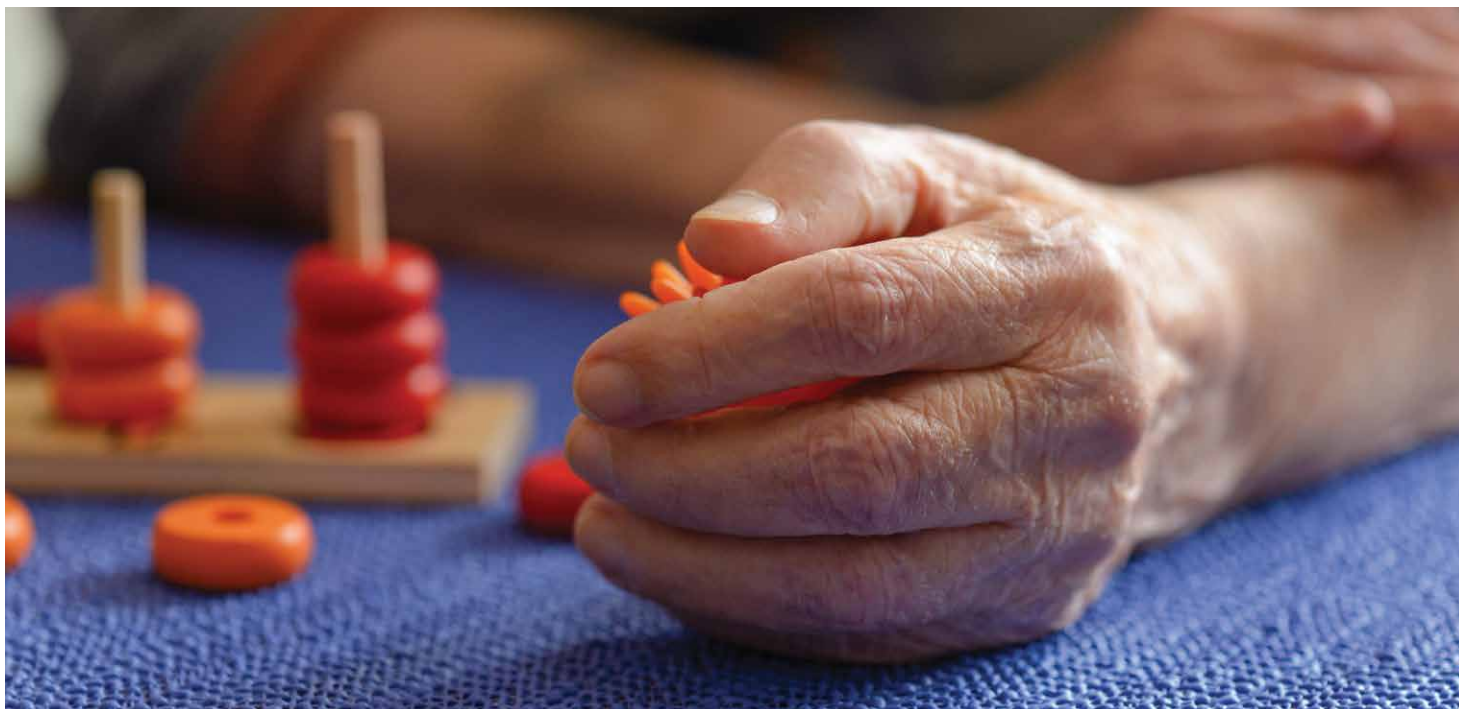
Reduce the chances of another brain injury

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.

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Neuropsych Assessment

What does a neuropsychological assessment evaluate?

A neuropsychological assessment will usually be provided in the early stages of recovery. The main aim of the assessment is to maximise the survivor's rehabilitation and participation in family, work and the community.

The assessment can also be used to guide rehabilitation, and evaluates the following areas of functioning:

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

The neuropsychologist will usually look at a person's case history and hospital records. They will also talk to family members to learn about the person's functioning before the brain injury.

Benefits of a neuropsychological assessment

As well as guiding the rehabilitation process, a neurological assessment will help the person and their family understand the impact of the brain injury. The neuropsychologist will usually meet with family to discuss the findings. It can be helpful to record the meeting or take notes for future reference. Family members can ask for a written report that covers the case history, current issues, tests conducted, observations, assessment results and recommendations.

The neuropsychologist should explain any expected problem area and the impact these will have on daily life. For example, if a person has damage to the frontal lobes of their brain, they will have difficulty planning and organising. The family can then help by providing structure, prompts and reminders. Similarly, a neuropsychologist can explain where it is unlikely that the brain injury will have an effect on ability.

Obtaining a neuropsychological assessment

These tests can be quite expensive and are usually done during rehabilitation. If this isn't the case, then often universities with programs in neuropsychology provide evaluations at low cost or sliding scale as part of their student training.

Guide to Low Cost Rehab

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

Information about the person's current level of cognitive and behaviour functioning is essential to develop a realistic program. 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,
- 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 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 used 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. These goals are accomplished when the person is able to awaken on their own, independently complete morning hygiene routines, prepare and clean up after eating, and 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 on community-based activities. Initial cognitive retraining activities should probably be conducted within the home setting. Appropriate activities might include working on craft projects, 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 which were learned pre-injury 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 Synapse.

It is critical that not all the points are negative, e.g. Designed to stop 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 you should begin to give honest, objective feedback to the injured person on specific 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. Synapse 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 practices, and 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 re-training 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 service (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 their 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 which is required to integrate the new information and skills with the old until they become as routine as possible.

Ending rehabilitation

At some point in time the injured person and/or family members decide that they no longer wish to pursue rehabilitation. On rare occasions this occurs 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 to adapt this article.

Steps to a Healthier Brain

The brain needs exercise to stay in optimum health, just like our body. Practising skills will lead to better performance and ongoing mental stimulation will help protect against mental decline.

Exercise and challenge your brain

Challenging the brain with new tasks will create new pathways. 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.

Brain exercise is anything that makes you think. Here are just some examples of how to exercise your brain:

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

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

- Not all fats are bad – unsaturated fat and protein is especially important for developing brains. Fish, a rich source of both, is sometimes called brain food.
- Your brain needs vitamins and minerals that only come from a balanced diet. In particular, the antioxidant vitamins E and C protect the brain.
- Avoid excess food. Reducing calories can help slow age-related brain changes.
- If you 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 with natural sugar, such as fruit, can solve the problem.
- The timing of meals is important, particularly breakfast.

Enjoy physical activity

Regular daily exercise reduces depression and the risk of cardiovascular disease. Anything that increases the heart rate and blood flow is also good for the brain. A simple walk is enough to increase feelings of wellbeing. A 12-minute bout of exercise (to 85 per cent maximum heart rate) releases serotonin, dopamine, and noradrenaline. Exercise can easily be built into daily activities, such as using stairs instead of lifts. Exercise physiologists and rehabilitation specialists can help you reach your goals.

Make “safety first” a priority

People with an existing brain injury are at greater risk of acquiring another one. Take common-sense safety precautions seriously. This includes wearing seatbelts and sports helmets when needed.

Manage anxiety, stress and depression

Learning to manage stress will enhance your wellbeing and help prevent very real health problems. Unchecked stress levels can lead to anxiety, which increases the heart rate and blood pressure. This can lead to stroke. Unlike acute stress (the fight or flight response), which is short-lived and normal, ongoing stress has a negative impact on the body and increases the risk of:

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

There are many strategies to enhance relaxation while decreasing stress and anxiety:

- use established relaxation techniques, such as actively tensing then relaxing individual muscle groups
- practice meditation
- exercise to channel internal stress into external action
- mentally let go of things outside your control
- ensure a balance between work and recreation
- take time out for yourself
- see your doctor if you have difficulty managing stress.

The importance of sleep

Deep sleep allows the brain to repair itself and boosts the immune system. During rapid eye movement (REM) sleep, the brain consolidates information learned during the day. Poor sleep leads to fatigue, immune suppression, lack of memory, poor concentration and mood disorders.

Worrying about perceived problems is the most common reason for not falling asleep easily. If you have trouble

going to sleep, try the relaxation techniques above and follow these tips:

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

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. This means 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.

Neurological Physiotherapy

Neurological physiotherapy treats movement disorders caused by injury to the nervous or neuromuscular systems.

The causes of this type of neurological impairment include:

- brain injuries
- spinal cord injuries
- Parkinson's disease
- multiple sclerosis
- motor neuron disease
- stroke.

There is increasing evidence that this therapy can improve situations even when the condition is degenerative.

In the case of brain injury, common effects can include tremors, spasms, weak muscles and a lack of balance and coordination. A therapist will look at the functions a person has lost as a result of injury, and then determine the type of training needed to regain those skills.

Neurological physiotherapy requires a sound knowledge of anatomy, biomechanics and neurology. Typical work involves being able to:

- maintain a seated position
- move from sitting to standing
- walk with assistance
- cross a road safely.

The techniques involved in neurological physical therapy are wide ranging and require specialised training in tailored exercises, mobility aids and splinting.



Speech Deficits and Speech Pathologists

Speech language pathology encompasses the diagnosis, assessment and treatment of communication and swallowing disorders.

The complexity of language

The ability to communicate effectively is a skill that most people take for granted. It isn't often that we stop to think about the complex nature of speech and language.

For example, have you ever stopped to consider how our brain is able to process over 200 words per minute every hour of the day without tiring? Or why, when you finish reading this sentence, your voice will instinctively rise to mark the use of question? Further, how do you know that the combination *mgla* could not possibly be a word, but the combination *flast* is permissible?

Speech Language Pathologists

These and other questions are investigated by speech language pathologists (SLP). Formerly known as speech therapy, the allied health discipline of speech language pathology encompasses the diagnosis, assessment and treatment of communication and swallowing disorders.

Communication - the means by which we understand and make ourselves understood - can break down in the areas of speech, fluency, voice, language use, hearing, reading and

writing. As one in seven Australians experience some form of communication disability, the role of the SLP in hospitals, educational settings, nursing homes as well as specialist and private practice, is growing.

Speech language pathologists work as part of a multidisciplinary team, often alongside physiotherapists, occupational therapists, doctors and nurses. As the caseload of the SLP is so varied, their responsibilities may include treatment of swallowing disorders following stroke, working with parents of a new born baby with a cleft palate, reducing voice strain in teachers and providing information and rehabilitation to patients who have suffered an acquired brain injury.

As with all frameworks for speech pathology intervention, it is the aim of the SLP to treat not only the presenting impairments, but to also determine their impact on a patient's activities and participation.

Consequently, it is the role of an SLP to not only diagnose and assess patients, but to consider the patient as a whole, understanding the impact of impairment on a patient's social, emotional and vocational aspects of life.

Speech, Language and Acquired Brain Injury

Human communication comprises three fundamental neurological processes that may become impaired as the result of an acquired brain injury.

The overall aim of these processes is to facilitate effective communication, in which we can plan and execute exactly what we want to say. The three steps involved include:

Understanding and organisation of a thought, e.g. knowing that saying 'hello' requires the production of four distinct sounds h-e-l-l-o.

Programming of the motor components, e.g. knowing that to produce the /h/ you need to release a quiet stream of air from the back of your throat.

Execution of the thought, e.g. actually producing the word 'hello' by using certain speech muscles.

A breakdown can occur at any one or more of these stages, depending on the location and severity of the acquired brain injury.

A breakdown at Stage 1 - APHASIA

Aphasia is characterised by an impaired understanding and production of language and is usually the result of damage to the left or 'language competent' half of the brain. People with aphasia may find it difficult to:

- participate in a conversation, particularly in a noisy environment
- comprehend jokes or sarcasm
- write a letter or use the telephone
- use money to understand numbers.

In terms of neurology, two major areas can account for the specific deficits seen in patients with aphasia:

- a motor speech-language area, or Broca's area
- a sensory speech-language area, or Wernicke's area.

Essentially, a patient with Broca's aphasia will produce non-fluent, slow and effortful speech, while a patient with Wernicke's aphasia will produce fluent but confused speech.

A language sample from a patient with Broca's aphasia, explaining a scene in a picture:

"Uh...mother and dad...no...mother...dishes...uh...running over...water...and floor".

A patient with Wernicke's Aphasia in conversation:

"His wife saw the wonting to wofin to a house with the umbelor. Then he left the wonding then he too the womin and to the umbrella up stairs."

Aphasia is not considered by most to be a disorder that can be cured, however the overall aim of speech and language therapy is to increase an individual's potential to function effectively in their own environment, to facilitate meaningful relationships and restore self esteem and independence.

A breakdown at Stage 2 - APRAXIA

Apraxia of speech (AOS) reflects an impaired capacity to plan the movements necessary to direct speech. AOS can occur on its own as a result of an acquired brain injury, however it is also seen as a secondary disorder to aphasia. AOS can also occur in childhood.

A patient with AOS is unable to produce correct articulation and flow of speech, despite having functioning speech musculature. Essentially, the impairment occurs at the level of planning the speech output. Therefore, although the patient has enough muscle strength and coordination to produce the word 'hello', they have an impaired ability to plan exactly how to move their lips, tongue and other speech organs in order to produce the word. As a consequence, a patient with AOS will often be seen groping for words as they attempt to program their speech musculature.

The goal of the SLP working with patients with AOS is to maximise effectiveness, efficiency and naturalness of speech. Speech programs may need to be relearned, for example the program that tells us instinctively how to produce the /h/ in hello, in order to restore lost function.

A breakdown in Stage 3 - DYSARTHRIA

Dysarthria is the term given to a group of disorders that reflect impairment in the actual speech muscles. Unlike AOS, patients with dysarthria can plan their speech output, but due to damaged central or peripheral nerves, no longer have the strength or coordination to execute speech.

As a result of nerve damage, for example cranial nerve damage following a motor vehicle accident, various components of the speech system may become impaired. A patient may experience difficulties in respiration control, articulation, resonance or phonation. These difficulties can then present as lowered strength, coordination, range, steadiness or accuracy of speech movements.



Pain Management

Pain can be one of the many effects of a brain injury and it needs appropriate management.

Types and causes of pain

Acute pain starts quickly and is generally short-lived. Chronic pain is more persistent and usually lasts beyond the normal time for healing.

Pain management is important to maintain a reasonable quality of life, as the effects of chronic pain include:

- Faster heart rate and higher blood pressure
- Potential mental health disorders e.g. anxiety and depression
- Increased stress, fatigue and tension
- Gastrointestinal issues.

Early detection of pain and appropriate management are important as otherwise the person may adopt negative ways to cope with the pain. Some of the more frequent causes for pain following a brain injury are:

- Headaches and migraines
- Neck and shoulder pain (after traumatic brain injuries)
- Abscess and skin sores
- Cervical or spine injuries
- Heterotopic ossification (bony overgrowth)
- Kidney stones and bladder infections
- Fractures
- Spasticity
- Constipation.

Chronic pain

Chronic pain can lead to depression, anger and anxiety disorders as sufferers may have many other negative events and stressors to deal with, such as losing their jobs, experiencing financial hardship and having increased stress upon their families. With chronic pain, people may believe the pain is increasing even though there is no medical evidence for this. In these cases other factors are at play including:

- Emotional functioning
- Past learning experiences
- The way others respond to the person's behaviour.

Sleep and appetite disturbances intensify the disability that results from chronic pain. As time goes by, the person may become depressed and preoccupied with normal changes in bodily functioning and may worry about experiencing new illnesses.

The individual can develop a tendency to view all activities in terms of how much pain will be experienced. This can lead to a cycle of helplessness and despair, often accompanied by anger toward professionals who never seem to be able to cure the pain. In turn, professionals lose patience with the person with persistent pain who appears to have limited medical justification for these complaints.

Managing chronic pain

Pain management strategies are usually based on one ultimate and constant objective—the reduction of pain, not its total elimination. If the person experiencing the pain and all of the professionals who treat the individual do not make this the goal, frustration will grow, resulting in failure to coordinate treatment efforts in a successful manner.

Research has shown that having realistic, helpful thoughts is an important part of pain management. Cognitive behavioural psychologists help chronic pain sufferers to change their thoughts about their pain, its effects, and other sources of stress.

One approach views pain as a learned behaviour and is done by a psychologist or neuropsychologist. Other approaches help the person to identify inappropriate and unhealthy beliefs about pain and provide strategies to deal more effectively with pain behaviour. Techniques may include relaxation training, hypnosis, stress management, attention-diversion strategies and biofeedback.



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. Later, narcotics are a problem because of their potential for substance abuse and their negative side effect on the ability to think clearly.

Non-steroidal anti-inflammatory drugs (NSAIDs) which include aspirin, ibuprofen (Nurofen), Voltaren, and other COX-2 inhibitors are appropriate for musculoskeletal pain. However, they can increase the risk of serious gastrointestinal complications (including ulcers) and may increase cardiovascular events in some people, so check with your doctors before taking them.

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

Where to get help

There are support groups and medical facilities set up to help people cope with chronic pain. Ring your local doctor or call Synapse on **1800 673 074** for further information.

Complementary Therapies

People often turn to complementary 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 therapies such as, craniosacral therapy, massage, acupuncture, biofield therapies, hyperbaric oxygen treatment and naturopathic medicines. Anecdotally, these types of approaches have been found to be successful for some when applied to ease the more intractable impacts of brain injury, such as chronic pain, sleeplessness, and mental health issues like anxiety and depression.

Complementary 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.

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/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; ingesting certain herbs while pregnant). It is therefore important to choose a therapist who is accredited in their field. 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, which can have severe interactions with a wide range of prescription medications, including antidepressants and the contraceptive pill. Usage should be discussed with your doctor.

Find quality evidence

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

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.

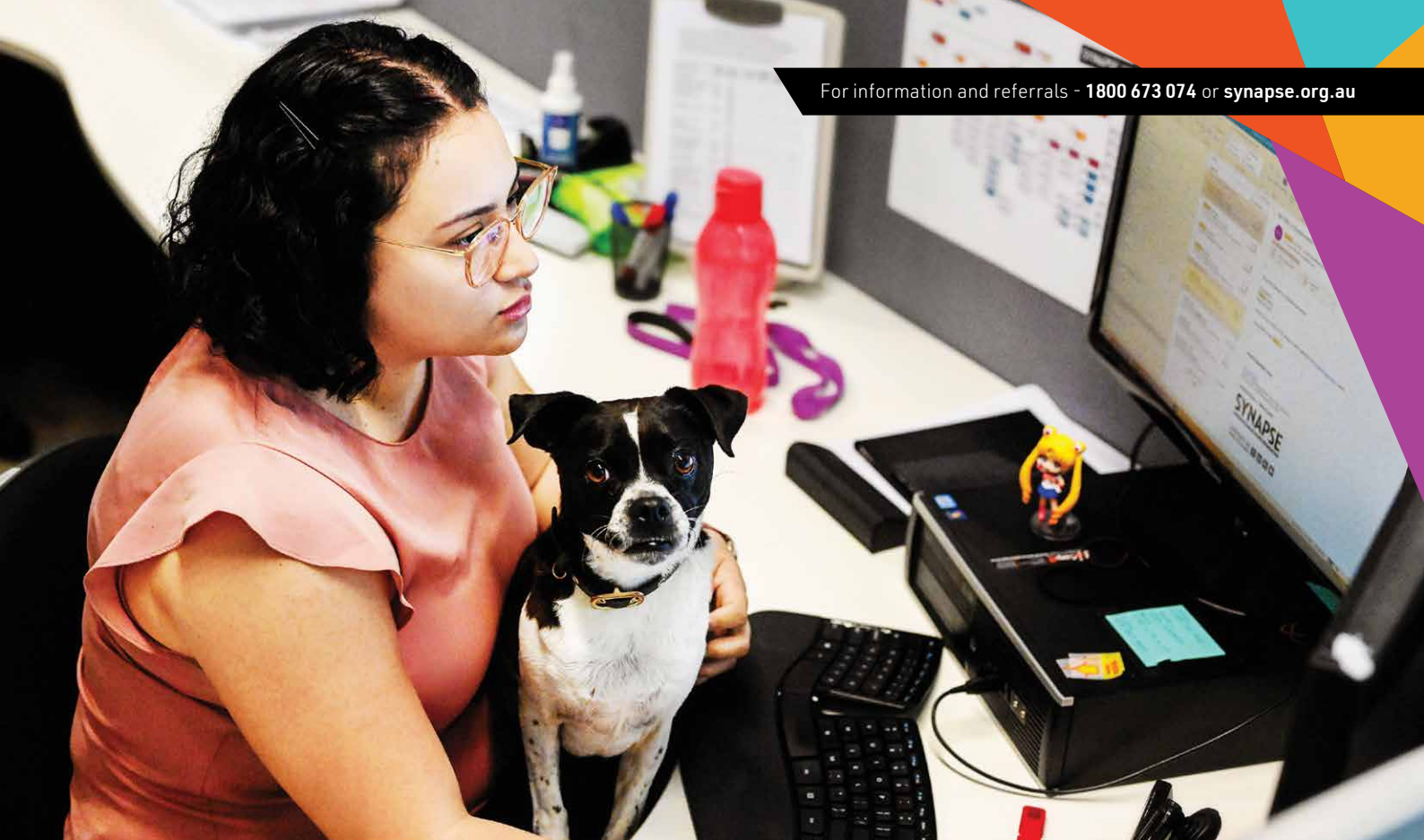
Validity - is the supporting evidence unbiased, performed by knowledgeable researchers and published in a well-respected journal? For example, internet claims that bee stings improve memory could be doubtful.

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 they were in pain.

Applicability - is the treatment performed easily, available to most people, medically possible, and cost-effective? E.g. Is it convenient for a person to transport their own bees around to sting them three times a day?

Purpose - does it do what it should, and for most people? E.g. The bee sting approach should be tested across a broad range of people.

By assessing each approach on its own merits, and thoroughly examining potential risks in conjunction with your doctor, you can decide whether a specific complementary therapy or course of treatment is for you.



Pets as Therapy

While dogs have long been portrayed as 'man's best friend' - a loyal companion - it's not only canines that can prove a source of support and reassurance following brain injury.

The inclusion of pets into hospitals and rehabilitation environments is now widely considered therapeutic; offering acceptance, love and motivation through the most difficult parts of rehabilitation and recovery after a brain injury.

But their impact doesn't cease when the rehab process ends. Pets are excellent companions and have been shown to reduce feelings of loneliness, which can be useful after brain injury if friendships have not been maintained. Indeed, because almost everyone loves animals, this can increase social skills building for individuals when encountering others out and about. Most people, whatever their disability, can take some responsibility for the care of an animal, even if it is no more than a daily stroking or play session.

From a practical perspective, 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 and/ or other assisting devices that increase mobility. Pets can also respond with feedback, which can help reduce inappropriate behaviours, and interest in a pet may redirect egocentricity that often accompanies brain injury.

Selecting a pet can be turned into a cognitive exercise of planning - considering their needs and yours. For example, a sophisticated set up of aquariums with pumps and filters

may be too complex for some. 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, and pets always have time for sharing with their owners.

Importantly, the responsibility for pet care can enhance cognitive functioning in ways that are subtler and more enjoyable than traditional therapies. Fun activities often stimulate individuals with low motivation in ways that are not often achieved by, for example, sitting in front of the television for hours. 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.

Pets are wonderful companions and can frequently impact positively even on those for whom other therapies, exercises and/or future promise for continuing recovery hold little interest. 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 of choice, 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.



SECTION 6

Living with Brain Injury

Living with a brain injury can be a significant adjustment, both to the person with a brain injury and their loved ones.

People with a brain injury often have a goal of regaining any lost skills, and returning to work or study. Looking after your health and wellbeing will give your brain the best chance of improvement, along with strategies that can be put in place to help relearn these skills.

Social

Social skills and self-confidence can be affected after a brain injury. People can lack awareness about their impairments or lose general self-awareness and insight.

People often feel that they need to relearn social skills lost after their brain injury. Regaining these skills can be vital to maintaining existing friendships and making new ones. Joining a peer support group can be helpful to practise your social skills.

Steps to Independence

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

Setting realistic goals

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. Frequently families expect that discharge from a hospital or completion of a rehabilitation program indicates the injured person is 'well' or 'cured', but most individuals 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 person's injury impacts on 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 might want to consider the need for guardianship and other future planning needs.

Neuropsychological assessment

The neuropsychological evaluation is a task-oriented assessment of cognitive functioning. It is 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
- an inability to control impulsiveness
- an inability to 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. 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 toward 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.

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 the bike 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 person to manage independently. This could be 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.

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 often poor, which can be detrimental to 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. For example, behaviours that are considered anti-social or 'disruptive' can be difficult for the general public to understand and sometimes frightening. A combination of positive behaviour support strategies for individuals along with awareness and education for the general community is needed to shift attitudes and increase inclusivity.

Social Skills and Confidence

Social skills and confidence can both be affected following an acquired brain injury.

Rebuilding social skills

Social skills are a complex system of behaviours that determine how well we communicate with others. Our ability to do this is just one of the many life skills that can be affected by brain disorders such as traumatic brain injury (TBI).

Social skills are the foundation for getting along with others. When they are lacking, it becomes difficult to maintain friendships and make new ones. It is also harder to relate to others in the workplace, learning environments and the wider community. People with an acquired brain injury need help in identifying and rebuilding lost social skills.

Those who have sustained frontal lobe damage can lose self-awareness and insight. At the same time, orbitofrontal damage (injury to the very front of the brain) can disrupt an individual's ability to inhibit unwanted responses such as inappropriate anger or sexual expression.

Social skill deficits may be related to the following:

- impulsivity, both verbal and motor
- poor visual perception of facial and body language cues
- poor auditory perception of vocal cues
- invasion of the personal space of others
- inappropriate touching
- disorganisation or untidiness.

Social skills are something we learn and develop with social reinforcement from the people around us. It is important that those with brain injury have feedback from others in order to relearn the skills they have lost. Bear in mind that the learning process can be a challenge when a person is also experiencing mood swings, depression or overreaction as a result of an acquired brain injury.

Social skills training (SST)

Social skills training is a form of behavior therapy used to help people who have difficulty relating to other people. A social skills program will start with an evaluation of the strengths and weakness of a person's ability to function socially. Intervention strategies will then be selected and put in place to address areas of need.

It is important that the physical and social environment is adjusted to create positive interaction. For example, family, friends and work colleagues are likely to be more accepting once they are educated on the effects of a brain injury on social skills.

Using effective ways to teach skill development will also improve a person's chance of rebuilding lost skills. Finally, a person's ability should be assessed and interventions modified continually throughout the program.

Here are some tips if you are unable to access a social skills trainer:

ENLIST THE HELP OF FAMILY AND FRIENDS

This may involve teaching them about acquired brain injury and the effect it has had upon you. Some people may not accept that you have lost skills. On the other hand, others may be prepared to accommodate even severely inappropriate behavior. You may need to ask people to be more critical, and to give you more feedback in the home so that you can relearn how to act appropriately in the community.

JOIN A PEER SUPPORT GROUP

Some groups are for everyone with a brain injury, but there are also groups for specific causes of brain injury - for example, motor vehicle accidents or stroke. Contact Synapse to find a peer support group in your local area.

WATCH OTHER PEOPLE

Don't be too obvious about this! The best way of learning social skills is to practice them, but the second-best way is to watch other people. Of course, not everyone you watch will behave appropriately - a good tip is to avoid reality television and focus on busy public places. Sit at a café in a shopping centre and watch the world go by.

Self-confidence and brain injury

It is natural for people to lose self-confidence following a brain injury. The injury itself can lead to depression and fatigue, which have a major impact on self-esteem.

A group of brain injury survivors once met to discuss and find strategies for issues such as self-confidence.

They agreed that confidence arose from:

- having a purpose to life
- feeling loved
- doing well in a chosen role
- having hope for the future
- being content with who you are.

Brain disorders such as traumatic brain injury (TBI) were seen as having an impact in all these areas, therefore self-esteem was likely to be affected.

Factors influencing self-confidence

The group found that the degree of understanding shown by people close to them and the reaction of the general public made a big difference to how they felt about themselves. Families who understood the effects of the brain injury and were supportive instead of critical played a major part in the brain injury survivor feeling more confident. This issue was a difficult one when there were no outward visible signs of a brain injury, such as a wheelchair or facial scarring. In these cases families were more likely to be critical of the survivor's cognitive problems.

Those who constantly compared their current situation with their situation before the brain injury had more trouble with self-confidence, as did those who could not cope with negative comments from others.

Being assertive about your needs

The group found that being assertive about their needs helped build confidence. By contrast, being either too passive or too aggressive had negative consequences.

A **passive approach** led to feelings of being 'pushed around' and meant agreeing with others despite personal feelings. This often led to resentment and levels of distress building up over time.

The **aggressive approach** was viewed as people 'getting their own way' by arguing, making demands, threatening and generally stepping on others. This behaviour was thought to lead to social isolation.

The group found that being assertive in a positive way involved two-way communication where problems were solved and the message put across in a way that allowed people to feel good about themselves. Survivors knew that they needed to work on communication skills so that they could see the other person's viewpoint and know how to approach topics appropriately.

The group agreed that body language was an important part of being assertive, including: maintaining eye contact, straight body posture and calm speech. Sometimes it helped to practice what they had to say to someone else.

Communication skills for self-confidence

Survivors often feel that they needed to relearn social skills lost after their brain injury. Regaining these skills can be vital to maintaining existing friendships and making new ones. They include:

BEING PREPARED TO LISTEN TO THE OTHER PERSON

If someone is tired or in a particularly upset mood, it is better if they calmly tell the other person that they are unable to listen, rather than trying to listen when unable to concentrate. The other person may appreciate the suggestion of another time that will be more suitable.

LISTENING AND CLARIFYING

It was considered important that people give their full attention when listening and ask for more information when needed, e.g. *'I don't follow, can you explain more clearly?'*

ACKNOWLEDGING THE OTHER PERSON AND LISTENING EFFECTIVELY

This was considered an important part of letting the other person know they have been heard and understood. The best way to do this is by acknowledging their ideas and feelings, e.g. nodding or saying 'I realise that you must be really frustrated about this too', or, 'I can see where you are coming from'.

Personal strategies for self-confidence

People who have survived a traumatic brain injury or similar brain disorder have suggested the following personal strategies for feeling better about themselves:

- spend time with supportive people and avoid negative people
- become more self-aware and try to minimise negative, unhelpful, unproductive thoughts
- try hobbies you might enjoy
- set realistic goals and recognise small gains and achievements
- learn problem-solving skills to handle the bad times
- help someone else
- practise relaxation
- write a poem or verse that has personal meaning for you
- work on meeting new people and improving existing relationships
- make a plan for keeping in contact with others, and do something social every week
- be assertive and communicate your needs to others – not aggressive or passive
- accept that there will be setbacks, but know that things will improve if you persist

- join a support group for survivors
- look after your health by eating well, exercising and getting sufficient sleep
- accept personal limitations while aiming towards self-improvement
- look for inspiring stories in books and films
- grasp opportunities, experience life and make the most of it!

Mantras

Some survivors have found mantras useful. These are personal statements or affirmations that can help you get through a tough time. Some examples are:

- if it is to be, it's up to me
- always stop and think before you act
- learning is an active process and I will learn by doing
- actions speak louder than words.

Some take comfort in the centuries-old prayer:

Grant me the serenity to accept the things
I cannot change, courage to change the
things I can, and wisdom to know the
difference.



Social and Recreational Activities

Having a social life and pursuing interests make life worthwhile and are important to consider following brain injury.

Staying socially connected

One of the most frustrating aspects of brain injury is that people often find themselves cut off from their previous life; unable to do the things they love or keep up with the social life they once had. As with other aspects of recovery, there are ways around these challenges. Although it may not be possible to return to life as before, it is important to seek ways to stay socially connected and find activities that are rewarding and fun.

The first step is to speak with rehabilitation specialists and family to determine what your capabilities and limitations are at your current stage of recovery. It is common for people with brain injury to feel that they are further along the road to recovery than they actually are.

Sport and recreation

The work of organisations such as Disability Sports Australia ensures all Australians have access to sport at a recreational and professional level. Participating in sporting activities is good for your health while having the added benefit of social support networks. Most state governments and some local councils have sport programs for people with a disability.

Learn new skills

Short courses are a great way to discover new skills and hobbies. Local councils across Australia run community programs with short courses and workshops, and usually keep lists of programs run by other organisations. TAFE colleges run adult education courses covering a range of activities such as art and crafts, boating, job skills, computers, cooking, languages, relaxation, interior decoration, photography, sports and creative writing. Online courses are an option when it is difficult to attend classes.

Volunteer

For many, work is an integral part of self-esteem and being unable to work can be a contributing factor to the depression that is common after a brain injury. Volunteering can be rewarding and allows you to work at your own pace according to your current capabilities. Organisations such as GoVolunteer help people find volunteer work.



Study

If returning to previous employment is not an option, studying can be the first step to a new career. Think carefully when choosing a course and speak to rehabilitation specialists for an assessment of your abilities. It might be better to start at a certificate level and commit to one subject at a time, then increase your study load gradually. Most educational institutions should have a Learning Assistance Officer who will help provide you with support through your course.

Social support

Having the support of others is important following brain injury. However, it is not always easy to maintain friendships, particularly if the injury has an impact on communication and social skills. This can be exacerbated by fatigue and sometimes a lack of physical mobility.

During the rehabilitation and recovery phase, staying in touch with friends can be worked into a schedule and might be as simple as making a phone call or sending an email. It is helpful when friends understand what kind of support is needed. For example, allowing time for you to answer or knowing that you will tire easily. Brain injury support groups are a great way to make new friends and share the experience of recovery. The rise of online support groups means you don't need to live nearby to share the benefits.

Emotional

During rehabilitation, people are able to focus on recovery goals and progress is apparent. After rehabilitation ends can be an emotional time without this focus.

When moving on from the structure of rehabilitation, it is important to create a meaningful routine which will make life easier and avoid boredom. It is also important to remember that someone with brain injury will continue to make gains, even after the initial rehabilitation process.

Post-rehab slump

Survivors of a brain injury often make excellent recoveries through, 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.

Why does this occur?

For many years during rehabilitation, people are able to focus on recovery goals and progress is more apparent. Although the recovery process continues after the initial rehabilitation phase, progress can slow down. Some may feel disappointed if they leave rehabilitation without the level of function that they hoped for. It is important to remember that someone with brain injury will continue to make gains with the right support.

'Who is this stranger?'

The life changes experienced by people after brain injury take time 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'. It is common to feel angry, depressed or under stress as a result. Extra support may be needed given that these feelings are harder to manage with a brain injury.

Accepting the new self

With support, 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 might be possible if it is possible to be flexible about how this can be achieved. For example, working again may involve changing careers or volunteering. A person might not go out to socialise often, but invite friends to visit instead.

Accepting a new self, and even learning to appreciate it, can be seen as the final, and often hardest stage of recovery. For some people, being able to re-frame their experience can be helpful. For example, a person might discover new strengths as a result of working to overcome cognitive impairments.

Being unable to work gives people an opportunity to develop new skills and hobbies such as art or gardening, and a lack of energy might be seen as having time to 'smell the roses'. Some survivors make sense of their experience by helping people in similar situations. For example, wrestling with depression gives an insight into the pain and suffering of others.

Joining or starting a support group is a way to share hard-won lessons. Paid work supporting others with a brain injury may also be an option. For others, a spiritual approach or commitment to self-improvement may be the key. In other words, each difficulty can be seen as an opportunity for self- growth and development.

People often find gradual improvement in some areas for 5 to 10 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 by putting strategies in place to avoid or lessen the post-rehabilitation slump. They can work together to develop new goals and activities before formal rehabilitation ends. A clinical psychologist can 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.'*

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.

Recovery after brain injury

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, this idea that recovery reaches a plateau at some point has been questioned. Many people report continued improvements and even significant breakthroughs 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 to make 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.

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.

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.

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 (Eapen & Cifu, 2019). 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 (Galletto & Sacco, 2017).

Avoiding Boredom

Boredom after a brain injury

It is often the case that a person finishes rehabilitation and is not yet ready to return to work or study. If this period of time is unstructured, people can easily become bored or depressed. Structure and social contact are very important after a brain injury, but are often missing during the recovery process.

The following tips show what can be done to create meaningful routines to make life easier and avoid boredom.

Make a weekly timetable

Brain injury can affect a person's ability to plan their day, prioritise activities, make decisions, get started on tasks or know when to stop. Having a regular routine saves you from having to do this every day because it is thought out beforehand.

A weekly plan can be drawn up with activities marked against daily time slots.

Examples of activities might include:

- meals
- housework
- exercise – both general and for rehabilitation
- rest breaks and short naps
- social activities
- hobbies
- reading.

Pace yourself

It is important not to overdo things as fatigue can set in and take a few days to recover from. Work out how long you can do physical, mental and social activities for and stick to time limits. Also, plan these for when you feel most energetic, and if necessary take a short nap or rest in the early afternoon.

Rehabilitation never finishes

Unless a brain injury has been very mild, it is likely that you will have some ongoing effects for the rest of your life. Don't assume the hard work finished when you stopped seeing the rehabilitation team. People who continue their rehabilitation often find they are still making progress years later. Work out what issues you still face, and possible strategies to compensate for them. Work these into your timetable.



Break big things into small steps

Having a project to work on can be very motivating, but a common problem after a brain injury is feeling overwhelmed by the details, or not knowing where to start. Break it down into small manageable steps that you can work into your timetable.

Develop your social skills

This area can be neglected in rehabilitation. A brain injury can cause the following issues:

- talking constantly and not listening to others
- asking intrusive questions
- self-centred behaviour
- inappropriate comments and behaviour
- standing or sitting too close to others.

Regaining lost social skills is critical to retaining friendships, making new ones, keeping healthy family relationships, and any eventual return to work, study or community involvement. If you have any of these issues, talk with close friends or family members about ways to relearn social skills and work these into your weekly plan.

Celebrate the small things

A brain injury can be very humbling, e.g. the former CEO of a multinational company who cries with joy the first time he manages to dress himself without help. Celebrate the small things, because in reality they aren't small things at all. Usually only another person who has a brain injury can understand the incredible effort and willpower it has taken to accomplish those 'small' steps.



Health and Wellbeing

Looking after your health is an essential part of maximising your brain's potential after a brain injury.

One way to look after your health is to make sure that you eat a healthy diet. This is important as our brains need energy and nutrients for healthy brain chemistry, functioning of nerves, and correct neurotransmitter levels. You should also make sure that you take any medications prescribed to you by your doctor.



Nutrition, Diet and BI

A healthy diet is an essential key to maximizing your brain's potential after a brain injury.

The basics of a healthy diet

Poor diet can affect mood, behaviour and brain function. Our brains need energy and nutrients for healthy brain chemistry, functioning of nerves, and correct neurotransmitter levels. That is why a healthy diet is so important for recovery after brain injury.

Fad diets come and go, but the essentials of a healthy diet remain:

- eat a variety of foods including vegetables, fruits and grains
- eat lean meats, poultry, fish, beans and low-fat dairy products
- drink enough water
- limit your intake of salt, sugar and alcohol
- eat unsaturated fats in moderation, strictly limit saturated and trans fats.



Are there special supplements which could help when recovering from a brain injury?

Studies suggest that choline, creatine, omega-3 fatty acids and zinc are helpful during the recovery process. A healthy diet will generally supply all key vitamins, minerals and fats needed - supplements typically are only a semi-effective way to make up for a poor diet.

Guide to vitamins

Each vitamin is found in different foods and has a different purpose for our brains.



Vitamin B-1: Grain products, pork, legumes, nuts, seeds and organ meats. Helps metabolize glucose (blood sugar) - glucose is a primary energy source and promotes growth and muscle tone.



Vitamin B-12: Milk, meat and eggs. Protects our nerve cells by maintain a myelin sheath (outer coating) - B-12 deficiency can result in nerve damage and impaired brain function.



Folic Acid: liver, yeast, asparagus, fried beans, peas, wheat, broccoli, and some nuts. Prevents a buildup of blood, reducing the risk of heart disease and stroke and can also lower levels of serotonin in the brain (neurotransmitter and functions the brain).



Vitamin B: enriched grains, meat, fish, wheat bran, asparagus, high quality milk and peanuts. Vitamin B deficiency can cause mental symptoms such as irritability, headaches, loss of memory, inability to sleep, and emotional instability. Also pellagra (causes psychosis, delirium, coma, diarrhea, dementia, dermatitis and death).



Vitamin A: meats, fish, eggs, carrots, yellow squash and spinach. Helps provide protection against infection, bone and teeth formation, smooth skin and promotes growth and repair of body tissue.



Vitamin E: plant oils, green leafy vegetables (e.g. spinach) and some breakfast cereals. Supplies oxygen to the brain, slows down ageing process, nutrition for cells and prevents blood from clotting.

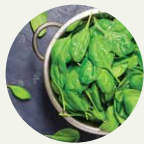


Vitamin B-6: chicken, fish, pork, whole-wheat products, brown rice and some fruit and vegetables. Helps with metabolism of carbohydrates and fats, supports nervous system and maintains healthy skin.

Guide to Minerals



Iron: meat, poultry and fish. Iron helps the formation of hemoglobin (which carries oxygen to cells throughout our bodies).



Magnesium: Green leafy vegetables (e.g. spinach), whole grains, nuts, seeds and bananas. Assists with bone structure and aids in the transmission of nerve impulses.



Manganese: Whole grains and nut, also some fruits and vegetables. Helps metabolise carbohydrates and assists in the brain functioning.



Copper: organ meats, seafood, nuts, seeds, whole grain bread and cereals and chocolate. Deficiency can cause anemia and impairs brain function and immune system response.



Zinc: red meats, liver, eggs, dairy products, vegetables and some seafood's. Maintains cell membranes and protects our cells from any damage.



Selenium: Seafood, liver and eggs also some grains and seeds. Provides synthesis for some hormones and protects cell membranes from damage.

Alcohol, Caffeine and Other Drugs

Most rehabilitation specialists will advise against drinking alcohol for at least one to two years after brain injury, or even indefinitely.

The body uses essential vitamins and minerals to break down alcohol, which can lead to nutritional deficiencies when alcohol intake is excessive. There is also a risk of further injury when a person with brain injury is under the influence of alcohol. For those who choose to drink alcohol after a period of time, it should be in moderation. Family members can observe any negative impacts, such as worsening behaviours or other impairments.

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

People who already had a dependence on alcohol or other drugs prior to injury might continue to struggle with this after, and in some cases it can become a bigger problem. While, for others, drug use can become a problem for the first time as they struggle with the many changes that come with a traumatic brain injury

or other type of brain disorder. Potential issues 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, if not permanently, while the brain is recovering.

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 recognise when social skills, coordination, behaviour and cognitive abilities are suffering with drug use. Honest feedback from family and close friends can help, and doctors and brain injury specialists are available for further support.

Dealing with dependency

After a brain injury, someone may develop an alcohol or drug dependency for a number of reasons, perhaps trying to cope with depression and frustration during the recovery process, or personality changes lifting their internal controls around what was once a safe usage.

If possible, discuss the dangers of continued drinking or drug use after a brain injury and 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, the boredom, social isolation and unstructured days can contribute to a dependency on alcohol or other drugs. A preventative measure is to develop a weekly routine 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 a combined approach on the type of activities that could be enjoyed 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 on **1800 673 074**.

Pain Management

Managing pain after brain injury is a key part of recovery and long-term quality of life.

The acute pain people experience after injury starts quickly and is generally short-lived. Chronic pain is more persistent and lasts longer than the time it usually takes to heal.



The common causes of pain following brain injury are:

- headaches and migraines
- neck and shoulder pain (after traumatic brain injuries)
- abscess and skin sores
- cervical or spine injuries
- heterotopic ossification (bony overgrowth)
- kidney stones and bladder infections
- fractures
- spasticity
- constipation.

When pain becomes chronic, a person will cope better if it is detected and managed early. Research has shown that having realistic and helpful thoughts reduce pain, while fear and a negative mindset make it worse. A realistic goal is to reduce, rather than eliminate pain. Cognitive behavioural psychologists help chronic pain sufferers to change the thoughts they have about pain, its effects, and other sources of stress.

One approach views pain as a learned behaviour and is done by a psychologist or neuropsychologist. Other approaches help the person to identify inappropriate and unhealthy beliefs about pain and provide strategies to deal more effectively with pain behaviour. Techniques may include relaxation training, hypnosis, stress management, attention-diversion strategies and biofeedback.

Medication

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

Non-steroidal anti-inflammatory drugs (NSAIDs) which include aspirin, ibuprofen (Nurofen), Voltaren, and other COX-2 inhibitors are appropriate for musculoskeletal pain. However, they can increase the risk of serious gastrointestinal complications (including ulcers) and may increase cardiovascular events in some people, so check with your doctors before taking them.

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.

Opioid or narcotic painkillers

Many of the symptoms of brain injury, such as fatigue, sleep disturbance, anxiety and depression, are affected by chronic pain and can actually make the pain seem worse than it is. With careful management, a person can increase their resistance to pain. It is also helpful to reduce the fear of pain because fear can get in the way of activities that are healthy and help with recovery.

Other effects of chronic pain include:

- faster heart rate and higher blood pressure
- increased stress and tension
- gastrointestinal issues.

Medications

A brain injury may result in an ongoing need for medications prescribed to you by your doctor.

Medication safety after a brain injury

A brain injury may result in an ongoing need for medications which need to be taken in the right dose, at the right time, and under the right conditions.

Possible problems with medications are an overdose, an allergic reaction, or a negative interaction with an existing medication. Medications prescribed after a traumatic brain injury can include:

- Anticonvulsants for the treatment of epilepsy
- Analgesics for pain management
- Psychotropics for the management of behaviours of concern
- Mood stabilisers and antidepressants.

It is very important to take medications as prescribed, and keep your doctor updated on all your medications and if they are working correctly or not.

Important tips to remember:

- read the instructions and follow them carefully
- don't stop taking a medication until your doctor says to stop
- don't use medications after their use-by date
- don't use other people's medications
- keep all medications out of reach of children
- give any unused medications to your pharmacist for disposal
- don't change the dose or the time the medicine is taken.

Medication side effects

All medications have potential side effects and it is important that these don't worsen any of the problems a brain injury has caused.

Although it is never possible to predict which side effects a person will experience, all prescription drugs have a list of those that are most common. This information can be used to select the most appropriate medications for a patient.

Sedation, confusion, dizziness, balance disturbances, blurred vision, and tremors are examples of some fairly common medication side effects that can be particularly detrimental after a brain injury, so medication doses may be prescribed at lower rates than normal.



Antidepressants

Newer antidepressants, such as selective serotonin reuptake inhibitors (SSRIs), serotonin-norepinephrine reuptake inhibitors (SNRIs), and selective serotonin-norepinephrine reuptake inhibitors (SSSRIs), usually cause fewer side effects than the older ones. For example, tricyclic antidepressants (TCAs) can have high rates of side effects such as sedation, dizziness, dry mouth, confusion and constipation. Even though they are cheap and have proven effectiveness, the TCAs are rarely used if someone has a brain injury. Newer antidepressants such as sertraline (Zoloft), citalopram (Celexa), venlafaxine (Effexor XR) and others are preferred because of their better side effect profiles.

Older anticonvulsants such as phenytoin (Dilantin), phenobarbital, and primidone are usually not recommended for use after a brain injury for the same reason.

Drowsiness

Sedation is a common effect of many medications. Although usually beneficial at night, it can be problematic when it occurs during the day and interferes with normal activities. Sedation is usually most pronounced when a new medication is started and will sometimes disappear with continued treatment. This process is due to the development of "tolerance" within the body and occurs with many medication side effects.

Drugs with strong "anticholinergic" properties can cause confusion and other types of cognitive impairment, so are best avoided after a brain injury. Examples of these include diphenhydramine (Benadryl), benzotropine (Cogentin), TCAs, and many antipsychotic agents.

Dealing with side effects

The primary goal with any medication is a beneficial effect with minimal side effects. First, it is important that patients taking medication have an understanding of what side effects to expect and which ones might indicate a serious problem. Since tolerance does develop to many side effects, the problem may resolve with continued treatment. The doctor may also be able to make a change in the dose or dosing schedule to minimise unwanted effects.

Sometimes a switch to another medication may be necessary. Patients must be willing to report any unusual or concerning events to their treatment provider in order for them to be addressed. Medication should never be abruptly discontinued without the doctor's knowledge, as potentially serious discontinuation symptoms can occur with some medications.

Questions to ask your pharmacist or doctor

If you don't understand something your pharmacist or doctor says, ask them to explain in an easier way. Important questions to ask include:

- How much should I take, how often and at what times of day?
- Should I take the medicine on a full or empty stomach?
- Do I swallow the pills whole or can they be crushed or chewed?
- What should I do if I miss a dose?
- Will we reassess my need for this medication, and when?
- What are the possible side-effects and how can I manage them?
- Are there serious reactions that I need to look out for?
- Are there potentially serious interactions with other medicines?
- Do you have a brochure with information on this medication?

Organising your medications

Use a dosette box. These plastic containers come in different shapes and sizes, and have compartments labelled by days of the week and meal times. A dosette enables you to organise the week's medications and prevents uncertainty about whether or not a medicine has been taken.



If you take multiple medications, many pharmacists can now pre-package these for you in a Webster pack, so that a dosette box isn't needed. Never put your medications in other bottles as it is easy to forget which ones are which.

Other points to consider:

- Check the 'use by' date on your medications
- Always consult your doctor if you are thinking of becoming pregnant
- Always keep medications out of children's reach
- Get a dosette box / pill organiser to make taking medications easier
- Keep medications in their original containers in a cool dry place
- Some medicines need to be refrigerated.

References and further information

Medicines Line: Call **1300 MEDICINE**



Future Medical Problems

Most people with a brain injury are expected to experience a normal life span but families and carers can play a crucial role by monitoring for any further medical problems arising post-injury, particularly after hospital.

Problems may not always be as obvious as brain injuries can be invisible. Carers should be aware of some potential consequences so valuable treatment time is not lost in the case of the following:

Muscle and bone abnormalities

Heterotopic ossification (HO) is abnormal bone growth, most commonly in the hips, shoulders, knees and elbows. It is bone growing in unusual places like soft tissue – and usually occurs within the first nine months of injury. While a carer can keep an eye out by looking for swelling around joints or decreased range of motion, it would normally be picked up by a GP or a physiotherapist. It is treatable with medication that slows bone growth.

Other effects post brain injury might be arthritis, osteoporosis, worsening spasticity (involuntary muscle stiffness) and dystonias (muscle problems causing movement disorders). These should all be reported to the clinical team, as these are warnings of future problems.

Hearing loss

Hearing problems can occur, particularly when there has been trauma to the inner ear or temporal lobes as the temporal lobe affects hearing. The clinical team should be performing the correct examinations alongside behavioural observations to monitor hearing loss.

Vision dysfunction

Vision and perception should be evaluated by a GP or an optometrist. If needed, an optometrist or occupational therapist can teach methods for compensating for vision disorders. An ophthalmologist should be part of the ongoing process.

Visual processing should be monitored. Symptoms of disfunction are double vision, rapid eye movement and near-sightedness.

Nerves and hormones disorders

The neuroendocrine system is where nerves and hormones interact, and functions to regulate the body. Following brain injury, the neuroendocrine system should be monitored, particularly in the early stages. There are unfortunately reports of difficulties in the years following, with problems such as weight gain, changes in hair and skin, body temperature and thyroid changes.

Signs of neuroendocrine damage include chronic sleep disturbances, blood pressure abnormalities, increased infections and complaints of arthritis.

Reintegration

Many people with a brain injury see returning to work or study as an important milestone.

A brain injury can result in a combination of disabilities that require accommodations, but, going to school, university or other learning options can be rewarding, given the right support.

Returning to Work

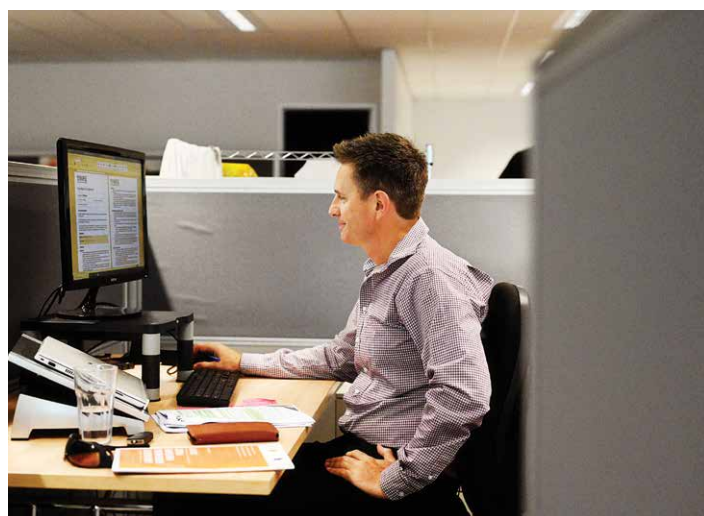
One of the main hopes and expectations people have when leaving hospital is that they will return to the work or study they were involved in prior to the brain injury.

What to consider

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 readiness and ability to return to work. People often feel they are ready to go back against the advice of family and health professionals. 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 areas that will need to be worked on to return 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.

A very important factor in predicting return to work is active participation in rehabilitation and in the therapeutic community. A very predictor is the injured person's self-awareness and ability to regulate emotions.



Potential barriers

Some of the barriers in returning to work are:

- an individual's desire to work being greater than their actual readiness
- problems accessing support, e.g. being linked with the right employment support agency
- cognitive impairment
- poor emotional regulation
- fatigue and other physical problems, e.g. dizziness and headaches
- experiencing a loss of self-confidence after unsuccessful attempts
- reduced motivation.

Support

Employment support agencies and rehabilitation services might provide programs that focus on the person returning to their previous position when the time is right (not usually possible straight away). Rehabilitation professionals can provide insight into a person's capacity for employment in different areas. 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 is another option, 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 building capacity at work

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 might benefit from capacity building strategies.

Remediation involves relearning skills with practice until a certain level is achieved e.g. practising typing speed.

Substitution requires maximising previous skills or learning a new one to overcome a difficulty e.g. using self-instruction to improve concentration.

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 workload.

Assimilation involves modifying the environment and expectations of other people, e.g. introducing specialised equipment, supportive workplaces and educating employers and colleagues about the nature of support required.

Some common recommendations for returning to work include having:

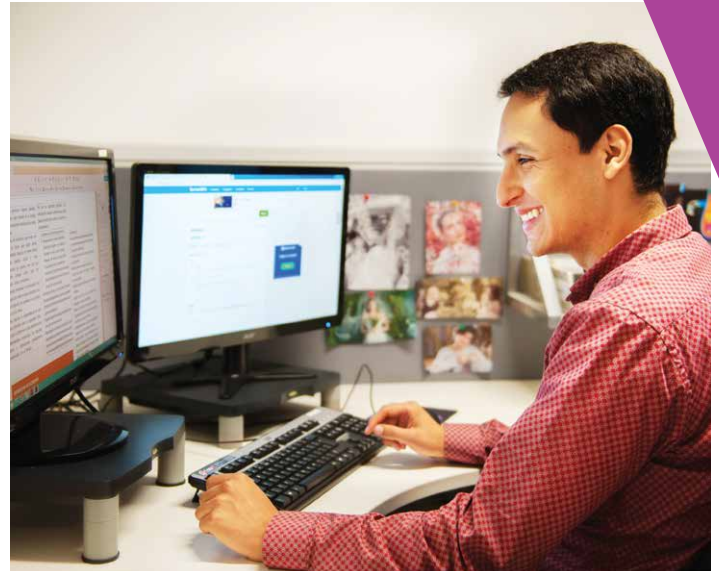
- plenty of rest periods
- routine and structure to tasks
- flexibility
- reduced hours
- supervision and support.

Volunteer work

People who are assessed as being unready for work may wish to pursue volunteer work to improve their skills and experience, and to better understand their capabilities. However, for some people employment may not be a realistic option after brain injury.

This can be very distressing for people who have often spent most of their lives building a career.

It is important that this loss and grief is acknowledge and accepted, and that, when ready, they are supported to pursue other avenues for achievement, satisfaction, and a meaningful use of time.



Managing fatigue

Fatigue is very common after brain injury, and it can be a significant barrier to returning to work particularly when intense concentration or fast-paced decision making are required. Survivors will often manage a workload if they can approach one task at a time, work in a quiet environment without distractions, and have a flexible schedule for rest breaks when needed. Employers should provide assistance to ensure the right practices are in place to support those returning to work.

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.

Australia has also been a party to the Convention on the Rights of Persons with Disabilities since 2008.

Returning to Study

People with brain injury who have done very well in their recovery may still face significant challenges in returning to their studies.

Common challenges

Going back to school, university or other learning institutions can be rewarding given the right support. Common challenges include learning new material if there are memory problems, managing fatigue and fitting in socially where there may be a lack of understanding by others. There are ways to overcome these and other barriers to learning as outlined below.

Reduced 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. Keep periods of concentration short by allowing regular breaks. Start with ten minutes and build up slowly with a few extra minutes daily.

Impacts on insight

Some students with a brain injury have a lack of insight regarding their level of ability and may be unable to recognise that their performance and capabilities are lower than before. They may respond to negative feedback by believing that teachers are against them or find other ways to convince themselves that their performance is as it was pre-brain injury.

Impacts on planning and organisational skills

Planning and organisational skills can be impacted to the extent that the student knows what he or she wants to do, but has difficulty getting started. Students need support to develop a step-by-step plan. They can be encouraged to identify the task, keep it simple, and address one task at a time. The following tips can assist with planning and 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.

Impacts on short-term memory

Most brain injuries will result in impacts to short-term memory and the ability to retain or process new information. Students might lose books and equipment, forget appointments, ask the same questions again and again, or forget which classroom they are supposed to be in. Fortunately, there are ways to assist memory by working out new avenues to compensate for problems. It is important that students are 'aided', not 'rescued' from their own failing memory.

Students with poor memory should use memory aids and will need the support of others through constant reinforcement. Common memory aids which can help with memory include:

- a tablet or smart phone with planning apps that store timetables, calendars, maps, links to the university and library, and reminders. A smart watch can also be helpful for reminders and alarms.
- 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.

Confusion

People without brain injury can use their planning and organising skills to work their way through confusion. It is difficult for a student with brain injury to deal with confusion, as these skills are often impaired. Confusion typically arises due to:

- unrealistic self-expectations, e.g. the student may have a memory of achievement that is inconsistent with their post brain injury ability
- the student's struggles to recognise that a disability exists
- others placing expectations that are unachievable on the student
- the student is 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 once.



Teachers can play a role by discussing any issues with the student and making changes to minimise confusion.

Stress, frustration and anger

A common trigger for stress is the feeling of helplessness or being trapped in a situation over which we have no choice or control, and people with brain injury can become agitated in these situations.

The triggers for these emotions should be identified, and where possible, avoided. When this is not possible, relaxation techniques such as mindfulness or deep breathing can be helpful. Teachers and students might agree on a strategy whereby the student takes time away from the environment when high levels of anger or aggression arise. This needs to be seen as a chance to restore balance and perspective, not as a punishment.

Impulsive behaviour

Impulsive behaviours as a result of brain injury are not intended to be hostile, however they can be disruptive and sometimes inappropriate. Again, teachers and students can agree on a strategy to shift the behaviour. The teacher might give a sign for the student to stop and think about what they are doing, such as a word or gesture designed to be a 'circuit breaker' in the behaviour.

Educational support

Educational facilities are able to provide additional support for people with disability in their study, including during tests and assignments. It is a good idea to contact the school or university to let them know about anything that may impact on study such as short-term memory difficulties, mental fatigue, lack of concentration, susceptibility to stress and lowered organisational ability.

Schools and universities have resources and supports available to assist students with a disability, such as:

- learning support assistants
- extra time for assignments and examinations
- exams in a quiet room without distractions
- copies of class notes if concentration and attention are affected.

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; and see what is the best time of day for study
- structure study times and stick to them no matter how you feel
- make use of study groups or a 'study buddy'.

There are many resources available on good study techniques. Students with a brain injury may take longer to learn these strategies, but the same benefits are available once the skills are acquired.

Brain Injury Information for Employers

Post-brain injury many employees are eager to return to work. Employers may find some simple adjustments can be made to allow this to happen.

Planning for adjustments

Important questions

- What needs to be considered due to the brain injury?
- Are there any specific tasks that are likely to require support?
- Has the person been asked about their needs?

Examples of adjustments

Physical supports: the use of ramps, handrails and disabled parking spaces. All paths should be cleared of unnecessary equipment and furniture. The Federal Government may provide financial assistance for workplace modifications for employees with disabilities.

Visual supports: the use of large print, good lighting,, increased natural lighting and glare guards on computer monitors. Vision specialists are available for advice, particularly for employees who have lost part or all of their vision.

Maintaining stamina during the workday is possible with flexible scheduling and longer or more frequent work breaks. Employees might have extra time and a self-paced workload to learn new responsibilities, with others available to cover for breaks and necessary time off. Job sharing and working from home are other examples of flexibility. Employment coaches are another way to support employees in the workplace.

Maintaining concentration is easier if distractions in the work area are reduced. Typical adjustments could include space enclosures, a private office or allowing the use of white noise or environmental sound machines. Increase natural lighting and reduce clutter in the employee's work environment. Soothing music using a headset can be useful. Plan for uninterrupted work time and divide large assignments into smaller tasks and steps.

Organisation and deadlines are easier with daily 'to do' lists. Calendars can be used to mark meetings and deadlines. Helpful reminders can be sent via memos, email or weekly supervision. Use a watch or pager with timer capability or an electronic organiser.

Impacts to memory can be managed by providing minutes of meetings, or allowing the employee to record them. Notebooks, calendars and sticky notes are used to record information for easy retrieval. Employees may need both written and verbal instructions, as well as extra time for training. It is easier to remember where things are kept when they are labeled, colour coded or listed on a bulletin board. Instructions can be written on or near equipment when necessary.

Impacts to problem-solving are common after a brain injury. Picture diagrams like flow charts show problem-solving techniques. A supervisor, manager or mentor should be available to answer any questions and jobs can be restructured where necessary.

Working effectively with supervisors is achieved through positive praise and reinforcement. Written job instructions and clear expectations of responsibilities are very helpful. Allow for open communication to supervisors and establish written long-term and short-term goals. Develop strategies to support the individual and any challenges they may face post brain injury.

Difficulty handling stress and emotions can occur after a brain injury. Employees may need to seek support through counselling and employee assistance programs. Allow the employee to take a break to use stress management techniques to deal with frustration if required. Educate co-workers on brain injury and its impacts.

Attendance might be impacted by the need to attend regular medical appointments or due to managing fatigue. Employees may require leave for health problems, a self-paced workload and/or flexible hours. Working from home or part-time work schedules can help.

References and further information

Australian Human Rights Commission.

Adjustments In the Workplace for People with Disabilities

www.humanrights.gov.au/quick-guide/11931



SECTION 7

Family and Carers

Caring for a family member with a brain injury can be challenging, and carers also need support particularly those providing direct care.

There is often a shift in the division of household responsibilities and carers may find themselves juggling a lot more than before, as well as providing physical and emotional support to their loved one.

Challenging Behaviours

A brain injury can affect a person's ability to self-regulate which can affect their behaviour.

This can mean difficulty with self-awareness, communication, mood, social skills and behaviour. Family members can play a productive role in influencing behaviour by reacting positively and consistently.

Understanding Challenging and Complex Behaviour

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



What are the causes of challenging behaviours?

People develop behaviour skills over many years as they grow and mature into adulthood. A brain injury can affect parts of the brain involved with emotions, impulse control, self-awareness and ability to monitor and change behaviour. Brain injury often means a person needs to relearn behaviour skills, which in some cases may be extremely difficult.

Behaviour that is considered a 'social norm' is set by thousands of unwritten rules. Some examples include:

- how close to stand to other people
- 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, restricted access to community services, family breakdown and in some extreme cases even have criminal consequences.

Is there a 'cure' for behavioural issues?

There are no easy solutions because they are the result of many complex factors that may not change. However, family members can often influence behaviours by responding consistently and positively.

What are Complex & Challenging Behaviours?

These can be behaviours where the reasons behind the behaviour are difficult to understand or that people find hard to accept. These behaviours usually break unwritten social rules and can be confronting to others.

Examples include:

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



Tips for dealing with challenging behaviours

It is important to develop a good understanding of how brain injury affects behaviour to recognise the 'message' behind each behaviour and develop positive responses. All behaviours are an attempt to communicate something.

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
- get support for yourself and for the person with the brain injury.

Advice for family and carers

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. Family and carers need to remind themselves that the brain injury has affected the person's ability to manage their own behaviour. Family members can play a productive role in influencing behaviour by reacting positively and consistently.

The Message Behind Behaviour

There are many reasons why a person with brain injury might develop challenging behaviour. Understanding the message behind the behaviour is key to helping in a constructive and positive way.

All behaviour serves a purpose and, as such, communicates a message. Understanding this can be useful in situations that otherwise leave partners, carers and family members feeling powerless, frustrated and angry.

While it can be difficult not to react negatively to challenging behaviour – particularly if you feel upset or scared – it is better to look for the underlying message in order to reduce the behaviour in future.

A complex or challenging behaviour usually communicates:

- an unmet need, e.g. emotional or physical discomfort
- an expression of mood, such as sadness, anger or frustration
- a response to stimulation, whether it is too little, e.g. boredom, or too much, e.g. a noisy crowd.

Boredom - a common message

Behaviour specialists report that the most common message behind challenging behaviours is 'I'm bored'. A brain injury can result in unemployment, loss of friendships and difficulty forming new ones leading to social isolation. Some behaviours may simply be based on the principle of 'any attention is good attention'. This can be a challenge for family members who find the caring role demanding. Often there is little time and energy left to find recreational activities for their loved one.

Other common messages behind behaviour

“ there are too many demands being put on me at once

“ this is an unfamiliar environment/activity and it's disturbing me

“ I've got sensory overload from too much noise/light/overcrowding

“ I'm tired

“ I haven't got the social skills to cope with this situation.

CASE STUDY

HELEN'S UNFINISHED SENTENCES

Helen often screamed loudly when talking with family members. Her family thought this meant she was either in a bad mood or seeking attention. When they looked closer at Helen's behaviour they noticed that she usually screamed when someone had finished her sentence for her. Helen speaks slowly and needs extra time to say what she wants to say.

Unmet need: Helen wants to be able to express herself and understandably resents having control of her own communication taken away.

Expression of mood: Screaming is Helen's way of expressing her frustration at being interrupted and unable to say what she would like to

While this message appears obvious, it is surprisingly easy to fail to see the message behind certain behaviours. Helen needed time to gather her thoughts and express them because of her brain injury. At the same time, her family mistakenly thought they were helping by finishing her sentences.

Giving Feedback on Behaviour

Clear, direct and immediate feedback is a key part of a positive response to behaviours of concern after a brain injury.

Why behaviour feedback is important

After a brain injury, some people will have difficulty with self-awareness, communication, mood, social skills and behaviour. They might not realise when their behaviour is inappropriate, so providing immediate, kind, direct and clear feedback is very important. Using subtle cues about behaviour, or giving information that is too vague or general, makes it difficult for the person to gain a clear understanding of what is expected.

Relearning sociable behaviour is easier when family, friends and co-workers agree on set limits and give the same feedback on what is acceptable or unacceptable behaviour. This can be achieved by:

- identifying behaviours that are inappropriate and appropriate
- deciding on management strategies
- using the strategies the same way in each situation.

Redirecting behaviours

When a person says or does something inappropriate, use simple language and be specific. For example, *'I don't like it when you shout loudly at me'* is much clearer than *'I don't like it when you are rude'*.

It might be necessary to remind the person of the unspoken rules of social behaviour that are otherwise taken for granted. Again, this should be clear, direct and immediate. For example, *'I would rather you didn't talk about...'* or *'you are staring at that woman - she might feel uncomfortable'*.

Be patient

Simplify feedback if the person has trouble understanding. Pictures, diagrams or other communication aids can be helpful. Let the person know which behaviours are acceptable or expected and check whether they understand.

Repeating information at regular intervals is helpful if the person with brain injury has difficulty with memory and learning. Memory strategies such as writing things down, using signs, checklists or prompts are also useful.

Focus on the behaviour, not the person

Talk about the behaviour, rather than the person when giving feedback. This allows the person to feel supported, while knowing that their behaviour is not.

For example, *'I understand why you are frustrated, but I don't want you shout at me'*, or *'let's talk about what we can do about your frustration'*.

Feedback should be given in a calm and uncritical way. Be matter-of-fact and firm, without strong emotional reactions such as anger, impatience, shock, disapproval or fear. Negative reactions can trigger more anger and aggression.

Give direction

It is important for the person to know what they should do, as well as what they should not do. For example, ask the person to say please, or speak politely, or wait until you are finished talking.

Provide an alternative path to the behaviour. For example, *'you sound angry, do you want to talk about this later?'* or *'could you wait until I have finished, please?'*

It also helps to understand why the behaviour occurs. If it is because a person feels overwhelmed by a noisy environment, it is better to leave than stay and manage the consequences.

Redirect the person to other activities or topics that are appropriate or acceptable. For example, jokes with a sexual content might not be acceptable, but other jokes might be; touching on the breast or bottom may be off limits, but touching on the hand may be an acceptable alternative.

Encourage positive behaviours

It is just as important to mention examples of appropriate behaviour using positive behaviour support techniques. For example, *'I've noticed how calm you have been today'* or *'you really seem to be listening to other people's points of view'* and *'thanks for waiting until I finished what I was saying'*.

Positive feedback and encouragement is an important part of learning and maintaining appropriate behaviour. Experiment with genuine ways to give encouragement.

Examples include:

- *'I like to see how you are helping others'*
- *'I admire you for...'*
- *'I like the way you did that'*
- *'you are doing so well with...'*
- *'thank you for your help'*
- *'you put a lot of effort into that task'*
- *'you got that finished quickly'*

The ABC Approach to Behaviour Support

The ABC model is an effective way to understand challenging behaviour and develop suitable responses within a positive behaviour support plan.

It looks at the:

- A Antecedents**
what happened before the behaviour?
- B Behaviour**
what is the actual behaviour?
- C Consequences**
what happens afterward?

This is an effective technique to remove the emotion from challenging behaviours, analyse the behaviour and create effective responses.

Creating a positive behaviour support plan

When creating a positive behaviour support plan, it is important to decide on which strategies to adopt. Once chosen, the strategies need to be applied consistently by everyone who encounters the targeted behaviours. While it might seem difficult at first, these techniques will eventually become second nature. In some cases, the support of a behaviour specialist, such as a psychologist, may assist to identify strategies that make up the positive behaviour support plan.

Antecedents – possible triggers

The antecedents are the things that happened before the behaviour occurred. They can also be considered as triggers for the behaviour, such as:

- things that other people did or said
- an emotional state, e.g. depressed, tired, anxious
- the environment, e.g. hot, noisy, cramped, smelly, bright lights.

Managing these antecedents, or triggers, is a proactive way to avoid behaviours occurring in the first place. Here are some useful strategies:

- build and maintain good rapport
- avoid or minimise known triggers
- involve the person in discussing triggers
- work together on possible coping strategies in dealing with triggers
- suggest and encourage these strategies when a trigger occurs
- sometimes a distraction or redirection away from the trigger may be all that is necessary.

Graduated exposure to the antecedent

This is useful when antecedents cannot or should not be avoided. With time and patience, it can be a powerful technique.

For example, Kirsten starts screaming in supermarkets due to sensory overstimulation. Her mother says they will just stand outside the supermarket for 30 seconds then go home. The next time, they go in for 30 seconds then go home. This is gradually lengthened until Kirsten has adapted to this difficult environment.

Preparing for the antecedent

An inability to cope with chaos, unpredictability and lack of routine is common after a brain injury.

For example, if someone finds the activity and noise of a supermarket unpleasant, it can help to talk about expected reactions and ways to cope before the event.

Behaviour – what is its purpose?

Before you respond to an actual behaviour, the key is to understand the purpose of the behaviour and what it may be expressing about unmet needs. Although emotions can be running high, there are still strategies that can prove useful during the behaviour itself:

- appear calm and speak in an even tone
- give simple directions and prompts about coping mechanisms
- use non-threatening hand gestures
- manage your personal safety and remember the strategies agreed on for dangerous incidents
- recognise when it is time for disengagement/exit strategies for crisis situations
- ignore the behaviour.

In some cases, behaviour occurs in order to get attention, so the best strategy may be to ignore it. As with many of these techniques, tactical ignoring is best linked with positive reinforcement.

For example, a child is ignored during a tantrum, but is rewarded with praise, a treat or favourite activity once the tantrum is over.

Consequences

What are the immediate and delayed reactions from everyone involved? The consequences, or our responses to behaviours of concern, are very important. For example, a pleasant consequence can simply reward the behaviour, while a negative consequence may discourage it.

Pleasant consequence:

'When I yell everyone gives me what I want'.

Negative consequence:

'When I yell everyone ignores me completely'.

When we use the ABC technique to analyse behaviour, we tend to stop reacting emotionally in ways that often make the situation worse. A consistent response from everyone to challenging behaviour can have a very strong effect over time.



Responding to Acute Behaviour Disturbance (Crisis)

Brain injury can sometimes result in behaviour that is dangerous to the person with the injury and those around them.

Even with the best behaviour support plans in place, there may be times when a person's behaviour escalates. There are ways to help a person in crisis, while still maintaining personal safety as a priority.

It may be possible to prevent a crisis after a person's behaviour has started to escalate. However, when a crisis develops, personal safety takes priority over everything else. Ensure you have a crisis management plan that includes:

- when to disengage from an escalating situation
- making sure your exits are always unobstructed
- prior removal of any items that could be used as a weapon.

As behaviour starts to escalate, continue to work at understanding the triggers and purpose of the behaviour. It may still be possible to prevent a behaviour disturbance with:

- a calm even tone of voice and reassurance
- active listening and expressing empathy
- simple, clear directions about what is required.

Tone of voice is very important. It is normal to feel adrenalin and speak in a higher pitch during a crisis situation, even if the intention is to defuse the situation. Being aware of this

and deliberately speaking quietly in a normal tone can make a big difference.

Try to identify the message behind the behaviour. You might be able to avert a crisis if you can find the trigger and deal with it directly. A positive behaviour support plan should include how to respond to each possible crisis situation. Typical strategies during the escalation phase include:

- promoting coping skills
- breathing exercises
- redirection (distraction)
- stimulus change
- 'help me' requests
- introducing humour (this can be a difficult technique and should only be used by a familiar person)
- exiting the troubling environment.

Once the crisis is over, it can be helpful to talk about the situation with a family member or a psychologist, particularly if it is a regular occurrence. It is important for carers to look after themselves and ensure they are well supported.

Impact on Families

The care needs of people affected by a brain injury often fall informally onto their parents, spouse or siblings.

Caring for someone can be stressful, and it is important for carers to maintain their own health and wellbeing. Long-term carers find that taking time out for themselves each day is vital for wellbeing, with longer breaks also needed.

The Importance of Family After Brain Injury

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 ripple effect expands to partners, friends, family, carers, work colleagues and the wider community. There will be changes in relationships and altered social networks for both the person and their family.

Sometimes, family members can experience as great or greater distress than the injured person. The sudden and massive disruption in everyday life and family relationships are likely to have a profound impact.

It is important to recognise that recovery is a process, and each stage will bring its own hopes, joys, as well as challenges and needs.

The hospital stage

It is natural for people 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. Accepting practical help from friends who can step in to take care of children or daily household tasks is advised. Some might coordinate and communicate on a carer's behalf.

The rehabilitation stage

A supportive family can be an important part of care and rehabilitation. Family engagement in rehabilitation can improve outcomes for people with brain injury. Once the injured person is medically safe, and has been moved to a rehabilitation centre, families can find or start to restore some normality. Friends of the family will need to show patience, as traumatic events cause preoccupation and exhaustion. There may be some comfort in being with other families in the rehabilitation unit who are going through similar experiences.

The return back home: readjustment

Family units are often the primary source of financial and accommodation support. 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. There will be a readjustment period.

For many people who sustain a brain injury, returning to the family home is the most desirable outcome for both them and their families and in many cases, the only viable option. However, this can represent a significant loss of independence and self-reliance. Challenges in this stage can lead to family crises and relationship breakdowns if not understood.

Brain injury can have a significant impact on the financial circumstances of the entire family, if the injured person was the main income earner, or if carer responsibilities restrict employment opportunities. Homes may also need extensive and costly modifications (although if the person with brain injury is able to access the National Disability Insurance Scheme, they may receive funding for modifications).

Depending on the severity of the injury, primary carers may find it difficult to leave their loved one and go out. They may want a friend or two to visit, but even that may feel like it is too much. Some friends may feel uncomfortable with the difference they observe in the person with the brain injury, and the carer. In times of grief, often friends can find it difficult to know what to say. Educating friends about the injury can alleviate some of this discomfort.

It helps to seek out support groups and other families who are in similar situations to find some social support.

Long-term

Future plans may be put on hold or altered while the family readjusts to social and financial consequences. There may be personality and behavioural changes in the injured person which change the family dynamic.

Partners: Partners of people with brain injuries will often be affected by taking 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. Changes in their sexual relationship can occur.

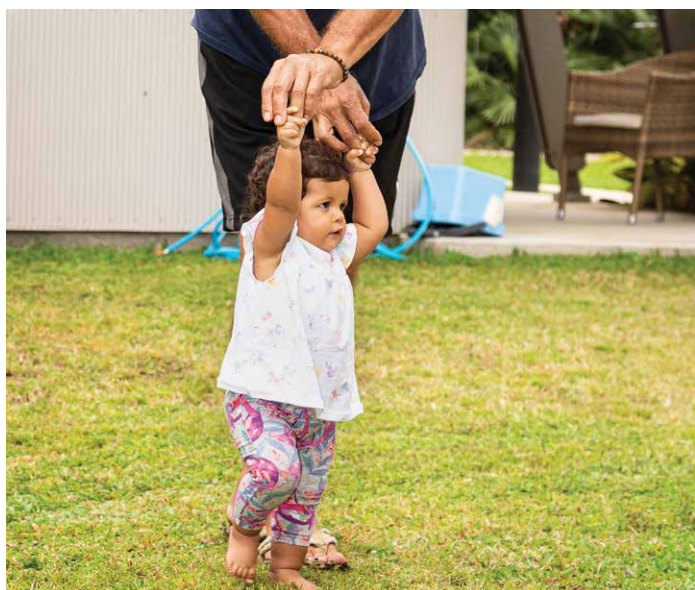
Children: Children may be confused and need time to understand why their parent has changed including why they need care, why they walk or talk differently, and why they don't remember things. This can lead to acting out, emotional problems, or relationship difficulties. Both injured and non-injured parents can be affected by negative behaviour of their children, particularly when stress is already heightened, with relationship breakdowns and depression being reported as a result. Patience and communication is key so the child fully understands what is happening in their family life.

Friends: Unfortunately, friends and friends of family members can disappear at a time when the person most needs their support. It is 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. They can feel very socially isolated as a result. 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.

Support Groups: Social support has been identified as an important contributor to wellbeing for people following brain injury. With old relationships being altered, the person with the brain injury may wish to meet other people in similar situations by joining a specialised group rehabilitation program or a less structured brain injury social group. This might also apply to carers and family members who can connect with other like-minded people.

Contact Synapse to join online and in person peer support groups.

Family Resilience Following Brain Injury



The changing circumstances following brain injuries will have a huge effect on the everyday lives of the person with brain injury and their immediate circles. How families respond can have a big impact on the wellbeing of the person affected.

Families can be struggling to adapt to new circumstances, including loss of income and roles changing. This might also include sudden changes in behaviour, emotion and personality from the person with the brain injury.

It is important to seek support for the whole family, so families can draw on their unique strengths to develop resilience, find positivity and cope with this trying time.

Self-Care for Carers and Family Members

Carers need to maintain their own health and wellbeing as part of their caring role.

Important tips for carers

Maintaining your health and wellbeing provides the energy and capacity to navigate your caring role and other parts of your life such as family and work. Good health and wellbeing mean that you can provide the best care to your loved one and yourself.

Some 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 your feelings and accept them as a natural response to the situation. If you are feeling overwhelmed by your feelings, speak to a clinical psychologist for some tips on ways to regulate your feelings and some ideas on self-soothing.

Respite care

Long-term carers find that taking time out for themselves is vital for wellbeing. Respite care 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. Initially families may dislike a stranger caring for their family member but there are plenty of services around that can make a big difference to helping you care more effectively. For those eligible, the National Disability Insurance Scheme (NDIS) is also able to provide respite, known as 'short term accommodation'.

Managing 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 on major issues
- talking to friends
- exercise
- meditation
- counselling.

Regaining control of your life

In the aftermath of a brain injury, a family understandably tends to put life on hold and focus everything on supporting the person with the brain injury. However, in the long-term families may find this single focus remains, and the whole family begins to suffer.

Carers need to establish a balance in life that allows enough self-care to enable them to maintain their caring role long-term. Respite care is an important part of this, but it also means good time management and priorities to allow everyone's lives to return to normal. Make time for your usual hobbies and interests as much as possible.

It is easy to fall into the role of 'super carer', thinking you can work, look after the rest of the family, and care for your loved one single-handedly and indefinitely. Many people find this tough to manage longer term and require additional support and strategies.

Depression & difficult feelings

Guilt, anger, resentment, fear, stress, anxiety, depression and grief are some of the emotions that will be encountered while caring for someone with a brain injury. With time, the worst of these feelings will go. It is normal to feel as if you are going crazy at times, and it does not help to try to suppress or deny what you are feeling.

The best way to deal with your feelings is to accept them, but make sure you can talk about your feelings with someone who understands, whether it is a family member, friend, counsellor or support group. Depression is always a potential concern for carers, and you should seek professional help if you find you have been experiencing a low mood for more than a few weeks, before it becomes a serious issue.

Self-advocacy

At some point, carers will find themselves unhappy with the level of support from a particular hospital, health professional or welfare association. You have the right to expect appropriate support or treatment and should be assertive in claiming what you want. There are grievance procedures and appeal processes in most cases. Synapse may be able to assist you with, or link you to appropriate advocacy organisations.

Support groups

You can meet others in a similar position, have a break, find information and get support from others who know what your situation is like. Sharing ideas, feelings and concerns can help you feel less isolated. Sometimes friends won't understand your situation, but a support group will. If there are no support groups in your area, consider joining our online brain injury forum or closed Facebook group for carers.

Maintain your friendships

Maintain an identity of your own separate from the caring role and keep your links to the world outside caring. Be aware that some friends may tire of you talking about the problems of being a carer. You may become resentful and lose friends by expecting them to provide more support than they are willing or able to give.

Where possible, seek support from other carers and link in with carer organisations.

Social isolation

A common issue faced by carers is the feeling of isolation that can occur after brain injury. Friends and family often drop away when they don't understand the impact of a brain injury, and distance themselves to avoid embarrassment or being offended. Emotional and behavioural changes can occur after a brain injury which often lead to social situations which are strained and/or embarrassing for the carers and the person impacted by brain injury.

Carers often need to constantly adapt to new situations due to the unpredictable nature of the effects of a brain injury.

Change in roles

Another issue that carers face is the changing of the roles within their family. The lack of employment opportunities for people with disabilities, costs involved with caring, lack of time, and the everyday costs of running a household places a significant financial strain on themselves and their families.

Getting to know the new person

The behavioural issues after a brain injury can have a tremendous effect on day-to-day life for carers. These can include emotional and personality changes, violent outbursts, substance abuse and inappropriate sexual behaviour. These changes place significant pressure on relationships within the family.

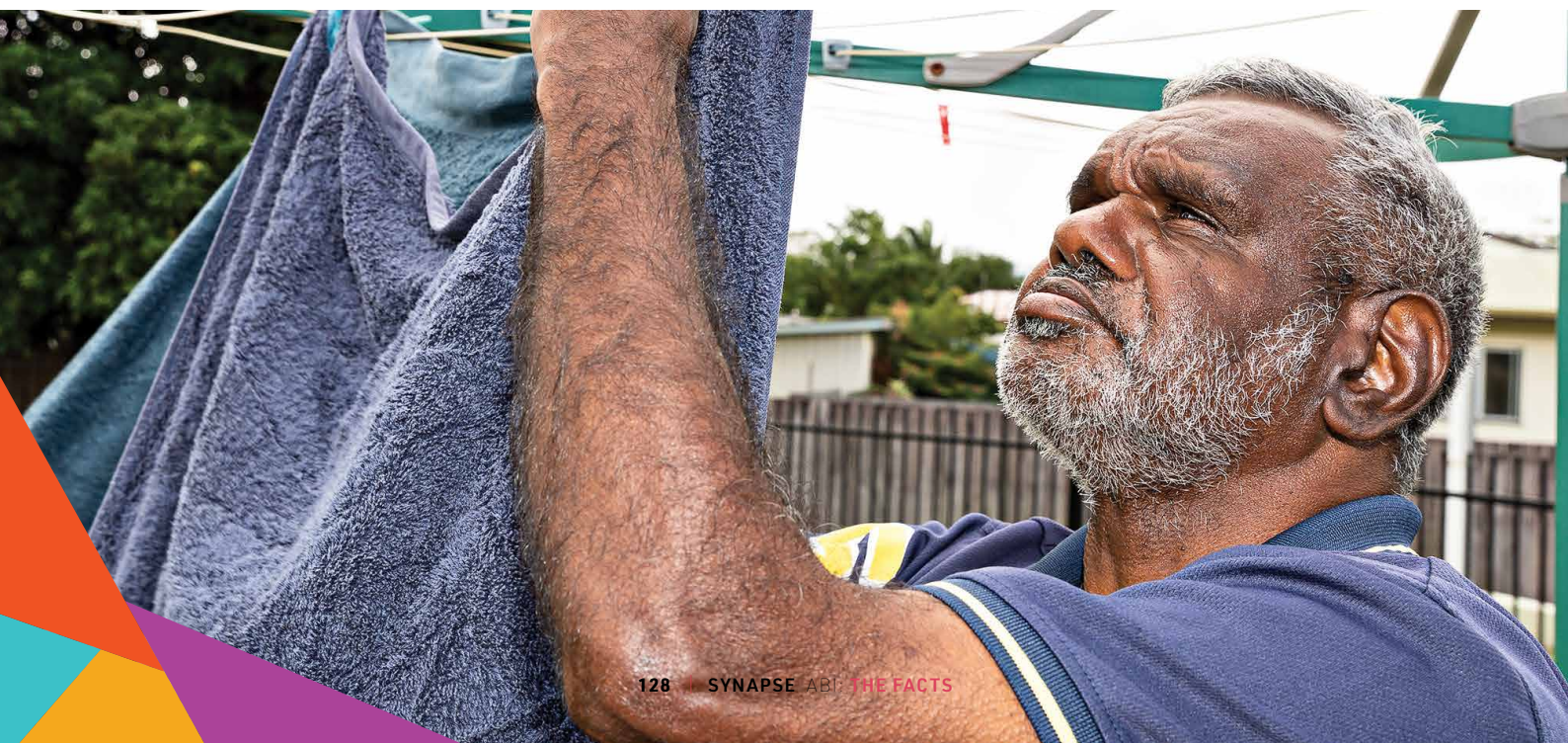
Lack of services & support

A major issue is the frequent lack of appropriate services and support available for carers and their family member when they return to work, study and/or the wider community. A common issue for carers is the lack of knowledge of where, who and what they need to be looking for in terms of support.

Plan for the future

Where possible, it's better to act than react. Instead of worrying about the future (e.g. who will take on the caring role if you can't?) think about what may lie ahead and make plans now. It will bring peace of mind to yourself, family and the person you are caring for.

Planning for future emergencies and events can give you some peace of mind and reduce your stress.





Mental Health - Depression and Carers

Caring for someone can be a 24 hour job that is emotionally, physically and financially taxing.

Carers and depression

Many carers experience depression and low levels of wellbeing.

While the term "depression" is commonly used to describe a temporary decreased mood when one "feels blue", clinical depression is a serious illness that involves the body, mood, and thoughts and that cannot simply be willed or wished away. It is often disabling and affects a person's work, family and school life, sleeping and eating habits, general health and ability to enjoy life.

Signs to watch out for

Sometimes, despite the best efforts, carers may start to show signs of depression such as:

- moodiness that is out of character
- increased irritability and frustration
- finding it hard to take minor personal criticisms
- spending less time with friends and family
- loss of interest in food, sex, exercise or other pleasurable activities
- being awake throughout the night
- increased alcohol and drug use
- increased physical health complaints like fatigue or pain
- slowing down of thoughts and actions.

If you are experiencing these sorts of symptoms then it is important that you speak to your GP about it as soon as possible. Clinical depression does not just go away, and early treatment is much more effective than delayed treatment.

Prevention

Caring for a person with a traumatic brain injury is difficult, especially when there are challenging behaviours. Respite care can provide carers with the opportunity to recharge their batteries. Other tips include:

- ask for help when you need it
- take time for yourself
- exercise, eat well and rest
- relax regularly
- keep up social contacts
- attend a carers group for support
- access and use available services
- acknowledge your feelings.

Managing Stress in the Caring Role

Caring for a family member with a brain injury is one of the most difficult challenges that can confront a family especially for those providing direct care

Adjusting to the caring role

Carers usually find life begins to revolve around the person with a brain injury. The workload often leads to stress and frustration, along with dramatic changes in lifestyle and roles as they access community services, provide health care and look after the family as well.

When the caring role is a long-term one, it is very important to manage stress to avoid health problems, depression, anxiety and retain reduce your capacity to be an effective carer.

You will probably use coping strategies that you have used for difficult times in the past. This is useful, but the caring role may also require experimenting with new ways of dealing with stressful situations.

Tips from other carers

When family members are asked how they coped with brain injury occurring within the family there were some commonalities. While we all manage differently, here are some strategies that other family members have found helpful:

- look after yourself
- find support groups either face-to-face or online
- maintain a sense of humour
- be assertive about your needs
- try to see things realistically
- be careful not to blame everything on the injury
- redefine roles and responsibilities for yourself and the family – you don't have to be everything to everyone
- make sure you have time to yourself when possible (to see friends, exercise or for things you enjoy).

Learn to relax

Taking a few moments to relax can help you manage. Learning to relax is not easy - even when you rest at the end of a long day, you are probably thinking about what you need to do tomorrow or how to solve a problem. Here are some techniques to train your body and mind to relax. Experiment and find the ones that work best for you.

Focused breathing

Your breathing becomes quick and shallow when you are stressed, instead of breathing deeply from your diaphragm (the muscle between the chest and abdomen). Taking full breaths from your diaphragm puts your body in a relaxed state. Try this exercise several times a day:

- lie down on your back in a comfortable place
- put your hands just below your belly button
- close your eyes and imagine a balloon inside your abdomen
- inhale fully (but not too deep), and imagine the balloon filling with air
- exhale slowly, and imagine the balloon collapsing.

Muscle tensing & relaxing

This helps you to understand the difference between how your muscles feel when tense and relaxed and is practised as follows:

- lie down on your back in a comfortable place and close your eyes
- curl and tense the toes of one of your feet as you breathe in
- relax your toes as you breathe out and note the change in tension
- repeat this with the toes of your other foot
- repeat this exercise with other body parts.



Use a focus word or phrase

This clears your mind of negative thoughts and stress. Choose a focus word or phrase - it can be something with a positive meaning like "peace" or just a word that is easy to remember such as "one". Take full deep breaths from your diaphragm. Say the focus word to yourself each time you breathe out.

Visual imagery

Lie down and imagine yourself in a place where you feel calm and relaxed. It can be a real place you've visited, or somewhere you have imagined. For example, imagine yourself on a beach lying in the cool sand - feel the sun on your face, the sand against your skin, and listen to the surf.

Develop a positive approach

We all respond differently to difficult situations - some people take things in their stride while others will barely be able to cope. Much of this comes down to how we choose to see the situation

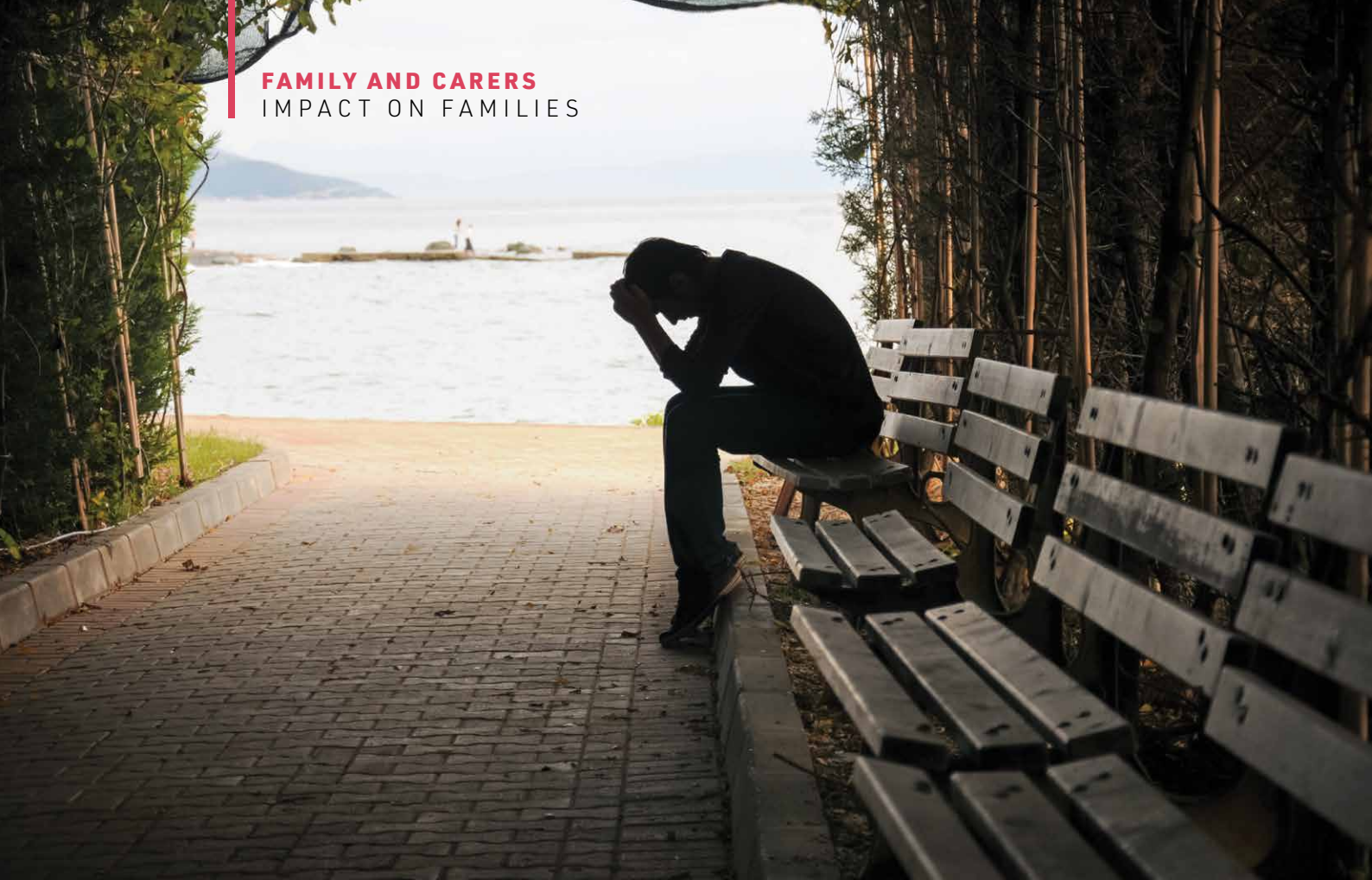
For example, the person with a brain injury yells at us. A rational response would be *"emotional outbursts are common after a brain injury so this could be due to fatigue, anxiety or feeling unable to cope"*.

A response that might lead to negative thoughts is *"how rude, and after all I've done as a carer, I feel so unappreciated and don't deserve to be put down like this"*.

This will lead to unpleasant emotions that prevent us from responding in a healthy way. Most of these types of responses will stem from one of these attitudes:

- “ | *I must do well and win the approval of others*
- “ | *Others should treat me the way I want them to*
- “ | *People should be punished if they don't act the way I want them to*
- “ | *I should get what I want quickly, easily, and without hardship*
- “ | *The world is a horrible place and bad things keep happening to me.*

Remember, learning new ways to think and cope takes time. Be kind to yourself, allow yourself the chance to make mistakes. Focus on your successes no matter how small. Coping effectively is like any other major challenge. It requires tenacity, endurance and commitment for change.



Grief and Ambiguous Loss

Coping with grief and loss following brain injury is an ongoing journey. When a loved one survives an incident resulting in brain injury, there will be an adjustment period as family and friends get used to the new normal. Grieving who the person used to be can be confusing, as the injured person can be physically present but psychologically absent. Ambiguous loss occurs when there is no resolution for grief (Boss, 1999; 2006).

It is important to acknowledge ambiguous loss and seek support for the entire family unit, as this will allow families to focus on strengths and find meaning in their new realities.

Grief is an ongoing process in which people may move forwards, backwards or miss different stages. Models developed for family therapists for ambiguous loss can be helpful guidelines for families and carers, and involves:

- Looking at your circumstances through a variety of lenses and perspectives and search for meaning. Recognising positives and viewing hardships as a part of life can be helpful.
- Accepting 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.
- Recognising and accepting changes within the family structure.
- Remembering that feeling ambivalent or neutral is normal.
- Letting go of expecting closure.
- Discovering hope in progress made, and achievements so far. This can help set goals for the future.

Support Needs of Carers

Depending on the loved one's injury severity, your needs will vary. A severe brain injury means the family is likely to be concerned with the following issues:

- Medical care
- Respite access
- Assistance with incontinence
- Equipment access
- Education
- Social support
- In home support
- Counselling support
- Future planning.

In contrast, the issues arising from a less severe brain injury are likely to be:

- Skills to cope with behavioural problems
- Skills to cope with the emotional changes
- Respite access
- Counselling support
- Education
- Social support
- In home support
- Employment opportunities
- Future planning.

Know where to find support

Knowing where to look for support can be daunting and frustrating. Depending on your area of location, services and support will vary and it is often up to the carer to go out and source these services for themselves. You can start by:

- searching for your local disability services in the area
- searching for local respite agencies
- contact a psychologist
- join online forums to connect and share experiences
- contact Synapse for information about services and supports in your area – **1800 673 074**

Respite for Carers

Carers find that to best manage in their caring roles they will need to take time out for themselves. This may just be taking time to sit down, relax and have a cuppa during each day, but often longer breaks are needed too.

What is respite care?

Respite care is an essential part of the overall support that families may need. It can be provided in the client's home or in a variety of out of home settings. Since not all families have the same needs, respite care is usually flexible to fit in with a family's requirements.

Respite involves someone else taking responsibility for the person you care for – often in a paid capacity. It might be for a few hours, a full day, or longer. It might be for some time

to exercise, attend a wedding, weekly shopping or to go on holidays.

There are three main types of respite care:

- In home
- Day centres
- Short term accommodation for short stays.

Relationship Changes After Brain Injury

Everyone wants to be loved, it's a fundamental human need. We all need people to talk to and laugh with, spend time with, share ideas, worries and joys. But after brain injury our relationships with partners, family and friends can often change quite significantly.

Some common statements people share with us after they or a loved one have experienced a brain injury are:

“ | *I am lonely all the time*

“ | *Our friends don't call or come by anymore*

“ | *I can't relate to other people*

“ | *Other people don't want to be around me or my loved one*

“ | *Who am I now? How do we fit together now as a family?*

“ | *No one understands me or what I'm going through*

“ | *I feel abandoned, rejected, unworthy and different.*

Why do relationships change after a brain injury?

After an injury, family roles can change; sometimes jobs are lost, finances can become a significant worry. Brain injury may have impacted or limited physical and cognitive function resulting in changes to a person's emotional, behavioural and mental state. With all these changes can come stresses on relationships.

We know that relationship dynamics frequently do shift after brain injury, and, adapting can be difficult, but the good news is that it can be done and relationships remain a significant positive factor in people's lives post brain injury.

PARTNERS

Partners of people with brain injuries will often take on extra responsibilities: sometimes 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 often occur. Maintaining a relationship through changes across a number of levels can be challenging for both parties.

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. They might find it hard to understand what is happening to Mum or Dad and why things are different, particularly if they look the same as before. Many families report relationships can become strained between children and their parent post brain injury.

FRIENDS

A very common statement made by people with a brain injury is: 'you find out who your real friends are'. It can be hurtful when friends disappear at a time when you need them most. It's 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.

Simple strategies to improve your relationships

- With brain injury-related cognitive changes come changes to communication abilities, problem solving skills and the ability to empathise and see another person's point of view. It's easy to see how this can make things trickier in relationships for both the person with brain injury and the other party.
- Addressing some of these challenges during rehabilitation and long-term recovery can play a huge part in rebuilding and maintaining relationships. Understanding common problem areas of relationships – all relationships, not just those where brain injury is involved – can be key to knowing where you can benefit from support and guidance.

Effective communication

Poor communication is an area identified in many relationship problems. The way people talk (or don't talk) to one another can cause a lot of distress and tension within a relationship.

TIPS FOR ENHANCING COMMUNICATION

- Try not to speak while the other person is speaking – wait for them to finish talking before responding. You can set a limit of 5 or 10 minutes and then it's time for the other person to speak.
- Try to avoid blaming and labelling – blame doesn't achieve positive outcomes. Whereas clearly outlining difficulties provides opportunity for change.
- Encourage each other – look for positive ways to discuss things and phrase things in ways that build up the other person.

Better supporting each other

In order for a relationship to survive and thrive, each person needs to feel supported by their partner. There should be clear understanding and reasonable expectations around each other's needs for support.

TIPS FOR PROMOTING SUPPORT

- Take time to figure out what your needs for support are – think about what would make you feel more supported in the relationship. Is it that you need your partner to listen to you more? Or to back you up with the kids/in-laws? Or do you need more help around the home? Be really clear and consider writing it down.
- Talk! Communicate your expectations clearly to the other person – ensure that they understand what you're asking for and how they can assist.
- Be forgiving and patient – nobody is perfect, try to maintain a gentle and forgiving attitude and keep your expectations realistic.



Joint problem solving

Focusing on the solutions to our problems, rather than getting stuck in the problem itself, can help us deal with many of the things we face in our day to day lives. Problem solving together in a relationship can really help each other feel supported and part of a team.

TIPS FOR BETTER PROBLEM SOLVING

- Break down big problems into smaller ones and solve them one at a time – this will make overwhelming problems easier to manage.
- Think of all possible solutions before choosing one – sometimes the unusual solutions can be helpful or at least useful later on.
- Involve the other person and work as a team – both parties need a sense of shared ownership in the problem-solving process.

Quality time and positive experiences

In couple and family relationships people often get so busy they don't plan quality time to enjoy meaningful shared experiences together

TIPS FOR INCREASING QUALITY TIME AND ENJOYABLE SHARED EXPERIENCES

- Plan regular quality times together, making sure they are free from distraction, where you can really be present for each other and do the things you love.
- Make enjoyable shared experiences an ongoing growth area – find activities you both enjoy and continue to do them together, expanding and deepening your individual interests in the activities.



SECTION 8

A Parent's Guide

The early days after your child's brain injury

Raising a child brings challenges to all parents, and for parents of a child with a brain injury, those challenges can be magnified.

Parenting a Child with Brain Injury

There are many issues to consider when parenting a child with a brain injury. Striking a balance between protecting them from harm while encouraging self-reliance and independence can be difficult.

It may not be clear in the early stages what impacts traumatic brain injury has had, and it can be difficult to predict how much a child will recover and how quickly.

Claim your place, and your child's place, as part of your local community and focus on your commonalities, rather than your differences, with other families.

At times the emotional challenges can seem overwhelming. Grief, in some shape or form, may take time to accept. Parents can feel they've lost their privacy and sense of control, and that everyone has 'good advice' and knows best. You may feel isolated and 'different' from other families, or that there is no one there to help.

But many parents also say that this life-changing event has also helped them realise what's really important and to value what they do have. Many families find that linking up with others in a similar situation provides great support.



Alongside the challenges, lots of good things happen too. By and large, families with a child with a brain injury are able to adjust well and enjoy life.

Will my child be okay?

This is the most pressing question for parents in the early days after a brain injury. You probably won't take in much of the information you are told at this stage so get people to write things down for you.

Your child may be in a coma, not opening his/her eyes or responding in any way. Coma may last for minutes, hours, days or longer. As your child emerges from a coma, he/she will move into a 'twilight' zone - awake but confused, disoriented, maybe agitated and not making sense. This is known as post-traumatic amnesia, or PTA.

In PTA, your child may remember things from the past, but won't remember things happening now. Ordinary things may look strange or different, or your child may imagine things that are not there; an experience that can be frightening or confusing both for them and their families. In addition, adults report experiencing quite terrifying vivid and realistic nightmares as they moved from the coma to the PTA stage. Younger children may find it difficult to believe it was a nightmare. Later on, your child will remember little or nothing of this time or may have a sense of it as no more than a blurred dream.

PTA may last for minutes, days, weeks or months. The length of time in PTA provides a reasonable basis for predicting how well your child will recover. The depth of coma and how long it lasts provide another indicator.

Talk to the staff on the ward - doctors, nurses, therapy staff - about your child and their recovery and how things may become clearer over time.

Things you can do

The most important thing for your child is feeling held, loved and supported by family and friends, even if in a coma. Always talk and behave as if your child is conscious. It is unclear at what point someone at this stage can hear and understand what is going on around them. However, it is best to err on the side of caution, and assume that they will be able to understand you before you are aware of that fact.

During PTA your child will be less able to deal with the amount of noise and activity around and might easily become more agitated or restless. Try to pace interactions and inputs, so things happen at a quiet pace and only one thing at a time.

Bring in photos, the child's doona and their favourite things to create a familiar environment. Help the staff to get to know your child; his/her interests, personality, habits, quirks and talents. You may find that you want to, or are expected to, do some of the routine care for your child. Talk to the nursing staff about what you are comfortable doing, and what you would rather have them do.

As the days go past, keep a book to record what's happening. A book of this nature can be reassuring to a young person who realises later, that they have 'lost' and forgotten some days or weeks of their life.

Looking after yourself

You will need all your strength to get through this difficult period. Make sure you look after yourself while your child is in hospital (and afterwards). Some hospitals have facilities to allow parents to stay overnight. Keep your energy up with regular meals, even when you don't feel like eating. If you want some quiet time, go to the hospital chapel. Accept offers of help from relatives and friends, so you can spend more time with your child and your family.

Pacing yourself is still important when your child comes home from hospital. This can be a time of major readjustment for parents. Aside from the physical demands of caring, changes to your child from the brain injury may suddenly become more transparent. Being prepared for this can help you to cope with it and continue the process of readjustment.

Should my child be assessed?

Careful and thorough assessment of the traumatic brain injury or other brain disorder is vital to find the best way to help your child, whatever the cause or the diagnosis.

In the months ahead

The long-term effects of a brain injury may not be evident for some time. Some impacts may not be evident until years later, when the child is challenged to learn increasingly complex skills and deal with more complex situations. Any of the following changes suggest the need for a thorough assessment to determine how best to help the young person:

- difficulty with new school work or activities
- difficulties with concentration and remembering instructions
- slow to learn about new things
- less ability to join in familiar games and activities
- difficulty understanding what is being said or following a conversation
- decreased ability to re-tell the day's events or find the right word
- inappropriate sexual discussions or activities.

Talking to doctors & other professionals

If you are concerned about any of these symptoms in your child, or if there is any question that the injury may be more severe than first thought, speak to your child's doctor. The doctor will normally examine your child and may make a referral to a specialist doctor such as a neurologist, rehabilitation specialist or paediatrician. Other specialists who may be involved in assessment include a neuropsychologist, speech pathologist, physiotherapist and/or occupational therapist.

If possible, provide the doctor or specialist with the following information:

- when your child was hurt, injured or ill, and what happened
- what was done in the Emergency Department
- the name of any doctor who treated your child
- the changes you've seen in the child
- problems your child is having in school, with friends or at home - you may need to contact teachers and get feedback from friends
- examples of how your child seems different now
- what you do to help your child on a day-to-day basis.

REFERENCES AND FURTHER INFORMATION:

The Royal Children's Hospital - Children with Acquired Brain Injury: www.rch.org.au/kidsinfo/fact_sheets/Acquired_Brain_Injury_ABI/

Challenging Behaviour in Children

Regardless of the effects of a brain injury, parents can still bring out their children's strengths, help them build resilience, and enable them to develop to their full potential.

Bringing out the best in a young person means:

- enabling each child to express fully his/her own talents and abilities
- learning to build caring and satisfying relationships with other people
- acquiring the skills to be as independent as possible and take on responsible roles in life.

Two qualities are of particular importance in this process; self-esteem and resilience - the ability to handle life's 'knocks' and challenges. Support, love and respect of family members and peers and friends are the foundation for building resilience and self-esteem. A brain injury can make it more difficult, but there are lots of positive things you can do to help your child build his/her skills, self-esteem and resilience.

Bringing out the best in your child can include facilitating and encouraging them to be involved in activities that their friends and peers are doing. Swimming at the local pool, joining the scouts, getting a pizza with friends; these all help to build self-esteem and confidence and focus on the person and their strengths.

Encouraging appropriate behaviour

The best basis for helping your child is a loving, caring relationship, but behaviours resulting from brain injury can prove challenging. Try to see your child as separate from challenging behaviours e.g. 'I love you, but I don't like what you're doing'. This can help you to work together on the problem, without a negative focus on the child.



Parents in general do lots of things to bring out the best in their child, and all these things can benefit young people with a brain injury:

- Set specific rules and structures for particular situations, and rehearse these each time a similar situation is coming up.
- Praise or reward behaviours you want to encourage but don't reward behaviours you don't want to see. Ignore them or, if necessary, offer comment or an agreed consequence quietly without drawing extra attention to the behaviour.
- Help your child to learn from experience by talking over with them what worked well in the situation and what could work better, and how there might be other ways of responding.
- Show your child, by your actions, how to handle challenges and get along with others.
- Behave in the ways you want your child to behave by being caring, empathetic and respectful of others.
- 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 example, who they should or should not hug), and parents may need to set very firm boundaries and keep a check on them.

Understanding challenging behaviour

In trying to understand challenging behaviour:

- Try to put yourself in your child's shoes, to see the issue from his or her perspective
- See behaviour as a form of communication and try to understand the underlying message; are they sad, angry, hungry, tired, feeling unheard?
- Be aware of your own responses so that you can enact strategies to avoid becoming agitated when your child is testing boundaries
- Young people with a brain injury can take responsibility for their behaviour, with the right supports. They can learn appropriate ways of behaving, but - like everyone - they'll learn best when the goal is something they want to achieve for themselves. It's important to respect young people's own choices and priorities.

Managing agitation, frustration & anger

It's not uncommon for young people with a brain injury to behave in ways that are challenging or sometimes aggressive. They may have difficulty coping with small upsets and not even know why they are angry. Everybody feels angry, irritated or annoyed at times, but we all need ways of dealing with these feelings that are appropriate, socially acceptable, and constructive. Physical violence, verbal abuse, avoiding someone, or just 'sitting on' the emotion are all unhelpful.

Very young children often hit out when they are angry, but over time they learn to use words (even if these aren't very polite). Saying 'I hate you' rather than delivering a punch shows that a child has learned the first step in anger management; a shift from a physical to a verbal way of expressing anger. Later on, a child may learn how to feel angry less often, as they learn to negotiate and see another person's point of view.

Young people with a brain injury may have difficulty developing these more mature ways of managing anger. Cognitive problems can make it difficult to see things from another point of view.

Other people's reactions vary. Some might try to ignore the problem, or blame somebody, or demand that the young person change, or they might just become upset. In the long-term, though, these responses generally don't deal with the situation very effectively.

Conflicts may be frequent and intense, and discipline that works with other children might not be effective. Parents may find it hard to apply discipline at all.

These situations can be very distressing for parents and families. They can also be distressing to the young person; nobody likes to feel that their behaviour is out of control.

Some helpful strategies

Young people with a brain injury can usually learn to avoid having their anger boil over into physical aggression. The following suggestions may help:

It doesn't help to confront the person or respond angrily. Ignore the behaviour, or simply say quietly that it's not appropriate now, and reward and praise other behaviours that are positive and appropriate. You can also set limits on what is acceptable behavior e.g. shouting may be OK, but no threatening gestures. Think about what you're willing to do to enforce these limits.

Give praise when your child stays within the limits of acceptable behaviour or does something that avoids confrontations, for example, learning to walk away.

If temper or aggression is a significant problem, talk to a specialist. This might be a neuropsychologist, or a psychologist or behaviour therapist who has expertise in working with young people, and preferably one with experience of brain injury. Don't wait too long before doing this as it is much more effective to tackle problems before they become entrenched, for the sake of both the young person and the family.

Anger can be a result of being misunderstood, and a longer term goal is to help the young person to develop socially appropriate ways to express feelings and opinions in words and to use language more effectively. A speech pathologist can help in this area.

A specialist may suggest a fairly structured 'behaviour management' approach. This involves working with you and your child to analyse what is happening, the problem areas and to reach agreement on how everyone involved will handle it in the future. This is essentially a system for rewarding behaviours you want to encourage and ignoring those you want to discourage. The same strategies need to be used at home, at school, in day programs and so on, everywhere the young person is involved.

Make sure the standards you set are acceptable (and applied) in all situations in which your child must function. The whole family may have to make some adjustments, for example, brothers and sisters may need to accept the same rules.

Dignity of Risk

Balancing risk and independence for children with a brain injury.

Growing up involves taking risks. This is normal as young people 'test the waters' and move towards independence and adulthood.

Risks come in many forms. Some are social, for example, inviting someone on a date for the first time. Some are emotional, such as talking about fears. The risks that most concern parents are usually those that might cause physical harm. Sometimes young people do dangerous things deliberately and sometimes they just don't see the risks.

One of the important things parents do is to help young people learn to manage and judge risk. As parents, you are better able to judge what risks are acceptable and make sure your young person has the necessary skills to avoid danger. Parents who encourage independence and allow a manageable element of risk are showing optimism and confidence in their child.

Decisions about risk crop up all the time .e.g your child wants to go to shops alone, go to a party where you don't know the parents, or cook something on the gas. Ask yourself:

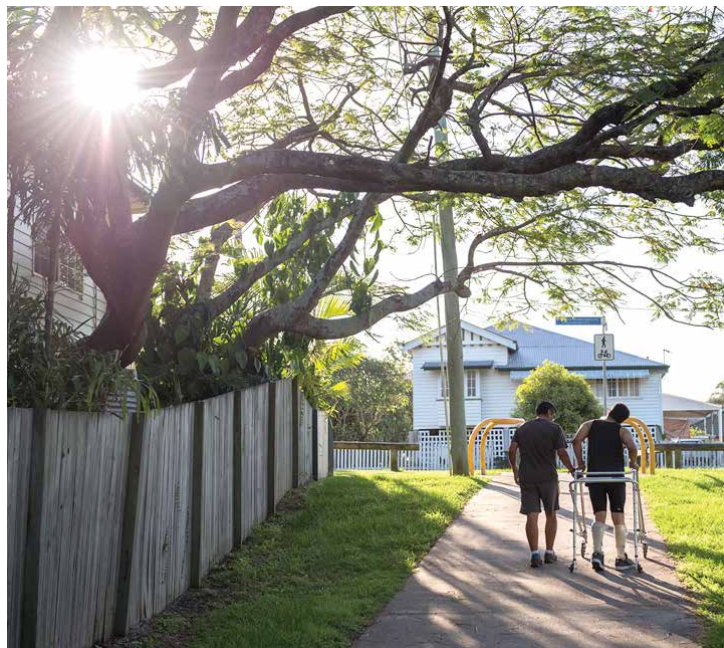
- Does he/she have the necessary skills?
- Can I trust him/her to follow the rules?
- What are the likely risks, including risks to others?
- Are there dangers outside his or her control?
- What would make it safe?

It may be tempting to put physical safety above all else but saying 'no' too often can have a cost. Kids lose confidence, or rebel, or simply miss out.

Brain injury, risk & your child

The pitfalls and dilemmas faced by all parents can be magnified when the young person has a brain injury. The young person may be less capable of anticipating danger, judging risk, or showing self-control. It may be harder to learn the skills needed to be safely independent. These might be physical skills, and/or skills related to behaviour, judgement, memory and perception.

Impulsive behaviour can place the young person at risk. Loss of confidence, self-esteem and friendship networks may make the young person more susceptible to the influence of peer groups, as he/she tries to impress, fit in, and make friends.



At the same time, if you try to protect your young person by restricting them more than others of their age, this can also affect their self-esteem and relationships with other young people.

What protects young people from risk?

Research has shown that some of the most important factors that protect young people from getting involved in some of the riskier activities of adolescence are:

- a strong and caring family and school
- sense of connection to family and school
- personal skills that enable the young person to develop self-esteem and confidence.

Other things that help are:

- a stable family structure
- open lines of communication
- a pro-active approach to solving problems
- having a good relationship with an adult who believes in them such as a grandparent or a teacher.

Managing risks

It is always important to equip young people with the skills, knowledge and confidence to say 'no' to things they do not want to do. At the same time, risky activities are a normal part of growing up, and it is imperative to try to minimise any harm that may result.

Where a brain injury is present, there are further considerations. For example:

- Can the young person understand and remember instructions, rules or laws and apply general rules to specific situations?
- Are impulsiveness and poor judgement issues?
- Does the young person need any training or instruction to maximise the chances that he/she will act responsibly and safely?

The following strategies may help:

- set sensible and firm limits based on your family's values and respect for laws and regulations
- be a good example and role model
- try to keep the communication lines open within the family and listen to what your children have to say, respect their point of view (even if you don't agree with it)
- provide a 'safety net' of appropriate supervision by being aware of your child's friendships, knowing where they are at night, and being awake when they get home.



Everyday risks

For young people with a brain injury, the small steps toward independence that their peers manage easily may require extra training or supervision. If they lack foresight or are impulsive, some activities possibly should be avoided, controlled or prohibited.

'Getting around'

Very young children are generally under adult supervision when they walk to shops or cross the road. Sometime during primary school, many children begin to do these things without assistance. Throughout secondary school, young people are generally expected to get themselves to school and other places. With increasing independence, children and young people might, for example, want to walk to local shops alone, ride a bike around the local neighbourhood or take public transport to social events as well as to school.

A young person will usually want to do what others their age are allowed to do. However, parents need to decide whether their child with a brain injury has, for example:

- The necessary skills for traffic safety
- A good enough memory to remember rules, how to get where they are going and home again, and what to do if they have problems
- The necessary physical skills and reflexes for a bicycle or roller blades
- The ability to organise what they need to do, including things such as handling transport timetables and buying tickets
- If your child does not have the skills needed, then a structured learning program - combined with an appropriate 'safety net' - may help.

Some children and young people with a brain injury may be worryingly ready to trust and be friends with anyone and everyone. Younger children may not have the separation anxiety that most of their peers experience, because they are so used to seeing many different people in hospital. All age groups can be very trusting. This openness can have positive aspects, but it also exposes the young person to risk of danger.

Rules need to be very specific and structured about how to behave in particular situations, and need to be practiced over and over.



Other everyday risks

If the young person wants to play a contact sport, a neurosurgeon (if one has been involved) can say whether it's safe and what precautions are necessary (for example, a helmet). Otherwise, ask your pediatrician or general practitioner to advise. The young person may need coaching to learn the rules of the game or to manage any frustration they may feel.

Using household equipment like stoves and knives can be risky if, for example, memory difficulties make it hard to learn a sequence of steps. Again, set very specific rules and practise and rehearse them repeatedly. Where necessary, you may need to put some activities off limits, or install protective devices around, for example, stoves. Talk to an occupational therapist about managing risks of this nature.

Some kids always seem to be looking for something ambitious - and possibly forbidden - to do. Try to step back and ask yourself what you would do for a child who didn't have a brain injury. Make sure lines of communication remain open, boost the young person's self-esteem, encourage more positive friendships and provide appropriate supervision - for example, have friends visit your house, rather than letting your child go out with them.

Driving

Obtaining a driving license will not be possible for some young people with a brain injury, but it will be an option for many others.

Brain injury related impacts that may affect a young person's ability to drive include:

- Physical weakness and/or poor coordination
- Altered sensation - for instance, lack of awareness of one side of the body
- Difficulties in perception - for instance, difficulty judging distances
- Slowed reaction time
- Changed vision - for instance, a restricted visual field
- Difficulty concentrating
- Impulsive behaviour
- Confusion between left and right, difficulty in understanding maps and directions
- Risk of epilepsy.

Even if the effects of a brain injury appear minor, it is crucial that you find out the requirements to be met if someone is applying for a driver's license and has a brain injury. It is important to get this done, as it provides you, your child and others with legal protection should an accident occur. Failure to disclose a medical matter may be an offence, and any license or permit obtained by false statement could be rendered null and void.

An assessment by an occupational therapist and/or a neuropsychologist is recommended.

Building Social Skills

Children and young people with a brain injury may have difficulty with the social skills that most of us take for granted.

About social skills

Young people learn their social skills from their day-to-day activities in the family, at school, at play, and in the various groups and clubs they may be part of.

A traumatic brain injury or similar brain disorder can cause children to interact in ways that aren't socially appropriate. This may include being tactless, poor at 'reading' social cues, talking too much, interrupting, or seeing the world only from their own point of view. Other social skills may be lacking - simple things such as using eye contact appropriately or they may be excessively friendly and accepting, hugging near-strangers and willing to trust and go with anybody.

They can be at risk of becoming socially isolated and cut off from friends and the normal things kids do together. Bullying or teasing can sometimes become a problem due to being impulsive and less able to judge social situations. Don't hesitate to contact the school if you suspect bullying.

Some strategies

- Understand your child's strengths and weaknesses in social skills, cognition and language. Be prepared to alter some of the ways you do things.
- Think about how you feel when your child behaves in ways that are socially difficult. Becoming angry isn't helpful so recognise your frustration, embarrassment, or anger. Set specific rules and practice these skills many times, in a range of different situations.
- Don't draw attention to an inappropriate behaviour by reacting strongly to it. Always praise or reward the behaviours and skills you are trying to encourage.
- Think about when the difficulties happen. Often you can improve things substantially by adapting what you and your family do and when you do it.
- Try using 'problem solving' techniques (a simplified version if necessary) with your child to find ways around difficulties.
- Help your child to rebuild social networks and friendships by asking other children to your house, and talking to the school about building friendship networks.
- One strategy that has proved helpful for some young people is "stop, think, do". Use a traffic light image - red, amber, green - to help the young person stop before reacting.

- Help and encourage your child to get involved with other groups in the community.

Getting help

Professional help and advice can be very valuable. Look for a professional who has expertise and experience in working with brain injury, ideally a neuropsychologist or clinical psychologist. If you can't find a psychologist, talk with other health professionals and/or parents to find out what might be available to you in your local area. Some schools and community health centres offer young people group training programs in social skills, and these programs can be of benefit to some young people with a brain injury.

Thinking, feeling, behaving and other strategies

Young people with a brain injury often have difficulties that affect their thinking, their feelings, and their behaviour. The best results come when parents, teachers and health professionals understand these difficulties and work together on a program.

Measures to help a young person overcome their difficulties require lots of repetition, practice and reinforcement. The child may find it very difficult to carry that skill into a different situation - to 'generalise' it. It may have to be dealt with anew.

- A memory aid is anything that can be used as a reminder such as a diary or notes.
- A cue is a 'signal' like a hand gesture for someone to start or stop doing something.
- A prompt is a reminder to do something, such as a note in a homework diary, a note on the fridge door - it can take many forms.
- Role playing is a bit like taking a part in a play - the person gets a chance to practice how to behave in certain situations.
- Behaviour management provides a system for 'rewarding' behaviours we want to encourage and not rewarding (or ignoring) those we want to discourage.
- To generalise is to use appropriately, in a new situation, something the person has already learned in a different situation.

A problem-solving approach

'Problem-solving' is a positive approach to dealing with difficulties; one that breaks the process into separate, manageable steps. A problem-solving approach can:

- Help you and your child decide which problems should be tackled first
- Provide you with something concrete and positive to do, when faced with a problem.
- People who use problem solving regularly, for small, everyday problems, find that it becomes a way of thinking. The approach is detailed, and takes time and commitment from everyone involved.



There are six steps of problem solving:

1 Define the problem

Work with others to identify the main problem. If you can't agree on the main problem, negotiate a compromise. Pick one problem. Avoid being overwhelmed by trying to solve lots of related problems at once. Be specific. Try to separate facts (the description of the situation) from the issues these raise (why the situation feels like a problem).

2 Brainstorm options

Search for anything that might offer a solution. List on paper as many new options as possible, even silly ones - and don't make any judgements yet. Just write them down. Get ideas from solutions that have worked only in part, or not at all. Be specific about what a particular solution involves and get options for different aspects of the problem.

3 Select what might work

Eliminate options with less chance of working, and options that some people don't agree with. Give everyone involved a chance to comment. Try to pick the solution that will make the most difference now, or 'take the pressure off'. Try to understand the meaning of the behaviour. Be prepared to try an option for a while. Don't give up on it too quickly.

4 Put a plan into action

Many plans fail because people don't carry out their part or because there's no coordination. It's often easier if there's a written summary and one person takes responsibility for checking that everything is happening as agreed.

5 Review what happened

People often forget to reflect on how well a plan is going - sometimes because the problem 'disappears' but usually because everyone gets caught up in something else.

Get the opinion of everyone involved and be as objective as possible about what's worked and what hasn't. Use this new information in future attempts to solve the problem. Acknowledge everyone's efforts.

6 Keep going

Most problems aren't neatly resolved, and new ones can spring up. Information from the first round of problem solving must be used to fine-tune solutions and solve other problems. Remember that problem solving skills must be learned and practiced.

Keeping the lines of communication open

Good communication skills are one of the greatest assets you and your family can have. Many aspects of communication can be disrupted by a brain injury. A person with a brain injury may need special training to master some elements of these skills:

- Difficulty talking about things in a general or abstract way so use more concrete or descriptive terms
- Be prepared to ignore repetitions or wandering off the point, and gently redirect the conversation if it seems to be 'getting off the rails'
- Respond positively and sound interested when you are talking with the young person
- Stay calm - don't let yourself get angry or aggressive.
- Speech pathologists, found in most public hospitals and community health centres or through school support services, can assist individuals with a brain injury and families with the development of communication skills after a brain injury.

Attention and listening

The first requirement is that you focus your attention on the other person. This means facing the other person from a comfortable distance, using the right amount of eye contact, and giving them your undivided attention. Genuine interest in the other person is the best starting point.

Responding and encouraging

Your responses show that you are listening and interested. For example, 'Uh huh', 'OK' or 'I see' all encourage the other person to go on talking. 'Reflective listening' goes beyond this and involves repeating or rephrasing something the person has said, or summarising the main point.

Open and closed questions

Open questions can encourage people to keep talking. Open questions invite the other person to provide more information - 'What did you do today?'

Closed questions, by contrast, generally have a single response - 'Do you like chocolate ice cream or vanilla?' They too have their place, sometimes we only want a brief response.

Young people with a brain injury may find closed questions easier to answer. If you are using closed questions, try giving a choice between alternatives ('Do you want tuna or cheese?') rather than asking a 'yes/no' question ('Do you want to eat something?').

'I-statements'

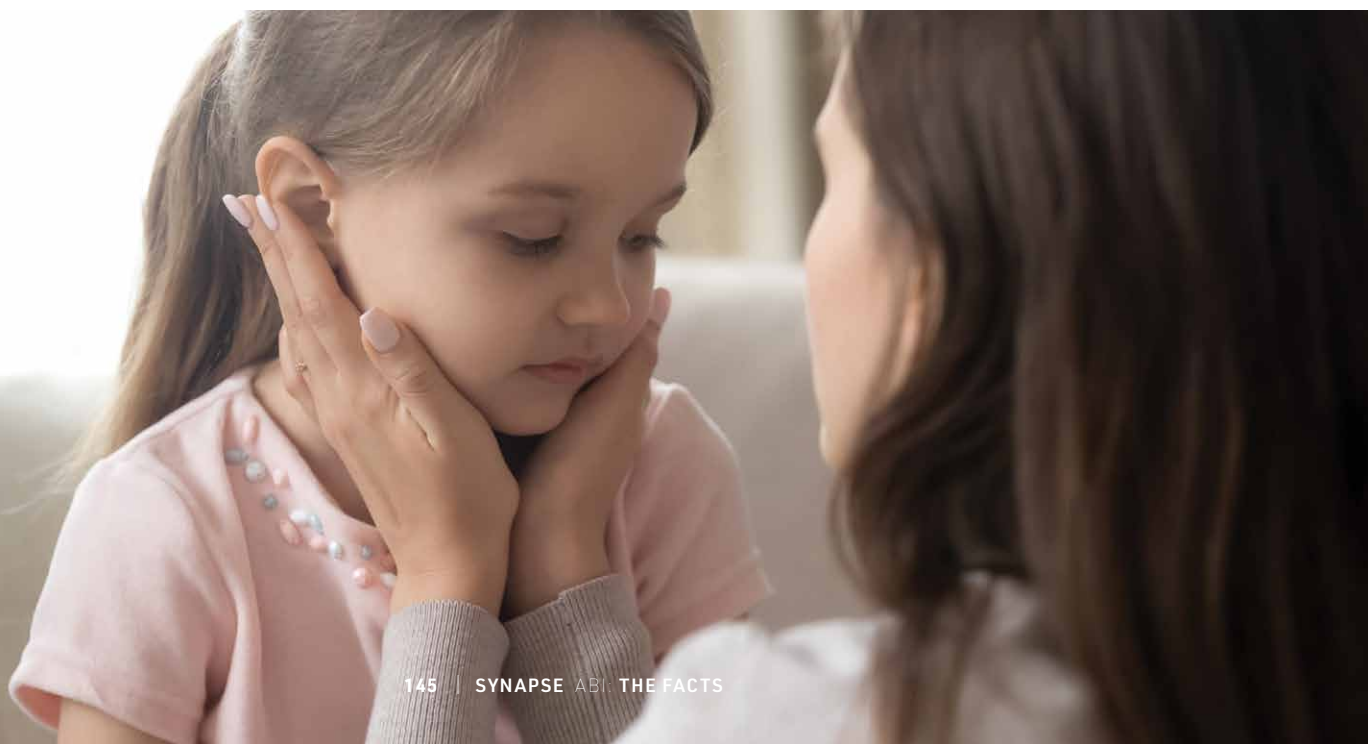
It is important to be able to state your own point of view, without blaming or accusing the other person-particularly if you are concerned about something they are doing. The 'I-statement' tells others how you feel.

For example: 'I get very worried when you're late', 'I get angry whenever I try to talk to you about your friends.'

It gives the other person a chance to say 'I'm sorry' or 'I didn't realise you felt that way'.

In contrast, a 'you-statement' places responsibility on someone else.

For example: 'You're so irresponsible', 'You make me lose my temper every time we talk.'
A 'you-statement' often leaves the other person feeling attacked and they may get defensive.



Language

Language and everyday living skills may need particular attention to ensure that a child with a brain injury recovers to the fullest extent possible over the years.



Language and brain injury

Language is one of our most important and complex skills and is often affected by a brain injury in ways that may be subtle but nevertheless important. We start to hear, respond to and learn language from the time we are born. By about five years of age, most of the basic language structures are in place, but the process of extending and refining these structures, building vocabulary and thinking skills, learning to read and write, goes on throughout childhood and adolescence.

A brain injury can interrupt this process. The younger the child when the brain injury occurs, the smaller the 'store' of vocabulary and language structures he/she has built up, and can call on after the injury. In general, the more severe the brain injury, the more severely the language is impacted, although there are exceptions to the rule.

A speech pathologist is the person to help with language problems, ideally one who is experienced in working with young people with a brain injury.

Language involves both 'comprehension' - understanding what others say, and 'expression' - saying things ourselves. And it also involves the thinking that links these two together, enabling us to respond appropriately to what someone else says. There are many skills and resources involved such as a large vocabulary, the rules of grammar, stringing ideas into a narrative and organising the mouth, throat and lungs in complex sequences to talk.

Using & understanding language

Children who are very young when they sustain a brain injury may have difficulty learning the building blocks of language. These are words, grammar, and skills such as how to talk about something that happened yesterday.

Most often, children with a brain injury can talk quite well. The problems are often less obvious, involving the processing of language - that is, the way we understand and organize things in language. Children with a brain injury may, for example, have difficulty with:

- understanding similarities and differences between things, and putting things in categories - the differences and similarities, for example, between a car and a truck
- being able to link ideas and build associations between different things
- sequencing and organising information logically
- knowing how much to say, or being able to think of what to say
- following instructions.

Children who have challenges in these areas may fail to understand humour, metaphor, innuendo and the 'social rules' in each situation. If the young person has difficulties with memory or with focusing attention, it can be more difficult to understand what is being said and to follow a conversation.

A young person with a brain injury may have difficulties in developing grammar and sorting out the order of words within a sentence.

Getting ideas in sequence can also be difficult, such as telling a story. Without strong oral language, it's very hard to develop good reading and writing skills. Sometimes children can read but find it hard to understand what they have read, put it into their own words, or write down their own thinking.

A speech pathologist can often help substantially to develop these skills. If a child is unable to communicate verbally then a speech pathologist can also help by providing the child with an alternative way of communicating. This may include using pictures, words and/or hands.

Articulation

Slurred and jerky speech - 'dysarthria' - can be a problem after a brain injury. Usually this clears over the first few days or weeks, but sometimes, with more severe injuries, speech is more affected. A child with weak or tight muscles of the face, tongue, jaw may have slurred or imprecise speech. You will have to pay good attention to your child's efforts to speak.

Helping your child to listen & understand

Use language that is concrete and straightforward. If you are giving instructions, use short, simple sentences and limit yourself to one or two at a time.

Model or demonstrate what you want, while you say it as well. Ask your child to restate the information you've just given: *"Now tell me, how are you getting home from school today?"* Allow time for your child to take in what you have said.

Say the same thing twice, in different ways (allowing your child time to take in each): *"We're going to the beach soon. Are you ready to go to the beach?"*

Allow your child time to think of what he/she wants to say. Talk with your child a lot - just ordinary, everyday conversation. Listen, don't correct and interrupt, but hear what is said and respond in a way that shows your interest. Make talking enjoyable and rewarding.

Help your child to listen as well as talk - for example, explain that everyone has a turn in conversations, and it's your turn now (or the turn of another member of the family, etc.). Then encourage your child to respond e.g. *"what do you think about it?"*

Organise things so that your child has to ask for things at the shops such as buying the milk. Make opportunities for talking in all sorts of everyday situations.

Do things together and talk through the steps together. For example, packing a bag to go away for a weekend - ask your child what he/she is going to take, help to write a list and fill it out, e.g. *"What's going to happen if it rains?"*

Find out what games are 'in' at school or in the playground and rehearse them at home. Or play other games; cards, checkers, etc. Take it slowly, talk through the rules step by step, practice each step, and help your child learn to take turns. Use the communication aids you and your therapist might make.

Physical and Everyday Living Skills

A brain injury can interrupt and complicate the development of a young person's physical and everyday living skills. There are, nevertheless, many positive and constructive things that can be done to minimize the difficulties, maximise recovery, and find ways to work around ongoing challenges.

Physical and sensory skills

Physical and sensory problems can affect, to a greater or lesser extent, a person's ability to get about and do simple, everyday things such as walking, dressing and managing cutlery.

Impacts may include weakness and changes in muscle tone, decreased coordination or balance, fatigue, visual problems and changes in sensations such as touch, pain and temperature. Often these are coupled with cognitive and behaviour problems, making it more difficult for the child to compensate for the physical difficulties. When the brain injury has been caused by an accident, the situation may be further complicated by other serious injuries.

The physical, cognitive, sensory and visual realms are all interwoven. For example visual impairment, slow reaction time and poor coordination can make it very difficult to do something apparently simple, like throwing and catching a ball against a wall.

Recovery from physical impacts is usually more rapid than recovery from cognitive, thinking and behaviour impacts. Much of the physical recovery happens within the first 6-12 months after the injury with active rehabilitation.

Growth

Growth spurts can disrupt abilities that were previously under control. This is because a child's musculoskeletal system is often less adaptable after a brain injury. The long bones may grow faster than the muscles, so the muscles become tight and less well controlled.

Physical demands and challenges increase as the child grows older, and physical problems may show up as the child is increasingly challenged - even years after the initial injury.

The complexity of games and rules also increases as children grow older. For example, a lot of sports and games for 4-6 year olds are about drill training and learning the skills. But when the child has to take these skills into the context of a competitive game and respond to lots of other things going on around about, it can often be much more difficult.



Major transitions can create extra challenges. For example, the move from primary to secondary school involves a change from having all lessons and books in the one classroom, to having to walk from one side of the school to the other between lessons, carrying books, negotiating stairs, and in a sea of other kids all going different ways.

What you can do to help

Break down the skills involved into small components and practice them with your child. You might, for example, play in a smaller space, use a bigger ball, practice somewhere where there aren't lots of other distractions.

Talk to your child's teachers, and any sports coaches, so they understand your child's special learning needs, are aware of the challenges that can be expected over time and can help to reinforce a structured approach in teaching skills.



Children with a brain injury need lots of encouragement to take part in physical activities, in order to maintain their physical ability and a basic level of physical fitness. You might need to help your child find a sport or activity that is not competitive, so he/she can experience success in it, for example, swimming or cycling.

Aids & equipment

Children and young people with a brain injury may benefit from a range of different equipment and aids, including:

- mobility aids including walkers, crutches, splinting
- bath equipment, bath chairs, toilet chairs
- adapted car seats, adapted bicycle seats
- aids for writing-different work surfaces, adapted pens
- ways to make eating easier such as adapted spoons, cups, plates
- computer access e.g. laptops with modified screens to make print larger
- splints to maintain range of movement, stretch tight muscles, or provide stability.

An occupational therapist (OT) and a physiotherapist can both assist with aids and equipment. The OT can advise on bathroom equipment and self-care aids for eating, dressing, or managing at school, the physio can assist with mobility.

A small proportion of children with a brain injury develop long-standing spasticity which may be helped by splinting, surgery or medical treatments such as 'botox'.

Personal care

Personal care includes a wide range of everyday activities that we take for granted - dressing, washing, eating and toileting. Personal care can present problems for someone with a brain injury, particularly during adolescence when young people are striving to become independent of parents.

There are various ways to support independence:

- **Clothes, utensils and environments** can be adapted. Look for different shaped cutlery or specially adapted cutlery. Experiment with different types of clothing and fastenings-for example, T-shirts or tops that don't require buttoning, clothes with larger buttons, slip-on shoes rather than laces or small buckles.
- **Break down tasks** into small steps and start by getting the young person to do only the easiest step, or maybe the last step. And provide lots of opportunities for practice.
- **Use cues** to remind the young person of a daily routine, for example, list what has to be done to get ready for school. List might include - Get dressed, Brush teeth, Brush hair, Pack bag. Put the list on the fridge door, or your child's wardrobe door.
- **Set priorities** and do the important things first, so fatigue and stress don't interrupt them. If necessary, help with the less important tasks so you've time and energy to focus on the skill currently being learnt.
- **Arrange with the school** and/or other agencies involved to use a daily diary system, to keep track of what has been learned.

Wellbeing

Protecting Your Family's Wellbeing

In the aftermath of your child acquiring a brain injury it can be easy to neglect your family. Caring for a child with a brain injury can take a great deal of time and energy. It's easy for everyone else's needs to get side-lined, and can be difficult to get the balance right.



Some strategies for wellbeing

Let your other children know that you care about them and that you understand that things are tough for them. Try to give each child some time regularly, when he or she is the focus of your attention.

Don't be afraid of feelings - your own or other people's. Let everyone in the family understand that it is okay to express their feelings. Try to maintain as much family structure as possible, to give you all a sense of security and continuity. Keep on doing some of the things you used to do as a family.

Encourage teenagers to get on with their lives and make their own plans (remembering that it's always best to know where your teenagers are and who they are with).

Don't sweep conflicts and problems under the carpet - talk about them openly, and deal with them. Set aside times when the family can discuss responsibilities and problems.

Let teachers or school counsellors know what's happening at home. Keep in contact with the school to make sure things are okay and 'troubleshoot' any problems.

Use respite services or find other ways to give everyone a break (including yourself). Accept offers of help from friends and relatives.

Take care of yourself - both for your own sake, and for your family's. Do at least one thing a week that is just for you - pamper yourself occasionally. If your children see you having fun and getting satisfaction out of life, they will tend to see this as a good model to follow, a good way to be.

Try to make opportunities to recognise and celebrate what's been achieved. Observe the same special occasions as you did before the injury.

Responding to your other children

Your child's brain injury will affect any other children in your family. Parents usually see these effects, but professionals may be unaware of what siblings are feeling.

Children's reactions to a brain injury in a sibling

Sadness is common and reactions may include both positive and negative elements. Different responses can occur at the same time or in quick succession. It's a challenge to encourage more positive responses without 'putting the lid' on the negative ones.

Helping children express themselves

The most important thing you can do for your other children is to listen and be there for them. This means making time to be with them - something that is often not easy, either practically or emotionally. Brothers, sisters and other young relatives need opportunities to express their feelings freely. They may believe that some of their normal responses - anger, resentment, rejection - are wrong or abnormal. Let them tell you their worries without judging or trying to change how they're feeling.

Some young people don't talk to parents because they don't want to worry them or be a burden. They may prefer to talk to friends, other relatives or counsellors. This can be a good thing, but if these people have little knowledge of brain injury try to tactfully correct the wrong information if it comes up.

Young children can't take in too much information at one time. Keep explanations simple and respond to questions at the level the child can understand.

Take advantage of the chances you get to be with each of your children whether it is clearing up the kitchen, getting some breakfast together or watching a match. You can't force children to talk, but you can be there when they are ready.

Active listening is very important. Give the child your attention and show that you're interested without breaking the flow of the conversation.

Often children don't volunteer how they're feeling but they may answer direct questions. Sometimes a gentle prompt can help, when the child is ready to talk, such as *"How do you think (your brother or sister) has changed?"*

When children do talk try not to jump in too quickly with reassurance or advice. Give them time to talk and to express their feelings. It is important to remember children's behaviour may give clues to how they are feeling; by withdrawing, acting out, sleep disturbances or poor school results.

Providing factual information to children

Children who are well informed are better able to understand and accept what has happened. They are also usually better able to support and understand the difficulties facing their brother or sister with a brain injury. Don't overload your children with information but answer their immediate questions and concerns. Be aware that

children vary widely in the amount of information they want, and their ability to take it in.

In the early days after the injury, hospital or rehabilitation staff may help to explain to your children what's happening, or they may have useful pamphlets, books, videos or computer programs. Ask the staff how your other children can be involved with your child - maybe helping with care in some way, talking and listening, or simply just being there and being reassuring.

Brain injury & mental health

Ups and downs are a normal part of life. Teenagers in particular have wide swings of mood as they learn to deal with increasing independence and a changing body. This is to be expected, it's a normal part of growing up, though it can often be demanding to live with.

Sometimes, however, changes in behaviour are the first sign of something more serious. Many children with a brain injury can remember how they were before the injury and adjusting to the changes can be very difficult. Changed abilities, disrupted schooling and loss of friendships can cause great unhappiness. Young people can often become depressed as they gradually become aware of the full impact of their brain injury.

If depression is severe or prolonged, it can interfere with a young person's normal development and increase the risk that they will harm themselves in some way. Anyone with depression of this nature needs treatment for their depression.

The young person may find it helpful to talk about what he or she is experiencing. Sometimes it's easier to talk to a friend or professional rather than a family member.

A brain injury may impact on thinking and speech that make it harder to talk through problems, so it's particularly important to teach concrete ways to help the young person cope. But even if speech and thinking are reduced, the young person can often communicate their sadness and distress. It's important to listen to what your young person is saying rather than how he or she is saying it. Simply having someone listen and care is a help.

Can a brain injury lead to mental illness?

Mental health issues can occur in anyone and are common in our society. Most disorders don't have a single cause but result from a complex combination of events and conditions, including the person's biological and inherited make-up, their psychological make-up and skills, and their family, social and community environment.

Risk factors such as stress increase the likelihood that a person will develop a mental illness. Protective factors, on the other hand, help people to cope with adversity such as

an easy temperament, a strong and supportive family and school environment, and a sense of belonging.

Adolescence - particularly later adolescence - is the time when mental health issues are at their most common. Some of these disorders start in childhood, some during adolescence.

Many young people with a brain injury will not develop a mental health issue, but some inevitably will. Each young person's level of risk and protective factors will be different, but some of the effects of a brain injury do increase the risk of some mental health issue. For example, a brain injury can erode a young person's confidence and self-esteem, and behavioural problems can put teenagers and young adults at high risk of becoming socially isolated and without friends.

In short, a brain injury may both increase stress and decrease the person's ability to cope with stress.

The most common symptom in young people with a brain injury is depression - often probably a response to the adjustments necessary after an injury. Young people with a brain injury may also experience severe anxiety, sometimes diagnosed as 'post-traumatic stress disorder'.

There is no evidence that a brain injury increases the risk of a number of other mental health disorders, including schizophrenia and bipolar disorder.

Suicide is always a concern for parents. Remember that only a small number of young people actually take their own lives, though many more attempt suicide, and still more think about it. Mental illness, particularly depression, is one of the main risk factors for suicide. Young people who have previously attempted suicide, or have deliberately harmed themselves in some way, are particularly at risk.

Symptoms of a mental illness

Parents are the people most likely to notice signs of a mental illness or emotional disorder. The signs can be difficult to pick, as many resemble the effects of a brain injury. They include:

- a drop in school performance
- rigidity in thinking and behavior
- unwarranted worry or anxiety and inability to cope with day-to-day problems
- changes in sleeping or eating habits
- aggression (verbal or physical) towards others
- excessive fear and feelings of persecution, paranoia

- recurrent nightmares and seeing, hearing or experiencing things that are not there
- depression or social withdrawal
- difficulty 'getting going'.

What to do if you suspect a mental illness

If you're worried about your child's mental health or suspect a mental illness, it's useful to consult a health professional, preferably someone who understands brain injury and its effects on your child, and preferably someone you've worked well with before.

Refusing to go to school may reflect relatively mild anxiety that could be helped by changing the child's school environment, or by using carefully chosen strategies to change the child's behaviour. If the anxiety is severe - for example, if the child is having panic attacks - medication may be necessary.

Treatment for mental illnesses has improved vastly over recent years. Medication can usually reduce symptoms, and a range of psychological, behavioural and social therapies help people to address the problems in their lives and learn healthy ways of coping and behaving.

If the young person's mental health concerns continue, try to see a mental health professional with experience of both brain injury and young people (ask about their experience). If you can't find someone with these skills, make sure the mental health professional knows your child's history. Mental health professionals include psychiatrists and psychologists.

Brain injury specialists and mental health specialists must coordinate their care, as treatment needs to take account of both conditions. For example, the dose of medications for mental illness may need to be adjusted for a person with a brain injury.

Coordination may not be easy. The brain injury and mental health treatment systems are separate, and experts in one area may know relatively little about the other.

Good case management can help to ensure that services are co-ordinated and the right treatment identified. Often, though, parents have to be the 'go between' to make sure information is shared.

Development

A brain injury can disrupt the long and complicated process to move from childhood through to being a mature adult.

Developmental changes

At each stage of development a child needs to master a particular range of physical, intellectual and social skills. Over time, these developmental changes should include:

- ability to handle complex ideas
- ability to concentrate and to remember what is learned
- increasing physical and social independence
- physical abilities, stamina, strength and coordination
- increasing self-awareness and sense of identity
- ability to express negative feelings and frustrations verbally.

These general trends are all important, but there is plenty of 'normal' variation in how they occur. Changes seem rapid during some periods and slow at other times and at any age, a young person may switch between more and less mature behaviours. 'Transition' times place extra stresses on children. These are times of major change. Some are imposed from outside: starting school, moving from primary to secondary school, leaving school. The most important 'internal' transition is puberty.



How a brain injury affects development

A traumatic brain injury and other types of brain disorder can disrupt development to a greater or lesser extent in areas like language and speech, learning, memory, thinking, behaviour, and physical functioning.

For children and adolescents with a brain injury, the situation is further complicated because their development isn't complete. They still have many things to learn and tasks to accomplish to reach mature adulthood.

A brain injury can range from very mild to very severe, with everything in between. There may be only a few observable effects, but with increasing severity, more areas of life are usually involved and effects tend to be more obvious.

Direct effects of a brain injury often involve social, intellectual and language development.

They might, for example, affect abilities such as:

- getting organised,
- controlling impulses,
- learning new skills or
- remembering things.

Many young people also have slower reactions and weakness in some parts of the body, which may affect what they can do and take part in, and their self-image. People with a severe injury may also have major physical challenges that impact on their ability to move about, care for themselves, and communicate.

Indirect effects result from the way the young person and others respond to the direct effects. These can include loss of confidence, changes in behaviour, social isolation, frustration, emotional problems and low self-esteem. Brain injury is not widely understood and some people may confuse it with mental illness or intellectual disability.

If there are no visible signs of having acquired a brain injury then a child's behaviour can be easily misunderstood.

Cognition

Generally, 'cognitive' (that is, thinking or intellectual) skills are most affected. It is often harder for young people to remember things, harder to concentrate, work logically through a process that involves many steps, or manage several things at the same time. They may also have some physical issues, for example, slower reaction times and poorer coordination than before.

These difficulties don't just affect school work. Because thinking skills play a large part in getting along with others, social interactions can be changed. There can also be a tendency to be impulsive, irritable, even aggressive, and this can affect relationships.

The myth of the resilient brain

It used to be thought that younger children were more resilient and 'bounced back' after a traumatic brain injury. But as children develop and grow, they build up an ever-increasing 'bank' of memory, learning, knowledge, language and life skills - the younger the child when the brain injury occurs, the smaller is the bank of stored learning. The young child has less to draw on.

This makes good recovery and adjustment more challenging. Effects of the injury may continue to appear over years, as the child's brain matures and is challenged to learn new and more complex tasks and skills.

How to assist your child's development

Helping the young person to deal with and/or overcome these effects can involve:

- Taking special care to teach him or her the necessary skills; and/or
- Finding ways around the problem - 'compensating' for it
- The best approach will vary from person to person, and problem to problem. Professionals can provide advice. The key to success is to identify the nature of the difficulties, and to deal with them before the young person becomes discouraged and loses confidence. Young people with need lots of opportunities to practice skills that others learn more easily
- Assessment: the first and essential step is to obtain a clear and accurate assessment of all the young person's abilities and difficulties - whether the brain injury has just occurred, or there are worrying symptoms months or years after the event. Assessment is the basis for planning a specific program to build on the young person's strengths and address their particular needs
- Setting goals: this planning and goal-setting should always be a team effort, with the young person, the family, and the professionals involved - a partnership that works to find the best ways of meeting each young person's needs, and the needs of the family as a whole
- The program needs to be tailored to your child's and your family's priorities and circumstances, to build on your particular strengths and skills. It needs to help you and your child adapt positively to the way things are now, and to foster your child's learning and independence.

- In the first six months after a brain injury, recovery is at its fastest although progress will continue for many years in cognition, language, physical skills, behaviour, emotional and social skills.
- Re-assessment and planning, both formal and informal, needs to continue often over years, to track the young person's development and progress, and map out the path ahead. Remember that predictions made by professionals-even the most competent-may not always turn out to be accurate. This simply reflects the difficulty of making accurate long-term predictions with something as complex as brain injury.

Some general strategies

Individualised plans are important, but some general strategies may also help:

- Pitch your expectations at a level where success is likely
- Praise or reward small but significant steps toward a goal
- Break larger tasks (be they physical or cognitive tasks) down into small steps that can be learned and practiced separately
- Practice how to deal with difficult situations, recognising that it may be hard to apply existing skills to new situations
- Focus on tapping into the young person's strengths, and changing the surroundings to compensate for things he or she finds difficult
- Respect the young person's dignity, help them achieve their goals for themselves and aim continually to build self-esteem and confidence
- Be consistent in your expectations and approach - don't chop and change the ground rules for the young person
- Use a 'problem-solving' approach to difficulties, to find the solution that best suits the needs of everyone involved
- Think about building informal supports for your child - for example, contact with other young people who have had similar experiences
- Try to give yourselves time off from rehabilitation every now and then, and just be together for a bit. Don't expect to change everything at once. It's easy to feel impatient when the young person is struggling to learn or re-learn skills after meningitis, a traumatic brain injury, encephalitis or other type of brain disorder.

Family Response

Reactions and Responses to a Child's Brain Injury

Brain injury in a child causes many different reactions in the family. There is no single, predictable pattern but the ongoing emotional stress can be very difficult.



Feelings change over time and finding ways for everyone to adjust and get back on an even keel can take a long time. It can be confusing, chaotic, and difficult at times to work out exactly what you are feeling. Relationships within the family may change.

Often, the first reaction is shock and disbelief, particularly if the brain injury is sudden and obvious. On the other hand, a diagnosis of brain injury may be a step forward, if you have been concerned for some time about unexplained problems for your child. An explanation may help you to move on and focus on finding the best ways to address the problems.

Gradually, families adjust to what is happening, and become more aware of the implications and the effects on everyone's lives. Some may search far and wide for a cure or a treatment, others rest their faith in the treatment team and concentrate their efforts on simply getting back on track.

Rebuilding hope

It takes time to realise that, although everything won't return to the way it was, there are ways of adapting and

coping, and good things ahead. Parents who have lived for a long time with the changes a traumatic brain injury or similar brain disorder brings know that things can and do get better. Their messages of hope for people just beginning this journey include:

- You haven't failed, even though you may feel you never do enough
- It's possible to work with negative responses in positive ways
- Grief doesn't necessarily go away, but over time, it becomes possible to see things from a new and positive perspective.
- All the many different and conflicting emotions you may feel are normal.



Let yourself grow gradually into your own situation

- Find people you can talk to - friends, your partner, family, support groups, people in your community.
- Remember that, first and foremost, you are a mum or dad, even when you're doing the work of an occupational therapist, speech therapist, physiotherapist or counsellor.
- Ask for help, and if you don't get it, ask again and again.

Professional help

Many people have found professional help from a psychologist or social worker can provide a positive pathway through these emotions. It can help to prevent difficult emotional patterns from becoming entrenched and can also help you to keep family relationships on track.

If you or one of your family members is struggling with these emotions, consult a mental health professional about appropriate treatment, including medication. Look for a therapist - a psychiatrist or clinical psychologist - who has experience dealing with carers. If medication is needed, it can be prescribed only by a medical practitioner (a psychiatrist or GP).

If mental health professionals are in short supply in your area (for example, in some rural and remote areas), find another health professional in your community whom you trust and can talk to. Social workers are trained to provide families with considerable support, both emotional and practical. Some GPs are very good in this role, and therapists and community nurses also provide emotional support as part of their work.

Positive way to work through negative emotions

A child's traumatic brain injury is often a devastating event for parents and families. Everyone reacts differently, but parents and families often feel guilt, grief, hopelessness and despair, a sense that the difficulties will never end. Everyone else may seem to know better and have advice for you - often when things are at their most difficult. All these feelings are common and normal - but they don't help you to cope.

Guilt

When someone has a brain injury, other family members often feel guilty in one way or another. This feeling is common, but you need to work through it if you are going to get on with your life productively. The first step is to accept that guilt is normal, and that you can't stop it appearing - you don't need to feel guilty about feeling guilty!

Look carefully at your guilt - how realistic is it? If there is something you really could have changed, try to forgive yourself for not doing it, focus on what you can do now, and move on. If there was nothing you could have changed, recognise that your guilt has no basis in fact. In either case, you'll need time to deal with feelings. Talk to a good friend or consider finding support through a counsellor.

Grief

Grief and anguish are normal, though everyone experiences them differently. It can be a real struggle to adjust to these losses and changed expectations - but there are many positive things you can do.

Try to treat your child as you always have done - don't let yourself turn your child into someone different, a 'patient'. Retain what you can of the good things you used to have together. Talk to other mums and dads of children with disabilities.

Be kind to yourself. Try to acknowledge and accept what has happened, and look ahead. There will be sad moments, but good times are possible, too.

Hopelessness

Parents can feel despair and hopelessness - particularly when recovery slows down - as they realise life will never return to its former pattern. These suggestions may provide a starting point to help you work through this despair:

- Don't put arbitrary time limits on your child's recovery - that sets you up for disappointment.
- Be ready to modify your hopes and expectations. A young person with a brain injury may not return to their pre-injury self, but they can be happy and achieve in other ways. Take this as your starting point.
- Focus on the things your child can do, rather than dwelling on what they can't do as well as before.
- Find ways to see, and to celebrate, the good things in your child's life. For example, some families find it helps to sit down together regularly (e.g. monthly) to review what's been achieved, celebrate the good things, and set more goals.
- Consider finding support from a professional (psychologist, social worker, etc.) to help work through emotional issues - and consider doing this early on, before problems become entrenched.

Blame or criticism

Sometimes it can seem that everyone knows better than you. Family, friends, even people who have little contact with your child, give you advice, pass judgement, or tell you what to do - particularly when things aren't going well. You have less privacy, and everyone is an expert except you.

Such criticisms and remarks may stem from the person's own feelings of frustration and powerlessness in the face of your child's injury - particularly if the person is close to your child. Understanding this may help you to cope better with the comments. If criticism comes from someone close to you, consider talking openly to that person about the impact on you.

It's also worth listening to comments to see whether they include anything that is actually helpful - even if you feel hurt. It's not wrong to get frustrated or 'lose your cool'. But you may feel better about yourself and more in control of the situation if you can learn how to manage and express your feelings in ways that don't damage relationships and friendships.

Remind yourself of the positive things you are doing and achieving. You might, for example, make a list and stick it on the fridge door, of "good things we've done this week".

Look after yourself

An injured child can place enormous strain on parents. Sometimes the relationship becomes stronger, but couples can also drift apart.

Some things that put strain on relationships are a sense that one or other of you is to blame, differences of opinion about how to handle specific issues and differing views on how family life should change in response to the injured child.

Open communication between a couple (even if they're separated), supportive friendships and the right professional help can all assist. Opportunities to talk to others - and cry - in safe, confidential surroundings give many parents the strength to carry on.

Assistance from carer respite services or disability services can be vital, especially for single parent families.

Keeping in touch with friends

When the young person comes home, family members often focus on providing a quiet environment and emotional support and see less of people outside the home. It's easy to establish a pattern where life revolves around the child with a brain injury.

Some friends may offer great strength and support. Others may drift away. This can be hurtful, but it usually happens because they can't cope with the situation in some way.

Here are some suggestions to consider:

- Let friends and family know they matter to you
- Let them know how they can support you - for example, doing the washing, baby-sitting other children, coming to an appointment with you, or just having a coffee together
- Try to talk about issues other than your child and brain injury
- Schedule family outings or social activities even if you don't feel like it
- Don't think you're the only one who can care for your child
- Involve extended family and close friends in the 'team'.
- Ask for professional help in dealing with emotional upheaval. If there are waiting lists for public services, consider seeking help privately if you can afford it (Medicare often will cover some of these expenses).

Adult Children

A brain injury can be a devastating experience for the parents of an injured adult child.

Changes as a result of brain injury

Parents say they have had no time to prepare for the many changes that occur to their lives as a result of a son or daughter's brain injury. Often, now that their family have grown, parents are at the stage of planning for their own future. It seems that life and those plans disappear in an instant. Changes in personality and behaviour of their child can be very disconcerting for parents. Displays of certain behaviours can be embarrassing, while mood swings and having to provide guidance and feedback can be challenging.

Possible reactions

Like all family members, parents can experience many emotions coming to terms with the fact that their adult child has a traumatic brain injury or similar brain disorder.

These could include:

Shock and denial at the immediacy and severity of the injury and the consequences of brain injury / changes to your child

Anger and frustration at the circumstances of the injury, of how it has impacted on your life and how your child's life will change

Loss - changes to plans, financial losses, grieving the loss of the future parents had anticipated for themselves and their children

Resentment and guilt - resenting the changes, feeling that you could have "done something better", feeling guilty for feelings of anger, resentment and frustration

Loneliness and isolation - many parents report the gradual withdrawal of their friends as their lives have now taken different directions with different priorities

Mourning/chronic sorrow - Grieving processes rarely end, as a loved one remains in your life, but often as an altered person.

It is common to mourn the personality and characteristics that have been lost while learning to relate to a different person. Mourning is never completed but can begin again with reminders of what has been lost. Some parents say that they have lost interest in things they used to enjoy.



Relationship & role changes

Depending on the severity and nature of the brain injury relationships can change in several ways.

A brain injury places strain on many relationships and marriages. Concern about a child's relationships, practical issues of how to help, and uncertainty about how the situation will work out is common.

Tensions between parents themselves can occur. Different attitudes and expectations and different ways of coping can aggravate this.

It is possible that the injured adult may move back home and parents may become carers. If this involves basic personal care and cueing with daily living tasks, it may be like parenting a child all over again. The relationship is no longer an adult relationship and this can be especially difficult if there are challenging behaviours as well.

Having carers or lifestyle support workers coming into the home on a regular basis can place a strain on relationships as parents feel that their lives are less private.

Help with grandchildren may be needed when one parent has a brain injury and the other is committed to a significant caring role or full-time employment.

Parents often worry about how the brain injury has affected their relationships with their other children. Some parents find themselves being more over-protective of their other

children. Others worry that they are neglecting their other children and feel their resources (emotional, financial, time) are stretched in this regard.

Relationships with friends and extended family may also change especially if parents feel that others do not understand the brain injury.

Many parents find that roles in the family change as a result of their adult child sustaining a brain injury:

- Parents may have to take on a carer role with their adult son/daughter
- Previously valued roles may change e.g. giving up work to be a carer, loss of retirement plans
- Grandparents may become more involved in their child's own family as a result of the brain injury and may even take on the parenting role with their grandchildren
- Parents may need to take on a more supportive role in relation to the spouse of their son/ daughter
- Parents may need to help educate and support other family members and friends about brain injury.

Practical consequences of a brain injury

There may be many practical consequences of the brain injury. At times a brain injury will result in challenging behaviour which requires what the person is trying to communicate with the behaviour. Professional assistance may be required in some cases.

Parents may need to assist financially, particularly if the injured person was the primary income earner. This may result in an inability to meet previous financial commitments such as mortgage repayments, car payments, childcare or school fees. Parents may find that they need to be involved in provision of:

- Accommodation
- 'Hands on' assistance e.g. feeding, bathing
- Transport to appointments and activities
- Assistance with managing finances and making decisions
- Assistance with maintaining pre-existing relationships
- Social support and social outings.

Remember to ask other family members or services to provide assistance. Encourage the person with a brain injury to gain as much independence as possible by learning new skills. Be guided by the professionals working with them. Remember that a traumatic brain injury does not change everything about a person and some personality traits, behaviour traits and interests will remain unchanged.



Useful Strategies for Parents

Become involved in the hospitalisation and rehabilitation stages

Learn as much as possible about the brain injury to assist developing realistic expectations

Realistically consider the strengths of individual family members

Identify areas where assistance would be beneficial and ask for help

Talk about concerns with other family members/ friends

Take time to deal with the effects of the injury

Keep daily routines as normal as possible

Be open to involvement in support groups and counselling

Spend quality time with other family members, and develop a network of friends and activities

Use supports such as regular respite when needed to rest, rejuvenate, and care for yourself.



SECTION 9

Legal and Advocacy

Advocacy

Advocacy relates to access 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 can be 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.

Self-advocacy

Self-advocacy is important in many areas such as housing, in accessing the National Disability Insurance Scheme and in receiving care that suits the needs of the person with a disability. 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 records 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.

Contact Synapse for information and support with advocacy **1800 673 074**.

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.

'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?'

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.

Guardianship / Decision Making

Reduced decision-making capacity

Everyone has a legal right to make decisions and control their own life. If a person loses the ability to make decisions in life, legal guardians and administrators can make decisions for them.

A person has capacity to make decisions if they:

- **Understand:** An individual must be able to understand the nature and effect of a decision
- **Decide:** An individual must be able to come to a decision freely and voluntarily
- **Communicate:** An individual must be able to communicate that decision to others

Making “bad” decisions is not the same as impaired capacity. People have the right to make decisions that may result in physical, financial and psychological or other harm – it is called the “dignity of risk”. However, a consistent pattern of decisions that result in harm to the person or their quality of life may suggest that there is impaired capacity.

Guardians

A guardianship board or tribunal has the power to appoint someone to deal with the day-to-day personal decisions of an adult with impaired decision-making capacity. These can include:

- Accommodation
- Health and dental care
- Access to services
- Social contact.

They cannot make decisions about financial matters. Guardians can be a friend or relative, as long as they are over 18 years of age.

Administrators

An administrator is appointed in the same way to make financial decisions on behalf of an adult with impaired capacity.

Office of the Public Advocate/Guardian

In each state and territory there is an Office of the Public Advocate (OPA) or Office of the Public Guardian (OPG) to protect the rights of people with disabilities. They will take responsibility for people who don't have a relative, friend or service provider to take on the role of Guardian, and have the power to investigate charges of abuse or neglect against an adult with impaired capacity.

Powers of Attorney

There are two Powers of Attorney – General and Enduring. Anyone with the capacity to make decisions can appoint a Power of Attorney to make financial decisions on their behalf.

A General Power of Attorney: is appointed in cases where a person is absent. For example, they might be travelling overseas and appoint someone for the time that they are away.

An Enduring Power of Attorney: is a way of arranging guardianship and administration in advance. Two people enter a formal agreement where one is given authority to make decisions for the other once that person is no longer able to make decisions for themselves.

Advance Care Directive

An Advance Care Directive, also known as a “living will”, is a document that explains your wishes regarding health care if you become incapacitated.

Each state and territory has its own rules around Guardianship and Administration, including the Advance Care Directive. Contact the Office of the Public Advocate/Guardian in your state for more information.

Compensation Claim

When another party has caused an injury through negligence there may be grounds for making a claim for compensation.

NOTE: *The information below only provides general information relevant to Australia - consult a solicitor in your state or country for accurate legal information.*

Can I make a compensation claim?

A case for making a compensation claim is usually based on:

- your injury was caused by someone else's negligence or carelessness
- this injury has caused you pain and suffering
- this suffering may continue into the future.

There may still be grounds for a claim even if you were partly at fault for the traumatic brain injury (TBI). Examples of claims include:

- an employer with poor or inadequate workplace practices
- the driver of a motor vehicle who caused your injury
- a property owner whose negligence caused your injury
- a health professional providing the wrong diagnosis or treatment
- the manufacturer and/or distributor of a faulty product.

Changes due to the National Disability Insurance Scheme

There will be an impact on compensation claims due to the National Disability Insurance Scheme (NDIS) being introduced across Australia. The scheme has a "no-fault" basis which means people with a substantial and permanent disability will receive financial support to re-establish their lives after an injury, regardless of who was, or wasn't, at fault.

What can you claim for?

In many cases you can claim for pain, suffering and expenses both in the past and anticipated into the future. Examples include:

- loss of income
- medical, pharmaceutical and travel expenses
- care from professionals, carers and family members
- compensation for pain and suffering
- home alterations, modifications to your car
- vocational retraining
- trustee fees and charges.

Most Australian states have placed restrictions on the amounts that can be claimed for pain and suffering, economic loss, and care. It is often difficult to calculate what

the amounts payable are, so you should consult a solicitor to ensure that you can claim the maximum amount available to you.

Are there time limits for making a claim?

There are strict time limits in making a claim for damages that vary from State to State. If you miss that time limit, you may be precluded from making a claim forever. In most States of Australia there is legislation that requires an initial notice for a common law damages claim to be lodged with an insurer within much shorter time frames.

To avoid losing the right to claim, a solicitor should be consulted as soon as possible after any incident that leads to a traumatic brain injury.

Keep records

People claiming compensation should keep a careful record of all expenses, reports and emails relating to the injury. Make sure you take notes after conversations with relevant professionals and specialists. Keep a diary of visits to medical or therapeutic services. Proof of loss of projected earnings can be more difficult for self-employed people and it is wise to keep a record of any work that would have been obtained had the accident not happened.

Choosing a solicitor

Most solicitors will give free preliminary advice regarding the prospects of success. Many solicitors work on a "no win no fee" basis in personal injury claims. The quality of legal representation can have a serious impact on the amount of compensation awarded.

Legal action takes time

It may be a long period of time before settlement, so don't stop keeping records and receipts. Be prepared for a long and frustrating legal process and try to stay positive and focus on everyday life, not the legal process.

Victim of crime?

In some Australian states there is support provided in terms of counselling, financial assistance and compensation available where an injury has been caused directly by a criminal act.



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