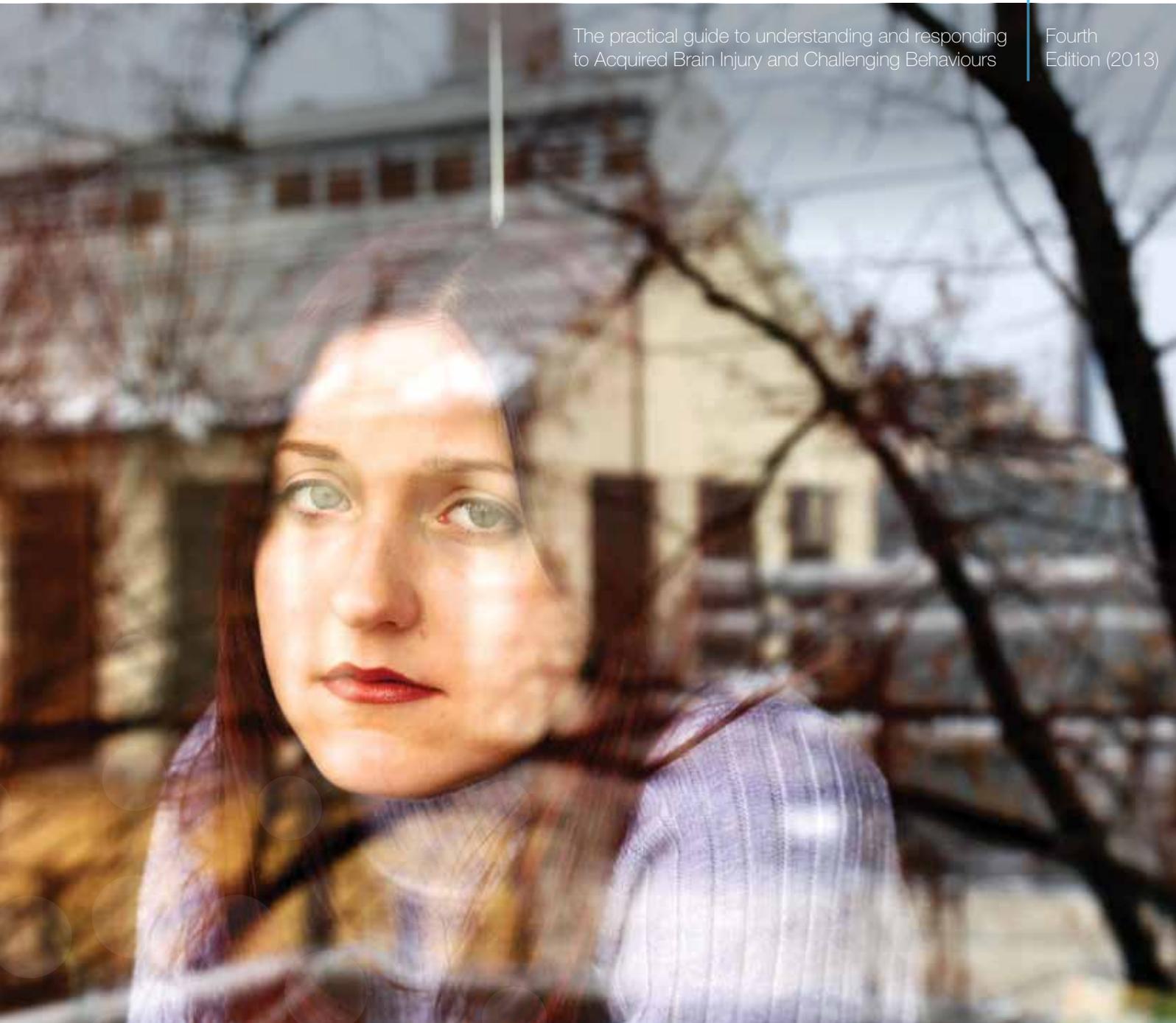


ACQUIRED BRAIN INJURY: **The FACTS**

The practical guide to understanding and responding to Acquired Brain Injury and Challenging Behaviours

Fourth Edition (2013)



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The Brain Injury Association of Queensland

The FACTS is produced by Synapse and is proudly endorsed and supported by Brain Injury Australia.

Synapse is dedicated to improving the quality of life of people living with and affected by Acquired Brain Injury, or people whose behaviour challenges our understanding.

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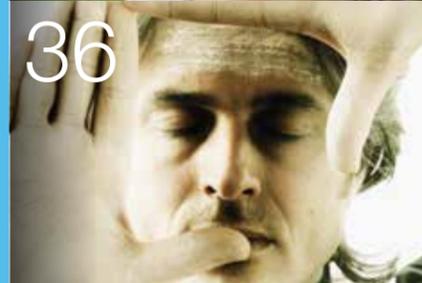
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Acquired Brain Injury is often called the Invisible Disability.



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Communication problems

Communication problems that result from a brain injury vary, and depend on many factors which include a person's personality, pre-injury abilities, and the severity of the brain injury.

Acquired Brain Injury

The difficulties people with brain injuries face are easily ignored or misunderstood. Even family members and friends may regard a person with Acquired Brain Injury who exhibits cognitive problems or changed behaviour, as lazy or hard to get along with.

There is very little understanding or knowledge in the community about brain injury and the impact it has on people and their families. Long-term effects are difficult to predict and will be different for each person. Many people will experience increased fatigue, difficulty with short-term memory and impaired concentration and retention skills.

There are five areas in which Acquired Brain Injury may cause long-term changes:

- medical difficulties
- changes in physical and sensory abilities
- changes in the ability to think and learn
- changes in behaviour and personality
- communication difficulties.

The extent of some of these changes (such as being more impulsive or getting lost easily) may only become apparent as time progresses.

Causes of brain injury

The brain can be injured as a result of an accident, a stroke, alcohol or drug abuse, tumours, poisoning, infection and disease, near drowning, haemorrhage, AIDS, and a number of other disorders such as Parkinson's disease, Multiple Sclerosis, and Alzheimer's disease. The terms Acquired Brain Injury (ABI) or acquired brain damage are used to describe all types of brain injury that occur after birth. The complications and difficulties that arise are varied and may include a range of hidden cognitive disabilities such as short-term memory loss, through to physical difficulties such as fatigue, paralysis and visual or hearing impairment. Whatever the nature of the eventual disabilities, the lives of people with Acquired Brain Injury change, as do the lives of those close to them.

Acquired Brain Injury is not to be confused with Intellectual Disability. People with an Acquired Brain Injury do not necessarily experience a decline in their overall level of general intellectual functioning. Rather, they are more likely

to experience specific cognitive changes that lead to difficulty in areas such as memory, concentration, communication and behaviour.

While the outcome of the injury depends largely on the nature, severity and location of the injury itself, appropriate rehabilitation and support will play a vital role in determining the level of recovery.

Traumatic Brain Injury

Traumatic Brain Injury (TBI) is an Acquired Brain Injury caused by a blow to the head or by the head being forced to move rapidly forward or backward, usually with some loss of consciousness. As a result of this blow or rapid movement, 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.

The effects of Traumatic Brain Injury can be temporary or permanent and range from mild injury, such as being momentarily stunned while playing football, to a very severe injury that may cause prolonged loss of consciousness. Concussion for any period of time — however slight — can result in Acquired Brain Injury. While most people make a good recovery, many are left with lasting effects that, even if mild, may have significant consequences for everyday living.

Closed head injury

Closed head injury is the most common cause of brain injury. It occurs when the head is struck or moved violently but the skull and/or membrane lining of the brain is not broken or penetrated. Such damage often involves "diffuse brain injury" via widespread shearing, twisting and stretching of nerve fibres and bleeding due to the tearing of arteries and veins throughout the brain. The forward motion and rotation of the brain on the relatively fixed brain stem is a common cause of loss of consciousness and coma.

In addition to diffuse brain injury, focal lesions and bruising may occur as the brain collides

COGNITION

IN THE IMMEDIATE AFTERMATH OF BRAIN INJURY, FAMILIES ARE FOCUSED ON SURVIVAL.

It is often not until much later that they hear the word "cognition". This is the conscious process of the mind by which we are aware of thought and perception, including all aspects of perceiving, thinking and remembering. In general, cognition is knowledge – the way we learn and perceive the world around us. There is nothing simple about cognition, however. Often families are reassured when a family member awakens from a coma and recognises everyone. This initial recall of old learning lulls some families into a false sense of security, but a brain injury can involve impaired cognition which can lead to a wide range of problems that become apparent over time.

Excerpt from Cognition fact sheet at synapse.org.au

with the sharp bony inner surface of the skull. Focal lesions can occur at the site of impact inside the skull (coup injury) or at a different site (contrecoup injury) which is typically, although not limited to, the opposite side of the skull.

Open head injury

An open head injury occurs when the skull and membrane lining of the brain have been fractured, cracked or broken so that the brain is exposed or penetrated. When an open head injury occurs, pieces of bone or cerebrospinal fluid may enter the substance of the brain. Considerable local damage can occur in the area of the brain immediately below the impact area, as well as more widespread damage.

Primary versus secondary effects

The direct application of physical forces damaging nerve fibres, blood vessels and other brain tissue are commonly referred to as the "primary" mechanisms of Traumatic Brain Injury. Further complications are often called "secondary" mechanisms of brain injury. A large number of secondary complications may occur including: haemorrhage (bleeding), haematoma (blood clot), raised intracranial pressure, hypoxia (loss of oxygen), brain swelling and post-traumatic epilepsy. Such complications require close monitoring and medical management.

Mild brain injury

Sometimes, when the head is struck

or moved violently there will be no loss of consciousness and the person may appear not to need medical attention. Even so, there may be some mild damage to the brain that can interfere with the person's everyday living. The injury may not be diagnosed but the person may be observed responding more slowly than usual or complaining about physical and mental problems. Symptoms of mild brain injury may include fatigue, headache, dizziness, hearing loss, ringing in the ears, memory problems, sleep difficulties, irritability and short attention span.

Hypoxic/Anoxic Brain Injury

Hypoxic/anoxic injuries result when there is a substantial (hypoxic) or a complete (anoxic) lack of oxygen supplied to the brain. Diminished oxygen supply to the brain may produce profound cognitive, physical, and emotional impairments which may be slow to recover, if not permanent. As a result, hypoxic/anoxic injury (HAI) can have a wider ranging impact throughout the brain than Traumatic Brain Injury.

Anoxic anoxia occurs when there is not enough oxygen in the air to be absorbed by the body and used e.g. high-altitude sickness.

Anaemic anoxia occurs when there is not enough blood carrying enough oxygen to the cells. This can occur due to loss of blood or insufficient oxygen being carried in the blood. Acute haemorrhage, obstructed arteries, carbon monoxide poisoning and chronic anaemia are common causes of this type of injury. Acute haemorrhages can occur due to open head injuries or a burst aneurysm. Obstructions often occur due to clots, such as in a stroke. Chronic anaemia occurs when there are persistent low red blood cells or haemoglobin, the chemical which carries oxygen and gives blood its red colour. Carbon monoxide poisoning is seen in suicide attempts

using the exhaust of cars, but can also occur in home or industrial accidents. Carbon monoxide poisoning also appears to selectively damage areas of the brain such as the basal ganglia, caudate nucleus, putamen, globus pallidus, and central white matter. These brain areas are important for the control of movement.

Stagnant (ischaemic) anoxia is also called hypoxic-ischaemic injury, or HII. This type of injury causes general, diffuse damage to the cerebral cortex and cerebellum. Areas of the brain that are very sensitive to lack of oxygen include the hippocampus (a region critical for memory), border zone areas of the cerebral cortex (the parieto-occipital and fronto-parietal regions), cerebellum, basal ganglia, and spinal cord (thoracic region). Perhaps the most common cause of ischaemic anoxia is cardiac arrest.

Alcohol Related Brain Injury (ARBI)

ARBI is a term used to describe the physical injury to the brain sustained as a result of excessive alcohol consumption. Other terms that are often used are Wernicke's Syndrome and Korsokoff's Syndrome. Alcohol has a toxic effect on the central nervous system. It results in changes to metabolism, heart functioning and blood supply. It interferes with the absorption of thiamine (an important nutrient in the brain). Alcohol is commonly associated with poor nutrition. It can cause dehydration which may lead to wastage of brain cells.

The degree of brain injury resulting from excessive alcohol consumption depends on many factors, including the amount and pattern of consumption, age, gender, and nutrition. ARBI may be mild, moderate, severe or very severe. ARBI is associated with changes in cognition, difficulties with balance and coordination and a range of medical and neurological disorders.

Stroke

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

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

Types of stroke

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

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

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

Effects of stroke

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

Treatment

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

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

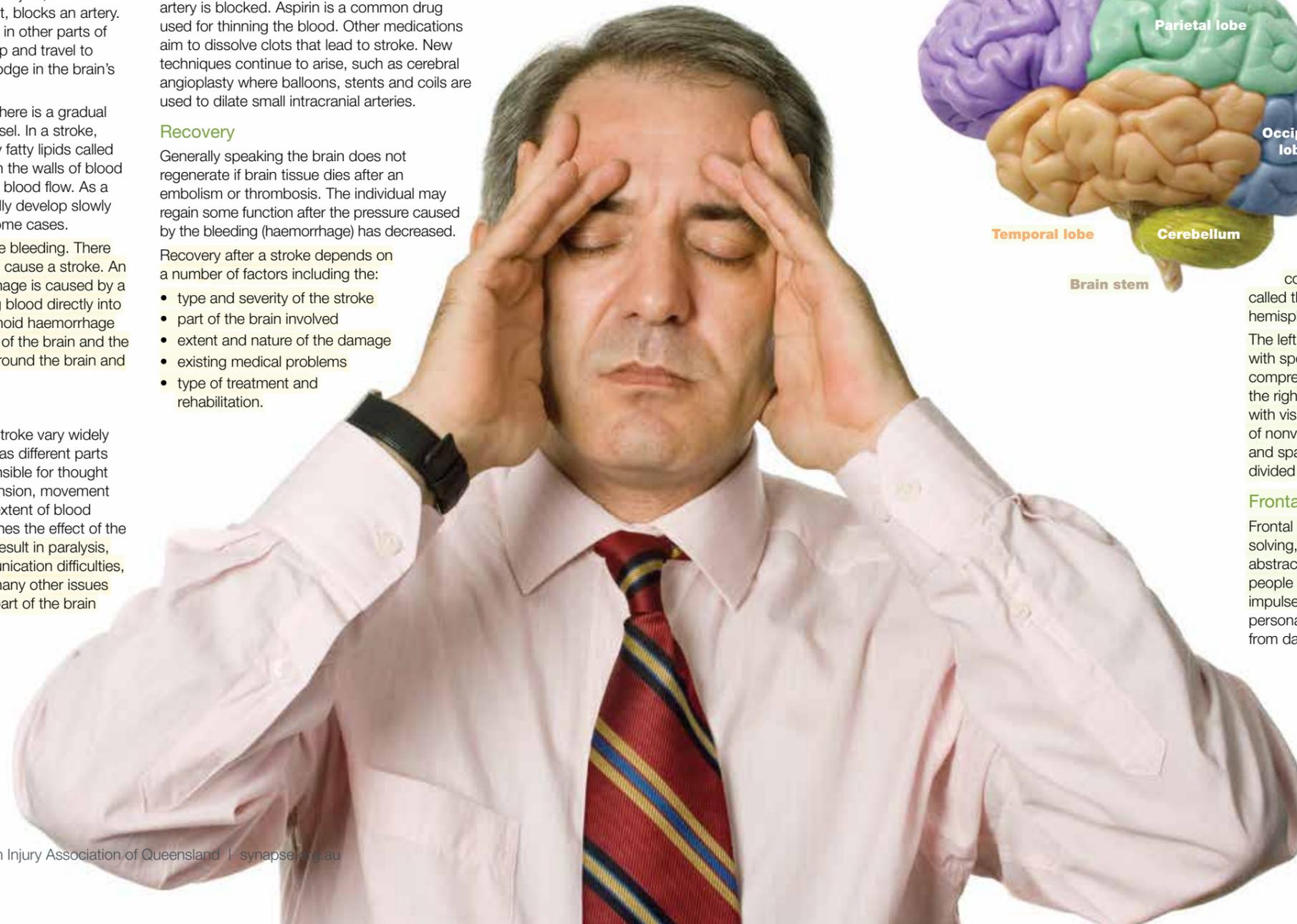
Recovery

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

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

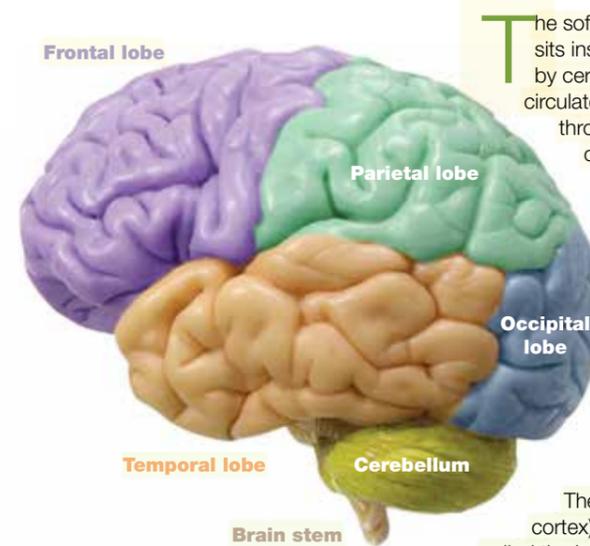
- type and severity of the stroke
- part of the brain involved
- extent and nature of the damage
- existing medical problems
- type of treatment and rehabilitation.

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



Understanding the brain

The brain controls and coordinates everything we do: movements, feelings, thoughts, breathing and bodily functions. The brain is made up of billions of nerve cells through which messages are transmitted by a combination of electrical and chemical activity.



The soft, jelly-like mass of the brain sits inside the skull, cushioned by cerebrospinal fluid. This fluid circulates around the brain and through a series of cavities called ventricles.

The brain is divided into a number of parts, which have specific functions and are designed to work together. The more these parts are coordinated and in tune with each other, the better the performance.

Left and Right Hemispheres

The largest part of the brain (the cortex) is divided into two halves called the left hemisphere and the right hemisphere.

The left hemisphere is mainly involved with speech and language (talking, comprehension, reading and writing) and the right hemisphere is mainly involved with visual perception and interpretation of nonverbal information, such as drawing and spatial analysis. Each hemisphere is divided into four lobes.

Frontal Lobes

Frontal lobes are involved in problem-solving, planning, making judgments, abstract thinking and regulating how people act upon their emotions and impulses. Marked changes in a person's personality and social skills can occur from damage to this area.

The motor strip at the back of the frontal lobes controls movement. In the left hemisphere the motor strip controls movement of the right side of the body while in the right hemisphere the motor strip controls movement of the left side of the body.

Temporal Lobes

Temporal lobes are involved in receiving and processing auditory information e.g. music and speech, language comprehension, visual perception, organisation and categorisation of information. A major function of the temporal lobes is memory and learning.

The temporal lobes are also involved in personality, emotions and sexual behaviour.

Parietal Lobes

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

Occipital Lobes

Occipital lobes receive, integrate and interpret visual information relating to colour, size, shape and distance.

The Cerebellum

The cerebellum is located at the back and below the main hemispheres of the brain. It integrates movement signals to produce fine motor control for co-ordination, precision, and accurate timing.

The Brain Stem

The brain stem connects the brain to the spinal cord and regulates wakefulness, breathing, body temperature and heart activity. Cranial nerves are located in the brain stem, which regulate a number of functions such as swallowing, speech and eye movement.

Mental health issues and Acquired Brain Injury

After a brain injury, mental health issues such as depression, anxiety and schizophrenia can greatly complicate rehabilitation and integrating back into the community.



Mental illness and psychiatric disability are both terms used to describe abnormal brain function. Because a brain injury changes brain function by changing brain structure, many of the symptoms of a mental illness can look like the effects of a brain injury. As a result, it can be difficult for the person — or their family — to realise a mental health issue exists.

Mental illness can occur at the same time as an Acquired Brain Injury: approximately 40% of all people with an Acquired Brain Injury also report having a psychiatric disability. The difference between a brain injury and a mental illness is that when the brain is injured, we can see it on a diagnostic scan. In a mental illness, we can't, although an EEG may show unusual patterns of electrical activity in the brain.

So what is mental illness?

Mental health and mental illness

What is the difference between mental health and mental illness? If you are afraid of giving a speech in public, does it mean you have a disease, or simply a run-of-the-mill case of nerves? If you feel sad, are you just experiencing a passing case of the blues, or is it full-fledged depression requiring medication?

Just what is "normal" mental health, anyway?

Mental health providers define mental disorders by signs, symptoms and functional impairments. Signs are what objective observers can document, such as agitation or rapid breathing. Symptoms are subjective, or what you feel, such as

euphoria or hopelessness. Functional impairment is the inability to perform certain routine or basic daily tasks, such as bathing or going to work.

In mental illness, signs and symptoms can appear as:

- Behaviours e.g. repeated hand washing
- Feelings e.g. sadness
- Thoughts e.g. delusions that the television is controlling your mind
- Physiological responses e.g. sweating.

Signs, symptoms, and functional impairments that mark specific mental illnesses, are spelled out in detail in the Diagnostic and Statistical Manual of Mental Disorders (DSM). This two-inch-thick book classifies and describes more than 300 types of mental disorders, and is used by mental health providers to diagnose everything from anorexia to voyeurism.

A mental health provider can evaluate your signs and symptoms, then refer to the DSM to diagnose your condition.

What is mental illness?

Mental illness refers to all the different types of mental disorders, including disorders of thought, mood or behaviour. To be classified as a mental illness, the condition must cause distress, and result in a reduced ability to function psychologically, socially, occupationally or interpersonally.

This means that someone who has a mental illness may have trouble coping with emotions such as anger and stress, and difficulties in handling daily activities, family responsibilities, relationships,

employment or studies. A person can have trouble — to a greater or lesser degree — with one area, or all of them. And there can be more than one type of mental illness at the same time.

What is psychiatric disability?

Psychiatric disability is the term used when a mental illness is debilitating enough to require support for the person. It is therefore possible to have a mental illness, but with the help of treatment, other people and/or learned coping strategies, to not have a psychiatric disability.

The distinction is a question of how severe the effect of the mental illness is, not what the mental illness is. We will continue to use the term "mental illness" here.

What are the classes of mental illness?

Our evolving understanding of genetics and how the brain works may eventually change how we classify mental illnesses. For now, we think of several main classes of mental illness:

Mood disorders: These disorders change how you feel e.g. persistent sadness or feelings of euphoria. They include major depression and bipolar disorder.

Anxiety disorders: Anxiety is an emotion characterised by the anticipation of future danger or misfortune accompanied by a feeling of being ill at ease. Examples include panic disorder, obsessive-compulsive disorder, specific phobias and generalised anxiety disorder.

Substance-related disorders: These

include problems associated with the misuse of alcohol, nicotine, caffeine and illicit drugs.

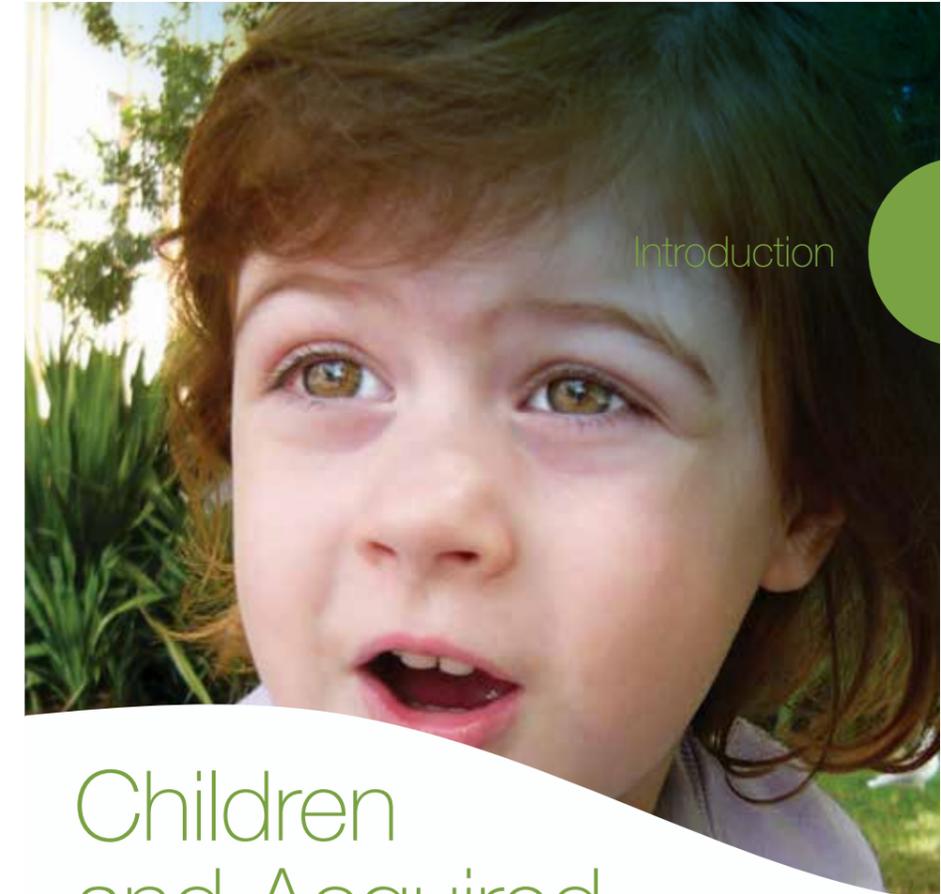
Psychotic disorders: These disorders impair your sense of reality. The most notable example of this is schizophrenia, although other classes of disorders can be associated with psychosis at times.

Cognitive disorders: These affect your ability to think and reason. They include delirium, dementia and memory problems. Perhaps the most well-known of these disorders is Alzheimer's disease.

Developmental disorders: These cover a wide range of problems that usually first begin to make themselves known in infancy, childhood or adolescence. They include Autism, Attention Deficit (Hyperactivity) Disorder and learning disabilities. Just because they're all grouped in this category, however, doesn't necessarily mean they share a common cause or that there's a relationship among the disorders.

Personality disorders: A personality disorder is an enduring pattern of inner experience and behaviour that is dysfunctional and leads to distress or impairment. Examples include borderline personality disorder and antisocial personality disorder.

Other disorders: These include disorders of impulse control, sleep, sexual functioning and eating. Also included are dissociative disorders, in which a person's sense of self is disrupted, and somatoform disorders, in which there are physical symptoms in the absence of a clear physical cause, such as hypochondriasis.



Children and Acquired Brain Injury

A crucial difference for children and adults who acquire a brain injury is that a child's brain is still developing.

In children, the injury may disrupt the development of particular areas of the brain and neural pathways which can lead to arrested or delayed development of specific skills and abilities. Damage to a young child's brain may often affect the development of global abilities rather than producing specific deficits. Previously acquired skills may also be lost due to substantial brain damage. It is important to remember, however, that there is significant variability in the rate at which children reach developmental milestones and every child is unique.

Causes

The most likely causes of Acquired Brain Injury change over the life-span. In infants, shaken baby syndrome is by far the most common cause. Before the age of two years, a baby's head is relatively heavy compared to their body and their neck muscles too weak to provide full support. As infants become toddlers, falls and near drownings are become by far the most common cause of brain injury. Other causes can include stroke, encephalitis, and meningitis, as young children have an immature immune system and also can not communicate how sick they are feeling.

Long-term consequences

The initial assessment following injury may not provide a very clear picture of the long-term consequences for two reasons. One reason is that a relative level of physical and cognitive recovery can be expected to occur over time. The second reason is that specific areas of impairment may become more apparent when the child reaches a particular stage of development.

Continued ...



At different stages of development children with Acquired Brain Injury may lag behind their peers in a number of functional areas unless intensive rehabilitation is provided. Such rehabilitation or special education assistance may be required to address uneven development across functional areas. The most common long-term Effects of Acquired Brain Injury in childhood may be divided into these areas:

Sensory and motor changes

A child may lose some previously acquired skills or may have difficulty learning new skills such as holding a pen, drawing, using a computer keyboard, constructing and manipulating objects, using cutlery, getting dressed, recognising objects, and a variety of other eye-hand coordination activities.

Other problems may be balance, coordination or swallowing and speech difficulties. Professionals such as physiotherapists, occupational therapists and speech pathologists play an important role in the assessment and rehabilitation of sensory and motor disorders.

Cognitive

An Acquired Brain Injury may lead to a general decline in a number of intellectual abilities. However, similar to adults, a child may be within the normal range on measures of intellectual functioning and yet display significant problems in specific areas of attention, memory, language, visuo-spatial and executive functioning. Deficits in these areas can affect a child's development across all areas of school-based knowledge and socialisation.

Language and communication

The necessary skills for reading, writing and oral communication may be divided into language reception, comprehension and expression. Many children experience receptive problems which involve difficulty processing different parts of spoken or written information. Comprehension problems occur when a child cannot understand what he or she is reading or what another person is

saying. Spoken or written language expression may be affected in terms of pronunciation, fluency, grammar, intelligibility or meaning and retrieval of words.

Social, behavioural and emotional

A child may experience difficulties relating to peers and siblings and have difficulty joining group activities. They may appear very demanding of their parents' or teachers' attention and have difficulty following rules and instructions. A range of behavioural problems may arise after Acquired Brain Injury, such as: depressed or anxious mood, hyperactivity, distractibility, impulsivity, poor judgment, reduced control of anger and frustration, mood swings, aggression, sleep disturbance, and poor motivation and initiation. When social, behavioural and emotional problems are recognised early in recovery, a number of rehabilitation strategies may be employed in the school and home environment.

The influence of age upon recovery

The relationship between a child's age at the time of injury and their long-term recovery is not well understood. One particular theory suggests that younger children make a greater recovery than older children due to 'neural plasticity', or the ability of the developing brain to reorganise itself to take over the functions performed by a damaged area.

In general, research suggests that injuries acquired at an earlier age are associated with lower levels of functional recovery or outcome across various skill domains. These findings support the view that long-term outcome is greater when basic functional skills are developed prior to an Acquired Brain Injury. The influence of a child's age upon level of recovery may prove less significant than other factors, such as: the severity and type of brain injury, the child's pre-injury skills and experiences, family functioning, rehabilitation and support within the home and at school.

Go to synapse.org.au for a comprehensive range of fact sheets on children with a brain injury.

In the hospital

It is important to become familiar with the hospital's departments, wards and key staff providing treatment for Acquired Brain Injury.

In some hospitals, all patients with brain injury are admitted to the neurosurgical unit and cared for by the neurosurgeon. Patients with multiple injuries may be attended by a number of specialists. For example in cases of bone injury, an orthopaedic surgeon will be in charge. In the Intensive Care Unit, a registered nurse (RN) is always available and assigned to patients.

Understanding medical information

Understanding medical terminology can be difficult, especially during times of stress. It is better, however, for people to ask questions than to not understand what is happening. People often prefer to direct such questions to a person with whom they feel comfortable, such as a member of the nursing staff, a doctor or an allied health professional.

It is common for hospitals to hold meetings with family members and various members of staff involved in the patient's care. If you are not offered a meeting, speak with the social worker to arrange one. These meetings provide a good opportunity for relatives to direct questions to specific professionals. It is often helpful if those attending prepare for these meetings by writing down the most important points or questions they wish to raise.

Advocacy

The best interests of patients and their families are easily overlooked during times of stress. This can occur unintentionally as a result of a lack of necessary resources, work overload or poor communication. Most hospitals provide support to obtain information and make decisions. The person providing this support is often the social worker.

Informing the patient

With so much energy being put into the patient's health, family members are often reluctant to say anything that may upset the injured person, especially topics such as another person's death. It is advisable to discuss these concerns with the appropriate hospital staff who will provide guidance in this matter. It is usually preferable to tell patients any traumatic news (although they may forget) but be aware that due to the brain injury, their reaction may be different to what is expected.

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 or through the local Brain Injury Association.

Coping strategies

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

- Acknowledge your personal reactions to stressful experiences
- Reduce sources of stress in your life
- Accept support: whether it be talking things over or getting help with the housework
- Talk with other people about your feelings and experiences as this can help you process what has happened
- Be aware other family members may deal with the situation very differently to you
- Maintain a sense of normality and make a routine for structure in your life
- Ring your local Brain Injury Association for advice on community services and support groups.



Treatment and diagnosis

When a brain injury occurs and medical attention is required, the initial place of treatment is likely to be the emergency department of a hospital. The priority of care is to make an initial diagnosis, stabilise the patient's condition, and arrange for appropriate treatment.

Stabilisation includes providing respiration (breathing assistance which may require the use of ventilators) and maintaining blood circulation. Medical staff will also attend to secondary problems that arise from the injury, such as blood clotting, bleeding and brain swelling. They will ensure that the oxygen supply to the brain is maintained. The treatment team caring for the patient at this point can be expected to involve emergency medical and nursing staff including the neurosurgical registrar and neurosurgical consultant.

Tests

X-rays, Computerised Axial Tomography (CT or CAT), Magnetic Resonance Imaging (MRI), and other tests may be performed to establish the nature and extent of the patient's injuries. The CT brain scan provides a series of X-rays at different levels of the brain and can be used to determine whether surgery is needed. Depending on the results of the scan the patient may be transferred to an operating room for surgery, intensive care unit (ICU) or a general surgical/medical ward. An MRI provides a more detailed picture of the brain without using X-rays.

Surgery

If surgery is required, it may involve removal of blood clots or bone fragments from the brain; lifting the bone of a fractured skull away from the brain; and/or insertion of a tube connected to a pressure monitor to measure brain swelling.

Intensive Care

It may be necessary for the patient to go to an intensive care unit (ICU) if special drugs or assistance with breathing are required. Here the patient is attached to a range of tubes and machines. This may

be disturbing or frightening for visitors to view, but is standard practice in ICU.

The patient is often heavily sedated for their own comfort and may be unconscious. Pads may cover the eyes to keep them closed and to prevent them from drying out. If an operation was required, the patient's hair may have been partly shaved. The patient's breathing may be assisted by a ventilator, in which case they will be unable to speak even if conscious. It is not known if the patient can hear or understand what is going on. Visitors are often unsure of how to behave but it is generally accepted that you should talk to the person and behave as if they were conscious.

Brain Swelling

Brain swelling can occur after a significant head injury. Normally the brain fits comfortably inside the skull but when it swells, cushioning space is reduced and the brain becomes compressed. This can cause further damage. Treatment for brain swelling is complex and includes drugs to sedate the patient and a respirator to control breathing.

Coma

Coma is a loss of consciousness in which patients typically do not open their eyes, do not speak and cannot follow instructions. In the case of a mild brain injury, the loss of consciousness, or coma,

GLASGOW COMA SCALE

CRITERIA	POINTS	
Open eyes	Spontaneously	4
	To speech	3
	To pain	2
	None	1
Best verbal response	Oriented	5
	Confused	4
	Inappropriate	3
	Incomprehensible	2
	None	1
Best motor response	Obeys commands	6
	Localises pain	5
	Withdraws to pain	4
	Flexion to pain	3
	Extension to pain	2
	None	1

A total score of **13 to 15** is classed as Mild Severity.
 A total score of **9 to 12** is classed as Moderate Severity.
 A total score of **3 to 8** is classed as Severe Severity.



may last for one or two minutes, while coma after a severe injury can continue for days or even years.

A person in a coma exhibits differing levels of responsiveness to touch, pain, and verbal commands. It is therefore better to talk about depth or levels of coma rather than thinking of coma as an all or none type of experience.

The person who is in a wakeful state but with profound nonresponsiveness is

referred to as being in a state of post-coma unresponsiveness or persistent vegetative state. In this state the cerebral cortex of the brain is not functioning, and the person is unable to respond to things in the environment. Many people can remain in this state for long periods of time.

In the condition of locked-in syndrome, the patient appears unresponsive and without the ability to move or verbally communicate, yet has full cognitive

abilities. They may be able to use an eye blinking response to communicate.

Glasgow Coma Scale ranges

A common tool used to measure coma is the Glasgow Coma Scale. It evaluates a person's ability to open eyes, best verbal response, and best movement response. It is used to monitor the level of coma and the patient's emergence from coma. It rates the patient according to response to stimulation, eye opening and ability to speak.



Rehabilitation during a coma

There are a limited number of rehabilitation interventions for people during a coma. Limbs need to be moved to prevent tightening of the muscles. Patients need to be regularly moved to prevent ulcers and pressure sores from developing. There are cases where people have emerged from a coma and claimed to have heard what was said around them, so family and staff are usually urged to be careful in their communications during the coma phase.

POST TRAUMATIC AMNESIA

LENGTH OF PTA	SEVERITY
Less than 5 minutes	Very mild injury
Between 5 to 60 minutes	Mild injury
Between 1 to 24 hours	Moderate injury
Greater than 24 hours	Severe injury
Greater than 7 days	Very severe injury

Post Traumatic Amnesia (PTA)

A person coming out of a coma doesn't just wake up, but will go through a gradual process of regaining consciousness. This stage of recovery is called Post Traumatic Amnesia (PTA) and may last for hours, days or weeks. In this stage, a person will not be able to store continuous or recent memory, such as what happened just a few hours or even minutes ago. Patients 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. They may be afraid, physically and verbally aggressive, disinhibited, agitated and restless. If physically able, they may wander. They may have hallucinations and delusional beliefs such as an adult believing he or she is a child. Too much stimulation during this time can compound the person's confusion and distress.

In conjunction with the Glasgow Coma Scale, length of PTA is frequently used as a guide to the severity of brain injury. A commonly used interpretation of the scale can be seen on this page. A general finding is that if the PTA stage lasts for more than one week, ongoing cognitive problems can be expected in the long-term.



WHO ARE ALL THESE HOSPITAL PROFESSIONALS?

THERE ARE MANY PROFESSIONALS WHO MAY FORM PART OF THE MEDICAL TEAM. SPECIFIC NURSES ARE USUALLY ASSIGNED TO A PATIENT AND ARE RESPONSIBLE FOR THE IMMEDIATE CARE OF THE PATIENT.

A more senior member of the nursing staff usually coordinates the overall management of the ward including patient care, staff and support services.

Medical specialists are involved in a patient's care depending on the type and extent of the injuries. Some specialists you may encounter include:

Intensive Care Physician: a doctor who specialises in the management of patients who require the complex support available in an 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.

Consultant: also known as Visiting Medical Officer or VMO. A senior doctor subcontracted by the hospital to provide oversight and mentorship for registrars and residents.

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

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

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

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

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

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

Why predictions of recovery are difficult

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

This uncertainty is common along the spectrum of brain injury. With a severe injury, doctors can make their best estimates, yet they will have seen exceptions to the rule, with some patients never emerging from a coma while others defy all odds and returned to work, albeit with cognitive problems.

Doctors may predict a good recovery from mild brain injuries and concussions, yet some people may wind up with severe lifelong problems.

Why there aren't accurate predictions?

Physical injuries do not give an accurate picture of the degree of brain injury sustained. The victim of a terrible 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.

The brain does have a limited ability to heal itself. This process tends to occur over two years, with the most rapid improvement in the first six months as swelling and bruising of the brain subside. This pace of healing usually tapers off to the two year mark. This is only a guideline as some will find improvement stops after a year, others may find gradual improvements two years afterwards. Generally, a slow rate of initial improvement is associated with a greater chance of permanent disability.

Importance of rehab

Proper rehabilitation is very important once a patient has emerged from coma



and post-traumatic amnesia, and has a significant effect on the final outcome. It should be noted that discharge from rehabilitation does not mean that recovery has finished. The person with a brain injury has hopefully learned the tools to continue with their own recovery.

Personal factors make a significant difference to the degree of recovery expected. For example, people who did well in the educational system and those with very determined, motivated personalities usually perform very well in rehabilitation.

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.

Factors influencing long-term outcome

An injury to the brain can result in a number of impairments that may create serious problems for the injured person. The ability of a person to cope with these

effects is influenced by four factors:

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

Of these four factors, it is the person's reaction to his or her situation that is recognised as the one that can most likely be changed to improve future enjoyment and success in life. Self-awareness, motivation, goal setting, coping strategies (use of memory aids etc.) and management of emotions are important reactions which influence long-term outcome following an acquired brain injury.

Hard work and hope

A brain injury is very different from other injuries where full recovery is the norm. The brain is a complex and highly organised organ which can be extremely vulnerable. Even with a mild brain injury lifelong cognitive effects can remain. The good news is that faith, hope, hard work and a systematic approach can enhance the recovery process and life afterwards.

Diagnostic tests and scans

Neurological tests fall into three main groups: tests that examine the grey matter of the brain, ones that examine the white matter, and those examining the functioning.

The first group includes CTs and MRIs; the second group includes Diffusion MRIs and HDFT; and the third group includes EEGs, SPECTs, PETs, fMRIs, and evoked potentials.

MRI and CT

MRI (Magnetic Resonance Imaging) and CT (Computed Tomography) scan the brain in cross sections to produce an image of the grey matter (neural cell bodies). MRI does this with magnetic fields; the CT scan uses X-rays. MRI has a higher degree of resolution than CT so trauma seen by MRI may go unseen by CT scan. The X-rays used in CT scans are better at detecting fresh blood while the MRI scan is better at detecting the remnants of old haemorrhaged blood. CT scans may be done frequently after the injury to keep an eye on the amount of brain injury.

Diffusion MRI and HDFT

Diffusion Magnetic Resonance Imaging and High Definition Fibre Tracking (HDFT) are both used to detect white matter tracts (interactions between neural cell bodies) with HDFT showing the highest resolution image. This differs from MRI and CT which detect grey matter. In some brain injuries grey matter may be relatively unharmed where white matter paths are damaged. This means that although the cell bodies are living, they can no longer communicate with each other - creating a brain injury. These imaging techniques therefore can detect brain injuries that may not be evident through MRI or CT.

EEG

An Electroencephalogram records the ever changing tiny electrical signals coming from the brain using electrodes placed on the scalp. Slowing of electrical activity may indicate a lesion or widespread disturbance of brain function.



PET, SPECT and fMRI

Positron emission tomography (PET), Single-Photon Emission Computed Tomography (SPECT), and functional Magnetic Resonance Imaging (fMRI) are all used to detect levels of activity in the brain. PET does so by measuring the use of glucose in brain cells and SPECT and fMRI by measuring blood flow. PET is often used to map specific receptors in the brain where fMRI specialises in being able to scan while presenting the subject with various stimuli. Both PET and SPECT use radioisotopes to image activity levels with PET's radioisotopes rapidly decaying allowing for a shorter window of capture. This also means a quicker scan, allowing for patients unable to be still for prolonged periods.

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 can often detect primary or metastatic brain or spinal cord neoplasm or cerebral haemorrhage.

MRS and MRA

Magnetic Resonance Spectroscopy is an imaging method of detecting and measuring activity at the cellular level. It provides chemical information and is often used in conjunction with MRI.

Magnetic Resonance Angiography is a type of MRI that 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.

Recovery from a brain injury

After acquiring a brain injury the most important issue is usually the degree of recovery expected.

Recovery is usually rapid at first with improvements occurring as swelling and bruising of the brain subside. Improvements continue as damaged cells heal, however healing can be slow. The most significant improvements usually occur in the first six months, however good gains can continue for at least two years. Generally, a slow rate of initial improvement is associated with a greater chance of permanent disability.

Of every 1,000 people who survive a severe brain injury:

- 64% are expected to experience good recovery but may experience ongoing cognitive and/or behavioural problems
- 25% are expected to have a moderate disability
- 10% are expected to have a severe disability
- 1% are expected to remain in a permanent coma-like state.

It is important for the person and the family to be optimistic but realistic about recovery. Always try to develop a clear understanding of what is or isn't possible in rehabilitation.

Stages of Recovery

There are three broad stages of recovery following an Acquired Brain Injury. The acute medical stage involves intensive medical treatment that may be needed for survival and preventing further complications.

The rehabilitation stage involves intensive therapy aimed at helping the natural process of recovery and reducing the likelihood of long-term disability. Emphasis is placed on the person regaining previous skills and learning strategies to overcome or compensate for ongoing problems.

Community re-entry, or tertiary rehabilitation, focuses on the issues of everyday living and returning to previous community activities such as work, study and leisure. It aims to help the person and family find ways to adapt to, and compensate for, any long-term problems or disabilities.

Managing Recovery

Family members may need to make important decisions when they feel least in control. This will require them to be clear headed and well informed. Many find it useful to keep a diary in which they record medical, social and financial information.

Medical information may include:

- Names of the doctors and areas of responsibility/titles
- Dates and times of assessments
- Key medical terms
- Diagnosis and test results.

Social information may include:

- Person's achievements
- Visitors' messages
- Milestones (physical and cognitive recovery)

A diary and a visitors' book can also be helpful in retelling the history of what has happened.

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

WHAT IS NEUROSURGERY?

NEUROSURGEONS SPECIALISE IN TREATMENT AND SURGERY OF THE NERVOUS SYSTEM AND SURROUNDING STRUCTURES.

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

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

When the brain is injured, the brain will swell. This 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.

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

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

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

In the hospital

Further support and compensation

At some stage it will be necessary to think about the financial impact of the injury including loss of earnings, hospital expenses, rehabilitation costs and long-term care expenses. Regardless of the situation it is recommended that legal advice be sought by a solicitor who is familiar with the issues and Effects of Acquired Brain Injury. The local Brain Injury Association can assist with the provision of educational information for legal advisors.

Factors influencing long-term outcome

There are many different affects felt by the individual following a brain injury. Equally, for each person there are different factors that will influence their speed of recovery, and the outcome of their injury. It is important to consider the following when supporting someone through recovery:

- Individual's personal assets and limitations before the injury
- Location, nature and severity of the injury
- Individual's reaction to the injury
- Level of social support provided by friends and family.

Often the easiest of these to influence is the individual's reaction to the injury and their situation. A positive attitude and good understanding around how, why, and what has happened can often greatly improve the outcome of rehabilitation. Also influencing long-term outcome is Self-awareness, motivation, goal setting, coping strategies and management of emotions.

Self-awareness

The ability to recognise personal strengths and limitations is particularly important during rehabilitation when the person has the most opportunity for specialised support. There are three different levels of self-awareness. Intellectual awareness is the ability to understand that a particular skill or ability has changed following the injury. Emergent awareness is the ability to recognise and understand when a problem is actually occurring such as noticing that concentration is poor when reading a book. Anticipatory awareness is the ability to anticipate that a problem is likely to occur in future situations such as knowing a shopping list will be needed at the supermarket.

Research suggests that the development of intellectual awareness can take up to twelve months following the injury, although some people will not develop a full awareness of their problems due to neurological or psychological reasons. However, specialised rehabilitation programs can assist the development of self-awareness.

A summary of long-term effects

People with an Acquired Brain Injury and their families often observe some or many of the following long-term effects:

- Poor attention and concentration
- Memory problems
- Low motivation and poor initiation
- Difficulty carrying out plans
- Reduced ability to behave appropriately in social situations
- Rapid changes in mood and difficulty controlling anger
- Decreased ability to cope with stress and multiple demands
- Depression and anxiety
- Reduced number and quality of relationships
- Social withdrawal and loneliness.

The long-term implications of Acquired Brain Injury can be difficult to determine during the early stages of recovery as they may be disguised by the impact of grief and loss and early swelling of the brain.

WHY REHABILITATION IS VITAL TO RECOVERY

WHY REHABILITATION MAKES A DIFFERENCE

Recent research indicates that the adult brain can show experience-dependent recovery of neural circuits. This finding has three important implications, as follows:

- A lack of use and lack of stimulation of the brain, such as the absence of rehabilitation opportunities or inactivity, may prevent experience-dependent recovery
- If people reduce their activity and participation in their world because of the effects of brain injury, they may develop secondary or additional social, cognitive and behavioural disabilities
- Depression and other emotional disorders, such as anxiety and post-traumatic stress, can lead to poor motivation and may lower a person's use of helpful coping strategies.

There are five common forms of recovery and adjustment following an Acquired Brain Injury. To explain these forms of recovery and adjustment, the following sections use speech impairment as the example.

Remediation

Remediation involves relearning how to perform tasks and skills in a similar way to pre-injury performance, e.g. investing time and effort to practice speech therapy exercises in order to relearn and master language skills.

Substitution or compensation

This form of recovery involves using previously acquired skills or learning new skills to perform tasks in a different way, e.g. learning alternative means of communication such as writing messages, using a communication board, sign language or maximising non-verbal communication skills.

Accommodation

Accommodation involves the adjustment of personal goals, expectations and priorities to reflect the changed level of abilities, e.g. accepting that the speech deficit is a long-term effect of the injury and adjusting self-expectations about speech abilities.

Assimilation

Assimilation involves modifying the environment or adjusting the expectations of other people, e.g. selecting supportive environments or tasks that match the person's level of communication skills or educating other people to use alternative means of communicating with the injured person.

Decompensation

Decompensation is often more problematic than it is beneficial. It involves reducing the need to use a skill, e.g. avoiding or withdrawing from social interaction to reduce the need to communicate.

Effects of Acquired Brain Injury

Impact of Acquired Brain Injury

A brain injury is potentially one of the most devastating disabilities due to its wide range of effects.

The number and severity of problems resulting from a brain injury will differ from person to person as each person's brain injury varies in the extent and location of damage. The extent of some of these changes may only become apparent as time progresses.

Cognitive changes

Cognition is the conscious process of the mind by which we are aware of thought and perception, including all aspects of perceiving, thinking and remembering. In general, cognition is the process by which we acquire knowledge through perceiving and learning about the world around us.

The nature of cognitive problems will vary over time depending on what the person with the injury is doing and where they are. Some of them may not occur at all. These changes may become more obvious over time and can be very frustrating because they can affect the person's ability to learn new things, to work and to be involved socially.

Memory problems

One of the most common cognitive deficits is poor memory. There may be problems in remembering people's names or appointments, passing on messages or phone calls, or remembering details read in a book or newspaper. In therapy the person may forget what they are doing from one session to the next. Many are able to remember things that happened before the accident, but may have difficulty remembering things that happen from day-to-day. The person may have problems learning new things. Memory problems may resolve as the brain recovers but giving repeated practice of memory tasks will not necessarily bring about recovery. It may be more effective to develop compensatory strategies and thereby minimise the impact of the problem on everyday life.

Poor concentration

Difficulty concentrating is another very



common cognitive deficit following a brain injury. This can result in being easily distracted or it can result in being unable to stay on a task even without distractions. Hospital staff or family members can often confuse this with poor memory.

Depression

Depression in a person with brain injury is a very common emotional consequence that usually comes some time after the injury. Signs of depression include lack of motivation, loss of sexual drive, sleep disturbance and tearfulness.

Lack of initiative

In spite of all good intentions, someone with a brain injury may sit around at home all day long and watch TV. If the problem is severe they may need prompting just to have a shower and get dressed or to participate in a conversation.

Poor planning and problem-solving

People with a brain injury may have difficulty solving problems and planning and organising things they have to do. They may encounter trouble with open-ended decision-making and complex tasks need to be broken down into a step-by-step fashion.

Communication

A broad range of social skills may be affected by an Acquired Brain Injury including the ability to start or take turns in conversation, interpret and respond to social cues, show interest in others, use humour appropriately, shift between topics of conversation and regulate the volume and tone of voice. A person with brain injury often loses their listening skills, and may talk excessively. Accompanying memory problems may mean that they often repeat topics.

Lack of insight

This is probably the most difficult problem to deal with. People with a brain injury have great difficulty seeing and accepting changes to their thinking and behaviour. It is often beneficial to provide frequent, clear and simple explanations about why a problem is being treated or why the person is unable to do something.

This is not to be confused with denial. A person who lacks insight genuinely does not realise that their physical, sensory or cognitive abilities have changed. This can result in unreasonable expectations about what they are able to do.

Slowed responses

The person with a brain injury may be slow to answer questions or to perform tasks and they may have difficulty keeping up in conversation. Their capacity to respond quickly in an emergency may also be lost. The person can be helped by allowing them more time to respond and complete tasks. An understanding employer may be willing to modify the work situation. It is also vital that we avoid letting the person get into situations where they may be at risk by virtue of their slowed responses. This is one reason why many people with a brain injury are not allowed to drive. There might also be a need for careful supervision in the home.

Inflexibility

People with a brain injury can be very inflexible in their thinking. They can't always change their train of thought, so they may repeat themselves or have trouble seeing other people's points of view. They may not cope very well with sudden changes in routine.

Impulsivity

People with a brain injury may be very impulsive if they have lost the filtering system or control that makes them stop and think before jumping in. This can lead to a wide range of behavioural issues and problems with relationships and finances.

Irritability

People with a brain injury tend to have a low tolerance for frustration and can lose their temper easily. If kept waiting for an appointment they may become agitated and walk out. They may also become

unreasonably suspicious and paranoid.

Socially inappropriate behaviour

People with a brain injury may have difficulty judging how to behave in social situations. They may walk up to strangers and start telling them about their accident, they may be over familiar with therapists or they may make inappropriate sexual advances. This area can be incredibly difficult for families or partners. In more severe cases these behaviours may place the person at risk of becoming homeless or entering the correctional system.

Self-centredness

People with a brain injury may appear to be self-centred, and may be very demanding and fail to see other people's point of view. This can cause resentment from family members, and it is a key cause of losing friends and having trouble establishing new friendships.

Dependency

One of the possible consequences of self-centredness is a tendency for some people with a brain injury to become very dependent on others. The person may not like being left alone, and constantly demand attention or affection.

Emotional lability

Just as some people with a brain injury have difficulty controlling their behaviour, they may also have difficulty in controlling their emotions. They may cry too much or too often or laugh at inappropriate times. Alternatively they may suffer rapid mood changes, crying one minute and laughing the next.

Physical changes

Loss of taste and smell

A blow to the head can cause anosmia by injury to the olfactory nerve. This nerve sits between the frontal lobe and bony protrusions from the skull and is vulnerable to trauma. A blow to the head can also cause anosmia by damage to smell processing cells in the orbito-frontal or anterior temporal lobes or by mechanical damage to nasal structures. This loss of taste and smell often leads to either lack of appetite, or obesity as the person compensates with very salty or fatty foods.



Dizziness and balance

These are very common complaints after acquiring a brain injury caused by damage to the brain stem, blood pressure fluctuations from damage to areas controlling the heart and blood flow or vertigo from damage to the inner ear.

Epilepsy and seizures

These are chronic medical conditions produced by temporary changes in the electrical function of the brain, causing seizures which affect awareness, movement, or sensation. Medication can usually control these conditions well but some lives are devastated by frequent, uncontrollable seizures or associated disabilities.

Fatigue

Cognitive fatigue, or brain fatigue, is quite different to the physical fatigue that everyone is familiar with. When parts of

the brain are injured the rest must work harder to compensate, and this results in becoming cognitively and emotionally exhausted very quickly. This can lead to people becoming irritable or frustrated if they do not carefully manage their limited energy levels.

Headaches

There are multiple sources of head and neck pain, both inside and outside the head. Headaches arising from a brain injury can be caused by displacement of intracranial structures, inflammation, decreased blood flow, increased muscle tone, inflammation of the thin layers of tissue coating the brain and increased intracranial pressure.

Visual problems

Vision and visual functioning is often adversely affected by brain injury. Some of the more common visual systems problems include double vision, field cuts, sector losses, rapid eye movement and nearsightedness.

Chronic pain

This kind of pain persists beyond the expected healing time and continues despite appropriate physical improvement in the affected area of the body. The pain can emerge as headaches, neck and shoulder pain, lower back pain and/or pain in other body areas if trauma caused the brain injury. The pain may be so intense and bothersome that the person withdraws from work, family and social activities.

Paralysis

Differing degrees of paralysis can affect all parts of the body depending on which part of the brain has been injured. Effects can include poor coordination, difficulty walking, visual difficulties or weakness on one side of the body.

Hearing problems

Hearing problems can occur for a

number of reasons, both mechanical and neurologic, particularly when the inner ear and/or temporal lobes have been damaged. Tinnitus is experienced as noises which are commonly like a buzzing, hissing or ringing in the ears. Meniere's syndrome is caused by excessive pressure in the chambers of the inner ear. Nerve filled membranes stretch which can cause hearing loss, ringing, vertigo, imbalance and a pressure sensation in the ear.

Auditory agnosia is impaired recognition of nonverbal sounds and noises but intact language function. In some cases trauma to the inner ear can cause the person to be extremely sensitive to certain noises or pitches and may not be able to tolerate many environments we take for granted.

Other problems

So far only the more common issues have been looked at. There are, however, many effects that are less common but no less debilitating. For example, Heterotopic Ossification is a secondary condition of ABI in which there is abnormal bone growth in selected joints, most commonly in the hips, shoulders, knees and elbows - usually occurring within the first nine months after injury. Chronic neuroendocrine difficulties can occur in women some years post injury, with weight gain, thyroid disorders, changes in hair and skin texture, and perceived body temperature changes. Other people struggle with typographical disorientation, where they cannot remember how to navigate even well known environments, such as their own home or suburb.

LONG-TERM SUPPORT NEEDS

COMMUNITY ACCESS IS A PRIORITY SUPPORT NEED FOR PEOPLE WITH A BRAIN INJURY.

It is important to assist a person's orientation to the community (e.g. knowing one's way around) and transportation. Support with community access, however, also helps to prevent loneliness and social isolation. Although most people don't want support in forming and maintaining relationships, many desire an improvement in this aspect of their life. This suggests the need to develop more naturalistic opportunities for people to develop

relationships without direct support. These opportunities need to be structured in a way that is minimally intrusive and acceptable to individuals. Further research is needed to develop and evaluate interventions for enhancing natural support networks following a brain injury.

This is an extract from the Views on long-term support fact sheet available at synapse.org.au

Memory problems

While existing long-term memories often remain intact, an Acquired Brain Injury can significantly affect short-term memory.

Common everyday experiences can become a nightmare of confusion without strategies to manage or compensate for the effects of memory impairment. Problems may 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.

Coping with Memory Problems

Although there is no "wonder treatment" to fix memory problems there are many effective strategies that a person can learn to improve the success of their memory.

Organising the environment

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

- Using a notepad system beside the phone
- Using a large notice board and making plans
- Having a special place to keep objects which tend to go missing (e.g. keys)
- Labelling or colour-coding cupboards as a reminder of where things are kept
- Tying objects to places e.g. a pen to the phone or a key to a belt.

Using external memory aids

Everyone uses an external memory aid of some type. 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. Types of external aids include:

- A diary for storing and planning
- Notebooks
- Lists and checklists
- Alarm clock/wristwatch alarms
- Calendars
- Wall charts

- Tape recorders or dictaphones
- Electronic organisers
- Pill reminder boxes
- Post-it notes
- A memory book containing historical events, personal experiences and names.

Mobile phone technology can often integrate many of these aids (notebooks, checklists, calendars, reminders, voice recording). They are compact and easily transportable, allowing for discretion.

Developing routines to use memory aids

It often takes time and effort for new skills to become automatic. A routine itself is a strategy for coping with memory problems. Sometimes a calendar or a diary is a helpful way to reinforce a routine. Using a memory aid involves a three-step routine, for example:

- 1 Writing in a diary information that will be needed later
- 2 Checking the diary entries regularly
- 3 Acting on the information (performing the tasks or attending appointments).

Improving general well-being

Factors such as anxiety, stress (cognitive and physical) and fatigue can have serious effects on concentration and memory. The improvement of a person's emotional and physical well-being, therefore, will most likely have benefits for their mental alertness and ability to process information. Important considerations for improving general well-being include:

- A balanced diet and appropriate supplements e.g. vitamins
- Sufficient restful sleep
- Regular exercise
- Relaxation and stress-reduction strategies
- Following prescribed medication guidelines and medical advice
- Avoiding alcohol, cigarettes and drugs.

Specific memory techniques

- Selecting and prioritising key information
- Repeating or rehearsing key information using self-talk
- Using visual and verbal association to learn information and assist in recall
- Categorising information into groups.

The use of visual and verbal association techniques helps to put information into a meaningful context. When a person tries to recall such information later they can use the associated visual and verbal information e.g. her name rhymed with chess - visualise her as a queen on the chess board (Jess).

A good way to remember numbers is by chunking. For example 4578 is remembered as forty-five, seventy eight. Likewise, 502145 would be remembered as half a century followed by the age we get the key to the door and the age a cousin has remained for the past five years.

The PQRS strategy can be used to improve reading and understanding of written material (practice this strategy using a newspaper article).

The steps include:

- P** Preview (look over a newspaper article)
- Q** Question: What is this article likely to be about?
- R** Read the article carefully with the goal of answering the question
- S** Summarise or state the main points of the article
- T** Test: try to recall the main points immediately and after a short delay (20 minutes).



Attention and concentration issues

Damage to the brain may reduce a person's ability to concentrate, but the injured person may not immediately recognise this.

In addition, there may not be any visible signs to alert other people that a problem exists. This often leads to misunderstanding by members of the community e.g. incorrectly thinking a person with attention difficulties is lacking intelligence or motivation. This problem is of particular concern with children who return to the classroom after acquiring a brain injury. Without support they may be seen as disinterested or lazy students. People who have sustained a brain injury may:

- Become easily distracted
 - Have trouble keeping track of what is being said or done
 - Have difficulty doing more than one task at a time
 - Experience information overload
 - Be slower at taking in and making sense of information.
- The effects of these difficulties on people's everyday lives may:
- Affect their ability to learn and remember information
 - Cause them to feel frustrated with themselves and other people (have a 'short fuse')
 - Make them feel overwhelmed and easily confused
 - Lead to fatigue, headaches and dizziness

- Encourage them to withdraw from other people and avoid socialising
- Result in low levels of achievement.

Approaches to aid concentration

Reassure the person that what is happening to them is influenced by the damage to their brain. Encourage them to generate strategies from their own past experiences. It is suggested that the person be encouraged to identify specific situations where particular strategies may be effective. The following strategies may be helpful:

- Reducing all possible distractions in the environment
- Taking regular rest breaks: having a nap or a walk
- Meditating, deep breathing and other strategies for physical and mental relaxation, such as coffee breaks or talking to friends
- Planning how to approach a task step-by-step
- Writing information down using notes and keep them in specific places
- Using a dictaphone to tape messages that can be regularly played back
- Using a white board to help organise, plan and store information
- Using 'association' techniques

- e.g. putting medication on the table with every meal
- Getting into a regular daily routine which has a structure
- Aiming for variety within an everyday routine
- Scheduling demanding tasks when levels of energy and alertness are greatest
- Eating a healthy diet and sleeping well
- Using self-talk to monitor thoughts and actions
- Using a timer or electronic organiser.

Monitoring success

Encourage the person to practise different strategies to work out which are most effective in different situations using the following self-guided steps (WSTC):

- W** What is the problem? Ask 'where is my attention letting me down?'
- S** Select a strategy. Ask 'what are all the possible strategies I could use? Which is the best strategy?'
- T** Try out the strategy. Ask: 'what do I need to do to use this strategy?' Do it!
- C** Check out how the strategy worked. Ask 'how successful was the strategy?' 'Would I do it differently next time?'

PERSONAL ACCOUNTS OF BRAIN INJURY

A STROKE THREE YEARS AGO HAS KNOCKED ME OUT OF ALMOST EVERYTHING.

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

I still experience disorientation and confusion, with memory impairments, and I have troubles with concentration and

fatigue. I've searched for some way of describing how I feel. The closest I've come to is to say that it is like having malaria without the fever. My eyes feel a long way behind my face; I have headaches a lot, and often have trouble finding my balance. Complicated conversations and noise are

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

We can learn from the experience of others. Visit synapse.org.au to read personal stories by people with Acquired Brain Injuries, as well as their carers and family members.

Fatigue and lack of motivation

Fatigue and a disorder of motivation called adynamia are very common outcomes following a brain injury.

Fatigue often results from having diffuse damage throughout the brain. It is different to the yawning and sleepy feeling of normal fatigue. This type fogs the mind, drains all energy, dampens movement and sleep may do little to reduce it.

Fatigue often goes hand in hand with adynamia, or lack of motivation - noted by a loss of drive, indifference, and placidity. There is usually slowed mental function, a marked decrease in ideas, and activity is rarely self-initiated. There is often not only a verbal reminder needed to start a task, but further reminders required throughout the task. It is easy to see how family members could get frustrated in these situations unless they fully understand the impact of adynamia.

Activities that were previously automatic will often require increased effort after the injury. These activities can be concentrating, warding off distractions, reading for meaning, doing mental calculations, monitoring ongoing performances, planning the day's

activities, attending to two conversations at once or conversing with background noise. The huge effort involved for someone who has sustained a brain injury means they often need to sleep in the early afternoon due to the mental exhaustion involved in getting through the morning.

Providing their sleep has not been disturbed, the person often starts the day with some feeling of energy. Hours later (often they say its like a curtain falling down) they find they are struggling to keep going, and can't make sense of what they're doing. If they recognise this warning and rest for an hour or two they may recover and be able to start again for another period. If they neglect the warning and go on working until they can cope no longer they bring on a state of severe fatigue which will stop them doing anything productive for the rest of the day. Often this can persist and prevent useful work the next day, or even longer.

Trying to look interested

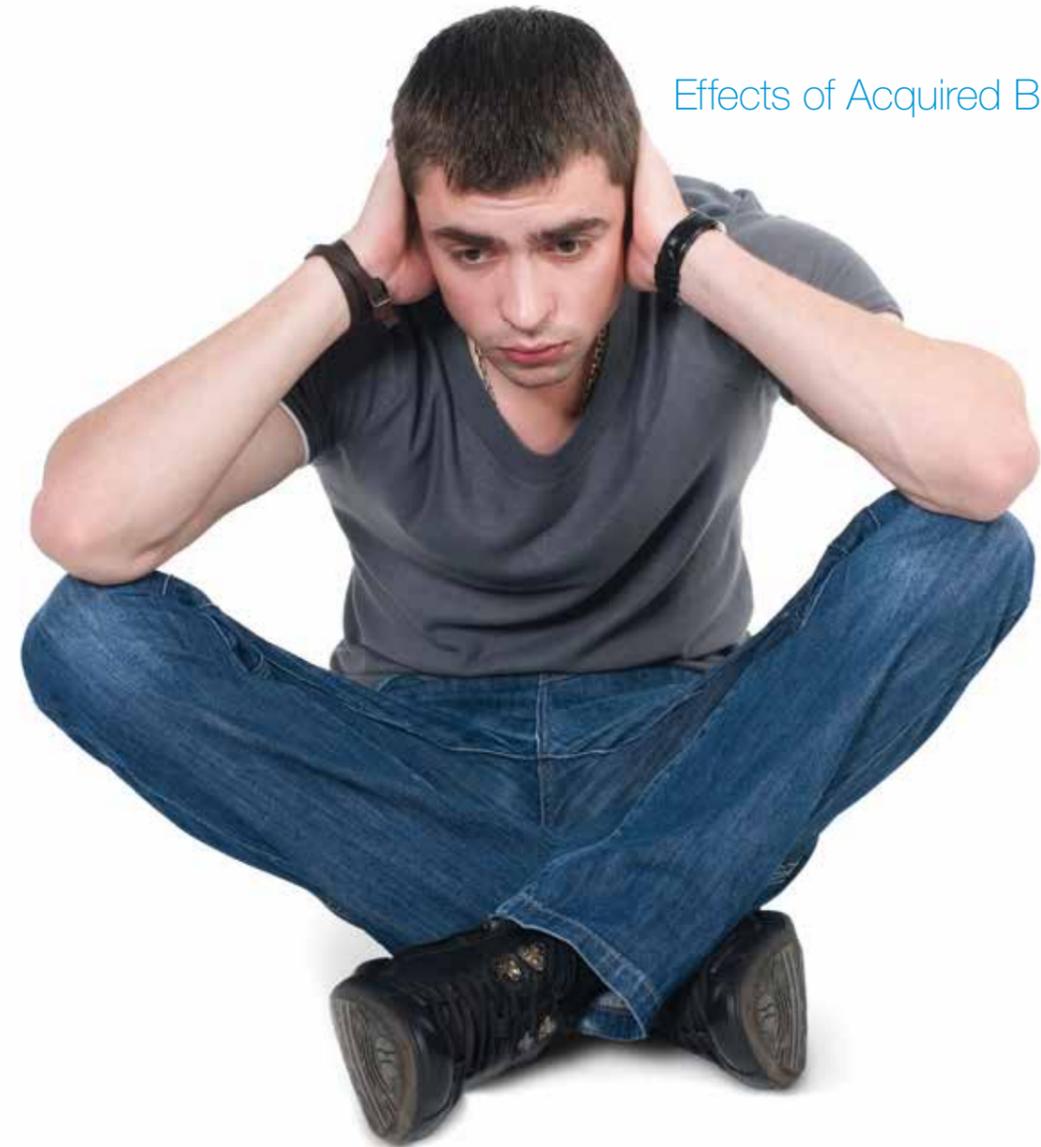
In social interactions the person may

not appear to be interested in the conversation, with dull responses to people or given situations. Social skills are exactly that—skills. Because they become second nature for most adults, however, it is hard to accept that someone with a brain injury may be struggling. Its hard work to keep up with conversation, to pay attention, to provide appropriate visual cues, to analyse what was said, to think of a response, and to look interested - especially for someone doing all of these things without automation.

Lack of understanding

Often a person will have no visible scarring from their brain injury, so all that their employers, family and friends may see is an apparently lazy person who enjoys an afternoon nap, gets upset when you give them a few tasks and doesn't give affection or take interest in other people.

The cruel irony of the situation is that the person may never have worked this hard to accomplish tasks, regain their social skills or achieve the simplest of



goals. When the injury is 'invisible' it may be crucial for employers, family and friends to be fully informed of adynamia to begin the process of understanding its devastating impact.

Managing fatigue

Learn where your limits are from experience. Even when you feel energetic, take your usual breaks or naps. Overdoing it can lead to feeling exhausted for several days. Schedule pleasant relaxing activities where needed — listening to music, watching TV or reading if these are not tiring. Make sure you eat properly, sleep well and avoid all drugs including alcohol, nicotine and caffeine.

Social skills

A logical place to start here is to find out how social interaction has been affected by adynamia. Usually family and close

friends can be relied upon to give you their honest impression if you insist on your need for accurate feedback. This should give you an idea as to which areas you need to work on, such as poor listening, or appearing vague or uninterested. Some therapists can assist in relearning skills through practice and repetition in functional situations. Alternatively you could buy books on effective communication and work on these in day-to-day situations.

In some ways the brain can be likened to a four lane freeway. The heavy traffic may be moving along rapidly but close just one lane and suddenly there is a traffic jam. The same can happen with your social interaction. You may need to avoid group situations or distracting environments as the ensuing 'traffic jam' will overload your ability to communicate effectively.

Should I tell other people?

In some cases it can be best to inform people about problems with fatigue. Given the right information, family and true friends should be concerned enough to understand your difficulties and make allowances. This also gives you the freedom to say you are getting fatigued and need to take a break. When they understand adynamia they should realise that it is not their conversation putting you to sleep!

Sometimes a brain injury can result in difficulties in making social judgements. People can be too open and trusting particularly after a frontal lobe injury. If you are wondering whether you should tell someone about your brain injury and how it has affected you, it may be best to discuss it first with a trusted friend or family member.

MANAGING LACK OF MOTIVATION

TASK ANALYSIS IS ONE POSSIBLE STRATEGY TO COMBAT ADYNAMIA, OR LACK OF MOTIVATION.

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

This reduces fatigue as it minimises the need to plan, organise, decide, prioritise, remember and put things in sequence. These are only some of the cognitive issues required to say, cook an omelette. The person with adynamia can be exhausted by these tasks before they've even opened the kitchen door.

Task analysis re-establishes the routines in our activities of daily living. With the use of checklists and lots of practice it can eventually make a great improvement in terms of drive and motivation.

The ingredients for rebuilding these automatic habits are the three P's: Plan, Practice and Promotional attitude. The result is rehabilitation, or removing obstacles to independence, and systematic achievement of incremental goals in desirable life areas.

Once you have goals in place, try building your motivation by:

- Telling people about the goal to confirm personal commitment
- Monitoring progress towards the goal by noting signs of improvement
- Developing a system of external rewards to reinforce personal effort
- Developing a routine which allocates time towards the goal
- Identifying people to provide support and encouragement.

Sleeping difficulties

Sleeping disorders after a brain injury can be another problem you don't need during your rehabilitation.

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

Unfortunately, a brain injury can often lead to a sleep disorder. This can be hard to detect as people with brain injuries can also experience fatigue. Although some people may have problems with getting too much sleep, the usual sleep disorder is trouble sleeping at night followed by feeling drowsy during the day.

Causes of sleeping problems

After a brain injury many find it not only difficult to sleep, but they are very easily

awakened, sometimes dozens of times a night. On top of this, they may find themselves unable to sleep at all around 3am, despite being desperately tired. Sleep will usually be very light, so the smallest noise brings the person instantly awake. Research suggests a major cause of disruptions or "sleep fragmentation" is a change in release of neurotransmitters in the brain during sleep.

There can be a variety of other causes for disrupting sleep. Discomfort from headache, neck pain or back pain will always make it hard to get to sleep. Depression is a common feature after a brain injury and people may find they fall asleep easily but wake up several hours before dawn, unable to sleep again. Anxiety and inability to handle stress are other common problems.

Negative thoughts whirring through the mind will usually make it very hard to fall asleep also.

Sleep your way to recovery

Sleep plays its part in not only helping the brain to recover from 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 this process.

Medication and sleep

There are medications that can assist with sleep problems. Some medications are designed to promote sleep but they are typically avoided by physicians who treat

brain injury. Physicians may sometimes use small doses of antidepressant medications for patients with head injury. Typically, the medication is taken a half hour before bedtime and assists with sleeping through the night. Sometimes this medication works too well and people sleep for 12 to 15 hours for the first two or three days. Some people report side effects such as difficulty waking up in the mornings. Lowered sensitivity to some medications can also occur after extended use - reducing medication effectiveness. It is important to always seek information from your doctor before starting, stopping or changing any medication. Only use medications as your doctor prescribes, and always inform them of any preexisting conditions (e.g. Brain Injury).

Practical steps to good snoozing

Routine is vital for sound sleep. Go to bed at exactly the same 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 may increase the likelihood of seizures.

Don't get the body stimulated 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 with family

members about respecting your need for a quiet environment.

So what about naps during the day? Some find that afternoon naps are essential due to the cognitive fatigue from a brain injury. Afternoon naps, however, 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 also help. Speak with your GP about seeing a Psychologist or Neuropsychologist who can help you out with this.

A POSITIVE APPROACH TO ACQUIRED BRAIN INJURY

There are common elements about getting through traumatic situations in an emotionally and physically healthy manner. What are some of the forces at work that help people cope with a brain injury?

The half full glass

In any traumatic event, some will groan and feel it just confirms for them that the world is an unjust place full of misery. Others will smile and say 'what doesn't kill you can only make you stronger'. It is the latter group who make the best recoveries after a brain injury. They see negative situations as a time to grow and develop. They also tend to be more selfless and concerned about others.

Laughter as medicine

There is certainly nothing funny about brain injury, but finding reasons to smile each day is a factor in health and raises the level of optimism. Our attitudes and beliefs have a strong influence on the body's ability to heal itself.

Determination

The good news is there is no limit to the extent of rehabilitation. How far you get depends on how much you put in, and

even if improvement is painfully slow remember progress is better than staying where you are. Set and prioritise goals, implement plans and make the most of support networks to stay motivated.

A spiritual angle

Many families and survivors say that spirituality helps them through the recovery process. Some families that have no religious affiliation found that when faced with tragedy involving a family member or friend, they found themselves praying, meditating, or exploring other spiritual practices - possibly for the first time. Taking a spiritual path can often assist people to make the most of learning from the experience.

Whatever works for you

Choose to not give in to negativity, and find strategies that will help you do this. The "whatever works for you" strategy does make you an active participant in the outcome. As Ronald E. Osborn said, "Undertake something that is difficult; it will do you good. Unless you try to do something beyond what you have already mastered - you never grow."

- 'Positive Approach to ABI' Fact Sheet at synapse.org.au

Depression after a brain injury

A number of factors influence a person's level of depression following a brain injury.

Depression is a common outcome following a brain injury. A person may be confronted with not returning to work, cognitive deficits that will never completely disappear, loss of friends, fatigue and difficulty with managing anger and frustration. On top of this they may have lost the strategies used in the past to combat depression and these will need to be re-learned.

A number of factors influence a person's level of depression following a brain injury. It is important to consider life situation, level of traumatic stress experienced and the person's perception of their life situation.

Other things to note are the personality and emotional well-being before the injury, the nature of the person's brain injury and the stage of recovery, and other health conditions that may cause or exacerbate the symptoms of depression, e.g. heart disease or kidney failure

Signs and symptoms

The common signs and symptoms of depression include changes in:

- Mood e.g. extreme sadness, despair, flat emotional reactions and irritability
- Thinking patterns e.g. a sense of hopelessness, pessimistic beliefs
- Behaviour patterns e.g. reduced attention to physical appearance, withdrawal
- Physical symptoms e.g. sleep disturbance, appetite changes, tiredness.

Some of the changes described are common symptoms following an Acquired Brain Injury, which means it can be difficult to recognise the development of depression. People's experience of depression usually occurs on a continuum ranging from very mild to very severe. The most important consideration is therefore the severity of the person's depression and how long it lasts. Many people are able to self-manage their depression using strategies. Other people require

psychological support or other forms of treatment from professionals.

One of the most important factors to consider when planning any treatment, or evaluating the success of a treatment strategy, is whether or not the person with depression feels as though they are in control of their own life. A feeling of not being in control can make depression worse, or can lead to depression in an otherwise healthy individual.

Endogenous and exogenous depression

Although the treatment approaches are usually similar, depression can be divided into exogenous ("reactive") depression and endogenous ("organic") depression. Exogenous depression occurs when life events overwhelm your ability to avoid depression and maintain good mental health, and endogenous depression arises as a direct result of chemical processes in the brain.

Exogenous depression can be helped by anti-depressant medication, but addressing the causes through life changes or coping strategies will remove the need for medications.

Endogenous depression can be helped by life changes and coping strategies, but medical intervention is often necessary - sometimes life-long.

Personal strategies for coping with depression

The following strategies have been suggested by people with Acquired Brain Injury and may be useful.

- Having a nap
- Listening to music
- Watching television
- Working on a personal project
- Socialising
- Walking or other exercise
- Mental stimulation
- Scheduling activities and making short-term plans
- Self-Talk or thought challenging.

Self-talk

Self-talk is a useful technique for modifying inaccurate and upsetting thoughts. It requires the practised art of replacing upsetting thoughts with constructive explanations. For example instead of thinking, "I'm useless and I never get anything right," the person can replace their thoughts with a constructive explanation such as, "My memory lets me down, I will make better use of my diary in future." A variation of Self-talk is to prepare a rethink card. Rethink cards contain helpful coping statements for particular situations. The card can be carried around and read when the person notices unhelpful thoughts in certain situations e.g. a coping statement

TOPOGRAPHIC DISORIENTATION

THIS DISORDER MEANS PEOPLE WILL EXPERIENCE DIFFICULTY IN FINDING THEIR WAY IN FAMILIAR SURROUNDINGS.

Topographic disorientation (TD) can be very disabling yet may go undetected. This inability to navigate through the environment usually involves the person being unable to learn routes in new environments as well. TD is generally viewed as an impairment in spatial memory and has been given different names such as visual disorientation, topographic amnesia and spatial disorientation.

Making our way around our house or driving across the city is a complex behaviour involving many components. TD varies from person to person depending on the area of the brain affected. For example one area of the brain acquires spatial information, another develops long-term representation of position while another will perceive relevant landmarks on a journey.

A person may not even remember how to get around their home any more. Another may remember strategic landmarks but not be able to compute their positional relationship to each other. Others may remember well established routes but be unable to learn a new one. The degree people are affected by TD depends on whether they can develop strategies that will compensate for the disorder. Some people can still make their way around town by using maps and constantly asking for directions. Some may benefit from the GPS satellite navigation units that can now be fitted to cars which will give verbal instructions to reach destinations. Small portable units are also available and becoming cheaper each year.

Condensed from the Topographic Disorientation fact sheet at synapse.org.au

for being stared at while riding public transport: "People may stare at me because they are naturally curious about why I walk with a limp – that is part of human nature".

Peer support

Do not underestimate the importance of social contact, and in particular peer support, for the maintenance of good mental health, including depression.

Your local brain injury association or mental health association can put you in touch with peer support groups for brain injury or for depression.

Exercise

For many people, exercise alleviates the symptoms of depression. A major depressive disorder can not be treated by exercise alone, but every little bit helps. Particularly if you have an attack of the blues - getting moving can not only help you feel better but accelerate your rehabilitation.

If you are currently recovering from physical injury or physical deficits as a result of a brain injury, discuss any exercise program with your GP or rehabilitation team.

Treatment approaches for depression

It is common for some people to experience depression after a traumatic event and require additional treatment to the strategies suggested. Treatment options can include the following:

Psychological therapy: This form of treatment is usually most effective with mild or moderate to severe forms of depression. In general, people with very severe forms of depression will require other interventions e.g. hospitalisation or medication. After a person's state of mind has improved they may be more likely to benefit from psychological support to further reduce symptoms and provide ongoing management.

Antidepressant medication: Medication is often used in association with psychological therapy for someone who does not respond well to psychological therapy alone. Medication may help

to relieve depression by adjusting the chemical levels in the brain. Depression is often caused by an excess or a deficiency of particular chemicals in the brain. Such chemicals are created naturally within our bodies and influence our moods, thinking, behaviour, sleep, energy levels, appetite, concentration and other daily functions. Medication can assist with balancing these chemicals when they become altered.

Most antidepressants take about two weeks before a person will notice any change in mental and physical state. Medication needs to be trialled for at least four to six weeks and should generally be taken for approximately six to twelve months even if the person feels better after a few months. People are advised to see a general practitioner or psychiatrist to discuss issues relating to medication.

Electroconvulsive Therapy (ECT):

ECT is an extremely effective, very fast acting, antidepressant treatment with an extremely high efficacy. Where other antidepressant medications have failed, ECT is often effective at reducing depressive episodes. The disadvantages of this procedure are the cognitive side-effects that are consistently evidenced. The method (voltage, length of administration, section of brain administered to) directly affects the cognitive deficits produced. It also directly affects the reduction of depressive symptoms, whereby the most effective reduction occurs concurrently with the highest incidence of cognitive deficits. ECT is used as a treatment of last resort – only when depression has not responded to other treatments. Always do your own research, consult a doctor, and then decide.

Suicide

Given the many difficulties faced by someone who has survived a brain injury, it is possible for thoughts of suicide to arise. It is crucial to look for support or see a doctor during this period as appropriate support will normally assist in getting through deep depressive episodes.



Problems with organising

Many people find that following a brain injury they have difficulty getting organised.

The frontal lobe of the brain is responsible for the act of organising our lives. Unfortunately it is very susceptible to injury and some people with Acquired Brain Injury find great difficulty with prioritising, sequencing, organising, initiating and completing tasks.

Improve your lifestyle

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

- A balanced diet and appropriate

supplements e.g. vitamins

- Sufficient restful sleep
- Regular exercise
- Relaxation and stress-reduction strategies
- Following prescribed medication guidelines and medical advice
- Avoiding alcohol, cigarettes and drugs.

Structure

Structure allows us to put most of our 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. It is crucial to have well defined tasks for the day.

Set a timetable each day that will ensure

the healthy lifestyle above. For example, sleep can be properly regulated by always going to sleep and waking at set times. Meal times should be at set times and never skipped. Work with family members to arrange a weekly plan for visiting others, exercise and any rehabilitation tasks.

Setting goals

We all have goals we have set out to achieve, often at a subconscious level. Goals keep us focused on a purpose and help us through difficult times when many others less motivated would give up. A person who wants to get the most out of life often has a number of goals simmering at the same time.

By setting goals you can get out of negative mind sets and help you gain

more control over your life. It pays to set these out in writing and approach them step-by-step. If your formal rehabilitation has finished, some goals may be to continue further work yourself. It is crucial to have an accurate idea of your strengths and weaknesses. After sustaining a brain injury, people often have unrealistic ideas here if their self-awareness has been affected, so the involvement of rehabilitation professionals or family is a good idea.

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

- Goal
- Task/steps
- Time frame
- Potential barriers
- Benefits of achieving the goal.

It is important to realise the underlying emotions or needs behind a goal. For example, you may want to return to work but find your cognitive deficits prevent this. Why do you want to return

to work? It may be the sense of being productive, of being part of a team and feeling esteemed by peers. In this case looking at volunteer work for a community organisation may achieve these underlying needs.

Achieving goals is a step by step process. It may seem too daunting at first but families can provide support and assistance in a graduated way. The recovery process is more like a marathon than a sprint. Both you and your family need patience, positive attitudes and plenty of loving support for each other.

Goals should be adjusted to fit your learning style and what you enjoy. If you hate reading or writing then your goals shouldn't use written exercises or reading of books. If you don't mind writing then keeping a journal is an excellent way to record your progress, especially when you feel you aren't getting anywhere. A journal can keep track of the "three steps forward, two back" that can sometimes feature in recovery.

Memory aids

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

- A diary for storing and planning
- Notebooks for various places
- Lists and checklists
- Alarm clock, wristwatch alarm and timer
- Calendars and wall charts
- Tape recorder.

Bringing it all together

All of these suggestions are compensatory strategies—that is they compensate for skills that your brain is not as good at any more. The good news is that the right strategies can go a long way to making up for a sluggish frontal lobe. All it takes is commitment to getting these strategies into place and being patient with yourself!

ORGANISING YOUR ENVIRONMENT

GET A DAILY PLANNER, DIARY OR ELECTRONIC ORGANISER AND WRITE THINGS DOWN IN THE ORDER YOU ARE GOING TO DO THEM.

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

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

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

Problems with anger

Anger is a common reaction experienced when coming to terms with how a brain injury has changed one's life.

Following a brain injury, there is often damage to the area of the brain that controls our actions. This area usually controls impulses to shout or hurt others, substituting for more appropriate actions. An individual with damage to this area can sometimes lose this control and may experience rage in situations they used to tolerate or ignore completely.

There can be an 'on-off' quality to this anger too. The person with the brain injury may be calm minutes later while those around are stunned by the angry outburst and may feel hurt or shocked for hours, if not days, afterwards. Family members and partners often struggle to understand these angry outbursts, with resentment and bitterness often building up over time. Once they understand their loved one's problem is in controlling anger, and not directed at them, they can begin responding in ways that will help to manage outbursts.

In some cases, the person with a brain injury can have problems with self-awareness. They may not be able to acknowledge they have trouble with their anger, and will blame others for provoking them. Again, this can create enormous conflict within a family or relationship. It may take carefully phrased feedback, changes in the family's responses, and plenty of time for the person to gradually realise they have a problem at all.

The next step is for the person to relearn anger management skills they used to take for granted. A good place to start is identifying a pattern in how the outbursts are related to specific frustrations. Such triggers may originate from the environment, specific people or internal thoughts.

It is important to have support from families and loved-ones when attempting to change behaviour. Often family can feel that it is not their 'problem', however, simple changes in their response can often cause the situation to become far easier for all involved to manage.

Common causes of anger

- Being confronted with tasks the person is no longer capable of doing
- Other people's behaviour e.g. driving, insensitive comments
- Inaccurate thinking e.g. falsely believing that people are laughing at them
- Unrealistic self-expectations
- Barriers getting in the way of goals or routines e.g. queues
- Build up of stress.

Identifying the cause of anger can be a challenge. It is important to consider all possible influences relating to:

- Environment e.g. too much stimulation, lack of structure, change of routine
- Physical state e.g. pain, tiredness
- Mental state, e.g. frustration, confusion
- Other's responses/behaviours.

Recommended Strategies for Coping with Anger

Steps to successful self-management of anger include:

Becoming motivated

The person identifies why they would like to manage anger more successfully. They identify what benefits they expect in everyday living from improving their anger management.

Self-awareness

A person becomes more aware of personal thoughts, behaviours and physical states which are associated with anger. This awareness is important in order to notice the early signs of becoming angry. They should be encouraged to write down a list of changes they notice as they begin to feel angry.

Awareness of situations

The person becomes more aware of the situations which are associated with them becoming angry. They may like to ask other people who know them to describe situations and behaviours they have noticed.



STOP - THINK TECHNIQUE

A person notices the thoughts running through their mind:

- 1 Stop! And think before reacting to the situation (are these thoughts accurate/helpful?)**
- 2 Challenge the inaccurate or unhelpful thoughts**
- 3 Create a new thought.**

A plan can also be developed to help a person avoid becoming angry when they plan to enter into a situation that has a history of triggering anger. An example of a personal plan is using the Stop - Think technique when approaching a shopping centre situation that is known to trigger anger.

My goal: improve my ability to cope with anger when I am waiting in long queues.

Typical angry thoughts: 'The service here is so slack. Why can't they hurry it up? I'm going to lose my cool any moment now'. Stop thinking this!

New calmer and helpful thoughts: 'Everyone is probably frustrated by the long line – even the person serving us. I could come back another time, or, I can wait here and think about pleasant things such as going to see a movie'.

Levels of anger and coping strategies

As the person becomes more aware of situations associated with anger they can keep a record of events, triggers and associated levels of anger. Different levels of anger can be explored (e.g. mildly annoyed, frustrated, irritated and higher levels of anger).

Develop an anger management record

The person may keep a diary or chart of situations that trigger anger. List the situation, the level of anger on a scale of one to ten and the coping strategies that help to overcome or reduce feelings of anger.

A simple and effective technique for reducing levels of anger is the *Stop – Think technique*.

Communication problems

Communication problems that result from a brain injury vary, and depend on many factors which include a person's personality, pre-injury abilities, and the severity of the brain damage.

Typical effects may include slow or slurred speech, difficulty swallowing, drooling, or a nasal tone. Communication problems can be a mixture of both receptive and expressive problems.

Receptive skills

Indicators of receptive difficulties may include lack of understanding or attention, problems with quickly given complex information, and requests for repetition. It should be remembered that hearing loss can also occur following a brain injury and lead to the same effects. Ideally a hearing test by an audiologist should occur before assessing receptive skills.

Behaviours that may indicate problems with receptive language include:

- Poor recognition of vocabulary
- Needing things to be repeated
- Difficulty with the speed, complexity or amount of information said
- Not paying attention in conversations
- Not understanding what is said
- Difficulty remembering instructions given.

Expressive skills

The ability to use verbal or written skills to express oneself may appear unaffected, but often there are subtle problems that emerge over time. Often communication tests during rehabilitation will not detect problems as these formal testing situations will not trigger many of these subtle issues. Some of these can include:

- Non-stop talking, rambling explanations or very rapid speech
- Difficulty remembering particular words
- Incorrect use of language
- Talking about/interrupting about unrelated topics
- Not observing the usual norms and customs in social situations

- Making up stories
- Minimal responses when detail is required in an answer
- Difficulty with abstract skills in understanding humour, puns, sarcasm and metaphors
- Hypervocal or rapid, non-stop talking
- Poor spelling and difficulty in learning new words
- Saying the same thing over and over (perseveration)
- Trouble with writing long sentences.

Anomia - trouble with finding words

People with a brain injury may talk normally; speech flows evenly and it's easy to understand. But some will have this very odd problem – they'll know



the word they want to say but just can't come up with it. This is called *anomia*, which means "can't name". Everyone has an occasional anomia; those with a head injury can have it frequently. It can become frustrating if you are dealing with people all day long. It may result in poor self-esteem when you're just not sure of what you're saying any more.

A variation on this problem is that you say the wrong word. Instead of saying, "pass me the spoon", you might say "pass me the noon." Or, instead of using a similar sounding word, you may use an entirely wrong word. Instead of "pass me the spoon," you may say, "pass me the car."

A speech/language pathologist is a professional who commonly works with this type of problem. This person can teach you techniques to decrease this problem. For example, you can use a technique called "circumlocution." Basically, you "talk around" the word. If you can't come up with the word "telephone," you might say "you dial it, you can put a quarter in it, you can call people." People eventually get what you were trying to say. Another technique that people sometimes use is to go through

the alphabet and try to get the first letter of the word. Or you can visualise spelling the word – picture a blackboard and try to "see" someone writing the word on the blackboard. Then read the word off the blackboard.

Dysarthria

Dysarthria results in slow, slurred, and difficult to understand speech as the areas of the brain that control the muscles of the speech mechanism are damaged. A speech pathologist may help with strengthening muscles, increasing movement of mouth and tongue, breathing exercises and slower rate of speech. In extreme cases alternative means of communicating may be looked at.

A person with dysarthria should concentrate on slow clear speech with frequent pauses. It may be an idea to commence a topic with a single word first, and to check frequently that the other person is understanding you. Try to limit or desist conversations if you become tired as speech often deteriorates quickly with fatigue.

Apraxia of speech

This is a condition in which strength and coordination of the speech muscles are unaffected but the person experiences difficulty saying words correctly in a consistent way. 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 such as, "I tried to say it yesterday."

The type of treatment depends on the severity of apraxia. In mild cases, therapy may start by saying individual sounds and contrasting them and thinking about how the lips and tongue should be placed. Sometimes the timing of rhythm of speech to tapping or clapping helps to speak more clearly. Contrastive stress drills use the natural rhythm of speech to increase intelligibility. In this exercise, the same sentence is repeated with a different stress patterns, changing the meaning of the sentence. People with mild apraxia can learn strategies to use to help them produce the longer words that give them trouble. For the very severe apraxia, alternative and augmentative systems are often employed.

Cognitive problems

In some cases the person may not appear to have communication difficulties until they are in stressful situations such as returning to work or study. These cognitive problems will usually stem from inability to maintain attention, difficulty with abstract language, poor organisation of language and a slower rate of processing information.

How professionals can help

Following a brain injury, these cognitive issues can make it harder to learn and apply knowledge to specific situations. A speech pathologist can assess and treat communication problems, and provide advice to rehabilitation teams. They can help the person with a brain injury to cope in given social situations, using compensatory strategies and treatment to help the person be more competent in social situations. Often the person can learn to compensate for a disability by learning a new and different skill or by using assistive technology such as a computer, calculator, hearing aid or augmentative communication device.



HOW FAMILIES AND FRIENDS CAN HELP

FAMILIES, COWORKERS, TEACHERS AND FRIENDS CAN PLAY AN IMPORTANT ROLE IN HELPING A PERSON IMPROVE COMMUNICATION SKILLS OR LEARN NEW COMPENSATORY STRATEGIES TO REDUCE LIMITATIONS.

This is particularly the case where they work together with the speech therapist to provide consistent support in the strategies being learned by the individual with the brain injury. Family should ask questions and expect to be involved in the process of rehabilitation.

Approaches to USE when communicating with someone with a brain injury

- Acknowledge the injury and be supportive
- Prompt the person to evaluate their own speech and be aware of issues

- Work with the person to find out what techniques assist them to communicate
- Use open and non-judgmental questions
- Allow people to take extra time to finish their sentence or to find a word
- Speak clearly and simply when there is a receptive communication deficit
- Use paraphrasing and summarising to ensure understanding
- Simplify terms into everyday language.

Approaches to AVOID

- False reassurance

- Minimising a person's feelings ("It's not that bad...")
- Pressuring the person beyond their current ability
- Finishing sentences for people who lose track of what they were saying
- Speaking excessively loudly or slowly
- Arguing with a person or telling them that they are being irrational
- Using technical jargon and lengthy explanations that the person cannot understand or follow.

BUILDING A CHILD'S 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.

Children and young people with a brain injury may have difficulty with the social skills that most of us take for granted.

An Acquired Brain Injury can cause children to interact in ways that aren't always socially appropriate – being 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.

Some strategies for parents

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 practise 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.

This is an extract from the Parents Guide range of fact sheets at synapse.org.au

Impaired self-awareness

Lack of self awareness is a common outcome for people with frontal lobe injuries and is related to emotional and personality variables.

People with a brain injury may be unable to recognise difficulties they are having that are obvious to others, and insist they are back to normal. In other cases they may not realise the extent of an issue and believe that others are exaggerating their impairments. They can often exaggerate their own abilities in terms of social skills or emotional control and have unrealistic ideas about the future.

This lack of self-awareness is not denial. Denial involves rejecting knowledge. Where there is lack of self-awareness, there is no knowledge to reject – the person is, due to their brain injury, simply incapable of understanding their true situation.

Not surprisingly this inability to recognise deficits causes many problems for rehabilitation. The need for rehabilitation services will be questioned and the individual often has a complete lack of understanding of how their cognitive problems impact upon their relationships with family and friends. People with a lack of self awareness may go back to their job and not understand why they struggle in the workplace. They are often unable to set achievable goals at work or evaluate their own performance realistically. Understandably this can affect one's vocational confidence.

Three types of awareness impairment

Impaired intellectual awareness is where a person is unable to understand that a deficit exists. The second type is impaired emergent awareness where a person knows there is a problem but is unable to realise when the problem is occurring so is unable to compensate for the deficits. The third type is impaired anticipatory awareness where the person is aware of the deficit, can recognise when the problem is occurring, but is unable to anticipate the likely situations in which the problem will occur.



The family takes the brunt

The impact on the family can be immense. If they raise the issue with their family member there can often be an angry reaction. At times the family may try to believe nothing is wrong - in their desire to see their loved one get well. This, however, could lead to dangerous situations e.g. an individual driving with a visual impairment. A family should set specific goals with their loved one that have to be met before the family member can forego treatment or supervision. Ideally this should happen with the involvement of rehabilitation professionals also.

It's your fault, not mine

Another impact on the family is that external causes may be wrongly blamed for problems that develop. Linked with a lack of self awareness can be a refusal to take responsibility for

actions. If someone is unaware of their deficits they may actively seek to find explanations elsewhere. A useful strategy is encouraging them to look at situations from an outside viewpoint and analyse what happened. Ideally a problematic situation could be videotaped to aid this process. The hardest part of being blamed for something is to not take it as a personal insult. Arguing will only worsen the situation so it can be best to agree to disagree. A common response could be "We both see this from different angles so let's leave it there". If blame is a constant problem the whole family should look at adopting a consistent response and seeking professional assistance.

Seeking professional help

If lack of self-awareness is treated professionally the first step is usually a neuropsychological assessment. This will assess the person's cognitive strengths and weaknesses, evidence the impaired awareness, and suggest a treatment plan. Usually the family will be included in this process.

There are various psychotherapeutic techniques used to help increase a person's self awareness. The therapist first builds rapport then gently helps the individual to see the discrepancy between their perceived level of performance and their actual level of functioning. The next step is normally to help the person anticipate and plan for the problems their deficits may bring about by teaching strategies to deal with them. Treatment methods will vary depending on the type of awareness impairment.

The long road to awareness

Lack of awareness can lead to poor recovery for people whose brain injury has resulted in this condition. Family members should be on the lookout for this and seek treatment when required to enhance the quality of life for the family member with brain injury.

Hearing difficulties

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



Our hearing process has two stages: the mechanical and a neurological process. The mechanical process is carried out by the ear 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, a thin membrane which vibrates in sympathy with any entering sound. The motion of the eardrum is transferred across the middle ear via three small bones to the inner ear where a tube called the cochlea is wound tightly like a snail shell. From here the neurological process begins and the brain translates vibration into electrical impulses.

Trauma most commonly affects the mechanical process. An eardrum may rupture, any of the small bones could break or there could be bleeding or bruising of the middle ear. Sometimes damage to the parietal or temporal lobes can disrupt the neurological process also. Thankfully many hearing difficulties are not permanent and can be reduced or eliminated with treatment.

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. Because accurate diagnosis and treatment is needed a trip to the doctor and possible referral to an audiologist is required.

Tinnitus can be exacerbated by exposure to loud noises, excessive stress, caffeine, alcohol, nicotine, some illicit drugs and medications, and quinine found in tonic water.

Some audiologists run clinics to help manage tinnitus. Other treatments include hearing aids, tinnitus retraining therapy or cognitive behavioural therapy to alleviate distress.

noise, can be a living hell for some people with a brain injury whose sensitivity to sound has been affected. A few examples of difficult situations include dining out, taking a walk, washing the dishes, using a vacuum cleaner or listening to music. Compounding the problem is that the disorder is often not diagnosed, and the person has trouble convincing others that the problem exists.

Ear-plugs and ear-muffs can be a great help. Activities can be restructured so that dining out or shopping can be done outside the peak hours, to avoid excessive noise. A commonsense approach to diet also helps. Avoiding stimulants such as nicotine or caffeine reduces the body's sensitivity to noise. A proper diet and exercise play their part in better overall health, which will impact indirectly on hyperacusis by reducing stress.

As with many effects of brain injury, hyperacusis is exacerbated by stress and fatigue. Good sleep and avoiding stressful situations will maximise the ability to deal with noise.

The most effective solutions involve increasing the tolerance of noise, so the person with a brain injury needs to walk the fine line between protecting their ears by minimising discomfort, yet exposing themselves to sufficient noise to build up their 'immunity'. Over-protection will only further increase the effect of hyperacusis.

Hearing clinics can provide therapy with a specially programmed hearing aid to manage the hyperacusis. They may also provide a soft noise generator to be worn while awake for up to 18 months. Long-term exposure to gentle sound at a barely audible level can desensitize the ears and improve both hyperacusis and tinnitus. This 'white noise' contains every frequency audible to humans, and can be likened to the sound of distant surf or wind. It can help up to 90% of sufferers.

Meniere's syndrome

This syndrome is caused by excessive pressure in the chambers of the inner ear. Nerve filled membranes stretch which can cause hearing loss, ringing, vertigo, imbalance and a pressure sensation in the ear. Although it can not be cured, treatment can alleviate the symptoms with medication such as diuretics or steroids, electrical stimulation or simply limiting movement. There are various surgical procedures that may decrease the pressure or remove or deaden the nerves involved.

Auditory agnosia

This is impaired recognition of nonverbal sounds but intact language function. This rare outcome is normally from damage to the temporal-parietal region of the brain which interferes with the cognitive process of hearing. There may be an inability to understand spoken language while the ability to speak is preserved. Auditory agnosia often gradually resolves itself over time.

Sensitivity or Hyperacusis

Sometimes trauma to the inner ear can cause certain noises or pitches to become extremely loud or soft. Our typical western lifestyle, with its barrage of

Impulsivity

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

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

This inability to control urges can lead to impulsive — and often inappropriate — social behaviour. For example, a previously shy person may become quite extroverted and talkative if the brain injury has led to mild disinhibition. When this inability to control urges is more marked, it may lead to a normally reserved, polite person making crude or sexually inappropriate comments to strangers following a brain injury.

When other people do not understand the reasons for this behaviour, it often leads to rejection and criticism from others. Impulsivity can therefore lead to social isolation as the person alienates existing friendships and cannot make new ones. Other inappropriate behaviours may include:

- Sexual promiscuity
- Acting without thinking
- Inability to save money or regulate finances
- Sharing personal details inappropriately
- Irritability
- Angry outbursts
- Over-familiarity with strangers
- Asking personal questions of others despite their discomfort.

Lack of insight

Another common outcome from a frontal lobe injury is lack of awareness. This can make it difficult to analyse one's own behaviour or to assess other people's reactions. This complicates the issue of impulsivity, as the person may refuse to acknowledge that they have inappropriate behaviour. They may be unable to understand their own limitations, or the consequences of their actions. A person lacking in insight is also often unable to

understand other people's behaviour or motives, and unable to empathise or imagine how someone else is feeling.

Strategies for carers

Impulsivity often arises in situations where the person is confused or fearful. These can be minimised by a predictable daily schedule. Any outbursts should not be automatically written off as impulsivity and ignored. They may be indicating a cause of fear or confusion that needs to be addressed.

When lack of awareness is not an issue, the person may apologise later. Try to be sensitive to this, despite any lingering anger or annoyance on your part. Prolonged complaints about the behaviour afterward are not likely to help, as usually the person's lack of control was not by choice on their part.

If the person engages in attention-seeking behaviour such as yelling or interrupting, tell them this is not a good way to get your attention, and advise them on an alternative strategy.

When managing impulsivity try to recognise that challenging behaviours have often arisen from a physiological cause – the frontal lobe injury, and are not 'chosen' by the individual.

Try to remember it is the impulsivity that is at fault, not your loved one. In most cases, they will not be speaking or acting intentionally to annoy you or hurt your feelings. Separating the person from the behaviour can go a long way to coping with the situation.

In serious cases, your local Brain Injury Association will be able to put you in touch with any specialists in behavioural issues who may exist in your State. In some cases medication may play a useful role. You should consult your rehabilitation specialist or GP to see if medication could help.

WHAT YOU CAN DO ABOUT HEARING PROBLEMS

IF YOU ARE EXPERIENCING AUDITORY PROBLEMS, SEE YOUR DOCTOR, AS THERE MAY BE A TREATABLE MEDICAL CAUSE.

A referral may be needed to have your hearing checked by an audiologist (hearing scientist) or you may be referred to an ear/nose/throat specialist. Some audiologists run specialist clinics to help manage some conditions and they fit hearing aids and/or therapeutic noise generators if needed.

Good quality and properly fitted hearing aids reduce and even eliminate most tinnitus associated with hearing loss. They take away the strain of listening and distract from the tinnitus by increasing sounds in the outside world.

Therapeutic noise generators are a hearing aid type device for people with no hearing loss that produces a blend of external sounds. This stimulates most fibres of the hearing nerve to deviate attention away from the tinnitus.

Tinnitus retraining therapy aims to reduce and ultimately eliminate tinnitus perception. It combines auditory therapy (hearing aids/noise generator) and counselling aimed to change negative beliefs, distract from tinnitus and reduce stress.

Cognitive behavioural therapy aims to alleviate distress and producing adaptation to some conditions. Your GP should be able to refer you to the necessary specialist, usually an ear/nose/throat specialist.

There are practical steps you can take to lessen many hearing problems:

- Avoid noisy environments where possible
- Tell others of your difficulty
- Use gentle music to cover constant noise caused by tinnitus
- Try to sleep well and avoid stressful situations
- Cut down on salt if your problem involves fluid pressure in the ear
- Stop using drugs such as coffee, cigarettes and alcohol.

Dizziness

We have all experienced dizziness – dim vision, the room begins to spin and there may be slight nausea. It is also a very common occurrence after a brain injury.

People who say they feel 'dizzy' are usually referring to a sensation of turning round or whirling. Alternatively, dizziness may be used to describe a swaying sensation, or a feeling of weakness, faintness, light-headedness or unsteadiness. Occasionally, some people say they have blurred vision, feelings of unreality, faints, blackouts or even epileptic fits. Dizziness is a very common complaint after acquiring a brain injury for a number of reasons:

- Brain stem damage
- Double vision
- Blood pressure fluctuations from damage to areas that control heart / blood flow
- Damaged areas of the cerebellum may lead to light-headedness or imbalance
- Vertigo from damage to the inner ear.

The vestibular system

The vestibular system is the remarkably sensitive system which is responsible for our sense of motion. It helps to keep your balance and focus your eyes in response to motion. It is also easily disrupted, both by disease processes and trauma. Although dizziness, nausea and vertigo are very common after a brain injury, they are completely missed or ignored in many cases. They can impose an extreme additional burden upon an injured brain. The profound challenges that come with any sense of motion may leave people with vestibular problems, literally unable to move without severe problems.

Diagnosis

There is a difference between dizziness and vertigo. Vertigo is triggered by the head moving in different ways that suddenly make the room seem to spin. Dizziness stems from light-headedness or a sense of imbalance and it will feel as if you are spinning, not the room. It is often worse in the morning hours.

A doctor should be able to diagnose the



cause of your dizziness by checking your ears and nervous system, taking your medical history, a blood pressure check and a possible referral to other medical specialists. In some cases brain scans or electrical recordings of the brain may be required to make the diagnosis.

Treatment

There are many medications available from over the counter motion sickness tablets to prescription only medications. Therapy can treat balance and spatial problems with exercises that can make the vestibular system adapt to problematic movements. These may include balance activities or eye movement exercises to help maximise the use of remaining vestibular function, sight, and sensation in the feet. Some may find that acupuncture can lessen dizziness by using certain pressure points to diminish

an attack.

Some useful tips are:

- Don't use alcohol or other drugs
- Get out of bed slowly in the morning
- Stop the moment dizziness starts and sit or lie down until it passes
- Avoid or reduce problematic movements, or change your environment
- Sleep without a pillow to keep your neck and backbone perfectly straight
- Cut down on salt as this can increase the sensation of vertigo
- Try to pinpoint times or conditions where you are more likely to get dizzy.

The good news is that dizziness is often only a short-term problem after a brain injury. Suitable and timely treatment can often lead to attenuation of symptoms.

Anosmia – loss of sense of smell

Traumatic Brain Injury often damages the part of our brain responsible for olfaction — our sense of smell.

Of the five senses, smell is often considered to rank fourth in importance for humans. Taste, considered the fifth sense, is mostly the smell of food in the mouth. The sense of smell originates from the olfactory nerves 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 taste and smell which is called anosmia.

Why does it happen?

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

Will it go away?

If the sensory cortex has been bruised, a gradual recovery of sensation may be possible. One study of 66 subjects showed that 36% improved slightly, 45% had no change, and 18% worsened. The presence of odour distortions, however, (including phantom odours) decreased over time.

Weight loss or gain

Our sense of food flavour is a mixture of both smell and taste perception. Since the ability to taste and enjoy food and drink depends on our sense of smell, anosmia often leads to reduced appetite and weight loss. In some patients it leads to weight gain, because they eat food with a high salt and fat content to gain any enjoyment. Approximately 30% of patients with anosmia know they have lost their sense of smell and taste before being tested by the doctor.

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 it may even be due to the effects of medications.

What can I do?

Find ways to make eating fun again. The texture of different foods becomes very important, particularly how you combine them. Mix half-cooked vegetables with cooked ones for a texture comparison. Eat a hot meal with a cold salad for different temperature experiences. Try spicy food from Eastern cuisines that cause sensations on the tongue.

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

If you have lost your sense of smell you may need to take some extra steps to become safety conscious. Install plenty of smoke detectors if you can't smell smoke in the house. Switch to electricity instead of gas. Read labels carefully in case you are using strong chemicals that need ventilation.



PANIC ATTACKS

PANIC ATTACKS ARE A POSSIBLE OUTCOME IF A PERSON EXPERIENCES HIGHER LEVELS OF ANXIETY.

A small number of these people will go on to develop panic disorder, whereby panic attacks are intense and occur frequently. If left untreated, panic disorder can be a debilitating condition, severely restricting the quality of life of the sufferer.

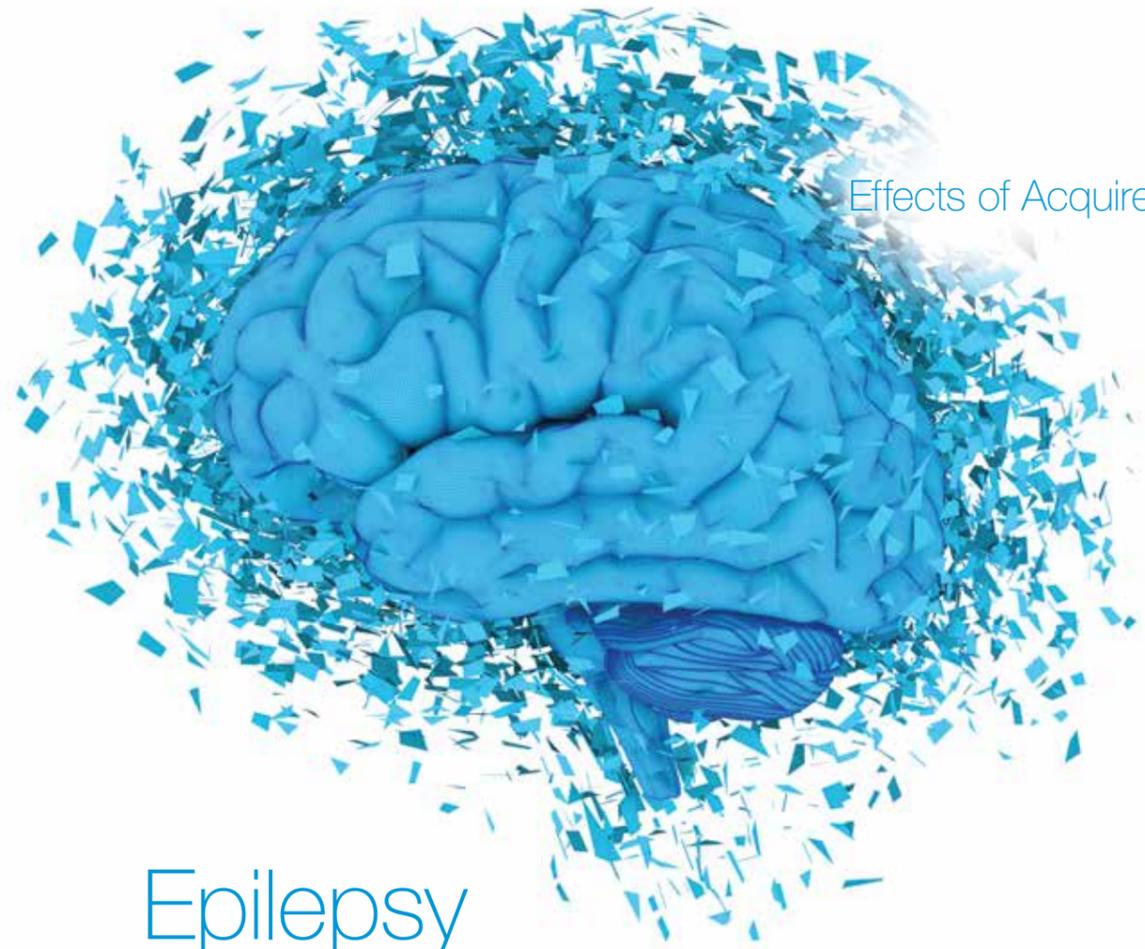
Panic attacks can occur at any time, repeatedly, and without warning. Mostly they last for a few minutes, but on occasion may last for an hour or more. In between attacks the sufferer often feels intense anxiety, worrying when and where the next attack will occur. Panic attacks are often accompanied by the unpleasant physical symptoms of anxiety including heart palpitations, hyperventilation, muscle pain, dizziness and sweating, along with the fear that the attack will lead to death or a total loss of control.

Why panic attacks occur

Panic attacks are just extreme versions of normal bodily responses to danger. Adrenaline being released into the blood stream causes the heart to beat faster and the breathing rate to increase in order to supply major muscles with more oxygen.

Treatments

There are a number of treatments for panic attacks with research showing cognitive behavioural therapy to be best practice. Some people choose to combine a number of treatment options. These can include cognitive behavioural therapy (CBT), medication, complementary therapies (herbs, vitamins and homeopathy), exercise and relaxation techniques. For more information, visit synapse.org.au for a fact sheet on Panic Attacks.



Epilepsy

Epilepsy is a chronic condition in which seizures are produced by temporary changes in the electrical function of the brain.

Seizures affect awareness, movement or sensation. Before a seizure some may get a feeling of unease called an aura. With medication, many patients with epilepsy who are otherwise healthy are able to live full and productive lives. Some patients' lives, however, are devastated by frequent, uncontrollable seizures or associated disabilities. Not everyone who experiences a seizure is diagnosed with epilepsy. Epilepsy is a long-term, ongoing, chronic disorder that causes repeated seizures if it is not treated. It may contribute to, or even cause, brain injury but may also develop after a brain injury.

There are two major types of seizures. The first type, a general seizure, begins on both sides of the brain. Full convulsions or brief staring episodes are often the result. The second type, known as a partial seizure, originates in one region of the brain. In a simple partial seizure, the seizure related brain messages remain localised so that one experiences a feeling, sensation, movement, or other symptom without any change in the level of awareness. Some may suddenly become confused, fumble, wander or

repeat inappropriate words or phrases.

Treatment

For most cases of epilepsy there is no complete cure, however anticonvulsant medications are the most common treatment. Used correctly they can be very effective in treating seizures.

Keep track of the frequency of your seizures and notify the doctor or nurse of medication side effects in case the medication needs adjusting. Surgery may be used to remove damaged regions of the brain but is generally not performed unless treatment with medication has failed.

If someone else has a seizure

For a grand mal seizure (convulsion) try to safely get the person laying down on one side. Place something soft under the head. Loosen tight clothing. Do not restrain the arms or legs. Do not put anything into the mouth. Be very careful whilst doing this, as the person may be moving erratically and could unintentionally cause you harm. The seizure itself should only last a few minutes.

Afterwards the person may be very sleepy and confused and should be talked to in a calm and quiet manner. If a person has a partial seizure (petit mal), stay with them, talk calmly, and protect them from self-injury. Do not restrain them. They may be able to respond to simple commands such as "sit down". After the seizure explain where you are and what has happened.

Living with epilepsy

Having to cope with epilepsy as well as other problems from a brain injury is not easy. But there are steps you can take to have some control over the situation:

- Take your medication on time and avoid alcohol, coffee and other stimulants
- Sleep well and minimise stress
- Avoid conditions that trigger seizures
- Wear a Medic-Alert bracelet
- Get medical advice before driving.

Inform your family and friends openly about epilepsy. They will feel more comfortable around you and be able to assist if you have a seizure.

Sensory and perceptual skills

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

The parietal and occipital lobes of the brain integrate the input from different senses. For example, the senses involved in recognising an apple may include touch (firm, spongy and smooth), sight (red or green, round, spotty, large etc.), sound (crunching and chewing), smell (fresh or rotting) and taste (a granny smith versus a red delicious, sweet or tangy).

The effects of brain injury may involve a range of sensory and perceptual problems which are often described according to the sensory perceptual system involved. These systems include:

- Auditory (perception of sounds)
- Visual (perception of colour, shape, size, depth and distance)
- Tactile (the perception of touch relating to pain, pressure and temperature)
- Olfactory (perception of smells)
- Gustatory (perception of taste).

A closer look at visuo-spatial skills

While deficits may occur within each sensory system, the area of visuo-spatial is often more dramatic. Visuo-spatial deficits may include difficulties in the following areas:

- Drawing or copying objects
- Recognising objects (agnosia)
- Telling left from right
- Doing 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.

People may experience selective difficulties or several deficits depending upon the nature of their injury. One well

known syndrome involves neglect: The person fails to notice certain aspects on one side of the world in front of them, most typically the left hand side. For example, a person with neglect may fail to notice food on the left side of a plate or fail to copy aspects on the left side of a picture.

Management of visuo-spatial deficits

The presence of neglect may be undiagnosed despite significant safety issues. People with neglect are often unaware of their problems and tend to use other explanations for the mistakes caused by the neglect. A key component of rehabilitation is therefore to educate the person and increase their awareness of the impact of the perceptual deficit in everyday living. Further components to a program for managing visuo-spatial problems may include retraining skills, changing the environment, changing expectations, or compensatory strategies.

Retraining skills

One approach involves retraining until the person regains, in varying degrees, the functional skill. Retraining typically involves repetitive and intensive exercises for a specific skill or task e.g. practise at drawing an object while receiving feedback. This approach tends to be more effective with specific skills.

Changing the environment or expectations

A second approach involves modifying the environment to provide more support or reduce the demands of a particular skill. One example may involve building a ramp or fitting a handrail for a person who finds it difficult to climb a flight of stairs to their house. Sometimes, the change

in the environment can be as simple as shifting furniture to ensure greater space when walking around the house. The person may also learn to adjust their expectations and educate other people about their difficulties.

Compensatory strategies

People often learn or may be taught a range of strategies to compensate for visuo-spatial problems. These strategies may be something like a person learning to turn their head or body to scan their environment, or moving objects into their ideal position. A range of specialised technology or equipment may also be available to fit into a person's home or assist with community access. Some external prompts may include colour stickers for object recognition, bright lights on the floor, musical or sound prompts, hand rails, and other safety devices. An example of a compensatory approach for object recognition involves the person learning to rely more upon other senses such as touch, hearing and smell. They may choose to shut their eyes to avoid inconsistent information from the visual system. The rehabilitation strategies described may be developed by a neuropsychologist, occupational therapist or physiotherapist. The eventual goal of a rehabilitation program is often greater independence and use of self-management strategies. Family members, friends and support workers can provide valuable support and reinforcement of rehabilitation techniques also.



Visual disorders

A brain injury can easily disrupt the sophisticated complex subsystems involving the flow and processing of information that allow us to see the world around us.

A brain injury can lead to focusing problems, eye muscle coordination deficits, changes in eyeglass prescription, and peripheral vision changes. The type and extent of any visual problem depends on the severity and location of the injury. Even when visual problems are diagnosed there is often little vision rehabilitation offered. Some symptoms to look for are:

- Headaches from visual tasks
- Blurred or double vision
- Sensitivity to light
- Inability to concentrate or focus
- Reading or comprehension difficulties
- Trouble judging distances
- Sore eyes
- Loss of visual field.

If you find it difficult to process visual information you may be straining without realising it. A general sense of fatigue can arise from visual problems.

Causes

Trauma, stroke and other Acquired Brain Injuries (ABI) can cause damage to parts of the brain responsible for visual information processing. Even if the head does not hit anything, whiplash can cause injury to the brain. Trauma may injure arteries, stretch nerves or damage the vertebral column itself. It can also create soft tissue damage that may cause eye muscle coordination problems.

Common visual problems

Dry eyes

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

Double vision

This condition may cause confusion and disorientation. People experiencing this are often given an eye patch, although this reduces the field of vision and can



interfere with daily function. Double vision can often be prevented without an eye patch, through the use of prisms and vision therapy.

Loss of visual field

This loss can occur in any part of the visual field and is a common visual affect following ABI. One example is loss of half of the field of vision in each eye. People can frequently bump into objects, and easily trip or fall over objects. They may be afraid of leaving home and have difficulty reading. Therapy can assist with object detection and encourage constant scanning to compensate.

Reading difficulties

These may arise from blurred or double vision, jerky eye movements, or visual field loss. Treatment can involve aids such as prisms or using a typoscope to focus on individual sentences. After injury, it can be hard to focus on a page due to nerve damage that affects the eye's refocusing. Bifocal glasses can sometimes compensate.

Low vision

Following a brain injury some people have a normal field of view but can't read print or watch television with conventional

glasses because of low vision. Low vision aids include telescopic lenses for distance vision and a range of magnifying aids for reading and other fine tasks.

Photosensitivity

Light sensitivity varies from person to person. Some have no trouble but others may find bright light painful. Solutions may include tinted eye wear, or amber filters.

Hallucinations

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

Impaired visual memory

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

Vision rehabilitation

After a brain injury, some people experience a natural recovery within six months. Recovery can be assisted by using the necessary prescription lenses, and speaking with your rehabilitation specialist.

Self-centredness

In some cases people with a brain injury can appear to become very self-centred and display the egocentricity more normally associated with a young child or teenager.

Individuals may 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.

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

Why does it happen?

Although we take it for granted, the ability to view the world from someone else's point of view is a very complex cognitive skill. This is just one of many sophisticated mental skills that occur in the frontal lobes of the brain. Unfortunately this is a very common area to be affected in a Traumatic Brain Injury. This is why self-centredness frequently goes hand in hand with lack of self awareness, anger, depression, fatigue and reduced social skills. It is no wonder that families are often brought to breaking point in the months after the injury.

Impact on the family

Families are usually overjoyed when their loved one survives the initial trauma of an Acquired Brain Injury (ABI). Following discharge, a relieved family will often 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.

As the months and years go by, families understandably become frustrated if none of their sacrifices are acknowledged. Some are even criticised by their loved ones for not being supportive enough. Friends will be even less likely to tolerate self-centredness meaning the

family is usually left as the only social network available.

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

What the family can do

Often the hardest part for a family is accepting that the self-centredness is not always going to go away. Some say that understanding that the brain injury has caused the self-centredness eventually brings them to a point where they can accept the changes and enact strategies to manage the situations that arise.

Sometimes the family unwittingly contributes to the problem. The family may wish to cater to all of the individual's needs following the injury, in the hopes of assisting with recovery. The individual with the ABI may then become dependent on this treatment. Families need to be very firm in setting boundaries, and realise that they must look after their own needs as well as their loved one's needs.

Understand that your loved one may no longer be able to be concerned about your rights and needs. Instead of feeling

hurt try to be assertive about what you require.

Sometimes following a brain injury the family can also feel that they are being manipulated by the individual with the ABI. If the individual's demands aren't met they may try various strategies to get what they want such as threats, pleading, criticising lack of compassion, or forced silences. Family members are often surprised that their loved one's skills in this area are so effective when their overall social skills have often dropped significantly. In these cases it is vital for the family to have agreed boundaries for positive behaviour, and for all family members to respond accordingly.

If there is a support group for survivors of brain injury it may help for the person with ABI and their family to attend. Sometimes seeing similar behaviours and attitudes in others can bring about some level of self-awareness in the individual, and understanding in the family.

Another possible way to increase a person's awareness of their behaviours can be through therapeutic sessions with a neuropsychologist. If an assessment indicates the person could benefit from therapy, the neuropsychologist can gradually build rapport then explore and challenge their beliefs and behaviours. With time this can gradually increase a person's awareness and insight into how their behaviour impacts on others.

SOME STRESS MANAGEMENT STRATEGIES

Visualisation

Use your imagination (e.g. pleasant daydreams or memories) to will yourself into a relaxed state. Start by getting comfortable, scanning your body for tension, and relaxing the muscles. Select a favourite place which is real or imagined.

Focus your imagination using all five senses, then use affirmations such as repeating 'I am letting go of tension'; or 'I am feeling peaceful'.

Practice using visualisation three times a day for a few minutes or longer. Eventually, with practice you can use visualisation in everyday situations when feeling uptight.

Slow breathing techniques

Proper breathing habits are essential for good mental and physical health. First, a person needs to focus upon their breathing pattern. They need to identify whether they breathe mainly through the chest or through their stomach. Short, shallow and rapid breaths from the upper chest should be avoided. The aim is to breathe deeply and slowly through the nose.

A person should feel greater movement in the stomach than the chest as they inhale and exhale. Practice breathing exercises everyday. Learn to apply slow breathing as needed e.g. when feeling stressed, angry or anxious.

Progressive muscle relaxation

A person learns to identify muscle groups and the difference between tension and relaxation in the muscles. This can often assist as relaxing muscles can reduce tension related to stress.

Focus upon 4 main muscle groups:

- 1 Thighs, buttocks, calves and feet.
- 2 Hands, forearms and biceps
- 3 Chest, stomach and lower back
- 4 Head, face, throat and shoulders

Therapists will suggest to start at the feet, and work your way up to the top. Tense muscles for 5-7 seconds and relax for 10-15 seconds.

Note the physical, mental and behavioural signs of stress each time and try different strategies to see which works best for you.

Stress

Stress is part of everyday life and a natural reaction in adjusting to major life changes.

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

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

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

Stress exacerbated by ABI

In the vast majority of cases people find it much harder to deal with stress after a brain injury. Coping with stress uses many different cognitive functions such as: recognising the symptoms; identifying causes; formulating a coping strategy; maintaining control of emotions appropriately; and remembering each of these techniques. A brain injury can dramatically affect these cognitive functions resulting in very little ability to cope with the normal stresses of everyday life. Family members can find this hard to realise and believe a person is simply 'whingeing', being over-emotional or immature.

Understanding and Managing Stress

The first step a person can take to reduce stress is to become aware of the major sources of stress that exist in their life. The person may like to keep a stress awareness diary for a few weeks that lists the date, time, event, severity, symptoms,

and coping strategies they 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 to view it more clearly and objectively.

Useful Skills

To develop skills to manage stress focus on the following three things: Awareness, Acceptance, and Coping. Some may be more useful in certain situations. Each skill may be explained better using a situation which people are often faced with after brain injury. Let us use the example of a person who is stressed because they have an appointment.

Awareness skills

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

Example: The person can find out what a appointment involves and the purpose of the appointment.

Acceptance skills

Acknowledging the stress and being realistic about how it affects a person's lifestyle e.g. what aspects are controllable/uncontrollable or important/unimportant.

Example: Recognise that the appointment needs to be conducted and that it will probably be quite tiring and demanding.

Coping skills

Prepare to cope with the stressful situation by learning various strategies. Identify what changes a person can make to control the situation and reduce stress levels.

Example: Using Self-Talk to develop a helpful outlook towards the appointment and writing down points if forgetfulness is a worry.

Headaches and other pains

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

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

Causes of headaches

The brain itself is not a source of pain.

Headaches arise from problems with a number of different structures both inside and outside the head. Those inside the head can be the dura, the venous sinuses, blood vessels and cranial nerves. Those outside the head can be the skin, muscles, nerves, arteries, joint capsules, cavities within the head, nerves and the periosteum.

A post-traumatic headache is only a

symptom of an underlying disorder. Often a doctor may make this diagnosis, and no further investigation is made of the problems causing the pain. The headache may be treated as a neurovascular or migraine headache, when the great majority are not primarily migraine-type problems. There are different types of injuries that may create the pain generators of headache. Ideally your

doctor should ask you questions about the injury.

Major types of headaches

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

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

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

Tension headaches are reported by most people to feel like a diffuse vice-like pressure throughout the head. An attack can last from 30 minutes to a week. Tension type headache may be chronic or episodic depending on frequency. There appear to be two types - one with

migraine features fairly responsive to anti-migraine medications, the other without such features.

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

Migraine headache can last from four hours to three days. They have perhaps the clearest diagnosis of any of the categories of headache, using the acronym **POUNDing**: **P**ulsating headache for between 4 and 72 h**O**urs, **U**nilateral (one-sided), **N**auseating and **D**isabling. Treatment should include reduction of triggers such as stress, foods that may elicit an allergic reaction, sleep inconsistency, and other allergies. Hormonal fluxes can also cause migraines, and hormone replacement therapy has been effective at controlling migraines in many cases. The most effective control is often awareness — people who are susceptible to migraines often have an “aura” that signals the approach of a migraine, and may be able to prevent it by immediately stopping stressful activities and/or taking pain-killers.

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

There are many other types of headaches which can be diagnosed with tests such as MRI scans of the brain, X-rays and magnetic resonance angiography.

Other types of pain

Apart from headaches, there are numerous other sources of potential pain after a brain injury, such as abscesses, skin sores, cervical or spine injuries, fractures, heterotopic ossification (bony overgrowth), kidney stones, bladder infections, spasticity and constipation. There are two kinds of pain—acute and chronic. Acute pain is relatively short in

duration. It has a readily seen cause and reduces with treatment. On the other hand, chronic pain lasts beyond the expected duration and it may continue beyond the physical healing of the body region involved.

Pain and rehabilitation

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

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

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

Medication

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

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

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



Always speak with your doctor about possible courses of action, however, and make sure to research emerging therapies.

SUICIDE AND ACQUIRED BRAIN INJURY

DEPRESSION IS VERY COMMON AT DIFFERENT STAGES OF THE RECOVERY PROCESS AND SUICIDE CAN OFTEN BE A RISK.

Families and carers are often well placed to be able to look out for the first signs of potential suicidal tendencies. There is often a gradual lead up to suicide, with a typical process involving planning, organising the means then enacting.

Some possible warning signs can be: the person becoming withdrawn and very depressed; expressing a desire to die and talking about suicide; or even suddenly becoming very cheerful or tidying up affairs, such as paying bills or saying goodbye to old friends. These can all indicate an individual may have made a decision to suicide.

A vital way to combat this is to let the person know that others do care about them. This may involve just spending time with the person even if no talking occurs, or arranging for others to spend time with them. Listening can play a strong part in prevention too. It is tempting to tell the person why they shouldn't kill themselves and give advice, when simply listening to how they feel can help much more.

Depression can respond well to medication so make sure the person is in touch with their GP about the depressive episode.

When there is a high risk of suicide, there are different strategies that can assist, including counselling, referral to a psychiatrist, medication, a hospital stay and case management. For more information, go to synapse.org.au for the fact sheet Suicide and brain injury.

CHRONIC PAIN SYNDROME

CHRONIC PAIN CAN LEAD TO DEPRESSION, ANGER AND ANXIETY DISORDERS AS SUFFERERS MAY HAVE MANY OTHER NEGATIVE EVENTS AND STRESSORS TO DEAL WITH.

With chronic pain, people may feel the pain is increasing even though there is no medical evidence for this. In these cases other factors are at play including:

- Emotional functioning
- Personality traits
- Past learning experiences
- The way others respond to the person's behaviour.

Sleep and appetite disturbances can 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 person 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 can lose patience with the person with persistent pain who may appear 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 person do not make this the goal, frustration will grow, resulting in failure to coordinate treatment efforts in a successful manner. Reasonable outcomes would include:

- Decreased medication use
- Fewer physician visits
- Fewer hospitalisations
- Improved flexibility and endurance
- Increased strength
- Improved functioning at home
- Improved social interaction
- Return to employment.

Research has shown that having realistic, helpful thoughts is an important part of pain management. Cognitive behavioural psychologists can help chronic pain sufferers to change their negative thoughts about their pain, its effects, and other sources of stress.

One approach that views pain as a learned behaviour is administered 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 neurofeedback.

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 Brain Injury Association to get the contact details in your State.

Changes in relationships

The impact of a brain injury has often been likened to throwing a pebble in a pond, the effects go far beyond just the person who has acquired the injury, including partners, friends, family, carers and work colleagues.

The issues and needs of partners and family members will vary according to the stages of the recovery process. Each stage will bring its own joys, challenges, hopes and needs. Old coping methods may remain helpful for some; for others, new methods will need to be developed.

Resentment, anger, despair, grief and numbness may be emotions encountered. Your task in the process of recovery is to sort out what you are feeling, and seek out help and support for yourself.

Acute stage

In the acute stage, the physical trauma to your loved one is often life threatening. No one wants to leave the hospital; everyone's focus is on the patient.

Your focus at this time is on your loved one who has been injured; your own needs right now hardly seem to matter. Your friends often want to help; this is the time to let them. The rest of your "outside-of-the-hospital" life still needs tending to, and your friends can relieve that worry by taking care of the house, children, car pooling, shopping, and so forth. Beyond attending to day-to-day tasks, some may want to offer emotional support as well. You may have conflicting feelings about this. Your good friends will understand and be there for your needs, whatever they are. You might find it helpful to name one or two of them as coordinators. They can return phone calls for you, offer apologies and thanks to others, and do whatever else needs to be done.

Post-acute stage

In the post-acute stage, the patient is medically safe and has been moved to a rehabilitation centre. At this point, you can relax a bit and start to put order back into your world outside of the hospital. Part of this may include offering multiple thank you's to your friends. You may feel



exhausted and out-of-sorts. This is part of the natural letdown of the initial trauma. This can be a time when you realise that you have been (and are) tired and worried. You may not feel like talking to, or being with, your friends right now. You may be preoccupied by your own concerns. You may not want to talk constantly about the injury and burden your friends, but you may not really want to talk about anything else, either.

You may want to be with your friends – but then won't want to. This is a perfectly natural reaction even if it feels disconcerting to you. Ask your friends for their patience and grant yourself the same. You may find more comfort being with other families in the rehabilitation unit who are going through what you are, than being with your old friends. Take advantage of the support if it is what you need.

Community re-entry stage

In the community re-entry phase, the person with a brain injury moves back into family life and begins to renegotiate his or her social world. You, as care giver, begin to redefine your world as well.

When a loved one returns home, everything initially readjusts around that person. Your friendship needs will often change again. You may find it difficult to leave your loved one and go out. You may want a friend or two to visit, but even that may feel like it is too much, because of the extra work that now goes on in your world.

Some friends may be comfortable with what has happened, and with the difference they observe in your loved one – and perhaps in you.

One of the first ways to address their fears or discomforts may be to educate these

friends about the injury. With information, they can become more comfortable with the situation.

Many at this stage will themselves feeling anger and resentment at friends' happiness. You may feel isolated, with no way to share these feelings with old friends. You may wish to seek out support groups of other caregivers, who are feeling just as you are; these groups can provide a good social support. Contact your local Brain Injury Association for information on how to access these. Above all, remember that it is time now to give your own needs priority. You do need to go out, to take time for yourself.

In the long-term

Family

One of the common issues that families face is their son or daughter with an injury returning to the family home despite having lived away from home prior to the injury. For the person with the injury this can represent a huge loss of independence and self-reliance. For the family, they now have someone who is either fully dependent or semi-independent. Family members' lives can change significantly. Their future

plans may be put on hold to take care of their loved one. They often have to cope with dramatic personality and behavioural changes. Some of the most distressing changes can involve aggression, rapid changes in mood, self-centredness, impulsivity, sexual and social disinhibition, poor motivation and lack of empathy. Friends of the family often distance themselves over time and can become quite bitter unless they have a good understanding about why this behaviour occurs.

Partners

The rate of marital and relationship breakdown is very high following Acquired Brain Injury. The pressures on a spouse or partner can be immense. They may have to take over the running of the house, become the sole wage earner, increase or decrease their hours of work, make most of the decisions and provide support to the person with the injury. Finances may become a major concern due to medical bills and loss of income. A change in the sexual relationship of a couple can also be a very distressing and sensitive issue. These changes can also involve either a reduced sexual drive (hyposexuality) or increased sexual drive (hypersexuality).

Children

The person with the injury may have had children before or after their accident or illness. From a child's point of view it can be more difficult to have known their parent before the injury. In this situation the child has to come to terms with why their parent has changed so dramatically after coming home from hospital. After the accident it can be extremely difficult for a child to understand why their parent needs care, walks or talks strangely, never remembers anything, gets upset so easily and why they no longer want to play with them.

Children may display increased acting-out behaviours, emotional problems, or relationship difficulties. Negative parenting such as yelling, ignoring or being impatient by both injured and uninjured parents is reported in most families. Most families report substantial breakdowns in relationships between children and their injured parent when it is the father who is injured. Most non-injured parents report substantial depression, which correlated significantly with negative behaviour in children.

Friends

A very common statement made by people with Acquired Brain Injury is 'you find out who your real friends are' after the injury. Unfortunately, friends can disappear at the time when the person most needs their support. It is also common for people who have spent a long time in hospital to feel that they have missed out on a lot of experiences with their friends and that they now have trouble relating to their friends and sharing their interests.

Supportive friends learn to adjust their expectations of the person with the injury and seek new activities for spending time together e.g. watching a game of sport instead of going to a nightclub. Alternatively, the person may wish to meet other people with a brain injury by joining a specialised group rehabilitation program or a less structured brain injury social group.

Issues for carers and family

Carers can often feel that their life is not their own. They have very little time alone to pursue their own interests and social life, and carers often have to do everything around the house.

Prior to the injury they may have relied upon their loved one's support for everyday chores, but now the workload increases and there is often reduced support to help the carer cope.

Carers may have difficulties accessing therapy for intensive rehabilitation and even act as case managers to ensure that their loved one receives much needed care.

Personality and behavioural changes

Families may be confronted with child-like behaviour, self-centredness, tactlessness, reduced emotional sensitivity and lack of gratitude. The person with a brain injury may show marked changes in their social skills and self-care. Impaired executive functioning may be displayed in a number of ways including impulsivity, verbal and physical aggression, alcohol and drug abuse, poor stress tolerance, and a lack of mental flexibility. Common emotional difficulties such as depression and anxiety may lead to challenging behaviours such as withdrawal and avoidance. Increased dependency may also lead to increasing demands for attention from caregivers.

When self-awareness has been affected, this places further stress on family as the loved one may refuse to believe they are acting inappropriately and may respond angrily to feedback.

Lack of understanding

People who are somewhat distanced from the person with the injury often have little understanding of what they are going through. The person with the injury may be able to act 'normally' for short periods in front of visitors or publicly, so that many won't believe the difficult home situation as described by the family. Rather than offer support, friends or members of the extended family may make judgements about how a person cares for their relative.

Emotions

All carers respond to the demands of caring for their loved one in their own way. Feelings are always individual and everyone will react differently. Some of the feelings that carers often say that they experience are feeling overwhelmed, confused and shocked by the diagnosis of brain injury, or realising the changes that caring will bring into their lives.

Given the many ways a brain injury can impact on a family, it is not surprising that carers will encounter a wide range of emotions. There are no right or wrong feelings. These feelings are a natural and normal reaction to caring.

Guilt can be a common feeling. Carers may feel responsible for the brain injury occurring, not wanting to be a carer, losing their temper or being embarrassed by the person being cared for. Carers should not feel guilty about taking a break from caring or placing the person in residential care.

Anger can arise when someone is the sole carer or others in the family don't do their fair share. They may become frustrated with the person they are caring for if they regularly face challenging behaviours, angry outbursts, or self-centredness.

Resentment can arise from lack of support when friends don't make contact any more, support services don't provide enough help, and the focus always is on the person with the brain injury.

Concerns about the future can result in **fear**, wondering how well the loved one will recover, what will happen if you don't cope or who will take up the caring role if you can no longer do so.

Caring can mean being cut off from others and facing high **stress** over a very long period of time. Carers are very vulnerable



to stress because of the demands of caring.

Sometimes being a carer can feel like an endless grind and result in **depressive symptoms**. You may find you are sleeping too much, or waking early or during the night. You might feel worthless or agitated most of the time, and have difficulty making decisions.

Family members also experience **grief**, often feeling they have lost their loved one but being unable to say **goodbye**. For some, the caring duties have overwhelmed their life to the point they feel they have also lost their former lifestyle.

Stress

It is typically the day-to-day stresses which take a greater toll on a person's physical and mental health. When people experience a major life change, they are more likely to recognise the need for support and use various coping strategies. Carers may initially seek support after the brain injury has occurred, but often they don't seek help years down the track as the day-to-day stress of caring can gradually wear them down.

Physical signs of stress may include a lowered immune system, breathing difficulties, fatigue, sleep disturbance and muscular tension. Carers may also find themselves feeling out of touch with reality, forgetful, or not looking after themselves.

MAJOR ISSUES FOR COUPLES

BOTH MEN AND WOMEN WITH BRAIN INJURIES FIND THE LOSS OF AUTONOMY AND INDEPENDENCE IS THEIR BIGGEST PROBLEM, AND BOTH MENTION PERSONALITY CHANGES AND MEMORY DEFICITS AS SIGNIFICANT.

Among married couples, wives identify their personality changes and cognitive deficits in their husband with a brain injury as primary problems.

Husbands, by contrast, place loss of autonomy and mood swings in wives with a brain injury at the top of their lists. Families in which husbands had sustained brain injuries place higher importance on job loss and income change than do families in which wives were injured. Women with brain injuries and non-disabled wives value support groups and other emotional support methods as coping strategies, whereas the men stressed problem-focused and goal-orientated strategies.

People with a brain injury who experience higher ratings of cognitive and social dysfunction are more likely to be depressed and anxious. Non-injured spouses also show increased anxiety and depression, with wives more affected than husbands.

Domestic violence

Challenging behaviours after a brain injury may lead to domestic violence in families.

It is possible that people with an Acquired Brain Injury (ABI) may develop behaviours that lead to domestic violence. Many of us were raised to believe that we should stand by our family members no matter what. This stance is put to the test when threatened or actual violence occurs. Choosing to ignore the behaviour can mean your family member does not get constructive feedback on the negative behaviour - which can lead to a cycle of violence.

One of the most aggravating things a family can experience is that the person with Acquired Brain Injury can be the picture of politeness when speaking to the rehabilitation nurse or a visitor. There are different explanations for this, that may not make challenging behaviour or aggression easier to tolerate, but they do provide a framework for understanding.

Reasons for violent behaviour

We all tend to let our hair down with family, as opposed to strangers or acquaintances. Of course, after a brain injury a person's interpretation of letting their hair down may be well beyond what most would consider acceptable, particularly if their self-awareness has been affected. They may justify their violence by saying that others provoked them, not realising that the brain injury has increased their sensitivity to stress and decreased their ability to handle it.

The frontal lobe is often damaged in brain injury. This area of the brain is involved in reasoning, problem solving and controlling our more basic instincts such as anger. A person who has sustained a brain injury has often lost these skills and therefore may have trouble controlling anger and violent outbursts. In many cases individuals with ABI often lose some of their social judgement capabilities.

Overall, a family's patience can be quite worn after months of care. What makes matters worse is that the individual with ABI may have little insight into their impact on the family.

The following are some examples of abuse a family may encounter:

- Grandfather yells constantly at his niece he adored prior to his accident
- The husband constantly accuses his wife of having an affair
- A husband hits his wife the moment she doesn't agree with him on an issue.

Management techniques

Do not allow a pattern of family abuse to become established in your home. You will need to make some allowances for changes brought on by a brain injury but continued abuse and violence is not acceptable. When the person still retains self-awareness, they will need to relearn communication skills, anger management, and relaxation techniques to manage their anger and tendencies towards violence.

Unfortunately there will be cases where a lack of self-awareness means that a person cannot relearn these skills. In these cases, it is necessary to develop a behaviour management program to minimise or prevent violent outbursts.

Do not take the abuse personally – this will only interfere with your ability to implement effective behaviour management. It pays to look at what the triggers were in each case, however, and see if these can be minimised.

Treat each occurrence as an isolated incident. A person with a brain injury may not remember their abusive outburst yesterday.

Try to find out what the triggers were and minimise these in future where possible.

Keep in contact with your support systems – you need to have people with whom you can discuss problems of family abuse.

Have a family meeting whereby all members are trained to treat family abuse in a consistent manner to keep the person from learning to use family abuse as a method of manipulation.

Join a support group in your area so that you can find out how others have handled this problem. Do not allow yourself to live in a 'reign of terror'. If problems persist, you may need to consider professional support with a program geared at behavioural management. Your local Brain Injury Association may be able to refer you to specialists in this area.

The last resort

Your State Brain Injury Association should be able to link you with services who can advise you on legalities, emergency accommodation and restraining orders.



Self-care strategies

Carers and family members often find themselves at the breaking point. Use these strategies to spoil yourself and make sure you care for yourself as well.

A carer needs to be aware of the cumulative effects of daily stressors and use strategies to reduce the impact of stress. Too much stress can have a negative impact on health, so carers (like everyone else) need to maintain regular exercise, a balanced diet, regular sleep and rest and relaxation. Other useful strategies to work on include problem-solving on major issues, investigating and altering irrational beliefs, stress-reducing self-talk and meditation.

Dealing with stress

A balanced life can go a long way to reducing stress. To last the long haul, carers need to balance their needs along with those of their loved one, developing a lifestyle that balances caring with family, hobbies, socialising and work. Time management, goal setting and

organisation can help to reduce stressors, create time for enjoyable activities and maintain social support.

Respite care

Long-term carers find that surviving is a matter of taking time out for themselves. Respite care is an essential part of the overall support that families often 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.

Dealing with 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. There is a reason you are feeling this way, and this will lessen when your body is ready.

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.

Always seek professional assistance if you feel you can't get past these issues.

Reasonable expectations of yourself

Avoid the superhero attitude! You may try to undertake all the caring whilst being a model of patience, courage, understanding and support and sacrificing



yourself in the process. Be prepared for times when you feel like quitting, yelling, leaving and breaking down. The caring role is similar to running a marathon – you need to pace yourself for the long haul. Trying too hard in the early stages may mean you lose all your energy further down the track when your caring may be more crucial.

Support groups

Why join a support group? You can meet others in a similar position, have a break, get information and get support from others who have a shared experience.

Sharing ideas, feelings, worries, information and problems can help you feel less isolated. Sometimes family and friends don't understand the condition of the person you are caring for. People in the support group will often understand.

Support groups bring together carers in local areas, sometimes under the guidance of a facilitator who is experienced in supporting carers. Often other carers or workers are invited to present information and training. Your Brain Injury Association can help put you in touch with carer support groups in your area.

Counselling

Counselling involves talking to someone who understands and can work with you to give you the encouragement, support and ideas to improve your situation. It can be a way to assist with the many changes in your relationships and roles, as well as dealing with the strong feelings associated with caring. Your local Brain Injury Association can put you in touch with support groups or organisations who can provide counselling or other psychological assistance.

Planning for health

Regular exercise, rest and nutritious food are all necessary in order to withstand stress. Try to plan your day so you get all three. Walking, swimming, yoga, gardening or dancing are good ways to get some gentle exercise. Learning to relax by listening to pleasant music, meditating or doing specific relaxation exercises can help you sleep better.

Self-advocacy

At some point, carers may 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 and treatment, and should be assertive in claiming what you want. There are grievance procedures and appeal processes in most cases. Your Brain Injury Association may be able to assist, or link you with advocacy organisations.

Keeping friendships and interests

Try to relax and enjoy yourself. Maintain an identity of your own separate from the person you care for. Try to keep your links to the world outside caring. Absorbing interests, having fun and relaxation are all good for your physical and mental health.

Be aware that some friends may tire of you talking about the hassles of being a carer. Some carers can become resentful and lose friends by expecting them to provide more support than they are willing to give.

Where possible, seek support from other carers and don't expect too much from friends - even if it means pretending to be interested in things other than your own problems as a carer.

Coping with serious drug issues

Some people will try an illicit drug once then move on. Others will use them occasionally, or stick to a level of regular use that avoids physical dependency.

Unfortunately, a small percentage of people develop a major dependency that can seriously disrupt their lives, and those around them as well. People with a brain injury are more likely to fall into the latter category due to depression, boredom, social isolation, impulsivity or lack of self-awareness. Everyone will have a different definition of exactly what a drug 'problem' is, but usually it will involve an ongoing disruption to family life, relationships, school or employment, health and finances.

Looking after yourself

Families will frequently find that they seem to completely revolve around the person with a serious drug problem. It is important that boundaries are set so that everyone's lives are not overly disrupted. This not only protects your lifestyle, but can assist the user as well. If the family is not overly protective, the person will have to start facing more consequences of their actions.

It helps to link up with an experienced drug counsellor who can help you keep a balanced view on the situation.

Try to continue seeing your loved one as a family member, not just seeing the drug problem. Try to separate the issue from the person - you will both appreciate the difference this makes.

Talk about your feelings with someone who understands the situation - don't let things build up inside you.

Try to continue the everyday things you do, particularly enjoyable activities. You may feel guilty taking 'time out' but it will give you a fresh outlook when you return.

Tough love

The family needs to agree on what is, and isn't acceptable, and what the consequences are. For example, it may be agreed that hurling abuse is not acceptable. Continued stealing of household items to finance drug use will

result in being kicked out of the house. No money will be handed to the person using illicit drugs, though some outstanding bills may be paid.

Setting boundaries is part of an approach that has been called 'tough love', which argues that protecting a person from the consequences of their actions means they are less likely to do something about it.

Formulating a plan

Family members need to agree on a consistent approach when a loved one

has developed a high level of dependency on an illicit drug. This is usually best done with an experienced counsellor, who can provide relevant information and possible approaches. There are many issues to be looked at such as dealing with inappropriate behaviours, how much support to provide and responses to various situations that may arise. It may help to link in with other parents through support groups to get experienced information from others who are further down the track.

SHOULD A PERSON DRINK AFTER A BRAIN INJURY?

A COMMON QUESTION ASKED IS WHETHER THE USE OF ALCOHOL AND OTHER DRUGS AFTER AN INJURY CAN CAUSE FURTHER BRAIN COMPLICATIONS.



Studies have suggested that the use of even 'normal' amounts of alcohol for people with a mild brain injury may be associated with poor neurological outcomes as indicated by brain scans, performance on neuropsychological tests and increased behavioural problems.

Many specialists recommend that people abstain from alcohol for at least one year after their injury. If people decide to have some alcohol it is suggested that they only drink a very small amount until they become aware of how alcohol now affects them and learn to recognise their personal limit, or the level that may be consumed without

any risks or negative consequences, such as coordination problems, becoming aggressive or socially disinhibited. It may be beneficial to ask a close friend or family member to provide tactful feedback on what they observe. Alcohol use can often become a sensitive issue, however, where a person may not appreciate being told how much they should drink or whether they should drink at all.

Some people are strongly advised not to drink or take drugs at all after their injury due to particular medical conditions or the use of prescribed medication e.g. alcohol can lower the seizure threshold for a person with epilepsy. For safety considerations people are encouraged to ask their doctor for advice on alcohol and drug use. Additionally, people may require an intervention or program from alcohol and drug support services.

Remember that alcohol can dampen recovery, and cause problems with coordination, impulsivity, concentration, depression and seizures.

COPING WITH GRIEF AND LOSS

CARERS OFTEN DON'T HAVE TIME FOR THEIR OWN PERSONAL GRIEF.

The losses involved may include the personality changes in their loved one, friends becoming distant, loss of career opportunities, less freedom or personal time and loss of financial security.

Grief is an ongoing process in which people may move forwards, backwards or miss different stages. One model has the following stages:

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).

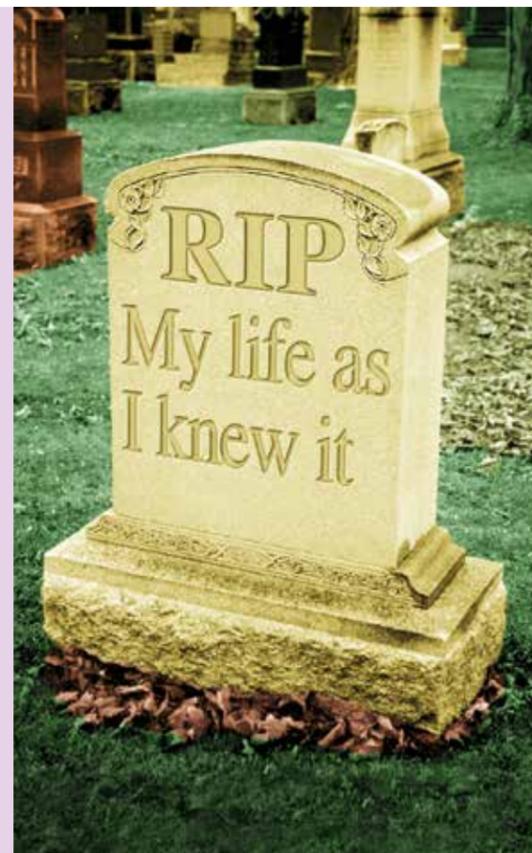
Disorganisation and despair – As it becomes clear that the loss will not

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.

Ultimately, it is important for carers to retain a sense of normality in their daily routine regardless of the extreme stress they may be under. People need to remember that they are experiencing normal reactions to abnormal and traumatic life events. Each person's reaction is unique and it is important to allow for delayed reactions or reactions that are different to your own.

If you would like more information on the grief and loss process, go to synapse.org.au to read the Emotional stages in recovery fact sheet.



MEDICATION NON-COMPLIANCE

A REFUSAL TO TAKE PRESCRIBED MEDICATION IS A COMMON PROBLEM FAMILIES FACE AFTER AN ACQUIRED BRAIN INJURY.

People who reject medications do so for a variety of reasons. Knowing which reasons will put the family in the best position to respond effectively.

Denial

Non-acceptance of having an Acquired Brain Injury can be a reason for refusing medication, or the person may believe that he or she is now well enough not to need it.

Side effects

Unpleasant side effects can be a strong disincentive — they can induce drowsiness, nausea, weight gain, muscle rigidity and other undesirable symptoms.

Influential friend

Some people with the best intentions give bad advice. If someone the person respects believes that medication or drugs are 'bad' then they could convince the person to refuse medication.

Power play

As in all families, there can be a clash of wills between two or more people. If the person with an illness refuses medication, they know the caregiver will do whatever they can to gain compliance. They may try negotiation or even manipulation to get their way.

Forgetfulness

Remembering to keep to a regular regime of medication can be difficult, especially if your thought processes are affected.

Sometimes no matter how hard a carer tries or pleads, the person may refuse to take medication. Taking medication is a personal decision. This doesn't mean that the reason for refusing medication is valid or reasonable, and if noncompliance continues with adverse effects professional advice should be sought.

For more information, go to synapse.org.au to read the *Medication noncompliance* fact sheet.

Sexual changes

A brain injury can have consequences for a person's sexual functioning.

In the hospital phase, impulsivity, disinhibition and lack of awareness may lead to rehabilitation staff getting unwanted sexual attention from the individual with the Acquired Brain Injury (ABI). The medical team, family and friends need to have a common response to inappropriate sexual behaviour that will assist the patient to regain control over very basic impulses when placed in close proximity to a person of the opposite sex. This behaviour can particularly be a problem for males from their late teens to mid-twenties when their sexual urges are strongest. Some of this behaviour may include fantasising, lewd verbal responses, disrobing and/or masturbating in public, impulsiveness, and touching others.

Understanding by the family

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

The individual with ABI must be encouraged to take control over aspects of their life, when there is a reasonable expectation for responsible behaviour. When sexual behaviour is inappropriate, steps need to be taken to learn better ways for managing or compensating for the lapses in social skills.

Common changes

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

Some common changes following an ABI include a loss of sexual drive, inability to achieve or maintain erection or inability to orgasm. On the other

hand, others may encounter premature ejaculation or increased sex drive along with sexual disinhibition.

Such changes may be a direct result of damage occurring to particular brain structures underlying sexual functioning or inhibition. 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.

Assessment

Seeking professional advice can be an embarrassing and sensitive issue for many people as sex is usually a very personal and private aspect of life. People are often more likely to discuss sexual issues with their general practitioner during a visit for other health reasons. Assessment of sexual issues 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 general practitioner, psychologists and psychiatrists may be involved in the assessment and treatment of sexual issues.

Management of Sexual Changes

Reactions of partners and family members

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

- Develop greater understanding by seeking information on how to support the person
- Learn different techniques and compensatory strategies e.g. different ways of giving and receiving pleasure with the person

- Alter expectations and negotiate about how often, how long and the type of sexual activity the person may desire
- Be assertive and sensitively communicate personal views
- Make changes to lifestyle and routines that improve quality time together.

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. They may not know how to cope with unwanted sexual advances or may not understand the consequences of their actions. Family members and friends need to be aware of these issues and discuss any concerns with a professional.

Masturbation

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

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

Treatment for Sexual Problems

Professionals can help people cope with a variety of physical and psychosocial changes. Following assessment, specific treatment of sexual problems may involve education, learning new skills and behavioural techniques, physical rehabilitation, aids and medical treatment.

Specific forms of treatment may include psychological support, medical and surgical approaches.

Psychological support

A psychologist or social worker can provide sexual and marital counselling to couples to enhance their understanding of sexual changes, communication skills, problem-solving, conflict resolution and caring behaviours. Professionals may also provide literature, audio-visual aids and advice on sexual positions, techniques and aids. A psychiatrist may prescribe medication for either psychological or physical problems.

Medical and surgical approaches

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



Challenging behaviours

Challenging behaviours are those behaviours that threaten the safety of the self or others, or limit access to the community.

Individuals and communities have a tendency to judge people by their behaviour. Anyone who acts outside the acceptable boundaries is then in danger of being excluded. People with an Acquired Brain Injury (ABI) may 'break the rules' associated with:

- How close to stand to other people
- When it is appropriate to interrupt another person who is speaking
- When and how to show emotions
- How to interpret and respond to nonverbal communication
- What parts of a person's body may be seen naked or touched
- When to speak and how to get a point across.

In the early stages of recovery these problems may not be obvious. Long-term irreversible brain damage sometimes occurs, however, resulting in specific problem behaviours.

Types of Challenging Behaviours

Impaired social behaviour is often evidenced by childlike behaviour,

self-centredness, tactlessness, reduced emotional sensitivity and lack of gratitude. People may show marked changes in their social skills and self-care. Impaired control may be displayed in a number of ways including impulsivity (acting first and thinking later), verbal and physical aggression, increased/decreased libido, financial irresponsibility, alcohol and drug abuse, poor frustration and stress tolerance, impatience, restlessness, and a lack of mental flexibility with the need for a highly structured and routine environment. Common emotional difficulties, such as depression and anxiety may lead to challenging behaviours such as withdrawal and avoidance. Increased dependency, which may be related to emotional problems, may also lead to increasing demands for attention from caregivers.

It is not uncommon for people with ABI to experience a lack of insight into the nature and effects of their injury. This may lead to feelings of frustration; particularly if they are forced to rely on others to do things they might normally do for

themselves. As people gradually develop higher levels of self-awareness into the impact of their post-injury changes, the most common reactions include depression and anxiety. Some people can experience a catastrophic reaction to their losses such as anger, fear, helplessness, suspiciousness and paranoia. Some people with ABI may lack trust in other people and become suspicious about their actions and ideas. In some cases, this leads to the development of paranoid tendencies in which the person has fixed beliefs and acts in a guarded and secretive manner.

How others respond to these behaviours will be an important factor in the successful rehabilitation of the person, as well as influencing the quality of life of family and friends. It is important when challenged by a person whose behaviour has changed as a result of an ABI, to keep the emphasis on behaviour rather than personality. This helps to:

- Maintain a greater sense that change is possible
- Specify what is happening in clear and concrete terms



- Direct any disapproval away from the person and onto the behaviour.

While the exact causes of challenging behaviour are not well understood, the two main causes of behavioural changes that follow an ABI often stem from:

- A learned response - reinforced for the person in their environment
- The inability of many to control their behaviour due to the direct effects of their injury.

Responding to Challenging Behaviour

Effective responses to challenging behaviour rarely happen by chance. A successful strategy will require a disciplined approach that coordinates and implements a number of steps. The steps for responding to challenging behaviour require the people involved to:

- Observe and measure behaviour
- Identify the causes of behaviour
- Develop realistic expectations about change and how to measure the results
- Identify and evaluate possible approaches and strategies for change
- Develop a behaviour management program
- Implement the program consistently
- Monitor progress and review
- Maintain gains and make further progress.

'STAGES OF CHANGE' MODEL IN DRUG DEPENDENCY

PEOPLE EXPERIENCING DRUG PROBLEMS TYPICALLY GO THROUGH A SERIES OF STAGES IN DEALING WITH THEIR USE. BY RECOGNISING WHAT STAGE SOMEONE IS IN, WE CAN RESPOND IN A WAY THAT IS MOST APPROPRIATE TO THAT STAGE.

Pre-contemplation

The person does not want to change or won't accept they have a problem. Because someone in this stage has no intention of changing their drug use, threats, ultimatums and external pressure to change not only have no effect, but can also result in reactivity (digging their heels in and becoming even more determined to keep using).

Helpful responses can be keeping communication open, but not discussing the need for change. It can pay to focus on harm minimisation with their existing drug use – if they're going to use, how can they do it most safely? Contact your local Brain Injury Association for referral to agencies who can help with information on harm reduction.

Contemplation

The person is thinking about making changes to their drug use. In this stage, someone is in the early stages of uncertainty, and they are starting to be torn between the desire to change and the desire to stay the same. They are weighing up the pros and cons, and start to consider change.

You can help them to explore more fully their thoughts on their drug use, but try not to indicate one way or the other your preferred choice for them. Acknowledge that just starting to consider change is a positive step and reinforce this.

Decision

In this stage the person has made the decision, to change, and is considering how they should go about it. They need to develop an action plan and prepare for how they are going to carry it out. You can help by talking to them about what they want to do and exploring the different options available.

Action

This is the stage where they carry out their action plan. This plan could involve entering into treatment, changing their environment, or reducing or ceasing their drug use. Their action plan may not necessarily mean abstinence from drug use. Helpful responses can be to recognise any action as being positive, don't focus on the negative if they slip back, and encourage their belief that change is possible and well within their capabilities.

Maintenance

The person now has to work to maintain the changes to their life, and avoid slipping back into the "old way" of doing things. This

stage requires constant attention and vigilance from the person. You can support them by working with them on plans to minimise risk of relapse and expressing your faith in them to manage their own life. Recognise and support the other important areas of their lives as well – work, studies, hobbies, relationships and so on.

Relapse

This is where the person falls back into an earlier pattern of drug use behaviour. This can be very discouraging for family members, but patience is needed. On average, illicit drug users go around this cycle seven times before finally making a lasting change! A brain injury with impulse issues, of course, makes relapse even more likely.

You can support your loved one by not panicking. See relapse as a short-term obstacle, not a waste of so much hard work. Encourage the person to see this as a mistake that can be learned from, not a sign that this situation is impossible. Focus on the positive changes already made.

QUESTIONS TO ASK WHEN FORMULATING A RESPONSE TO BEHAVIOUR

- What are the different challenging behaviours displayed by the person?
- Which behaviours will be focused upon initially?
- What pattern has been observed for each target behaviour?
- What seems to cause or contribute to the behaviour?
- What are the expectations of change (individuals versus family member or carer)?
- How will change be measured?
- What are the possible approaches and strategies for change?
- What level of control and participation can the person with a brain injury have?
- How will progress be measured and what outcome measures may be used?
- How will gains be maintained and generalised over time?
- Can further progress be made by extending the program to different behaviours?

Observe and measure the behaviour

During this initial assessment stage the main aim is to get a clear understanding of the specific behaviours that cause concern. Each challenging behaviour may require a different strategy. It is important to prioritise which category of behaviours will be addressed first. Measuring the behaviour involves questions such as how often and where does it occur, how long does it last and how do people react to it?

Identify causes and influences of challenging behaviour

The causes or influences of challenging behaviour may be divided into individual factors, environmental factors and factors related to people. Severe behavioural difficulties may require assessments conducted by professionals. These assessments will help provide insight into the person's level of cognitive and psychosocial functioning, the effects of the brain injury, the impact of the environment and the influence that mental illness may have upon the behaviour. To make sense of what causes or influences the behaviour, the antecedent, behaviour, and consequence (ABC) model can be used:

- Antecedent - examines what usually happens before the behaviour, and particular triggers or events that may set off the behaviour
- Behaviour - examines what happens during an incident
- Consequence - analysis involves

identifying immediate and delayed reactions following the behaviour from both other people and the environment. 'What outcome is achieved by the behaviour'

Develop realistic expectations and measure results

Setting realistic goals for change involves:

- The degree to which the behaviour/s may be eliminated, reduced, increased or influenced
- How long the behaviour has been present (before and after the injury)
- The person's capacity to control the behaviour
- The person's level of insight
- The person's level of motivation
- The environment
- The ability and willingness of others to assist with strategies
- The ability and willingness of the person to cooperate with other people.

Behaviour should be measured prior to the intervention to provide a 'baseline' against which progress can be compared. The period of time spent measuring the behaviour needs to be long enough to provide a representative view.

Identify and evaluate possible approaches and strategies for change

There are many different approaches and strategies to encourage people to change their behaviour. The suitability and effectiveness of each option will vary according to the person with a

brain injury, the people around them, and the environment. Some of the most commonly used and successful approaches are outlined as follows:

- Modify the environment or routine
- Give feedback about the behaviour
- Motivate the person to change
- Reward and acknowledge desired behaviour
- Change expectations and demands
- Teach new skills and behaviours
- Change how others react
- Psychological support
- Medication.

Develop a behaviour management program

Key questions in developing a behaviour management program include:

- What are the behaviours to address?
- What is the pattern of behaviour?
- What is the goal for change?
- Which steps will achieve the goal?
- How will change be monitored?
- Which approach(es) will be effective?
- How can the person with the Acquired Brain Injury have as much control and participation in decision-making, as their capabilities will allow?
- Who will implement the plan?

For all carers and family members involved in the program, a consistent approach is often the most significant factor influencing success. The expectations of behavioural change also need to be clearly defined and realistic. It may not be possible to change all behaviours at once, or in all situations.

The Right to Stay the Same

It is important not to lose sight of the person's rights. In spite of all the best intentions, the person concerned may not want to alter their behaviour. If this is the case, then they have the right to behave in a way that challenges the norms of the community. People cannot be punished for their behaviour unless it is by the law. Neither can they be restrained against their will or forced to conform to another person's rules without consent. The excuse 'It is for their own good' is not sufficient reason to deprive another citizen of their rights under the law.

Steps to independence

As one reaches adulthood, independence is a natural goal. However, to resume an independent lifestyle safely after a brain injury, independence should be approached in stages and based on the person's recovered physical and cognitive abilities.

For some people with severe cognitive deficits, achieving complete independence may be an unrealistic goal.

Determining when it is safe to let go after brain injury can be a heart-wrenching decision for families. All too frequently, families expect that discharge from a hospital or completion of a rehabilitation program indicates the person is "well" or "cured", however most people will experience some ongoing problems with cognition. There is a delicate balance between protecting a person from potential harm and promoting an opportunity to attempt independent actions and learn from the results of their efforts.

Involve family in rehabilitation

It is helpful for family members to witness first-hand how deficits impact on the person's 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 often function best within a structured environment. It is important for everyone with whom the person interacts to be aware of compensation strategies used for deficits, as well as the need to reinforce those strategies on a consistent basis. Ideally, the person should not use stimulants or depressive agents after a brain injury 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 troubling issue.

Additionally, family members should consider the need for guardianship and familiarise themselves with these protective tools.

Neuropsychological assessment

A neuropsychological assessment is a task-oriented assessment of cognitive functioning and the key piece of information that will help determine the extent of assistance a person may need to function in society. Many people injured as a result of acceleration/deceleration forces experience damage to the frontal lobes. Damage in this area usually results in a reduction or loss of ability to: exercise good judgment; reason things through; problem-solve; inhibit inappropriate behaviours; organise and structure time; control impulsiveness; and follow through with tasks.

If a neuropsychological assessment was not completed in conjunction with a 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 and gradually let go

Some people with frontal lobe damage lack awareness about their own impairments and may take unnecessary risks affecting safety. Over time this may change and increased insight may create a negative reaction to the new self. Although this change in awareness can be a positive sign of improvement, dealing with it emotionally can be quite challenging. Families must be alert to these changes to prevent self-injury, disruption of cooperation and/or increased demands for independence.

It is helpful to gradually establish some safe activities for the person to manage independently like a program at a local gym where there are staff trained to

monitor and assist the person.

Recreational activities are good for reestablishing community involvement. Whatever services your family member decides to participate in, ensure the persons in charge know the person's impairments and the extent of help he/she will need to participate effectively. Your local Brain Injury Association should be able to put you in contact with these services.

The importance of appropriate identification

With each step toward independence, it becomes more important for the person





Rehabilitation tips

With rehabilitation being so important after a brain injury, are there ways to maximise the amount of recovery possible?

to carry proper identification at all times. In the event of seizures, ensure that the person has information in the form of a bracelet, necklace and/or wallet card that accesses medical instructions. If the person could become lost then maps or a record of the address should be carried at all times.

Plan failures when applicable

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, a person with balance problems who wants to ride a bike again can start off

on a stationary bike. After the person has been evaluated getting on and off safely, allow him/her to progress to a two-wheel bicycle and — using good protective equipment such as elbow pads and helmets — allow him/her to practice skills in a relatively "safe" area with footpaths and grass in the event the rider falls.

Conclusion

It is easier for the family to be in a position of control at the onset of the community re-entry phase of recovery rather than experience a sense of failure when the person with an Acquired Brain Injury is unable to resume his/her exact pre-injury lifestyle. Gradual re-entry can provide a measure of safety and protection that can move the 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 proper 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.

Permission to adapt this article has been kindly granted by the Brain Injury Association of America.

gentle encouragement the theme to home rehabilitation.

Memory prompts

If the person is constantly faced with situations in which they have no recall and those around are constantly mentioning this lack of memory, it may eventually cause an erosion of self-esteem. Create some strategies to compensate for this problem by developing lists, post-it notes, or cue cards. These strategies can help the individual feel more independent, less likely to make mistakes, or feel nagged or scolded.

Familiar settings

A brain injury often creates difficulty learning new information and generalising new skills from one environment to another. The most effective rehabilitation occurs in the home setting where old learning is maximised. When injured people are transported to another city or state, much of what they learn cannot be applied when they return home. The familiar cues which facilitated recall in the treatment setting disappear and the new behaviour cannot be elicited.

Feedback on behaviour

People with a brain injury have enough problems without increasing their burden by accepting any and all behaviour. If family members tolerate behaviour which drives others away, the injured person may become increasingly isolated from human contact and the burden on the caregiver can increase. Try to provide accurate and realistic feedback on behaviour and its consequences.

Support groups

Support groups play a vital role in the lives of people with brain injuries and their families. This will be especially so when the person completes rehabilitation and finds that life is changed in ways that the person and the family find puzzling or difficult to manage. Groups enable the person to identify with others with

similar problems, and together solutions are often found. The person also feels less alone — a sense of belonging is very important to those whose lives have been dramatically changed. They also greatly influence the carer's ability to support the individual often increasing understanding and providing an outlet for frustration.

Get involved

During the rehabilitation process, try to be as involved as possible, ask questions, attend family conferences and learn all you can while your family member is in a structured setting. You know your needs best. Your rehabilitation team needs to hear your opinions and concerns.

Make sure you are provided with a sound and realistic discharge plan. Once home, don't sit back and assume everything will automatically fall into place. Establish a routine (structured environment), consistently enforce the discharge plan, and make sure that your family member has control over those aspects of their life that are safely manageable.

Injury prevention

One brain injury can make you much more susceptible to further ones. Some of these added traumas occur because of the cognitive and behavioural deficits following the original injury. The impulsive person who has poor judgment may repeatedly place himself in dangerous situations and then be unable to cope. Apart from supervision another useful tip is to avoid:

- Exposure to toxic materials
- Alcohol
- Nicotine
- Stimulants and other recreational drugs

Hopefully this information has been useful to you and you will begin to think about rehabilitation in terms of cognition and behaviour rather than medical and physical problems. People who have sustained head injuries have a great deal to offer to family, friends, and society if they are given a chance.

SHOULD I LEAVE MY PARTNER?

PARTNERS CAN BE THE UNSEEN VICTIMS AS THEY STRUGGLE TO COPE WITH THE EFFECTS OF THEIR LOVED ONE'S BRAIN INJURY — STRUGGLING WITH ANGER, DEPENDENCY, GRIEF, OVERLY DIRECT COMMUNICATION, EGOCENTRICITY, OR SIMPLY THE STRESS OF LOOKING AFTER THE KIDS AND THEIR PARTNER.

So often, underlying these issues lurks the question of whether they should stay or go. It pays to see if you have tried all the strategies available to make it work.

Strategies worth trying

Never underestimate the impact of relationship counselling, especially when both people acknowledge there is a problem and want to do something about it. Unfortunately, self-awareness is often a casualty following an injury. If your partner does not acknowledge the cognitive effects of the brain injury, counselling will probably only help you to learn adaptive strategies.

Try to see how you are part of the problem. Remember it takes two to tango! Even though you may be doing it tough, some of your reactions could be contributing to the problems. Relationship issues usually trigger our own insecurities and you may need to look within yourself at how you need to change too.

Get educated on the effects of brain injury. Remember, your partner is not



choosing to make life difficult for you. You must adjust your expectations of your partner for this neurological disability, as you would for a physical disability such as cerebral palsy.

Get support. Use respite services. Get into a support group and talk to others. Call your local Brain Injury Association for further information about support groups.

It's still no good!

People rarely make the decision to end a relationship flippantly. It usually only comes after agonising guilt, depression, frustration and having tried every option to make it work. When confronted by constant aggression, the decision may be relatively easy. Often the individual with the brain injury is apologetic, however, trying the best they can to improve — although the relationship may still not work any more.

But what about my partner?

When a partner leaves, the person with the brain injury may react in a number of ways. In some cases, there may be threats or physical violence which cannot be tolerated in any circumstances — you may need to obtain a restraining order.

A point to remember is that there are always options available. Some may continue to live with their partners to provide support, but make it clear that the sexual and romantic relationship is finished.

The post-rehab slump

People with a brain injury often make excellent recoveries through positive attitude, hard work and family support. Once formal rehabilitation is over, however, there may be a slump, leaving them trapped in a spiral of depression, despair and suicidal thoughts.

The major reason for the post-rehab slump is often psychological. The person with the brain injury is told that a positive commitment to rehabilitation will maximise results. This is a clear goal, and more importantly it is usually easy to see the progress resulting from hard work.

The brain does its best to heal itself to a limited extent for a year or two after the injury, which contributes to a sense of progress. Even beyond this point, improvement can still be made by working on strategies that will compensate for cognitive deficits – memory prompts, anger management, pacing and relaxation techniques.

Inevitably there comes a point where visible progress tapers off, and it is apparent that this is as good as it gets. The survivor has been focusing so much of their time and energy on this goal of recovery, and now it has been reached. The logical step is to set a new goal, and

this is the point where the limitations of the injury are often apparent.

Where to from here?

No matter what the new goal is, it will often be limited by the effects of the brain injury. Employment may not be possible, or only on a drastically reduced level. Any big project may prove difficult due to the impaired ability to plan, concentrate and remember. Goals involving social activities may be hampered by reduced self-confidence, social skills and energy levels.

Who is this stranger?

Particularly for those who have done well in their rehabilitation, this new self can be very difficult to accept. Despite being told things will never be the same again, there is still the secret hope that possibly enough hard work during rehabilitation may make good things happen. Being confronted by the reality of this new self can then be a crushing disappointment after many months of measurable

progress. Some describe the new self as a stranger living in their skin, and knowing that this will not change can be hard to accept. The brain injury itself can add to the impact of this disappointment as anger, depression and intolerance of stress are often much harder to handle post-injury.

Accepting the new self

Those who have done well in their recovery can find this plateau phase difficult to accept. In a way this is the final stage of rehabilitation and often the hardest. Coming to grips with a new identity and even learning to appreciate it is a very difficult step, and many people are unable to make it.

For some, the answer is focusing on a positive attitude. Cognitive deficits are viewed in a different way to see the strengths that can arise. An inability to work means opportunities to develop hobbies such as art or gardening. Lack of energy means taking more time to 'smell

“I know I should be happy. I'm one of the lucky ones. A mild brain injury, a big recovery and I'm even back at work, my family is supportive and most of my friends still hang around. But I've lost big parts of me forever. A year after discharge the loss hit me and I've lost the plot since then”.

“The crash came three years later. I'd always been a really positive person and I threw myself into rehab. The doctors were amazed at how well I did. Even after two years I kept working on new strategies, although my brain had ceased to improve at that point. Then suddenly I couldn't be bothered any more”.

“I tried to kill myself last year, and my family got me to counselling. I don't think it's helped – there's just no point really if I can't work or have friends. During my rehabilitation I was pretty positive about the future but there's nothing now. This is it. No more improvement”.



the roses'. Wrestling with depression gives an insight into the pain and suffering of others.

Some survivors have made sense of their experience by seeing how they can help others. They may attend or even initiate a support group where they can share their hard-won lessons with others, or write of their experiences. For those who can work, an option is sometimes casual work supporting others with a brain injury.

A spiritual approach or commitment to self-improvement may be the key for others. Each cognitive deficit is seen as an opportunity for self-growth and further development, not just as a disability. Remarkably, people often find that even many years post-injury, they still gradually improve in some areas with 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.

What the family can do

Families can help their loved one by putting strategies in place to avoid or lessen the post-rehabilitation slump. Work with them on developing new goals and activities before rehabilitation tapers off. Contact your State Brain Injury Association for support groups and activities that may exist in your area. A counsellor can also help the individual with ABI with their new identity. As one person put it, "For survival we must let go of what was, in order to become what we will be".



ALTERNATIVE MEDICINES

ALTERNATIVE MEDICINE IS EXACTLY AS IT SOUNDS: AN ALTERNATIVE TO CONVENTIONAL MEDICINE.

While conventional medicine is supported by scientists and pharmaceutical companies, alternative medicine (also referred to as "Complementary and Alternative Medicine" (CAM) or Alternative Therapies) is not endorsed in the same way. Most Alternative Therapies have existed for thousands of years, and many have been passed down from cultural groups the world over.

Many treatments that were once classed as/or considered alternative have now become 'mainstream'. Putting mouldy bread on wounds was once just a housewife's remedy until the antibiotic penicillin was identified. Vitamins were found to cure scurvy and other previously unexplained illnesses, and the acidophilus cultures commonly in supermarket yoghurt are now recognised as a major component for intestinal health.

People who seek Alternative Medicine are often those who are opposed to synthetic pharmaceuticals, and who prefer a more natural approach to health

and healing. Examples of Alternative Therapies can include, but are not limited to: Meditation, hypnosis, spiritual healing, massage, chiropractic, herbal supplements, homeopathy, naturopathy and acupuncture. Alternative Therapies can also include widely accepted practices such as nutrition, exercise, and relaxation.

Alternative medicine can often be misunderstood on initial presentation. The statement "Tai Chi cures illness" is controversial and unbelievable initially. When you look, however, at the fact that Tai Chi is a very effective way to improve balance, coordination, strength, flexibility and cardiovascular fitness - you can understand how it may now affect illness. Having a healthy body improves the immune system which in turn fights off illness - so Tai Chi then affects illness in an holistic way.

The main benefit of Alternative Medicine/ Therapies is often the lack of potential negative side effects. Massage and "green" or nature therapy are examples of effective Alternative Therapies

for use with children who have ADHD; all free from the negative side-effects often resulting from conventional medicine (e.g. cardiovascular issues, psychiatric symptoms, and even cancer). This doesn't mean there are no side-effects, however, so always research. Is important to assess the potential risks of the therapy objectively, to ensure the safety of the individual.

Claims of a miraculous cure should also be viewed with caution. They have been known to occur, however usually as a result of enormous amounts of time, effort, money, or unique circumstances.

It is very difficult for science to evaluate quality of life. Even when there is a limited medical benefit from a therapy there may be a very real benefit to the patient from the sense of purpose, satisfaction, or hope that the treatment can provide. So proceed with caution, but don't discredit something before you think about what it can do for you and your family.

Family guide to a low cost rehabilitation program

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

STEP 1: Obtain detailed objective information

The injured person: Since research has clearly demonstrated that the most disabling consequences of brain injury are cognitive and behavioural, information about the person's current level of functioning in these areas is essential if a realistic program is to be developed. You need specific information on things such as how much can be learnt, what is the best way to learn, what activities are most likely to present problems, what limitations there may be perceptually, and how you can set things up to maximise abilities. Your 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.

Your support system: Family members must objectively decide how much time, money and emotional energy they will be able to commit and how long they will be able to do so. This includes such factors as 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, many of which are paid for by your tax dollars, are available in most communities and are appropriate for people who have sustained brain injuries. Most of these agencies do not advertise; many are not aware of the special needs of those who sustain brain injuries and how their agency's services might be utilised by this population. Think outside the box and don't be afraid to approach these community services for assistance.

STEP 2: Develop and implement your program

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

Survival skills goals: Those activities which have the highest survival value (daily routines such as showering, grooming, toileting, dressing, sleeping and eating) should receive concentrated attention in the initial phase. Goals should address the mechanics of completing the task as well as the amount of time required. Goals in this area have been accomplished when the person is able to awaken on his/her own, independently complete his/her morning hygiene routine, and prepare and clean up after eating; they should be dressed as if going out in

the community each day.

Basic cognitive goals: People who have sustained brain injuries are frequently extremely distractible and can often have limited ability to attend to and concentrate on tasks. Until attention and concentration are improved, community-based activities may be problematic.

Initial cognitive retraining activities should probably be conducted within the home setting. Appropriate activities might include working on craft projects from books in the public library, playing simple board or card games, or playing simple video games. Since pre-injury information and skills are frequently relatively intact, the person may be able to play games which were learned pre-injury (such as checkers or poker) without having to learn new rules. At this stage, the ability to learn is not being addressed, only the ability to attend and concentrate.

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

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



to ensure that behavioural goals are not all 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 (if you are not already doing so) you should begin to give honest, objective feedback to the injured person on specific maladaptive behaviours and your reactions to them. Although such direct oral feedback is not customarily given in most social settings, the injured person may not understand why he fails to make friends unless he is 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, behaviour control 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 deficits following the brain injury and may seem generally unable or unwilling to modify his/her behaviour. This could be the case even in the face of interpersonal cues which are not at all subtle. Once the person's behaviour is positively altered in the home setting, community recreation activities are often introduced in the rehabilitation program. Your local brain injury association should have a list of recreation programs set up for people with disabilities. Don't be limited by disability programs, however. If you feel able, reach out to other recreation programs in your community - try your hand at opening their eyes to inclusive

practices, and including your family and loved one in their group. This can take time and education sessions (speak to your local Brain Injury Association), 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 deficits 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 note-taking, recorded lectures and one-on-one tutorials to assist.

Vocational goals: Some people with brain injuries may recover sufficiently to return to either sheltered or competitive employment; others will be able to contribute to their communities in volunteer positions. Many people will be unable to pursue vocational goals because their salary would not compensate for government or private sources of disability income and/or benefits. People who are not eligible for benefits may have to attempt to return to work if they wish to live above bare subsistence levels. If and when re-employment is a realistic goal, the

Commonwealth Rehabilitation Service can assist in exploring vocational options and getting back into the work force.

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 his 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.

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 Ph.D. for permission to adapt this article from her website at: brain-train.com.

Steps to a healthier brain

Exercise and challenge your brain

Like our body the brain needs exercise. Practising skills leads to better performance whereas unused skills often deteriorate or are forgotten. Ongoing mental stimulation has been shown to provide some protection against mental decline. Challenge the brain by trying things you don't already do, such as studying a new language. Challenging creates new pathways that can sometimes become alternate routes when neurones die off in middle and old age. Just remember if you have a brain injury to take on tasks that are realistic. If you have trouble with judgment you may need to discuss it with others first.

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

Some possibilities are:

- Avoid using calculators
- Swap TV for mind games or a book
- Play games that involve memory (bridge) or thinking ahead (chess)
- Take up a new hobby.

Nourish your brain with a healthy diet

Like any high-performance machine, the brain needs top quality fuel – a well-balanced, low cholesterol, low saturated (animal-fat) diet. Timing is significant as studies have demonstrated the importance of a good breakfast.

Not all fats are bad for you in the right quantities. Unsaturated fat and protein are especially important for developing brains. Fish, a rich source of both, is sometimes called brain food. Your body converts long strings of amino acids in the protein you eat to individual amino acids that your brain converts to the specific proteins it needs.

Your brain needs vitamins and minerals that only come from a balanced diet. In particular research suggests the antioxidant vitamins E and C can protect the brain.

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

Glucose is the fuel needed to keep the cells alive and functioning. When your concentration wanes in the late morning

or afternoon, eating a snack containing sugar, such as fruit, can solve the problem.

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

Enjoy physical activity

Exercise daily if possible by setting exercise priorities and sticking to them. Regular exercise reduces depression and reduces cardiovascular risk factors, even a simple walk lets you think freely.

Some exercise states may produce euphoria, but even 12 minute bouts of exercise (to 85% maximum heart rate) release serotonin, dopamine, and noradrenaline that can act like antidepressant medications.

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

Make "safety first" a priority

Brain trauma is the invisible disability. The major causes of adult head trauma are motor vehicle accidents, on-the-job accidents, falls, assaults and sports injuries. Take common-sense safety precautions including wearing seat belts and sports safety helmets as appropriate. Remember that if you have an existing brain injury you

are much more susceptible to acquiring another one.

Manage anxiety, stress and depression

Anxiety increases heart rate and blood pressure which can lead to stroke. Acute stress, such as the "flight or fight reaction", is normal and short-lived.

There is increasing evidence that stress actually damages the brain. The hormones linked to stress can actually kill nerve cells in animals and are thought to do the same in humans.

The steps you take to reduce stress are likely to preserve nerve cells and help maintain mental abilities which is crucial if you already have a brain injury.

One of the toughest stresses is depression. It affects memory, slows brain metabolism and can lead to some degree of brain damage. Some strategies for coping with stress are:

- Meditation
- Relaxing by actively tensing then relaxing individual muscle groups
- Channelling internal stress into external action through exercise
- Let go of things outside your control

DOES HOMER HAVE A BRAIN?

HOMER SIMPSON IS POSSIBLY THE WORLD'S BEST KNOWN CARTOON CHARACTER. HE IS ALSO THE MOST LIKELY TO BE SUFFERING FROM ACQUIRED BRAIN INJURY.

He has been hit in the head with countless objects, landed on his head repeatedly as he fell down a ravine (twice!) and became a boxer when it was discovered he could be repeatedly punched in the head without being knocked out, winning by default as his opponents wore themselves out and collapsed.

It doesn't take a neuropsychological assessment to see that Homer exhibits most of the classic symptoms of a brain injury. There are the anger issues as he is constantly choking his son, Bart. He has a raging alcohol problem, with too much time spent at Moe's tavern, and impulsivity with his tendency to do anything to get his hands on donuts.

What about his memory problems - always forgetting they have a third child, Maggie? Or lack of attention as he repeatedly ignores danger alarms as safety inspector at the nuclear power plant? What of his rapid changes in mood, inability to cope with multiple demands, low motivation and inappropriate social behaviour and hypersexuality?

The strange thing is he still has plenty of friends, despite his many issues. Unfortunately, the Springfield community does tend to show a lot more understanding and compassion for Homer's eccentricities than the real world does for people with a brain injury...

- Ensure a balance of work and recreation
 - Take time out for yourself
- Visit your general practitioner if problems persist past this.

Relax and sleep well

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

to fatigue and immune suppression, along with memory, concentration and mood disorders. Optimal learning cannot take place against a background of poor sleep.

What can you do if you can't get to sleep? The most common causes of difficulty are not being able to shut off the anxieties and worries of the day and preparing for tomorrow's problems. One useful strategy is preparing for sleep:

- Don't take one last look at email messages
- No phone calls or activities after 9 pm
- Don't go to bed until you feel sleepy
- Don't have caffeine after 12 noon.

Blood pressure, diabetes and cholesterol

If you have diabetes and high cholesterol, you have 4 times the risk of stroke. If you have only 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 in varying degrees, impair a person's ability to think clearly and control emotions and behaviour. These abilities are often impaired by an Acquired Brain Injury and therefore when people use drugs and alcohol they are likely to experience even greater problems with alertness, memory, problem-solving and controlling their behaviour and emotions.

Many thanks to Brain Foundation for their kind permission to condense an article from Brainwaves, Newsletter of the Brain Foundation, Autumn 2003. You can visit their website at: <http://www.brainaustralia.org> to read the complete article and a wide range of other information at info@brainaustralia.org.au.

Neuropsychological assessments

A person with a brain injury will usually undergo a neuropsychological assessment at some stage of rehabilitation.

The neuropsychological assessment is an evaluation of various areas of functioning and is a standard tool used in evaluating rehabilitation in a hospital or a workplace. It relies upon the use of standardised testing methods to evaluate areas such as:

- Perceptual sensory and motor functions
- Concentration and attention
- Memory, planning and organisation
- Emotions, personality and behaviour
- Language, hearing and sight
- Problem solving

The neuropsychologist will usually look at case histories, hospital records and talk to family members to find out about the person's pre-injury personality and skills.

How an assessment can help

A range of psychological tests is used to objectively measure brain functions, including evaluations of language, attention span, orientation, spatial perception, memory, concentration, new learning, mathematical reasoning, abstract and organisational thinking, problem solving, social judgment, motor abilities, self-awareness and emotional characteristics.

Possibly the most important outcome of this testing is the interpretation of the results which are used not only as the basis of the treatment plan for therapists but even more importantly for the person and their family. Once the neuropsychologist has completed the scoring and the narrative portion of the assessment, a meeting should be scheduled with the person and family to discuss the findings. It is helpful to ask that the conference be recorded or bring a tape recorder with you. Taping the

conference can be very valuable for other members of the family unable to attend the conference.

A written report should be provided following completion of the assessment that can be shared with everyone involved in the support of the individual. The report should cover case history and current issues, the various tests conducted, observations, assessment results and recommendations.

Benefits for the family

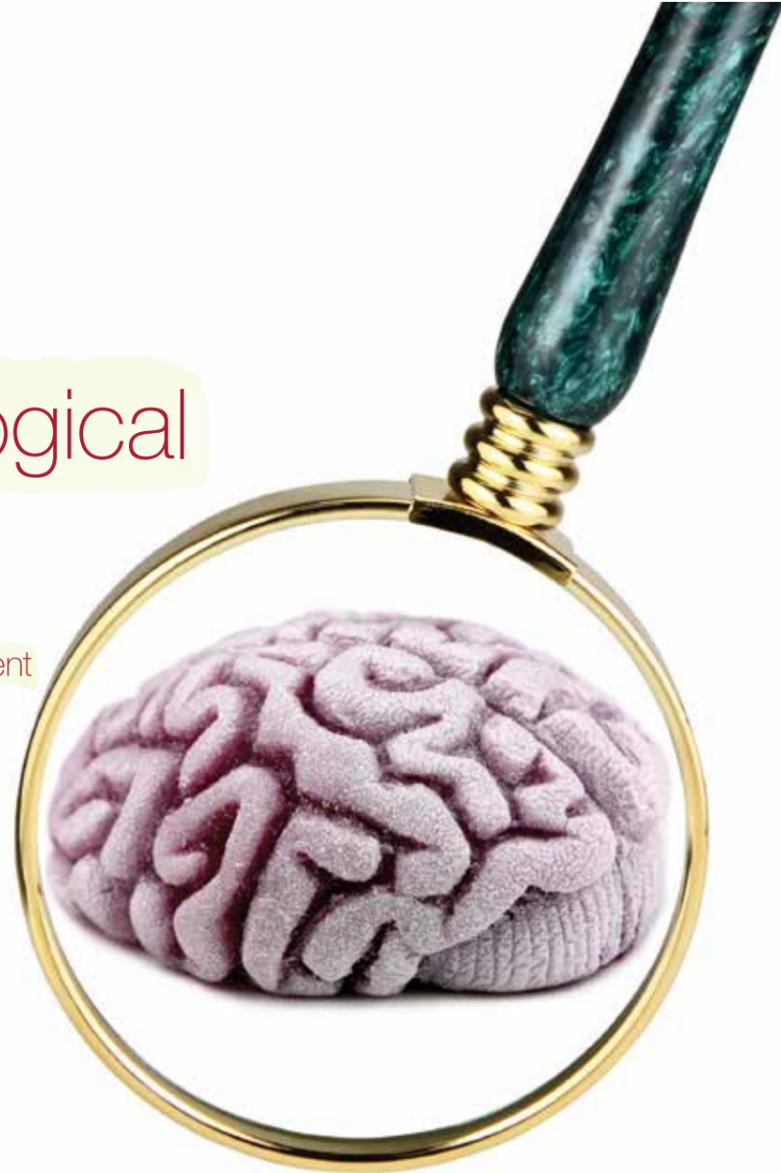
The neuropsychologist should explain the person's abilities that remain unchanged as well as areas of the brain that are adversely affected by the injury and how these deficits are expected to impact upon the person's life. It is helpful for the neuropsychologist to be very clear and informative about ways the injury will affect the day-to-day existence of the person (e.g. "damage to the frontal lobes of the brain is expected to create difficulties in planning and organising

tasks"). This important information can help the family more effectively guide and support the person and assist with activities that utilise the preserved abilities and reinforce strategies that compensate for deficits.

Knowing your family member's difficulties can increase your effectiveness as a caregiver and decrease the discord that often develops when the family is not aware of ways the injury has affected the cognitive abilities of a family member.

These tests can be quite expensive due to the time involved. Universities offering programs in neuropsychology often provide evaluations at low cost or sliding scale as part of their student training.

Ideally a neuropsychological assessment should explain how damage in the brain affects the way a person with a brain injury thinks, acts and deals with life in general, in a way that can fully maximise the survivor's recovery and participation in family, work and the community.



Potential future medical problems

Carers and family members are in a unique position to spot medical problems that may emerge after leaving hospital

Families need to be alert to various problems and changes that may indicate the need for re-evaluation or follow-up treatment. Problems developing after the person is home and no longer involved in medical or rehabilitation settings may not be as readily recognised as a result of brain injury. Valuable treatment time can be lost if caregivers are unaware of some possible medical consequences of brain injury.

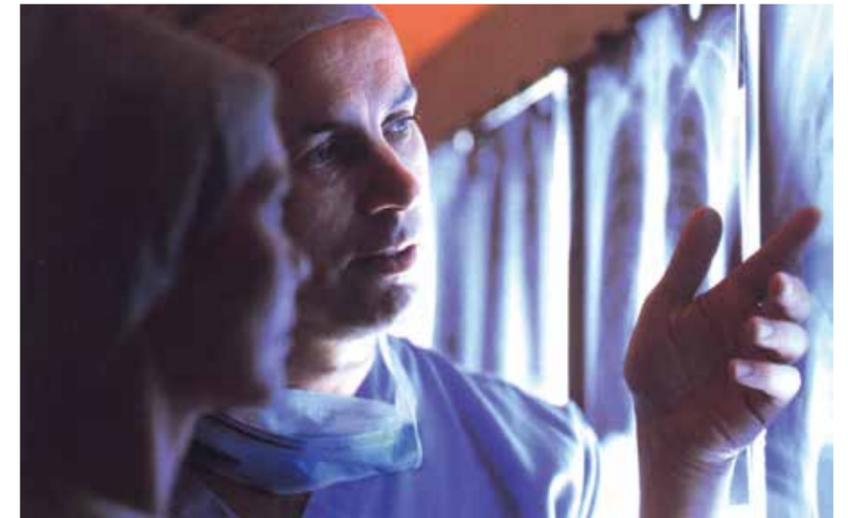
Heterotopic Ossification (HO)

This is a secondary condition in which there is abnormal bone growth in selected joints, most commonly in the hips, shoulders, knees and elbows. It usually occurs within the first nine months of injury and is most often discovered by the physical therapist when limited or painful range of motion is seen.

Medication can slow the growth of the excess bone. HO, along with changes in musculoskeletal system problems, such as various forms of arthritis, osteoporosis, and worsening spasticity (involuntary muscle stiffness) and dystonias (muscle problems causing movement disorders) warns of future problems that must be addressed.

Hearing loss

Hearing problems can occur for a number of reasons, both mechanical and neurologic, particularly when the inner ear and/or temporal lobes have been damaged. All patients should have an otoscopic examination and hearing screening followed by behavioural testing. External bleeding in the ear canal, middle ear damage, cochlear injury, and/or temporal lobe lesions can cause auditory dysfunction.



Visual system changes

Vision and visual functioning is often adversely affected by brain injury. Families, vigilant at the bedside, are often the first to notice changes in the eyes, such as redness, watering and other signs of a problem. A consultation is usually arranged with an ophthalmologist and with treatment, the problem can be brought under control.

Traditionally the occupational therapist evaluates visual perceptual functioning and teaches methods for compensating for any perceptual deficits. In addition, it is important that visual processing and visuomotor ability be evaluated. Some of the more common visual systems problems include double vision, field cuts, sector losses, rapid eye movement and nearsightedness.

Neuroendocrine disorders

Research suggests that chronic neuroendocrine difficulties can occur in women some years post injury. Although

these functions may have been monitored well in the acute phase of recovery, the participants report five or more years later that they were experiencing problems such as weight gain, thyroid disorders, changes in hair and skin texture and perceived body temperature changes. The women additionally complained of chronic sleep disturbances, difficulty controlling blood pressure, a reduction in levels of immunity to infections and arthritic complaints. Indications are that damage in the hypothalamus, limbic system and pituitary may play a role in these disturbances.

Most people with a brain injury are expected to experience a normal life span, barring unforeseen circumstances; families can play a crucial role by keeping an eye out for any further medical problems arising post-injury.

Thanks to the Brain Injury Association of America for permission to adapt this article from their site at www.biausa.org.



In the long-term

In the long-term

Accommodation options

The lack of support and services for people with a brain injury is probably most evident in the lack of accommodation options.

A brain injury can result in a range of accommodation issues. Frequent scenarios include:

- Elderly parents can no longer act as full time carers due to health problems
- An individual with a brain injury with no support, about to be discharged from prison

- A single mother who can no longer cope with her teenager's behaviours and needs him/her to move out
- Parents unable to look after their son/daughter who is about to be discharged and needs 'round-the-clock' medical care
- A person with a mild brain injury in

danger of being evicted as he/she can't budget well enough to pay the rent.

Unfortunately, these scenarios are extremely common and in most states there are very few options available. Any that do exist are usually in huge demand with very long waiting lists. Your local

Brain Injury Association can give you information on what is available.

Long-term facilities

Most States will have facilities that care for people with a severe brain injury on a long-term basis. In most cases, there are very long waiting lists and strict criteria involved. An indication of the chronic shortage is that many younger people with a brain injury wind up spending their lives in nursing homes due to a lack of other options.

Group homes

The most common examples of these are the homes set up in the community for people with a disability - with round the clock staff supervising residents. Unfortunately they usually are not set up for people with a brain injury. There may be group homes that provide a basic level of support for elderly people which may suit people with a mild brain injury who only need minimal support to live independently.

Hostels

Hostels are typically large houses divided into small bedrooms which may be shared or single. There are usually on-site managers who provide differing levels of supervision. Some will provide meals, supervision of challenging behaviours,

laundry services and medication supervision. Many hostels cater for people with a mental illness and have psychiatric support specialists visiting on a regular basis. There are few hostels set up specifically for people with a brain injury so they are frequently unsuitable or a compromise at best. The cost will usually be around 80% of the person's pension or benefit.

Public housing

Waiting lists for public housing are generally long but may be worthwhile for those with a permanent disability who can live independently. The options usually range from detached houses to duplex, town houses, and apartments or sometimes shared living. The relevant government department may be able to provide help with rental bonds, rental subsidies and help with the cost of moving. There may be rental assistance and other supports available for people with a disability, as well as an application list specifically for accessible housing.

Own home with support

Each State government will have its own eligibility criteria and application processes for people with disabilities. Usually there is little money available and people with a brain injury may find the process difficult and unrewarding.

If money is available, it is possible to hire lifestyle support workers to provide the necessary support which may enable a person to live in their own home (or provide carer respite).

There may be community health services who can provide free support through personal care attendants, but there is a long waiting list in most cases.

Call your local Brain Injury Association to find out about lifestyle support workers, community nursing services or Home and Community Care services in your State.

Hope for the future

Synapse has a range of Accommodation Projects for people with Acquired Brain Injuries and Complex and Challenging Behaviours. These establish a continuum of accommodation options from intensive support in behaviour response units, to small group homes, to individual units with drop-in support.

Synapse supports six small group homes and a transitional complex consisting of a shared hub and four independent living skills units. We are developing another complex in Cairns also, to facilitate accommodation options for rural and remote people in need.

For more information, click the supported accommodation link at synapse.org.au

YOUNGER PEOPLE WITH A BRAIN INJURY IN NURSING HOMES

OFTEN, YOUNGER PEOPLE WITH A BRAIN INJURY ARE PLACED INTO AGED CARE FACILITIES AS THERE ARE VERY FEW APPROPRIATE FACILITIES AVAILABLE.

Younger people with a severe brain injury may still be physically fit, but are psychologically and socially debilitated with unique and individual care needs that are not met by generic disability or aged care services.

There are many reasons why aged care is not suitable for younger people with an Acquired Brain Injury. There is often a lack of peer interaction for younger residents who may have nothing in common with other residents. Younger residents are usually more physically fit and stronger, and would benefit from intensive physical rehabilitation which is not available in an aged care facility. Staff often identify difficulties with providing supervision, communicating with, and managing the emotions and moods

of residents with a brain injury. Challenging behaviours such as disinhibition, verbal or physical aggression are often evident following a Brain Injury and staff at aged care facilities are often untrained in management of these.

There is a need for redress in the attitudes of society and service planning provision for people below the age of 65 years with a brain injury requiring long-term high level care. Further research is needed on the views and experiences of younger people with an Acquired Brain Injury residing in aged care facilities and the views and experiences of their families.

Adapted from Younger people with ABI in nursing homes at synapse.org.au

ACQUIRED BRAIN INJURY

Dave was hit by a car while riding a bicycle when he was five years old. Three days later he was discharged from hospital. His behaviour subsequently deteriorated. He found it difficult to concentrate and keep up with his peers at school and was often reprimanded for fighting, leading to suspension from school at age 15. At age 20, he received a sentence for a serious assault charge.

Dave was introduced to illicit drugs and acquired drug dependency problems which, in addition to excessive alcohol consumption, further exacerbated his anger management problems. At age 29, he was assessed and diagnosed with a brain injury. The Crown opposed applications to appeal against conviction and sentence on the grounds that there was no evidence of "psychological cognitive difficulties exhibited by the

applicant, either during the trial or the sentencing proceedings". Dave's disability was dismissed despite the neuropsychological assessment.

Unfortunately Dave's story is a common one. There is an over-representation of people with Acquired Brain Injury in criminal justice systems throughout Australia. Poor community and government recognition of this disability is replicated in criminal justice systems to the detriment of people with Acquired Brain Injuries. As with the wider community, the justice system has little understanding of the devastating nature of Acquired Brain Injury as a disability.

Advocacy services across Australia are working hard to make sure Dave's case isn't the norm. Speak to your local Brain Injury Association to find an advocacy service near you.

INFORMATION FOR EMPLOYERS

SOME EMPLOYERS HAVE THE MISCONCEPTION THAT PEOPLE WHO HAVE DISABILITIES ARE EXPENSIVE TO ACCOMMODATE.

This is not necessarily true. Adapting the workplace and introducing changes are typically low cost and easy to implement. Simple modifications such as a handrail or reducing background noise can allow a person with a brain injury to manage their work environment better. When considering modifications for someone with a brain injury, it is important to remember that this process must be conducted on a case by case basis - with input from the individual. An Acquired Brain Injury may result in a combination of disabilities. The limitations resulting from each of these disabilities may need to be individually accommodated for.

Examples

A police officer, returning to work following surgery for a brain aneurysm had partial paralysis to the left side and could no longer use both hands for word processing. Transferring to a vacant position that involved computer research accommodated him and he was provided a one handed keyboard.

A therapist who developed short-term memory deficits had difficulty writing case notes from counselling sessions. Modification suggestions included: allowing the therapist to tape record sessions and replay them before dictating notes, to schedule 15 minutes at the end of each session to write up hand written notes and to schedule fewer counselling sessions per day.

A labourer working in a noisy factory had difficulty concentrating on job tasks. Modification suggestions included: erecting sound absorbing barriers around his work station, moving unnecessary equipment from the area to reduce traffic and allowing the employee to wear a headset or ear plugs.

Excerpt from the Information for employers of a person with ABI fact sheet at synapse.org.au

Returning to 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 injury.

It is very common, however, for a person to feel that they are ready to return to their previous position well before everyone else thinks they are. The individual's unrealistic expectations are often due to poor self-awareness or denial. If a neuropsychological assessment took place during rehabilitation, this can provide some indications about the areas of difficulty that will need to be addressed in returning to work.

The ability to hold a job is one of the strongest measures of community integration. The single most important factor in predicting return to work is active participation in rehabilitation and in the therapeutic community. The second best predictor is the injured person's self-awareness. The ability to manage emotions is also a significant factor in employability.

Potential barriers

Some barriers in returning to work are:

- An person's desire to work being greater than their actual readiness
- Accessing support e.g. linking with the right employment support agency
- Cognitive impairment
- A lack of opportunities for people to demonstrate what they are capable of
- Poor control over emotions
- Fatigue and other physical problems e.g. dizziness and headaches
- Experiencing a loss of self-confidence after unsuccessful attempts
- Loss of motivation.

Support

Employment support agencies and rehabilitation services often provide programs that may focus upon the person returning to their previous position. This is usually not possible straight away. The results of different assessments can gather information about the person's

strengths and deficits to provide guidelines regarding employment potential. Sometimes a meeting can be organised between the person who was injured, family members, the employer and rehabilitation professionals to discuss a gradual return to work plan. A work trial may be organised to assess how well the person can cope with the demands of different tasks. On-the-job training provides the opportunity for people to relearn previously acquired skills or learn new skills.

Strategies for managing impairments

Understanding the different forms of recovery and adjustment becomes particularly important when people return to work after their injury. It is often helpful to consider which area of impairment might benefit from which form of recovery and adjustment.

Remediation

This involves relearning skills with practice until a certain level has been achieved e.g. practising typing speed.

Substitution

Substitution requires maximising previous skills or learning a new skill to overcome a difficulty e.g. using self-instruction to improve concentration skills.

Accommodation

This is when a person adjusts their goals and expectations to match their level of capability e.g. aiming for a position with less responsibility and a reduced work load.

Assimilation

Assimilation is modifying the environment and expectations of other people e.g. introducing specialised equipment, supportive work environments and educating employers and colleagues about the nature of support required.



Some common recommendations for returning to work include having plenty of rest periods, a routine and structure to tasks, flexibility, reduced hours, supervision and support. Some individual characteristics that may influence level of achievement include self-awareness, motivation, determination and adaptability.

Volunteer work

People who are assessed as not being ready for work may wish to pursue volunteer work (e.g. at a charity organisation) to improve their skills, awareness of personal capabilities, and level of experience. Paid employment may not be a realistic long-term option for many people after Acquired Brain Injury. Accepting this situation can be very distressing for people who have often spent most of their lives building a career. It is hoped that people can pursue other avenues for achievement, satisfaction and productive use of their leisure time.

Managing fatigue

Fatigue is a very common outcome after a brain injury, and it has a serious impact on someone's ability to resume work, especially in jobs needing intense concentration or fast paced decision making. Often survivors can 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 if needed. The problem, of course, is that many work environments won't allow some, or possibly any, of these to happen.

There is a related fact sheet at

synapse.org.au, *Information for Employers*, providing tips for employers in supporting employees with a brain injury.

Legal issues

If a person returns to work after a brain injury they will often find that cognitive impairments can make this a difficult experience. The *Disability Discrimination Act* 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.

Two types of discrimination

Discrimination can be defined as treating people less favourably than others because of some real or imagined characteristic. **Direct discrimination** is treating a person less favourably (because of his or her disability) than a person without that disability in the same or similar circumstances.

Indirect discrimination occurs when a 'condition' prevents a person with a disability, or an associate of a person with a disability, from doing something due to physical barriers, policies, procedures, practices, selection or admission criteria, rules or requirements.

An employer cannot discriminate against someone on the basis of disability. If a person is able to carry out the 'essential activities' of a job despite their disability, they must be given the same opportunity to do that job as everyone else has.

Reasonable adjustments

Employers need to make a reasonable adjustment to the needs of a person with a disability. This means the employer must examine the physical and organisational barriers which may prevent the employment, limit the performance or curtail the advancement of people with disability.

Wherever it is possible, necessary and reasonable to do so, employers are required to make modifications or adjustments to the workplace to meet the particular needs of the person with a disability.

Exceptions are only made if this causes unreasonable disruption or creates a health or safety risk. Examples of reasonable adjustment include changes to work practices or job design, modifications to equipment or premises, and training or other assistance. Whenever it is necessary, possible and reasonable, employers should take into account an individual's needs and make appropriate adjustments to the work environment to accommodate people with a disability.

The first step is to identify the essential functions of the job. Marginal or peripheral functions of the position are not included as the job can be modified or these tasks given to others. Prospective and current staff with disabilities in any type of employment can qualify for reasonable adjustment.

Unjustifiable hardship

An employer can claim unjustifiable hardship in making adjustments for an employee with a disability. The employer is responsible for thoroughly assessing the applicant's request for work related adjustments before claiming 'unjustifiable hardship'. This assessment includes areas such as direct costs, any offsetting tax, subsidy or other financial benefits available, indirect costs and/or benefits.

Contact your local disability employment service to find out more about what is available to you.

In the long-term

Advocacy

As anyone with a disability knows, health services, employers, and society in general, are not always inclusive when a disability is involved. Advocacy is concerned with speaking out about fundamental human needs and rights — about justice and equity for all people regardless of disabilities such as a brain injury.

Advocacy usually addresses situations where:

- Others (service providers) have an obligation to you that they are not fulfilling
- Your rights are ignored or violated
- You have a responsibility that is particularly difficult for you to carry out
- You are being misunderstood or are having trouble understanding others.

So why is advocacy important?

Advocacy is important because you are important. Despite society's progress in the way it supports people with a disability, there is still a lot of unfairness, exclusion and general misunderstanding within the community. In many instances, people with a disability still do not have access to various buildings, services and community associations.

Where are all the advocates?

Many welfare organisations engage in systemic advocacy, which is primarily concerned with influencing and changing the 'system' in general (such as legislation, policy and practices) in ways that will benefit people with a disability as a group. Systemic advocates will encourage overall changes to the law, service policies, government, and community attitudes.

Individual advocacy

Individual advocacy is when the advocate concentrates effort on only one person or a family. The advocate could be a staff member of an organisation, a carer, family member, friend or volunteer. This type of advocacy is focused on the specific needs or situation surrounding the person with a disability.

Most welfare organisations do not provide individual advocacy. For some, their

“Our son has a severe brain injury, and 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?”

constitution or funding criteria may not permit it. For others, it is a lack of funding as individual advocacy is usually quite expensive to provide. Systemic Advocacy is about changing attitudes and ideas of systems and organisations in view of changing those systems for the benefit of many individuals. Most welfare agencies use their limited funding to provide a measure of systemic advocacy which can make a difference to outcomes in the long-term.

If you are seeking an advocate, contact your local Brain Injury Association to see if there is an agency providing individual advocacy services in your area.

Self-advocacy

Self-advocacy can be defined as the act of pleading or arguing in favour of something, such as a cause, idea, policy or active support, for oneself. By self-advocating you are providing yourself with not only the opportunity to resolve your issue, but to learn more about service providers, other people, and most importantly yourself. Trying to bring about positive change for yourself can sometimes feel like an ongoing struggle that requires considerable time, energy, and commitment. Seek assistance where possible, and try to speak with others in a similar situation - it may give you some perspective and add another voice to your cause.



SELF ADVOCACY PLANNER

Though the following plan is not specific to any particular type of advocacy, these techniques are based on educating rather than directing. Work through each step as they are presented before moving on to the next one. Remember, this is only a guide, so use your best judgement when planning to self-advocate.

STEP 1 What do you want to advocate for?

Identify your goals so that you have something to work towards. Gather as much information about the issue as possible then develop a strategy.

STEP 2 Who do you need to speak to?

Remember, you must always give the service provider or organisation a reasonable opportunity to resolve the issue. It will be helpful to become familiar with the complaint process of the organisation you are dealing with. Remember to make notes of the names of people you speak with, what you spoke about, and the date you spoke with them.

STEP 3 What do I say?

State clearly the issue you are talking about and indicate what action you think should be taken to resolve it. Make it clear that you are giving the service provider or organisation a chance to fix a mistake or omission if that is the issue. Where possible provide solutions - not just criticism.

STEP 4 What if I need someone else to assist me to advocate?

Don't feel bad if you wanted to advocate on your own but you had to involve someone else, sometimes it is the only way to resolve an issue.

STEP 5 How do I make contact?

Methods you can use to self-advocate include phone, email, letter, fax, or the media. Choose the method that best suits you, or the one you feel most comfortable with. It is often easier to advocate via email, as tracking is in-built, and there can be little discrepancy.

STEP 6 Where can I get help?

There are several ways you can receive assistance with self-advocacy planning:

- Call your local Advocacy Service for advice or assistance
- Speak to a friend or peer about your thoughts
- Talk to your local ombudsman about your rights
- Contact a lawyer or research online to understand the laws around what you're advocating

In the long-term



PETS AS PART OF REHABILITATION

The inclusion of pets into hospital and rehabilitation environments has long been considered very therapeutic. Pets can continue to be an important part of life long after rehabilitation has ended.

In addition to filling lonely hours with companionship, pets can be trained, much like the more familiar Guide Dogs, to perform tasks and assist persons with disabilities in many different ways. The responsibility for pet care can enhance cognitive functioning in ways that are more subtle and enjoyable than traditional therapies. Fun activities often stimulate people with low motivation in ways that are not often achieved by sitting in front of a television set for hours on end.

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

People 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 - their pet! Pets always have time for sharing with their owners and their loyalty is indisputable.

Pet therapy is a well-established routine in many hospitals, nursing homes and rehabilitation centres. Anecdotal accounts tell of the benefits of pets being in the presence of people in all stages of recovery, rehabilitation and even end-stage illnesses. The comforting and calming affect of stroking a furry animal often elicits more relaxing facial expressions and/or postures in persons even thought to be in minimally-responsive states. Nonverbal people generally respond with contented smiles when pets are introduced into their environment. Almost all people with disabilities can take some responsibility for the care of an animal, even if it's no more than a daily stroking or play session.

Many thanks to the Brain Injury Association of America at www.biausa.org for permission to adapt this article.

Returning to studies

Survivors of Acquired Brain Injury (ABI) who have done very well in their recovery still face a major hurdle in returning to their studies.



A number of factors following an ABI may make this difficult. First of all, loss of short-term memory will make it very hard to learn. Second, school has a fair amount of fatigue associated with it. With a brain injury, people can have limited energy and may be good in the morning, but fade early in the afternoon. Third, returning to school or university involves a social dimension — people very desperately want to fit in with their peers. For some people, having some friends they can hang out with is their number one priority.

Common problems and strategies

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 concentration daily but this is not as simple as it sounds. Keep periods of concentration short by allowing regular breaks. Start with ten minutes and build up gradually with a few extra minutes daily.

Lack of insight

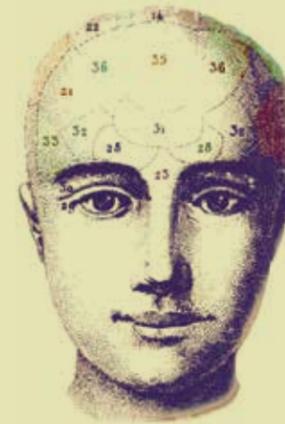
Many students with an Acquired Brain Injury have a lack of insight regarding their level of ability and are unable to recognise that their performance and capabilities are functioning at a reduced level. They may respond to negative feedback by believing that teachers are against them, or other ways that allow them to believe their performance is still normal. Teachers should be informed of appropriate

responses to gradually improve insight, if possible.

Lack of organisational skills

Planning and organisational skills can sometimes be impaired to the extent that the student knows what he or she wants to do, but has difficulty getting started. This means that the person will need a very clear plan of how to go about carrying out a task. The first step will be to stop and think – he or she will need time and support to work out a plan by identifying the task, keeping it simple and addressing one task at a time:

- Write down all the steps required to complete the task
- Sort out the list of steps in the order they are to be achieved



BRAIN SURGERY IN THE STONE

SURGERY HAS BEEN AROUND A LONG TIME. EVEN 12 000 YEARS AGO, PEOPLE HAD HOLES CUT IN THEIR SKULLS IN MANY DIFFERENT CULTURES.

Even more surprisingly, they occasionally survived. In the 19th century, Fijians were using this surgical technique, 'Trepination', to treat brain injuries.

When someone's skull was cracked, Trepination was used to reduce the pressure from brain swelling and reduce the risk of death and permanent brain injury. The most remarkable fact was that the Fijians achieved a 70% success rate while London surgeons at that time only had a 25% success rate!

The Fijian's trick was largely one of hygiene. They would wash their hands and the injury repeatedly in coconut milk which is remarkably similar in chemistry to our body fluids (it has even been used for transfusions when blood products have run out in war zones!) Scalpel and tweezers were made of bamboo for cutting and removing bone and damaged brain tissue. After sewing up the wound, it would be checked a few days later for infection which would be cleaned out again with coconut milk.

As you would have guessed, the main problem for the English surgeons was a lack of hygiene in badly overcrowded hospitals. Things have improved somewhat so thankfully there is no need to bring on the coconuts and bamboo today.

"Brain Surgery in the South Pacific", Medical Observer, 17 March 1995, pp. 74-75.

- 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 break between each step if needed
- Review each preceding step before moving onto the next.

Short-term memory problems

Students may lose books and equipment, forget appointments and arrangements, ask the same questions again and again, or forget which classroom they are supposed to be in. Fortunately, there are ways to assist memory and it can be an exciting challenge to work out new avenues to compensate for problems. Students with memory issues may need to become familiar with using memory aids and may need constant reinforcement by teachers, who should be informed of how to respond. Try to think laterally and come up with a way to incorporate aids into everyday living - like by using a mobile phone. This can make individuals more likely to use them.

Stress, frustration and anger

A common trigger to personal stress is a feeling of helplessness or being trapped in a situation over which we have no control. Disciplined or authoritarian environments can add to a student's belief that they are being deprived of alternatives. The student should be able to choose from a number of options in dealing with these emotions.

The triggers for these emotions should be identified, and where possible, avoided. When this isn't possible, relaxation and meditation can act as good insurance policies. When high levels of anger or aggression are imminent, the student should be able to take time-out, having planned for this already with teachers. This needs to be seen as an opportunity to restore balance and perspective, not punishment.

Impulsive behaviour

Behaviours displayed are often a genuine case of innocently doing what seemed to be a good idea at the time. Strategies should be discussed with teachers so that

undesirable behaviour can be replaced with an agreed alternative. It is also helpful to agree on a signal that the teacher can give as a sign for the student to stop and think about what they are doing. It could be a word, or a sign (e.g. arm up in the air). In time it will become an automatic process.

Allowances

All educational institutions now have policies that make allowances for people with disabilities in terms of tests and assignments. These institutions are often unaware of the multiple impacts on a student's abilities such as short-term memory difficulties, fatigue, lack of concentration, susceptibility to stress and lowered organisational ability. Students should contact their Disabilities Officer to make suitable arrangements for tests and assignments.

Many schools and universities will help you learn new material if you let them know that you have a disability. There is still little awareness of brain injury in many organisations so you may need to present this information to them to acquaint them with this particular disability. It may help if your doctor or neuropsychologist writes a letter to document that you have a valid disability.

You will need to explain the accommodations or special help you require, such as:

- Extra time for assignments and exams
- Exams in a quiet room
- Copies of teacher's notes if concentration is affected.

Some study strategies

Organising yourself will be crucial. Some useful suggestions to try are:

- A good diet, regular sleep and exercise
- Avoiding alcohol, cigarettes and drugs
- Structure your days and week
- Use memory prompts such as notepads, alarms and a notice board
- Experiment on study times and find when you're most alert
- Structure your study times and try to stick to them
- Join study groups

This glossary covers many of the basic terms used in the context of Acquired Brain Injury, both in the hospital stage and during rehabilitation.

A

Acquired Brain Injury/ABI: This is any organic damage to the brain occurring after birth. ABI can have a number of causes including (but not limited to) Trauma (TBI), Stroke, Degenerative Diseases (like Alzheimer's), Hypoxia and Alcohol & other Drugs.

ADHD: Attention Deficit Hyperactivity Disorder (sometimes ADD or Attention Deficit Disorder) usually manifests in childhood or adolescence, and tends to linger through adulthood. Behaviours can include difficulty maintaining attention, hypersensitivity to stimuli, incessant talking, impulsivity, incessant movement, ignoring or tuning out, anxiety, frustration and irritability.

Adynamia: A lack of motivation after trauma to the frontal lobes. Characterised by difficulty initiating activities or completing tasks. Gives the appearance of lethargy.

Affect: Your experience of an emotion, and the behaviour that arises from it.

Agnosia: A disorder of recognition from injury to higher order information processing cells which can result in an inability to recognise or distinguish faces or objects.

Apraxia: Inability to write that can arise from damage to areas of brain responsible for cognitive or motor skills necessary to write.

Alculia: A disorder characterised by an inability to comprehend or write numbers or perform arithmetic operations.

Alexia: Inability to read due to brain damage causing cognitive or visual problems.

Alzheimer's disease: Degenerative disorder of the brain with cognitive decline due to appearance of plaques followed by development of neurofibrillary tangles in the cells of the brain.

Amnesia: Inability to remember learned information. Acquired Brain Injury can cause retrograde amnesia (loss of recall of events right before the trauma) and/or anterograde amnesia (loss of recall of events for some period of time after the trauma). Another term for anterograde amnesia is post-traumatic amnesia or PTA.

Anoneiria: Inability to dream due to trauma of the areas of the brain responsible for

creating dreams, which may include the medio-basal forebrain, inferior parietal cortex, medial temporal lobe or occipito-temporal cortex.

Anosmia: Loss of the sense of smell by either mechanical damage to the olfactory nerve or damage to areas in the anterior temporal or orbito-frontal lobes that process the sense of smell.

Anoxia: No oxygen in cells of the body. If prolonged, will cause cell death. Can be due to no oxygen reaching the blood, e.g. through strangulation or suffocation, or can be due to no blood reaching the cells, e.g. through the heart stopping or blood flow being stopped in one area by an embolism.

Aphasia: Difficulty understanding or expressing language as a result of damage to the brain.

Apraxia: Inability to voluntarily perform skilled movements.

Arterial line: A thin tube (catheter) inserted into an artery to allow direct measurement of the blood pressure, amounts of oxygen and carbon dioxide in the blood.

Asymptomatic: Without symptoms. If someone is asymptomatic, they have no symptoms that are evident.

Ataxia: Abnormal movements due to the loss of coordination of muscles.

Autism: Developmental disorder of the brain that may lead to lack of social response, inability to cope with change, and ritualised behaviours.

Autonomic Nervous System: This is the part of the Peripheral Nervous System that controls functioning mostly below the level of consciousness. e.g. heart rate, digestion, respiratory rate, salivation, perspiration etc.

Axon: The long slender projection of a nerve cell that allows it to conduct electrical impulses and deliver them to other cells - allowing for communication.

B

Blood clot: A solidified localised collection of blood.

Brain stem: The lower extension of the brain where it extends to the spinal cord. Neurological functions located in the brain stem include those necessary for survival (breathing, heart rate) and for arousal (being awake and alert).

Burr hole: A 10-20mm surgical drill hole made through the skull.

C

CAT Scan: Computerised Axial Tomography, also known as Computerised Tomography or CT Scan. A scanning technique that uses a rotating X-ray machine to record slices of your body.

Catheter: A tube which is inserted into any body part to withdraw or introduce fluids.

Cerebellum: The portion of the brain (located at the back) which helps coordinate movement. Damage may result in ataxia.

Cerebral: Concerning the brain.

Cerebral Angiogram: X-ray picture of the blood vessels inside the head. A drug is injected via the groin artery which outlines these cerebral vessels.

Cerebral Cortex: The outer layer of the brain, responsible for cognitive processes including reasoning, mood, perception of stimuli and other thought processes.

Cerebrospinal Fluid (CSF): Liquid which fills the ventricles of the brain and supplies the brain and spinal cord with nutrients.

Chronic: In medicine, this means lasting consistently for a long time. A 'Chronic' condition lasts for 3 months or more. This is in contrast to acute (abrupt/sharp/brief) and subacute (between acute and chronic).

Cognitive: The function of the mind by which we become aware of all aspects of perceiving, thinking and remembering.

Coma: The state of not being responsive or able to be aroused. Person does not open their eyes, follow commands or speak.

Concussion: Disruption of brain function usually from a blunt impact to the head causing the brain to bounce inside the skull.

Contrecoup: Bruising of the brain tissue on the side opposite to where the blow was struck.

Contusion: Another name for a Bruise, caused when blood vessels are damaged or broken often as a result of trauma.

Craniectomy: Surgical removal of a section of the skull.

Craniotomy: The making of a surgical opening through the skull, by removing

a segment of bone, which is usually replaced. This allows access to the brain and its coverings.

CSF: see Cerebrospinal Fluid.

CT Scan: see CAT Scan.

Chronic Traumatic Encephalopathy (CTE): A progressive degenerative disease of the brain often found in athletes (e.g., boxers, football players) with a history of repetitive brain trauma, including symptomatic concussions as well as asymptomatic sub-concussive hits to the head (i.e., injuries without symptoms).

D

Dementia: Includes, but is not limited to, Alzheimer's Disease, Dementia following Head Injury, Parkinson's Disease, Dementia following HIV, and Substance-Induced Dementia. Dementia was formerly used in the DSM to define a disorder that presents with memory impairment and multiple cognitive deficits. See Neurocognitive Disorder.

Diagnostic Statistic Manual for Mental Health (DSM): This is the guide by which Psychologists and Neuropsychologists categorise and diagnose mental health disorders.

Diffuse Axonal Injury: This is widespread damage to the Axons in the brain that deliver signals between cell bodies.

Diffuse Brain Injury: Injury to cells in many areas of the brain rather than in one specific location.

Disinhibition: Loss of control over impulses due to frontal lobe trauma.

Dysarthria: Speech impairment resulting from damage to the nerves and areas of the brain that control the muscles used in forming words.

Dysautonomia: A malfunctioning of the autonomic nervous system, presenting primarily as ineffective temperature regulation and ineffective regulation of heart-rate and breathing.

Dysexecutive Syndrome: Impaired executive functioning, usually resulting from damage to the frontal lobes.

Dysphagia: Difficulty with swallowing.

Dysphasia: See Aphasia. Dysphasia is a milder form of Aphasia.

Dyspraxia: See Apraxia. Dyspraxia is a milder form of Apraxia.

E

Echolalia: Imitation of sounds or words without comprehension. This is a normal stage of language development in infants but is abnormal in adults.

EEG: EEG or Electroencephalogram is a test used to record any changes in the electrical activity of the brain. An EEG is often used in the testing of epilepsy.

Embolism: Blood clots are the clumps that result from coagulation of the blood (blood hardens from liquid to solid). A blood clot that forms in a blood vessel or within the heart and remains there is called a thrombus. A thrombus that travels to another location in the body is called an embolus. The disorder is called an embolism. For example, an embolus that occurs in the brain is called a cerebral embolism.

Embolus: See 'Embolism'.

Emotional lability: Repeated, rapid, abrupt shifts in emotion that are not related to external stimuli.

Epilepsy: A chronic condition caused by temporary changes in the electrical function of the brain, causing seizures which can affect awareness, movement and sensation.

Executive Function: Range of abilities to plan, monitor oneself, learn from experience and accomplish steps to reach a goal. Executive functions include attention, concentration, planning, initiation, and problem solving.

Focal Brain Injury: Injury restricted to one region (as opposed to diffuse).

Frontal Lobes: The region of the brain directly behind the forehead. Responsible for Executive Functions, a variety of "higher cognitive functions", and motor control. Damage can cause changes to personality, dysexecutive syndrome, problems with spoken language, impaired social skills, and paralysis.

G

Glasgow Coma Scale: Measures the degree of disturbed consciousness arising from trauma.

H

Haematoma: A collection of blood in an organ, space, or tissue, due to a break in the wall of a blood vessel.

Hard Collar: Stiff plastic collar worn to support the neck.

Hemianopia: Blindness in the same sides of both eyes which can follow damage to the brain. This can cause an inability to see on the left or right side.

Hemiparesis: Weakness, partial paralysis or loss of movement that only affects one side of the body.

Hemiplegia: Paralysis of one side of the body. May be associated with spasticity - increased muscle tension and spasms.

Heterotopic Ossification: Abnormal deposits of bone in muscle.

Homeostasis: The ability of the body to maintain a stable internal environment, e.g. temperature, breathing, blood-sugar levels. Mainly controlled by the Autonomic Nervous System through the hypothalamus.

Hydrocephalus: Enlargement of the ventricles due to an increase of fluid (CSF) on the brain. Often due to a blockage in the ventricles preventing them from draining into the nervous system. Can cause ABI.

Hypertension: Abnormally high blood pressure.

Hypotension: Abnormally low blood pressure.

Hypothalamus: Small region of the brain at the top of the brain stem which regulates the Autonomic Nervous System.

Hypoxia: An insufficient supply of oxygen to cells of the body. May result in cell death if severe. Can be through not enough oxygen reaching the blood, e.g. due to drowning or carbon monoxide poisoning, or not enough blood reaching the cells, e.g. due to bleeding or constricted blood vessels such as a blood clot causing a stroke.

I

ICP/Intracranial Pressure Monitor: is a monitoring device to determine the pressure within the brain. It consists of a small tube (catheter) in contact with the pulsating brain or the fluid cavity within it. ICP is measured by means of a metal screw or a plastic catheter connected to an electronic measuring device.

Impulsivity: A tendency to rush into something without thinking or reflecting first.

Intra-Cerebral Haematoma: A blood clot in the brain.

M

Meninges: The three membranes that cover the central nervous system. From outermost to innermost: Dura Mater, Arachnoid Mater, Pia Mater.

Meningitis: An inflammation of the meninges.

Migraine: Severe headache often associated with sensitivity to light or noise. May emerge after acquiring a brain injury.

Minimally Responsive State/MRS: A state of consciousness following a coma in which the patient appears to be awake but is unable to respond to their environment and can only make reflex movements. Previously known as Persistent Vegetative State or PVS.

MRI (Magnetic Resonance): Imaging enables detailed pictures of the brain to be acquired using a scanning machine. It uses a strong magnet rather than X-rays.

N

Neurons: Nerve cells in the brain, spinal cord, and peripheral ganglia that communicate via electrical signals. The cells most often comprise of a cell body, axon and dendrites.

Neuropsychologist: A psychologist with further studies in brain function, personality and behaviour.

Neurocognitive Disorder: The DSM-5 has moved towards this as a new categorisation of disorders attributable to changes in brain structure, function, or chemistry. The core or primary deficit is cognitive, and the deficit represents a decline from a previously attained level of functioning. ABI, Dementia, Stroke and Parkinson's are now able to be defined as 'Neurocognitive Disorders'.

O

Occipital Lobes: Region in the back of the brain which processes visual information. Damage to this lobe can cause visual deficits.

Oedema: Increased fluid content in the brain causing swelling.

P

Parietal Lobes: Located in the middle and top of the brain. Responsible for visual attention and processing, spatial awareness, touch perception and

manipulation, voluntary movements, and the integration of different senses. Damage can cause difficulty with identifying or naming objects, difficulty with writing or mathematics and difficulty with motor coordination or being aware of space and distance.

PEG Tube: Short for "Percutaneous Endoscopic Gastrostomy" tube. A tube inserted into the stomach through the abdominal wall to provide food or other nutrients when eating by mouth is not possible. Commonly used for patients in a coma or PVS.

Perseveration: Persistence of a response in a current task which may have been appropriate for a former task. Perseverations may be verbal or motoric.

Persistent Vegetative State/PVS: See Minimally Responsive State (MRS).

Post-Traumatic Amnesia/PTA: This refers to the period following brain trauma when the victim is unable to effectively imprint and retain a stable, continuous memory of events. See also Amnesia.

Premorbid: Existing before the injury. This can refer to attitudes, interests, personality traits or medical conditions.

Proprioception: The sensory awareness of the position of body parts with or without movement.

S

Seizure: An uncontrolled discharge of nerve cells, usually lasting only a few minutes. It may be associated with loss of consciousness, loss of bowel and bladder control, and tremors.

Sequelae: Pathological condition occurring as a result of an illness or injury, typically chronic. e.g. A loss in short-term memory following a brain injury.

Shunt: An apparatus designed to remove excessive fluid from the brain. A surgically placed tube which transfers fluid into either the abdominal cavity, heart or large veins of the neck.

Spasticity: An involuntary increase in muscle tone (tension).

SPECT: Single Photon Emission Computed Tomography. A diagnostic scan that uses a small, safe amount of a radioactive drug to measure blood flow inside the brain. Not as sensitive as a PET scan, but more useful for examining seizure activity.

Subarachnoid: Beneath the Arachnoid Mater. This is in between the Arachnoid and the Pia Mater, the inner two meninges covering the Brain and Spinal cord.

Subdural: Below the Dura, the outermost meninx. Most often in between the Dura and the Arachnoid layers.

Symptom: Evidence of an illness or injury e.g., anything that the patient experiences as a result of that illness or injury.

Synapse: Neurons communicate with one another via synapses. This is where the axon and dendrites of cells join together to facilitate communication and hence brain function.

T

Tachycardia: Excessively rapid heartbeat. Usually refers to a heartbeat of greater than 100 beats per minute (BPM).

Temporal Lobes: Located at about the level of the ears. Responsible for interpreting and understanding sounds, categorisation of objects, some visual processing and short and long term memory. Damage can result in impaired memory, hearing and recognition of objects.

Thermoregulation: The maintenance of a stable body temperature. Thermoregulation can be impaired through damage to the brain stem, particularly the Hypothalamus.

Thrombus: Blood clots are the clumps that result from coagulation of the blood (blood hardens from liquid to solid). A blood clot that forms in a blood vessel or within the heart and remains there is called a thrombus. See also Embolism.

Tracheostomy (Trachy): This is a breathing tube inserted through the middle of the neck just below the voice box. Through this tube an adequate air passage can be maintained. It may be necessary to leave the tube in the windpipe for a prolonged period.

V

Ventilator: This is a machine that does the breathing work for the unresponsive patient. It delivers moistened (humidified) air with the appropriate percentage of oxygen and at the appropriate rate and pressure.

Ventricles: Cavities (spaces) inside the brain which contain cerebrospinal fluid.



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The under 18's got the premiership... and two brain injuries.

It stuns a worrying number of people to learn that a simple game of footy can result in someone suffering an Acquired Brain Injury (ABI). At Synapse, we're dedicated to improving the awareness of ABI. Without your help however, we could not hope to achieve the level of awareness required to reduce the devastating effects of brain injury. For some 1.6 million Australians and their families, life will never be the same again. Don't let it be unbearable. Your support, no matter how small, will help us reconnect their lives.



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At Synapse we're dedicated to improving the quality of life of those living with, or affected by Acquired Brain Injury (ABI). One of the biggest issues facing people with ABI is finding a place to live. Through our accomodation services we can help those affected to lead a more fulfilling life.

The ultimate goal being self sufficiency and a return to the community. Without your help, we could not achieve the level of support demanded by the 1.6 million Australian currently suffering an ABI. Your support, no matter how small, will help us, help them reconnect their lives.



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Information, strategies and supports to ensure that people with a brain injury, their families and carers can make the most out of life.

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The Brain Injury Association of Queensland