Let’s talk about brain injury

A practical guide to support people impacted by brain injury

‘Let’s talk about brain injury’ has been developed as part of a suite of information products about brain injury produced by a joint committee of brain injury organisations with the support and assistance of the National Disability Insurance Agency.

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If you require a language interpreter contact:
Translating and Interpreting Service
(telephone: 131 450).
This service is free of charge.

This guide has been codesigned in partnership with people with lived experience of brain injury and their families and carers. We thank them for their participation.

It is common and understandable for family members to have many questions about the long-term effects of brain injury on the injured person's ability to function in the future. This booklet is a guide for your journey through the acute (immediate) and following stages of brain injury. All brain injuries are different and not every situation will be the same.

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About brain injury

Our brain is the body's control centre. It controls everything that we do, think and say. When our brain is injured, it can affect many aspects of life. It brings with it many adjustments and challenges – the stages of assessment and recovery are slow and it is a difficult time for everyone involved. It may also be some time before you know exactly how much damage has occurred.

What is Acquired Brain Injury (ABI)?

Acquired Brain Injury (ABI) refers to any damage that happens to the brain at any age after birth. Damage to the brain can occur in many different ways: through illness, such as dementia or a stroke, a heavy blow to the head, or by the head being forced to move rapidly forwards and backwards, such as in a car accident or assault.

Brain injuries caused by a blow to the head or rapid force often result in a loss of consciousness: either short term (less than 30 minutes) or long term (hours, days or months), which is called a coma. The effects of brain injury can be mild or severe, temporary or permanent.

Some common causes of brain injury are:

- Accidents: car, sporting
- Assaults
- Falls
- Tumours
- Stroke and aneurysms
- Infections such as meningitis and encephalitis
- Alcohol or substance abuse
- Interruption of oxygen supply to the brain during near drowning, heart attack or suffocation
- Neurological disorders such as Multiple Sclerosis, Motor Neuron Disease or dementia

Minor Brain Injury

Even minor brain injury can have a lasting impact. Sometimes the problems caused by minor brain damage are difficult to detect. For example, a person may feel less able to concentrate, they may be more forgetful or have more trouble making decisions. If you are unsure about whether you have a minor brain injury, ask your doctor for advice on the specialist testing available.

The Hidden Disability

Acquired brain injury is sometimes called the invisible or hidden disability because its effects are not easy to see or they are not recognised as ABI. The new ways of thinking, feeling and behaving are not as easy to recognise as other disabilities such as vision impairment or a loss of ability to walk.

As a result, the challenges people with brain injury face are often misunderstood or ignored. For example, it can be easy to lose patience with someone whose brain injury causes them to be forgetful.

Common effects of brain injury

Brain injury sometimes causes people to experience changes in their physical abilities, the way they communicate and think, and their ability to control their emotions and behaviour. It is important to understand that the number, and severity, of changes resulting from a brain injury will be different for each person and there are many management and coping strategies to help everyone with these.

Cognitive changes after brain injury

Cognition refers to our brain's ability to think, understand and remember. Injury to the brain can affect these cognitive processes and based on a variety of factors, may become more noticeable with time.

Common cognitive effects may include:

- Difficulty concentrating and taking in new information
- Short term memory loss
- Problem solving and decision making
- Understanding and awareness of their brain injury
- Disinhibition (display behaviours that are considered rude or offensive, be impulsive and display poor judgement of risk)
- Lack of motivation and ability to get things started

Speech and communication changes after brain injury

A brain injury can affect communication in many different ways. An injured brain may lead to weak or uncoordinated muscles resulting in poor speech or a soft, hoarse voice or the language centre may be affected making it difficult to form sentences and understand what others are saying.

Common communication changes may include:

- Hearing loss
- Vision impairment (poor eyesight)
- Dyspraxia (difficulty sounding out words)
- Dysphonia (difficulty controlling voice sounds)

Managing Fatigue

Fatigue is a common symptom experienced by people with a brain injury. It can occur for no apparent reason and may be caused by physical or mental activity. It can intensify the other effects from a brain injury as well. It is also common in people caring for someone with a brain injury as they find themselves managing increased workloads and greater responsibilities.

Fatigue is real, and it is important to know that there are ways to help you minimise and manage it.

For more information about the common effects of brain injury contact;

BrainLink Services – 1800 677 579
www.brainlink.org.au

Acute care

What might happen in hospital?

The acute care phase of a brain injury often includes emergency care in hospital. It can be one of the most overwhelming times for families. Since brain injuries often happen through an accident, it is not unusual for a person to have other injuries. A series of tests are performed to diagnose the injuries and a team of medical staff work to stabilise the patient's condition.

Some of the outcomes of a brain injury, which are treated in acute care, include:

- Brain Swelling
- Spinal Injuries
- Coma
- Post-traumatic amnesia (loss of memory)

Brain Swelling

Sometimes when the brain is injured, swelling occurs and it compresses the brain inside the skull. Swelling can create pressure on the brain which can lead to further brain damage. Treatments for brain swelling often involve medication, a catheter (thin tube) to drain increased fluid from the brain or surgery.

Spinal Injuries

If there is suspected spinal injury, the patient may be placed in a hard collar to restrict their movements and help prevent further injury to the spine until any damage to the spine has been investigated. Hard collars are used as a precaution and do not mean that the patient definitely has a spinal injury.

Coma

Deep in the centre of the brain is an area that is responsible for keeping us aware of what is happening around and inside us. If this area of the brain is damaged, a coma follows.

Coma is the loss of consciousness in which patients lose their ability to speak, open their eyes and respond. Mild brain injury can cause a coma that lasts for one to two minutes, but a severe brain injury can result in a coma that continues for days and, in some cases, even longer.

Coming out of a coma

A person does not suddenly wake up from a coma. As the coma lightens, the person may begin to respond to someone's voice or touch, but the process is slow. It can be an anxious time for family members, but great anticipation too.

Post-traumatic amnesia

At first, the patient may not recognise you or other people they knew before the coma. They may be confused about where they are, who they are and what has happened to them.

When a person is regaining consciousness, they may not be able to remember recent events or even the things that happened to them. This is called Post Traumatic Amnesia (PTA).

In the early stages of post-traumatic amnesia , a person may be fearful, aggressive, disoriented and restless. People experiencing PTA become easily agitated and are often unable to cope with a lot of noise, movement or activity. It is important to keep outside stimulation to a minimum, which may mean few visitors allowed and for short periods of time.

Treatment during acute care

Soon after admission to hospital, tests and scans may need to be done to rapidly assess the damage to the brain. There are a range of tests that examine the brain and determine appropriate treatment.

MRI, CT and MRA	MRI (magnetic resonance imaging) scans and CT scans (computer axial tomography scans) help to determine the location and extent of any damage and whether surgery is needed. An MRI scan uses a magnet and radio waves to produce a detailed image of the brain. A CT scan is a series of x-rays taken at different levels of the brain.

Intensive care unit

Each person in intensive care is allocated one nurse. Their condition will be monitored 24 hours a day. The aim of immediate treatment is to maintain breathing and to minimise brain swelling. While in intensive care, a person may:

- Be unconscious
- Be conscious but unable to speak
- Be heavily sedated
- Wear eye pads to stop their eyes drying out
- Have tubes in their nose, mouth or throat to assist breathing
- Have a shaved head from surgery
- Perspire excessively

Initially, it can be a shock to see so much machinery attached to a person. It helps to understand what these machines do. Don't be afraid to ask the nurses to explain their functions to you.

Family members can reassure a person in intensive care by simply talking with them and behaving in their presence as if they were conscious.

When a person's medical condition has stabilised, they will be transferred from intensive care to a ward. This is a good time to bring in some of their belongings: for example photos, which can give staff an understanding of who the person was before the trauma and helps staff talk to them in a familiar and supportive way.

Your care team

It is important to become familiar with the different hospital departments, wards and key staff that are providing the treatment for your loved one.

Many professionals make up the health care team. Your family member may go to the neurosurgical ward which specialises in the care of people with brain and spinal cord injuries or disease. Staff who work here include nurses with expert training in brain and spinal injuries, neuro-physiotherapists, occupational therapists, dieticians, speech therapists and social workers.

Caring for Yourself

When a family member is in hospital, it is natural to put their needs before your own. It is important to remember that to make sure the person you are caring for gets the best outcomes, you also need to look after your own emotional and physical health.

Here are some ideas on how to cope with the traumatic experience of having a loved one sustain a brain injury:

- Understand everyone reacts differently to stress
- Accept support from people around you. Ask a friend, family member or hospital social worker/patient liaison officer to help you in discussions with the health care team.
- Talking with other people about your feelings can help you process what has happened
- Setting up a Facebook page for your family member and updating this about their condition can keep friends and family informed about patient's progress and reduce pressure on you.
- Write down your questions for the medical staff.
- Ask for an interpreter at any meetings if English is your second language.

For ideas and advice about how to confront acute care situations visit:

Brainlink services
1800 677 579
www.brainlink.org.au

Carer Gateway — 1800 422 737
www.carergateway.gov.au

Rehabilitation

What is Rehabilitation?

Rehabilitation is a variety of therapy services that help maximise recovery. Rehabilitation often occurs in the hospital or a rehabilitation unit and can continue months after injury.

Depending on the nature of a person's injury, rehabilitation programs are tailored to the needs of each individual. The aim of rehabilitation is regaining previous skills and teaching strategies to overcome ongoing challenges. While medical therapy cannot repair brain cells destroyed by the injury, the brain can learn to develop new ways of processing information.

The type of rehabilitation program a person has depends on:

- The nature of injuries
- The type of professional therapy required
- A person's rehabilitation needs
- A person's capacity to pay
- A person's eligibility for insurance cover
- Where a person lives

Ask your health care team for information about the different options for rehabilitation and if possible, ring or visit several facilities to make sure their programs will meet your particular needs. Convenience and location are important, but your primary consideration should be the quality and level of therapy provided.

Is full recovery possible?

Predictions of recovery after a brain injury are difficult for the person with the brain injury and their family members.

It is important to understand that a person's condition is changing as they recover. Often when participating in a rehabilitation program families find that the information given to them in hospital about their loved one's condition, and their chances of improvement, has changed. Doctors make the best estimate they can based on the severity of the brain injury, but these are only ever a guide.

Some families feel very angry about this and can be frustrated at the lack of knowledge about the future. Families are entitled to ensure that their loved one's best interests are being served. There are many things people can do to maximise a person's recovery throughout rehabilitation and beyond.

Here are some tips on how to make the most out of the rehabilitation process:

- Request a treatment meeting with the doctor or nurse in charge.
- Keep a diary to record key appointments.
- Be resilient and keep a positive attitude about setting goals for recovery.
- Find comfort and learning in sharing your experience with others with a family member going through rehabilitation.

Watch an inspirational story about rehabilitation and recovery at **www.braininjuryassist.org.au**

For more information on rehabilitation and recovery contact:

BrainLink Services
1800 677 579
www.brainlink.org.au

Synapse
1800 673 074
www.synapse.org.au

Life with brain injury

What to expect

At the very heart of the recovery process is the question of how to live with a brain injury. When a loved one has a brain injury, it is often likened to a ‘ripple effect’ where the impact can be felt by the whole family, friends and the wider community. A person with a brain injury may behave differently and exhibit changes that are not in keeping with their personality before the injury such as:

- Egocentric or self centred behavior.
- Disinhibition around others (loss of ability to understand what social behaviors are OK) and poor social skills.
- Emotional outbursts.
- Increased anger and frustration.

Dealing with these changes can be difficult but there are experts at identifying these changes who can assist to develop strategies to manage and respond to behaviour.

Common reactions after Brain Injury

Adjusting to life after brain injury will present challenges, particularly for those who provide direct care. Carers often feel overwhelmed, confused and shocked responding to the demands of caring for someone and may feel there is no time to focus on their own needs. It is perfectly normal to experience these feelings. There are no right or wrong feelings. These feelings may include:

- Guilt
- Anger
- Resentment
- Fear and anxiety
- Stress
- Grief and Loss

Remember, you are reacting normally to a traumatic life event. Each person will have their own unique experience and it is important to acknowledge that your feelings are valid.

Coping with grief and loss

When we lose something or someone we value, we experience a great deal of emotional pain. It is a natural and normal reaction. Death is one such loss when we experience grief. There is no clear set of ‘steps’ in a grieving process and grief can often strain relationships to breaking point. The important thing is to allow yourself to grieve, in your own time and in your own way.

Coping with grief and loss for families following brain injury is complex. People with a brain injury may be physically present but they may appear to be a stranger to the family. Families often describe grieving for the person they used to be or over the loss of life they had before. This type of grief is known as ‘disenfranchised grief’ and can leave people feeling frozen in grief. Many carers often feel they cannot admit, even to themselves, how terrible they feel. It is important for people to acknowledge this loss and seek support when needed.

Ignoring grief won't make it go away and there are supports available for families that focus on finding strategies to strengthen resilience to manage grief and loss following a brain injury. These include:

- Learn to recognise your feelings and why you have those feelings.
- Acknowledge that you are grieving- it's OK to grieve.
- Find someone to talk to, perhaps a friend or trusted family member who will listen or consider a social worker or grief counsellor.
- With hope, there is a future. There is always something to hope for, however small or large. Don't let anyone talk you out of it.

Listen to personal stories from some of our carers about managing feelings during difficult situations at **www.braininjuryassist.org.au**

Help is at hand. Seek support by contacting:

BrainLink Services – 1800 677 579
www.brainlink.org.au

Carers Australia (VIC) – 1800 242 636
www.carersvic.org.au

Department of Health & Human Services
Carer & Family Support – 1300 650 172
www.dhhs.vic.gov.au

Adapting to life with Brain Injury

Many people with a brain injury will be unable to live alone without assistance. They may need help because of a physical impairment or they may have memory, planning and organising problems. Others may have lost their employment and cannot afford to live alone.

Accommodation options

Accommodation options are available, but they are limited so it is important to look ahead and plan early.

Below are some options for accommodation:

- Own home with support.
- Living with family or friends.
- Supported accommodation such as Specialist Disability Accommodation funded by The National Disability Insurance Scheme.
- Slow stream rehabilitation facilities.
- Supported Residential Services.
- Residential Aged Care (nursing home) for people over the age of 65.

Aids and equipment for the Home

Many people who return home or find alternative accommodation may need home modifications or equipment. This can be costly and time consuming so it's important that you start planning as soon as possible. Occupational, Physio and Speech Therapists can assist you with decisions about what equipment and home modifications may be required.

Some modifications/equipment to consider may include:

- Ramps at entry, exits and within the house if there are internal steps between rooms.
- Accessible bathroom, bedroom, toilet and kitchen.
- Communication aids.
- Mobility aids (eg walking stick, walking frame, wheelchair, hoist).
- Furniture (eg bed, commode, shower chairs).
- Car modifications.
- Continence aids (pads, mattress protectors).

Rural and Remote Services

For people living in regional and remote areas, it may be challenging to access services and information. You may have to wait until a specialist is in town or you may need to travel long distances to metropolitan areas.

Accommodation	You may need somewhere to stay while your family member is in hospital. The Country Women's Association provides affordable accommodation in some regional and capital cities or ask the Social Worker at your hospital for options. Ronald McDonald house offers accommodation for families of seriously ill children.
Assisted Travel	You may be eligible to use state-based travel assistance schemes to cover some of the costs of travel and accommodation
Ehealth and Telehealth	The use of technology can assist with consultation and communication about your family member's treatment. These include the option to have a My Health Record which can improve communication with and between your doctor, health services, specialists and hospitals.

Community Support services

Each local government area has a range of services that aim to increase the participation of people with a disability in their local communities by assisting people access mainstream services like:

- Education & training
- Transport
- Health
- Accommodation & housing
- Built Environment
- Sport & recreation
- Arts

For assistance in finding rural and remote services in your area, visit:

Healthdirect
www.healthdirect.gov.au

Find your local council
Know your Local Council
www.knowyourcouncil.vic.gov.au

Services for Australian Rural and Remote Allied Health (SARRAH)
1800 338 061
www.sarrah.org.au

Planning for the future

When a loved one sustains a brain injury, the last thing on your mind might be legal and financial matters. It can sometimes add more stress to an already difficult situation. Attention to these matters can make it easier for you and your family to cope with change. There is a large network of support services you can talk to about how they can assist you.

Making Decisions

After a brain injury, a number of decisions require immediate attention. A family member may be required to make decisions on behalf of the person who has the brain injury.

There are decisions about treatment and there may be financial or legal issues that arise as a result of the injury, or there may be pressing issues that the person was addressing prior to their injury. Then, once home, there are many decisions we make daily in response to finances, work and other responsibilities.

If a decision maker is needed and a family member is not available, an independent guardian can be appointed.

Enduring Power of Attorney	An Enduring Power of Attorney is a legal document in which a person appoints someone to make important financial and personal decisions on their behalf. If there is no formal order in place, the next of kin is legally allowed to consent to health care treatment. The Office of the Public Advocate and the Victorian Civil Administrative Tribunal (VCAT) can assist you with legal, financial and administrative rights on behalf of the person you are caring for.

For more information on arranging powers of attorney or guardianship contact:

- **The Office of the Public Advocate**
  Powers of Attorney — 1300 309 337
  www.publicadvocate.vic.gov.au
- **Victoria Legal Aid Legal Information Service** — 1300 792 387
  www.legalaid.vic.gov.au
- **Carer Gateway** — 1800 422 737
  www.carergateway.gov.au

Eligibility for compensation

In Victoria, how you were injured determines where you are treated and the range of services and compensation to which you are entitled.

If you sustain your brain injury as a result of a car, motorbike, train or tram accident, you will be eligible for compensation under the Transport Accident Act of 1986 which created the Transport Accident Commission (TAC).

If your brain injury is a result of an accident at work, you are covered by the Victorian WorkCover Authority Insurance Scheme.

Both may cover the cost of:

- Ambulance
- Medical Services
- Rehabilitation
- Nursing
- Related Services
- Disability Support

What if compensation is not available?

Not everyone with a brain injury will be entitled to compensation. If you have private health insurance, your entitlements will depend on the extent of your cover. Check your policy details and contact your insurance company if you have any doubts. If you don't have private health insurance, the public health system is free to people who need it.

For more information about whether you are eligible to receive compensation through WorkCover or TAC, contact:

Victorian WorkCover Authority – 1800 136 089
www.workcover.vic.gov.au

Transport Accident Commission (TAC) – 1300 654 329
www.tac.vic.gov.au

For more information about health entitlements contact:

Department of Human Services Medicare – 132 011
www.humanservices.gov.au

The National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) is a new method of supporting people aged under 65, living with a permanent or significant disability. The NDIS aims to provide people with a disability with information and connections to services in their community.

Early Childhood Early Intervention	The Early Childhood Early Intervention (ECEI) approach supports children aged 0-6 years who have a developmental delay or disability, and their families/ carers. The ECEI approach supports families to help children develop the skills they need to take part in daily activities and achieve the best possible outcomes.

For more information contact:

NDIS — 1800 800 110
www.ndis.gov.au

BrainLink Services — 1800 677 579
www.brainlink.org.au

My Aged Care

My Aged Care is a government gateway for people aged over 65 to access funded aged care services.

You can find out more about eligibility and assessment by contacting:

My Aged Care – 1800 200 422
www.myagedcare.gov.au

Depending on your other sources of income, you may be entitled to benefits and financial assistance such as:

- Disability Support Pension (DSP)
- Carer's Pension
- Carer's Allowance
- Companion Card
- Health Care Card, Pensioner Concessions Card
- Rent Assistance
- Multi Purpose Taxi Program
- Travel Access Card

To find out more about the different types of benefits and entitlements contact:

Department of Human services Centrelink – 132 717
www.humanservices.gov.au

Department of Transport – 03 9655 6666
www.transport.vic.gov.au

Your Rights & Responsibilities

If you are a person living with a brain injury or caring for someone with a brain injury, you are entitled to healthcare rights, as outlined by The Australian Charter of Healthcare Rights. These rights describe the rights of patients, consumers and other people using the Australian healthcare system and are important in making sure that healthcare services remain safe and maintain the highest possible standard of quality.

The Victorian Charter of Human Rights and Responsibilities Act 2006 explains your rights in relation to making decisions about your treatment and care, as well as your responsibilities to ensure healthcare staff can best meet your needs.

Visit **www.health.vic.gov.au** to access more information about the **Charter of Healthcare Rights**.

Making a complaint

If you are concerned about the services that you or the person you care for is receiving, you have the right to complain. You may feel uncomfortable about speaking up to staff in the hospital or to healthcare providers and worry it might make things difficult. You may even feel that you will no longer be able to use that service. Complaints can clear up misunderstandings and help get the supports you need as well as helping organisations and professionals make sure that their services are working for people they help.

Here are some tips on how to complain effectively:

- **Understand your rights:** ask or research documents that tell you what your rights are
- **Know what you want:** suggest how things might be done better
- **Be confident in communicating your concern:** honest and clear communication helps everyone to listen carefully and consider everyone's concerns
- **Talk to the people involved first:** try to talk with the person responsible first. It may be a misunderstanding that can be easily sorted out. If you do not think your complaint is being taken seriously, you can ask to speak to a more senior staff member or manager.
- **Make a formal complaint:** All organisations will have a formal complaints procedure. You may be asked to put your complaint in writing outlining a description of what happened, who was affected and how you would like the problem to be dealt with. You can ask an organisation for a copy of their complaint's procedure.

Advocacy

Advocacy is about having your voice heard in support of your rights to make decisions that affect your life. Advocates help you access information to make informed choices about important matters.

For more information about making a complaint visit:

- **BrainLink Services** — 1800 677 579
  www.brainlink.org.au
- **Carer Gateway** — 1800 422 737
  www.carergateway.gov.au
- **Carer’s Australia (Victoria)** — 1800 242 636
  www.carersvictoria.org.au

If you think you may need an advocate contact:

- **Disability Advocacy Victoria Inc.**
  www.disabilityadvocacyvic.org.au
- **Disability Advocacy Resource Unit (DARU)** — 03 9639 5807
  www.daru.org.au
- **Disability Advocacy Network Australia (DANA)**
  www.dana.org.au

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