

# 1. Ageing with traumatic brain injury

## Definitions

### Older person

For the purpose of this document, 'older person' refers to a person aged 65+ years, or 50+ years for a First Nations person (person of Aboriginal or Torres Strait Islander descent).

### Traumatic Brain Injury

Traumatic brain injury is when the brain gets hurt by an outside force. This might include a sudden and strong impact or jolt to the head or in some cases the body.

### Why did we create “Tools for ageing well with traumatic brain injury”?

More and more older adults are being affected by traumatic brain injury, making it a big concern for public health worldwide.<sup>1</sup> This increase is happening because countries like Australia have more older people than ever before. In fact, it's expected that by 2050, about one in four Australians will be over 65 years of age.<sup>2</sup> As a result, on average, people are older when they experience a brain injury, and they're living longer with the brain injury than before.<sup>3</sup>

There are two specific groups of people we created this resource for:

1. People who were injured when they were younger and are now getting older; and
2. People who were already older (over 65 years of age) when they were injured.

For people who were injured when they were younger and are now getting older, some of their problems might be related to their original injury, like issues with balance or moving around. But for those who were already older when they were injured, other health problems that come with age, like arthritis, might have made their recovery slower. In addition, both groups can have similar issues related to ageing, like diabetes, heart disease, and memory and mental health problems.

In 2020, researchers from Monash University and the John Walsh Centre for Rehabilitation Research at the University of Sydney received funding from the Transport Accident Commission in Victoria and icare in NSW to study how getting older affects people with traumatic injuries.<sup>4,5,6</sup> They found that it's really hard to separate the effects of getting older from the effects of a brain injury. They also discovered that there aren't enough easy-to-understand resources with good information about healthy ageing for older people with a brain injury, both in Australia and around the world.

Tools for Ageing Well with traumatic brain injury has been developed with older people with a brain injury, family members of people with a brain injury, and expert clinicians to help people with a brain injury maintain good health and well-being as they age. It is important to remember that all people age differently, and everyone experiences a brain injury differently. The information in this resource is of a general nature, and it is up to each person and their family members or carers to see which sections are most helpful for managing their own health and wellbeing.



## One of our contributors

### Grainne

Grainne's husband Peter sustained a severe traumatic brain injury at 35 years of age, 2 years into their marriage. For the next 32 years Grainne and Peter lived happily together as husband and wife and Grainne was closely involved in his care. With the support of friends, family, funding organisations and a committed team of health professionals, Grainne and Peter lived a full life, including interstate and overseas travel. Over the last 10 years of his life, Peter started to experience issues with coughing when eating and drinking, and growing challenges in maintaining his head in an upright position. Aspiration pneumonia became an issue. Peter, a remarkable man, passed away in 2019 after living a rich life full of travel and adventure, with his wife Grainne, whom he adored.



## Who is this resource for?

### People who are thinking about how to age well with a traumatic brain injury

This resource will help you to self-manage your health as you age with a brain injury and suggest when you may benefit from seeing a health professional. We have included some tools to help you along the way – see 'Tools and Skills' on page 43.

### Family members, friends, carers, and supporters of someone with a traumatic brain injury

If you are a family member, friend, carer, or supporter of someone with a brain injury this resource can help you to understand the health concerns and lifestyle challenges facing people who are ageing with a brain injury. It can also guide you on where to get support for them and for yourself.

For example, the section on behaviour (see page 17) will help you to understand how people's behaviour can change after a brain injury.

### Health professionals

This resource may help health professionals better understand the issues facing their clients who may be ageing with a brain injury. For example, it is important for health professionals to understand how pre-existing conditions may change or be impacted by a brain injury as well as how the normal ageing process will impact brain injury. The questions for your health professionals' section (see page 61) aims to promote discussion between you and your clients with a brain injury.



## How do I use this resource?

### Information on health and lifestyle issues

This resource has health and lifestyle information for people who are ageing with a traumatic brain injury. It makes suggestions for how to self-manage common physical health, mental health, and cognitive (memory and behaviour) issues that you may experience after a brain injury. This information is informed by current evidence and best practice, and co-designed by people with a brain injury, their family members, expert clinicians, and researchers in the field.

This resource also has lifestyle tips and suggestions that can help you to manage things like nutrition, physical activity, and sleep. Making good lifestyle choices can help to support good health and well-being as you age with a brain injury.



### Tools and Skills

The 'Tools and Skills' section has tools to help you self-manage things like mood, fatigue, and medication, including:

- Planning tools (for example, goal setting)
- Health diaries (for example, mood, anxiety, sleep, fatigue, and pain diaries)
- Health apps (for example, mindfulness and meditation apps)
- Tools to help you to manage your medication.

You can print out as many copies of these resources as you would like (see section 8, page 43).

### Knowing where to get help

While this resource will guide you to self-manage your health, you may sometimes want to seek professional help. A list of health care professionals and the health concerns they can help you with is provided in the 'Where to get help' section. For example, did you know that a speech pathologist can help you if you are having trouble eating and swallowing?

There is also a list of questions you can take to your appointments with your health care professionals, with a space to add your own questions or take notes. It is always a good idea to write down important information during your appointments so you can refer to them later.

The 'Where to get help' section also has a list of organisations and services where you can get help for things like funding and support.

In the section for people who are caring or supporting someone with a brain injury, you will find information about caring for yourself as a carer and accessing respite care.











## What do we mean by ageing well?

We all get older, and it's not something to be afraid of—it's a natural part of life. But if you are living with a brain injury, the effects of getting older can sometimes be more noticeable. However, we're all different and there's no "one-size-fits-all" way to understand how a brain injury affects someone as they get older.

It's important to know that getting older doesn't mean you'll automatically have poor health. There are lots of health problems that can be prevented or made better by regularly seeing the right health professionals, and making healthy lifestyle choices. Ageing well isn't just about staying physically healthy, though. It also means staying connected with others, finding things that give your life meaning, and being fully involved in life.



The Brain Injury Association of America has come up with ten rules to help people with a brain injury age well. These rules are based on ideas from the Alzheimer's Association:<sup>7</sup>

- 1** Take care of your heart by finding out early if you have any heart problems and getting treatment. 
- 2** Keep your body active by exercising regularly. 
- 3** Keep your brain active by doing things that make you think, like learning new things. 
- 4** Eat foods that are good for your brain, by following a healthy diet. 
- 5** Pay attention to your mental health and get help early if you need it. 
- 6** Limit substances that can harm your brain, like alcohol. 
- 7** Make sure you're not alone too much—spend time with other people regularly. 
- 8** Get enough sleep to keep your brain healthy. 
- 9** Connect with other people who have brain injuries, either through support groups or peer support programs. 
- 10** Remember that every person, whether they have a brain injury or not, has a special and amazing brain that can change and get better over time. 

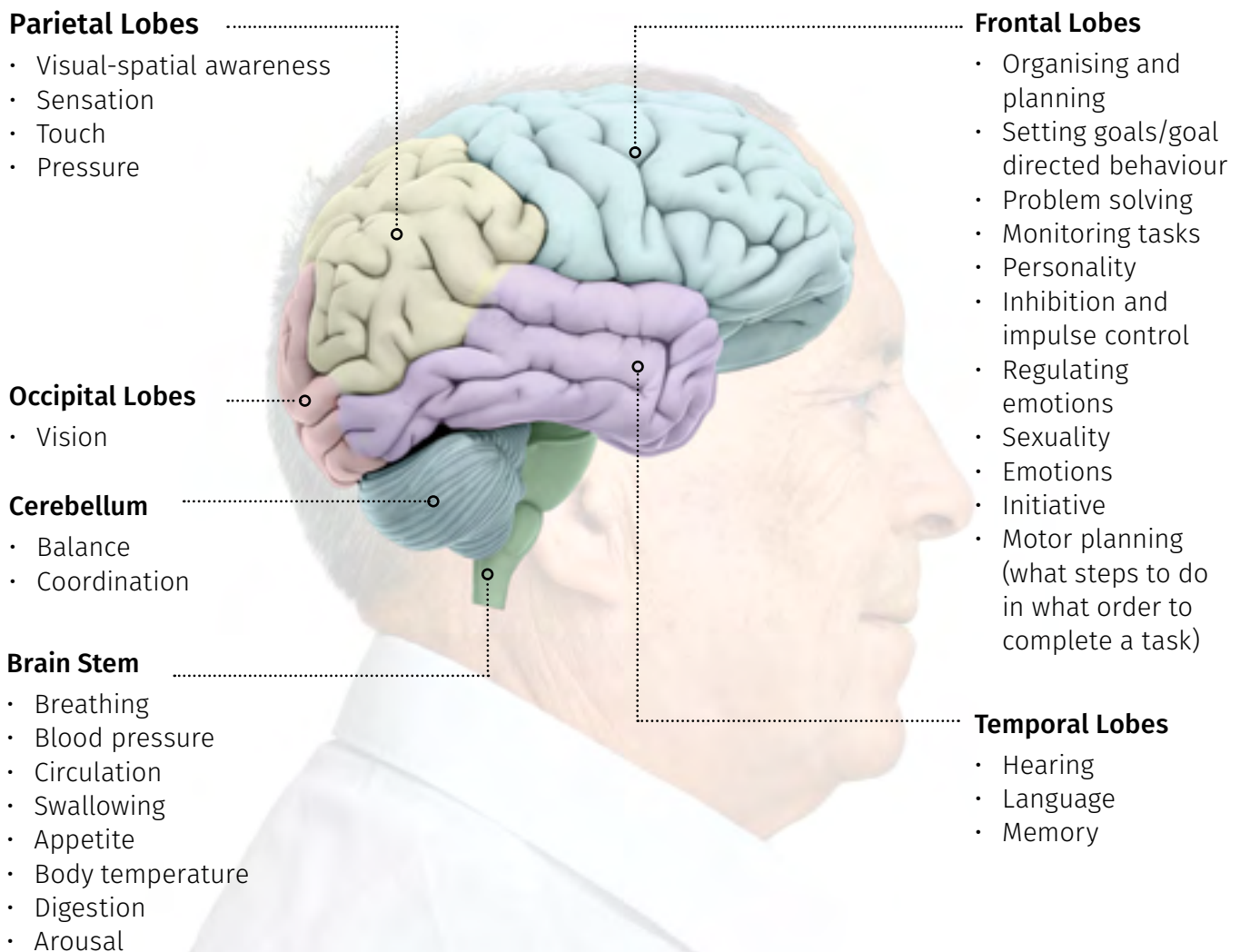
In this guide, you'll find ways to follow these ten rules in your everyday life.



## Map of the brain

Understanding the roles of different parts of the brain can be really helpful as it can help you make sense of why you might have certain problems following your brain injury. But because our brains are so complex, every brain injury is different.

It's also good to know that the brain has two halves, or "hemispheres." The left hemisphere controls the right side of the body, and the right hemisphere controls the left side of the body. This means that if there's a problem in one hemisphere, it might affect movement or other functions on the opposite side of the body. The brain also has lobes. The frontal, temporal, parietal, and occipital lobes can be seen in the picture below.



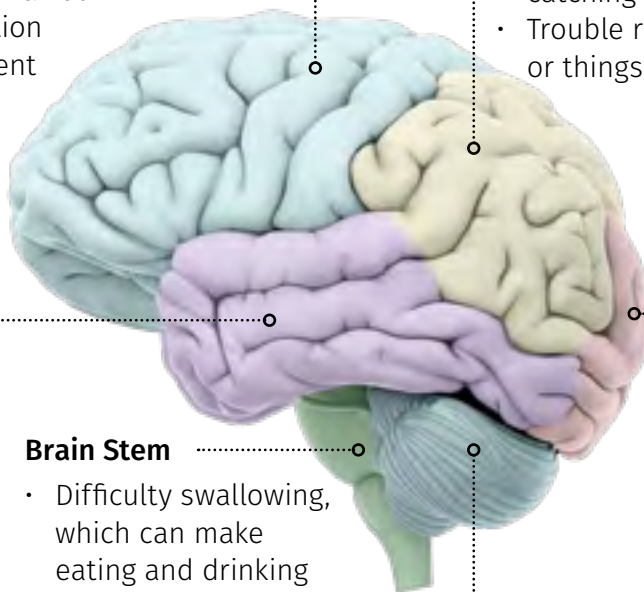
## Common problems

### Frontal Lobes

- Trouble solving problems and making decisions
- Trouble planning out the steps for tasks
- Trouble staying focused on one thing
- Having a hard time being flexible or spontaneous
- Trouble controlling impulses, or doing things without thinking
- Changes in mood or behaviour
- Difficulty paying attention
- Problems with movement and muscle weakness

### Parietal Lobes

- Difficulty retrieving information from long term memory (like word finding)
- Trouble with reading, writing, drawing, and maths
- Not being aware of certain body parts or the space around you
- Problems with hand-eye coordination, like difficulty catching or throwing a ball
- Trouble recognising objects or things you see



### Temporal Lobes

- Difficulty naming objects or people
- Trouble understanding what others are saying
- Difficulty expressing yourself verbally
- Trouble paying attention to tasks or conversations
- Problems with memory, both short-term and long-term

### Brain Stem

- Difficulty swallowing, which can make eating and drinking challenging
- Problems with balance and coordination, affecting your ability to walk or move smoothly
- Feelings of dizziness and nausea, especially when moving or changing positions
- Trouble sleeping, which can lead to fatigue and difficulty concentrating during the day
- Difficulties with breathing
- Trouble with vision and eye movements

### Occipital Lobes

- Vision problems and trouble recognising objects
- Difficulty with reading and writing
- Difficulty recognising faces
- Seeing or hearing things that aren't really there, which are called hallucinations

### Cerebellum

- Loss of coordination, making it difficult to move smoothly
- Trouble judging distances or knowing when to stop, which can affect activities like driving or walking
- Tremors, or uncontrollable shaking of the hands or other body parts
- Muscle weakness, making it harder to perform everyday tasks
- Abnormal eye movements, which can affect vision and balance

## Frequently asked questions

### What kinds of issues might I experience as I get older?

As you get older, you may face issues associated with normal ageing, such as high blood pressure, diabetes, heart disease, falls, and arthritis. However, it's crucial to understand that these age-related conditions can be improved by maintaining good health through regular check-ups and adopting a healthier lifestyle. This might include eating better, being more physically active, quitting smoking, and cutting down on alcohol.

Compared to people without a brain injury, you may have a higher risk of cognitive decline later in life. Therefore, if you've had a brain injury, it's important to talk to your doctor about ways to protect your brain as you age. It's essential to note that other factors, such as being physically inactive and having a poor diet, also contribute to dementia risk, so lifestyle changes may help a lot.

### Will it be harder for me to recover from a brain injury compared to a younger person?

There is some evidence that, when an older person has a brain injury, they might take longer to recover compared to a younger person. However, this isn't true for everyone. Some older adults recover at a similar pace to younger adults, especially if they receive good rehabilitation. Unfortunately, some older adults with a brain injury can't access all the rehabilitation they need because of issues like not having enough funding, not enough services available, or not being able to get to appointments.

It's also important to know that brain injury recovery can last much longer than we thought before. Some people keep getting better for many years after their injury.

### Will my brain injury get worse as I get older?

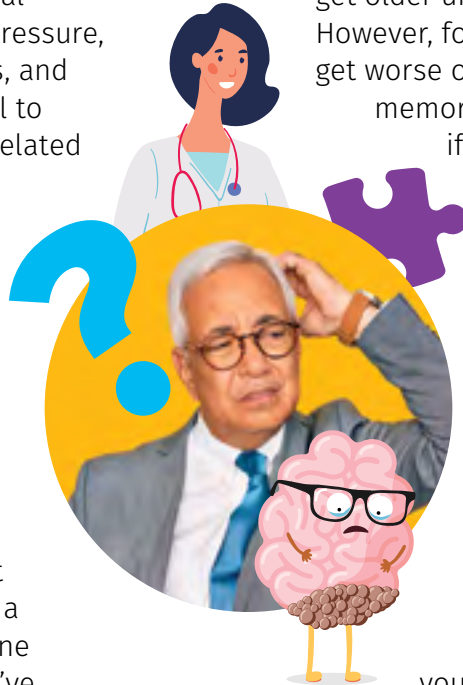
Your brain injury shouldn't get worse as you get older unless you have more head injuries. However, for some people, their symptoms might get worse over time, especially when it comes to memory and thinking. It's often hard to tell if this is because of the brain injury or just part of getting older. But many symptoms can be managed or improved with lifestyle changes and medicines.

It's important for you to try to see the same team of health care providers throughout your life (if you are happy with them). Having a consistent person, like a doctor or case manager, who oversees this team can be helpful. Sometimes, you and your family might not notice small changes over time, but a consistent health care provider will.

### Is there a link between brain injury and dementia?

Studies indicate that individuals who have experienced a moderate to severe brain injury may be in a higher risk category for developing dementia later in life. However, it's important to note that dementia is not guaranteed or a normal aspect of ageing with a brain injury. There are various other factors that contribute to dementia risk, and there are numerous ways to reduce this risk, such as maintaining a healthy lifestyle.

Furthermore, there are many treatments available for dementia nowadays, including medications, and it's best to begin treatment early. If you have concerns about dementia, it's essential to discuss them with your doctor, whether it's a general practitioner, neurologist, or rehabilitation physician.



## What are my options for accessing funding?

There are a range of options available for you as you get older. Your eligibility for these options depends on factors like your age, the cause of your injury, and where you live. Check out the list of organisations on *page 73* to explore compensation schemes and funding options that might be suitable for your situation.

## What is the difference between a traumatic brain injury and an acquired brain injury?

An acquired brain injury is an injury to the brain that a person may experience during their lifetime (as opposed to something they are born with). A traumatic brain injury is a type of acquired brain injury, which is caused by an external force or a knock to the head or body. An acquired brain injury can also result from a stroke, poisoning or infection, as examples.

## Am I going to get better?

After experiencing a moderate to severe brain injury, many issues may improve, but some ongoing problems may persist. In some cases, you may achieve a full recovery of function, even though there may still be deficits (for example, muscle weakness). This is because, over time, your body and brain can develop strategies to compensate for these deficits, allowing you to regain or maintain a level of function that enables you to lead a fulfilling life.

## What if I can't look after myself at home anymore?

If you are struggling to look after yourself at home, or the people who help support you at home are needing more help, there are several options for accessing extra support. For example, there are people who can come to your home to assist with chores, such as cleaning and laundry, or even with personal care, such as showering and dressing. There are also options for health care professionals to visit your home to provide nursing care or rehabilitation. If these supports are still not enough, you may consider some short-term restorative or respite care, or it may be time to consider moving into supported accommodation or residential aged care (for example, a nursing home). To find out about your options, see the section on 'Accessing extra support' on page 34.

## What should I as a family member do to help the person with brain injury?

Health professionals can provide guidance to family members on how they can support the person with a brain injury. This might include assisting with physical or mental exercises at home and involving them in social and recreational activities to reduce feelings of isolation. However, it's equally important for family members to remember their roles as husbands, wives, sons, or daughters, and maintain normal relationships as much as possible.

