

Ageing with Severe Traumatic Brain Injury: Helping the Person and the Family



Ian Cameron

Northern Sydney Local Health
District and University of Sydney

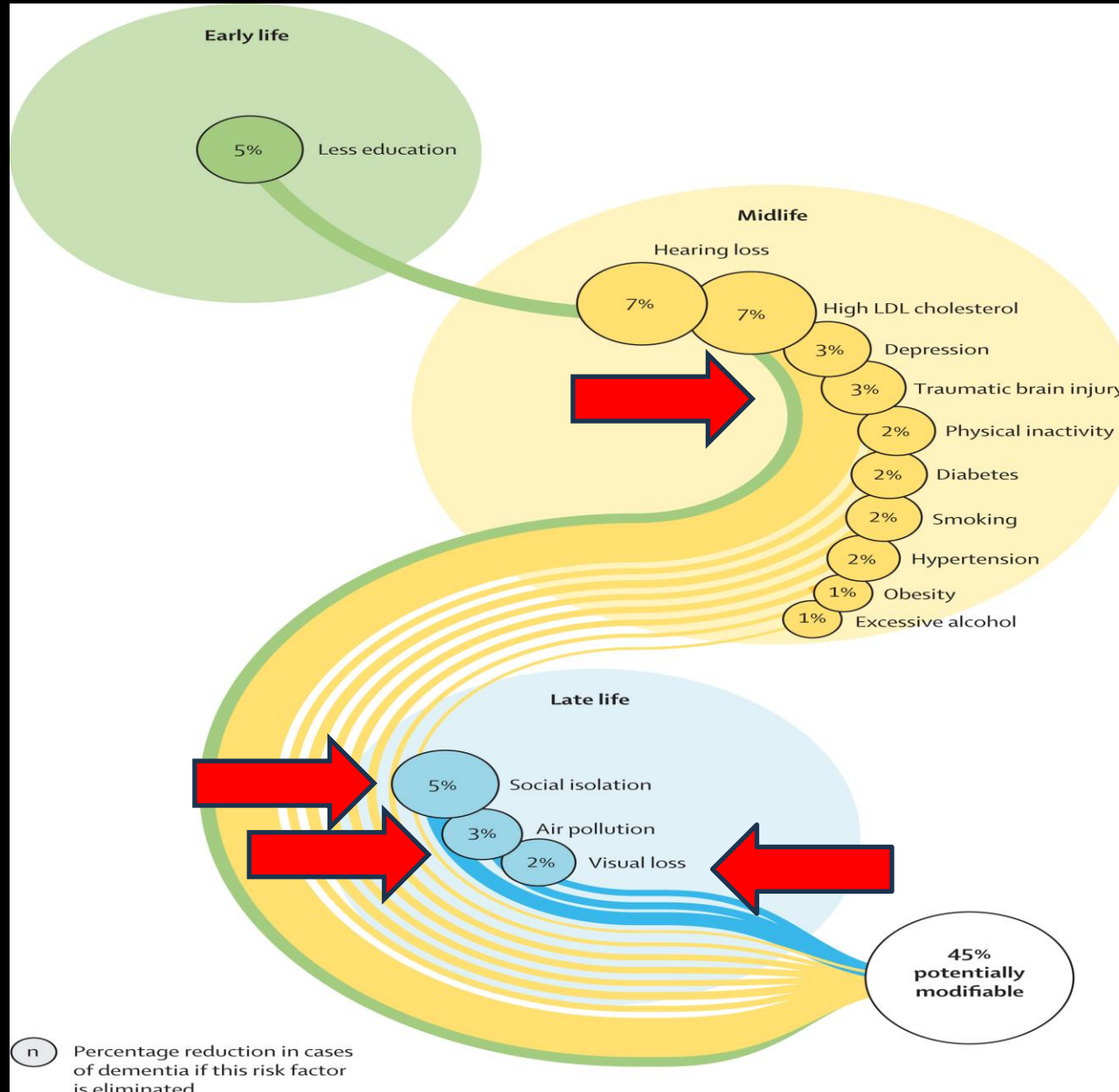
Friday 25th October 2024

Ballina

Ageing with Severe Traumatic Brain Injury - background

- The Lancet standing Commission
- Dementia, Prevention, Management and Care
- Updated July 2024

Figure 9



n Percentage reduction in cases of dementia if this risk factor is eliminated



Case study – Mrs K, age 74

- Note based on a lady living in rural NSW with anonymisation
- Fell down stairs at home
- Found by husband
- Ambulance, initial Glasgow Coma Score 3
- Intubated and ventilated
- Neurosurgical intervention at regional hospital
- Transferred to local rehabilitation unit
- Cognitive impairment
- Significant behavioural abnormalities
- Family liaison – husband and adult children



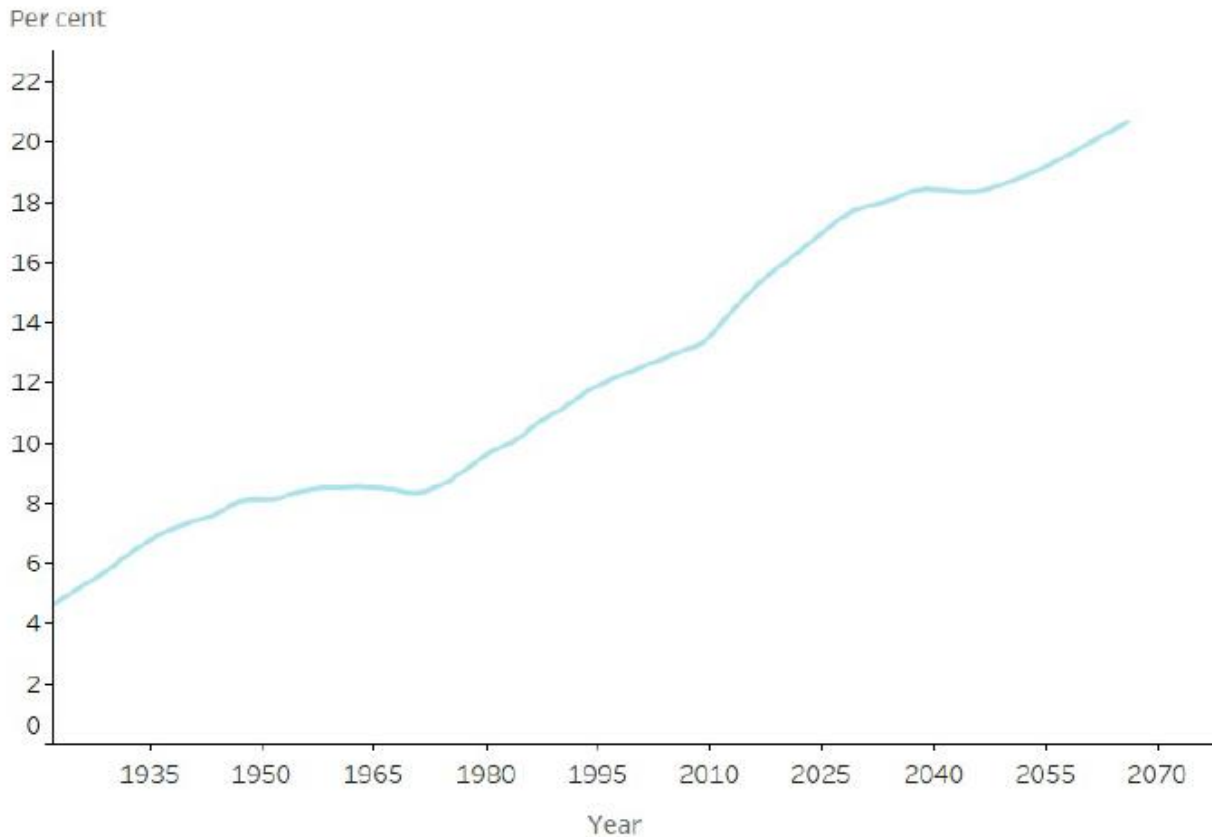
Case study – Mrs K, age 74

- Where to from here?
 - Family support
 - Education
 - Further rehabilitation
 - Transitional Aged Care Program
 - Home modification / equipment
 - Service availability
 - Other



Ageing in Australia

Figure 1.1: Percentage of the Australian population aged 65 and over, at 30 June, over time



Notes

1. Data for 1921 to 1970 are population estimates. Data from 1971 onwards are estimates of the resident population (ERP).
2. Population data from 1992 to 2011 are recast estimates following the rebasing of the 2011 Census. For more information, see the ABS explanatory notes.

As of June 2020:

16% of the population, 4.2 million Australians were aged 65 years and older

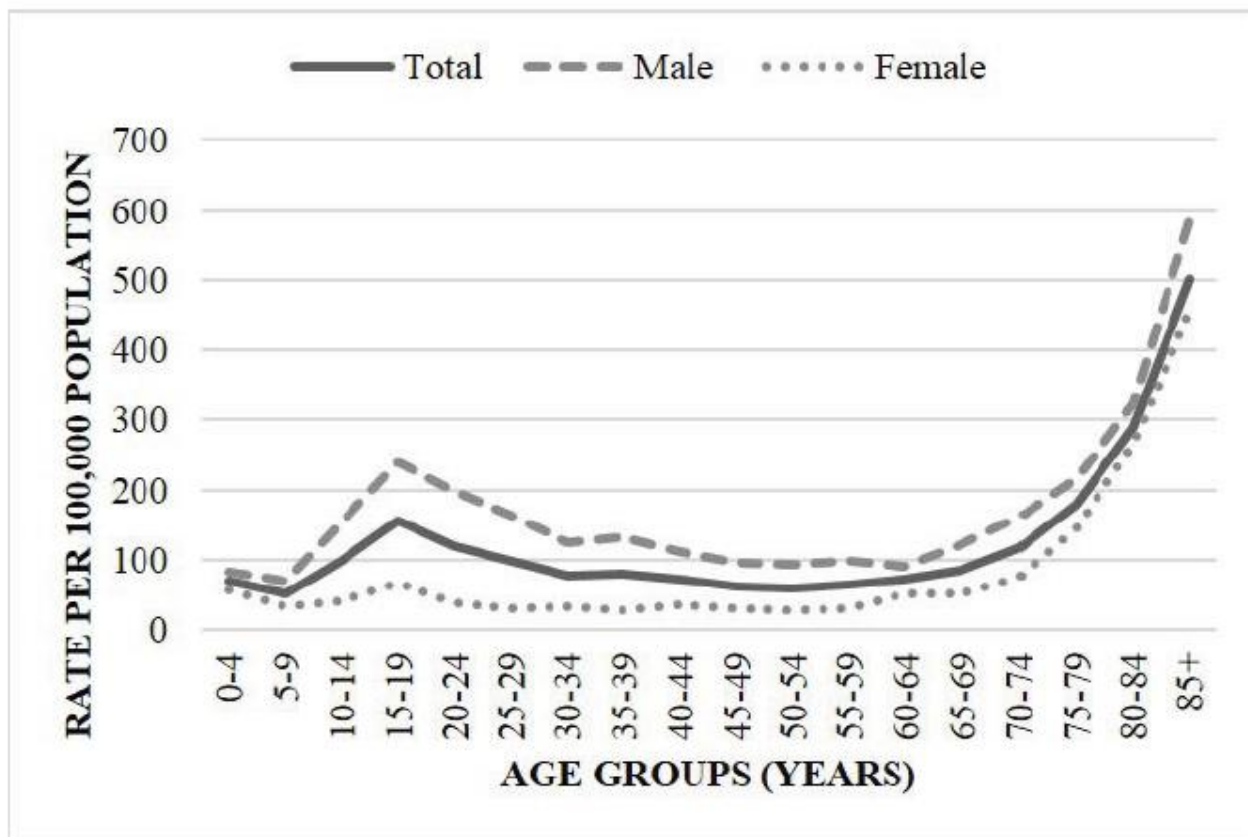
By 2066 it is projected that:

21-23% of the Australian population will be aged 65 years and older

Two main drivers:

- increasing life expectancy
- decreasing fertility rates

Ageing and traumatic brain injury in Australia



Risk of TBI highest in 75+ age group

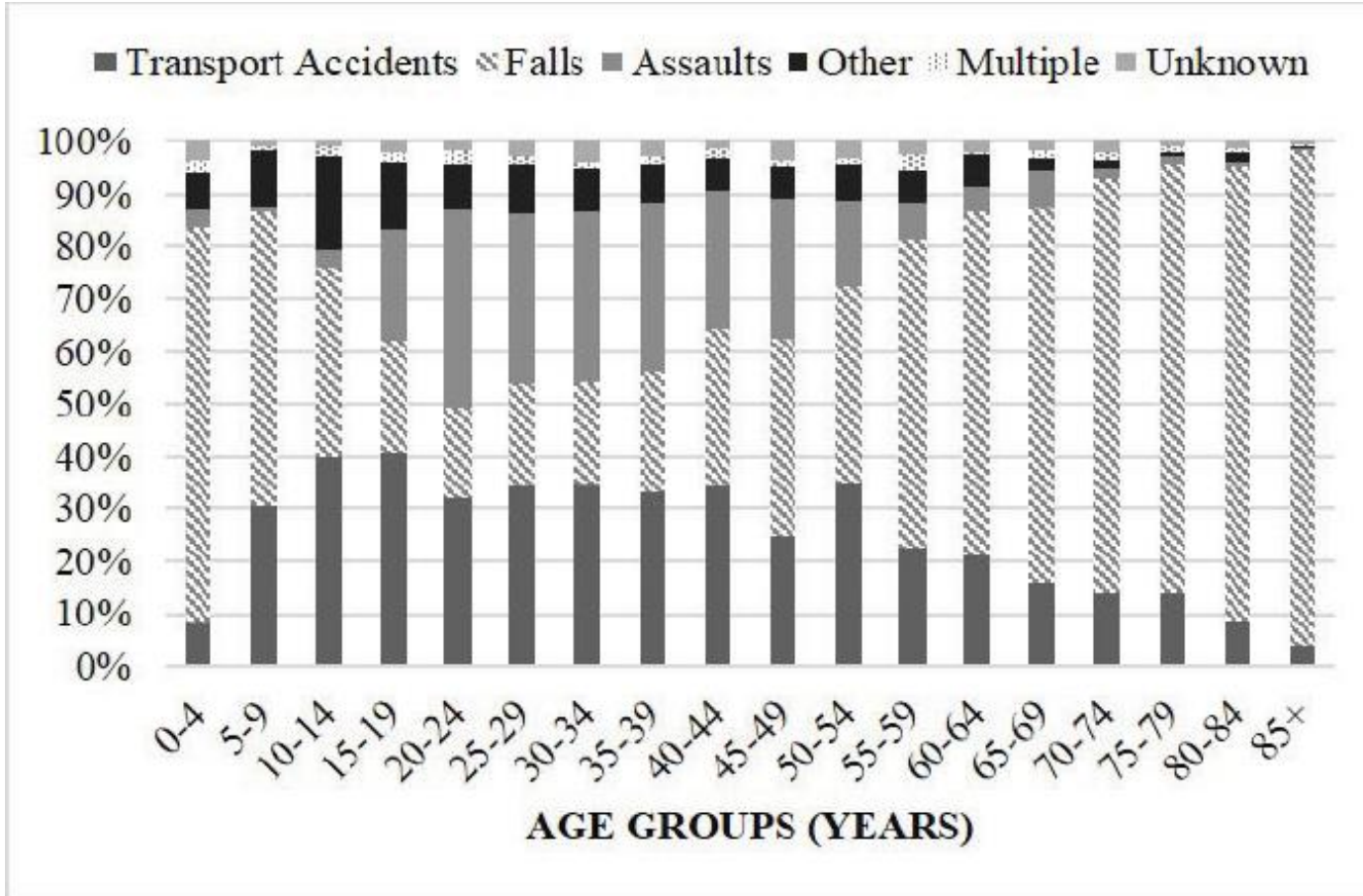
3x incidence for overall population

Difference in incidence rates between males and female decreases in older age groups

Findings reflect overseas trends in TBI epidemiology (Roozenbeek et al., 2013)

Pozzato et al., 2019

Ageing and traumatic brain injury in Australia



Common causes of injury

- 47.6% falls
- 25.9% transport accidents
- 15.8% assaults

Cause of injury among the aged

- At 87.3%, people over 70 years had the highest proportion of fall-related injuries

Pozzato et al., 2019

Ageing and traumatic brain injury in Australia

Falls were the leading cause of mild-to-moderate injuries (42-47%)

However, the 70 year + older age group (compared to younger age groups) had:

- Longest Length of Stay in hospital (average of 11 days)
- Highest fatality rate (14.5%)
- Largest number of comorbidities (62.8%)

Pozzato et al., 2019

Ageing with traumatic brain injury in Australia: Two groups

People who are aged who sustained a recent TBI

- May not get access to specialised brain injury rehabilitation programs
- Greater disability, reduced functional independence and less community participation, compared to younger onset

People living with TBI who are ageing

- First specialist rehabilitation programs for TBI rehabilitation opened in the mid 1970s early 1980s in Australia with the first cohort of patients from such programs are now in their 70s
- TBI-related changes may contribute to earlier onset or exacerbated levels of usual age-related changes (Mas et al., 2017)
- Complex relationship with possible increased risk of dementia (Mendez et al., 2017)
- Access to financial compensation (such as icare, TAC) can be beneficial, supporting people in the community as they age (Gates et al., 2017)

Ageing with Traumatic Brain Injury Project background and establishment

Overview of prior icare and TAC research

- Both the Victorian Transport Accident Commission (TAC) and icare (Insurance and Care NSW) have recognised ageing as a major issue
- Both organisations have commissioned reviews of research about ageing and traumatic brain injury



Project background and establishment

Victorian TAC report – Ageing with lifelong accident injuries, September 2020

- Older people with TBI (and spinal cord injury) may experience age related decline at an earlier age
- People who are old when they have their TBI recover less well than people injured at a younger age
- Other illnesses strongly affect ageing with TBI
- It is hard to separate the effects of ageing from health conditions related to TBI (and spinal cord injury)



Project background and establishment

Review commissioned by NSW icare Lifetime Care, June 2021

- Considers ageing broadly
- Also considers specific issues of ageing with severe traumatic brain injury and spinal cord injury
- Very similar conclusions to Victorian report
- Note the reviews were conducted completely independently
- Both reports noted that there was almost no experimental research on this topic



Project background and establishment

The 'Tools for ageing well with traumatic brain injury' project

- Commenced November 2022
- Co-led by Professor Ian Cameron (University of Sydney) and Dr Christina Ekegren (Monash University)
- Co-funded by icare and TAC



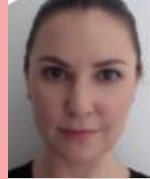
Contributors

Authors

Dr Christina L. Ekegren¹



Dr Candice McBain^{2,3}



Associate Professor Libby Callaway¹



Dr Liz Gill^{2,3}



Professor Grahame K. Simpson^{2,3}



Professor Ian D. Cameron^{2,3}



Steering committee

Dr Mohit Arora^{2,3}



Rhys Ashpole⁴



Rebecca Jackson⁴



Grainne Cruickshank¹



Professor Melinda Fitzgerald^{5,6,7}



Jade Hurst⁸



Professor Susan Kurrle AO¹⁰



Jeffrey Tonge⁴



Other contributors

Clare Douglas⁹

Associate Professor Leanne Hassett¹⁰

Dr Aleksandra Gozt⁶

¹ Rehabilitation, Ageing and Independent Living (RAIL) Research Centre, Monash University, Frankston, VIC Australia

² John Walsh Centre for Rehabilitation Research, Northern Sydney Local Health District, St Leonards, NSW Australia

³ Kolling Institute, Faculty of Medicine and Health, The University of Sydney, Sydney NSW Australia

⁴ icare, NSW Australia

⁵ Curtin Health Innovation Research Institute, Curtin University, Perth, WA Australia

⁶ Connectivity Traumatic Brain Injury Australia, Nedlands, WA Australia

⁷ Perron Institute of Neurological and Translational Sciences, Nedlands, WA Australia

⁸ Transport Accident Commission, Geelong, VIC Australia

⁹ Victorian Neurorehabilitation Network, Surrey Hills, VIC Australia

¹⁰ Faculty of Medicine and Health, The University of Sydney, Sydney, NSW Australia



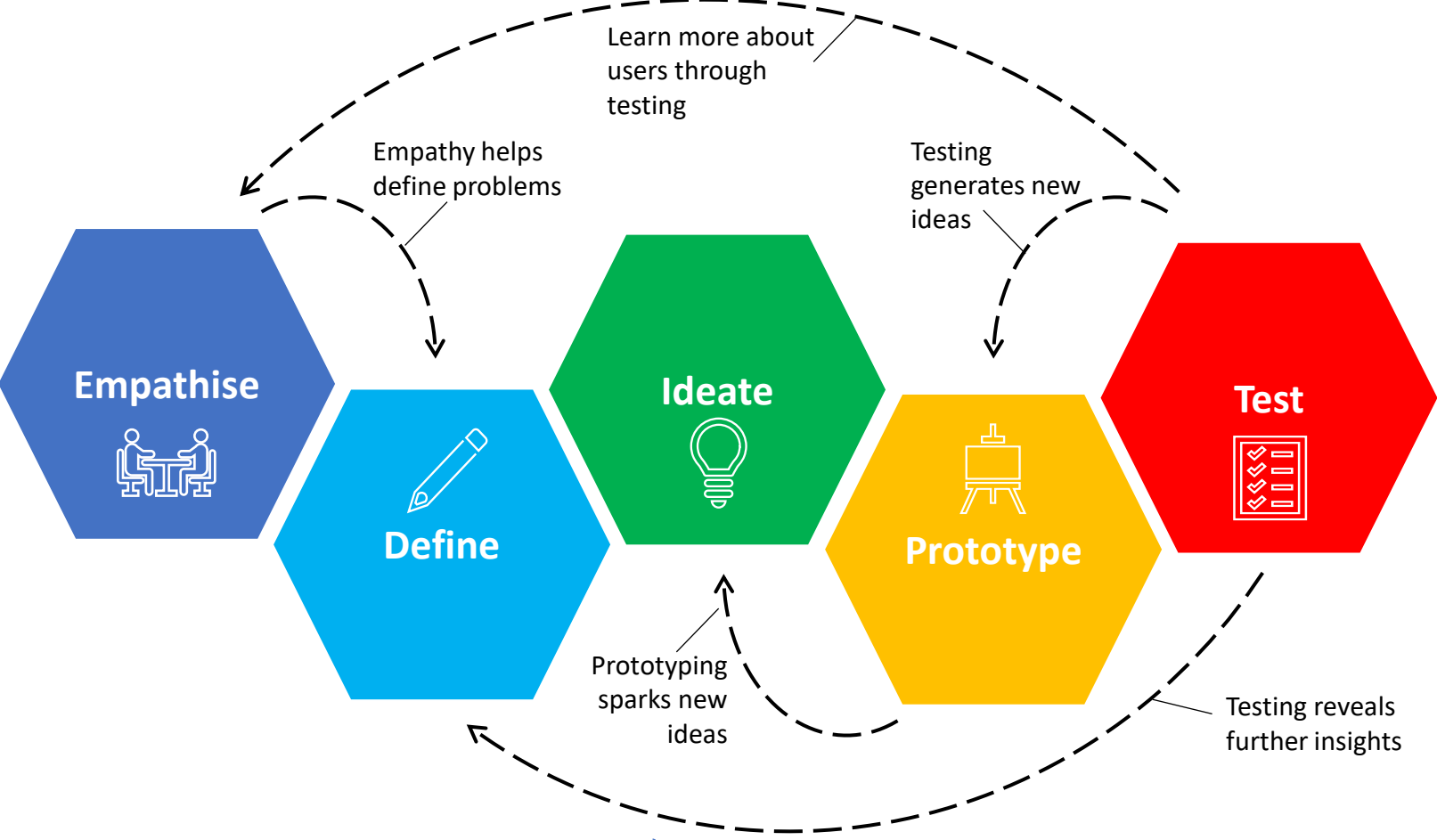
Tools for ageing well with traumatic brain injury

A co-designed resource for people ageing with TBI, older people with TBI, families, caregivers and clinicians

Tools for ageing well with TBI



Sources of evidence and process

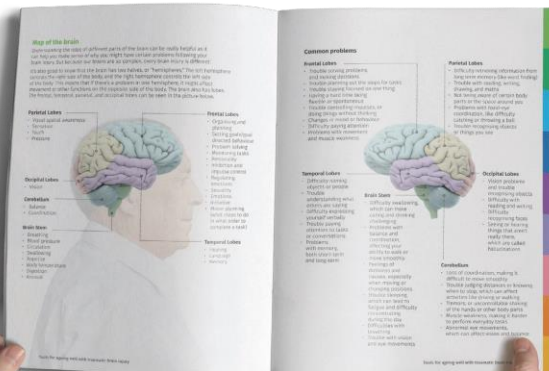


Stanford University's 'd.school' 5-stage design model

Auernhammer J, et al. The origin and evolution of Stanford University's design thinking: From product design to design thinking in innovation management. Journal of Product Innovation Management. 2021; 38(6):623-644.

Tools for ageing well with TBI

- Go to  <https://www.connectivity.org.au/tools-for-ageing-well/>



Tools for ageing well with TBI

Part 1

Ageing with traumatic brain injury

This section provides general information about ageing well with a brain injury and how to use this resource.

[Download PDF \(0.51MB\)](#)



Contents

- Definitions
- Why did we create “Tools for ageing well with traumatic brain injury”?
- One of our contributors
- Who is this resource for?
- How do I use this resource?
- What do we mean by ageing well?
- Map of the brain
- Frequently asked questions

Tools for ageing well with TBI

Part 2

Physical health

As people age risk of falling increases. Other physical changes such as vision impairment and hearing loss can become significant. These things might be made worse for those who have had traumatic brain injury. Discover recommendations for managing your physical health.

[Download PDF \(0.83MB\)](#)



Contents

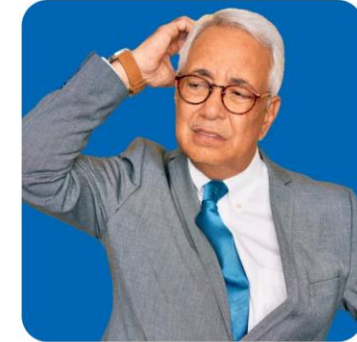
- Preventing falls
- Vision
- Hearing
- Pain
- Digestion
- Eating and swallowing
- Bowel and bladder

Part 4

Mind health

This section discusses memory, thinking skills and cognitive decline in older people and offers advice and recommendations for getting help.

[Download PDF \(0.57MB\)](#)



Contents

- Memory
- Cognition
- Dementia

Part 3

Mental health

Learn about possible behaviour and personality changes that may occur after a brain injury. Some people develop anxiety and depressed mood: learn the signs to look out for and some actions that can help these.

[Download PDF \(0.17MB\)](#)



Contents

- Behaviour
- Anxiety
- Depressed mood

Part 5

Lifestyle

A healthy diet, getting quality sleep, keeping active and doing things like connecting with like-minded people can all be beneficial for older people and particularly those living with brain injury.

[Download PDF \(0.31MB\)](#)



Contents

- Nutrition and weight management
- Physical activity
- Participating more fully in life
- Sleep
- Fatigue
- Alcohol and smoking
- Sexuality

Tools for ageing well with TBI

Eating and swallowing

Why eating and swallowing can be a problem for people ageing with traumatic brain injury

It's common to have swallowing difficulties (oropharyngeal dysphagia) after a brain injury because the brain controls the muscles that you need to chew and swallow. While this usually gets better after six months, it may then become more challenging again with age because of less saliva and weaker tongue muscles.¹⁵

Signs you may be having trouble eating and swallowing

- Changes in eating habits
- Increase or decrease in appetite
- Trouble chewing
- Coughing or choking with meals
- Recurrent chest infections
- Weight loss
- Problems with your metabolism (like increased blood pressure, high blood sugar, abnormal cholesterol levels)
- Uncoordinated eating (like an inability to perform certain movements involving facial muscles)
- Inability processing smells and taste

How to address eating and swallowing difficulties

- You may need to eat different foods – ones that you find easier to swallow. A dietician can help you to find out which foods are easier to swallow.
- You may benefit from a tailored treatment program to address your feeding and swallowing difficulties.

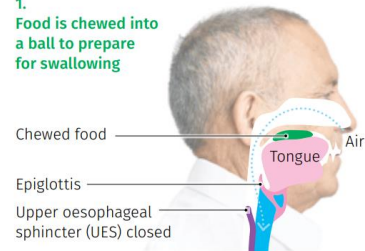
Where to get help

A specialised speech pathologist can help you with eating and swallowing difficulty.

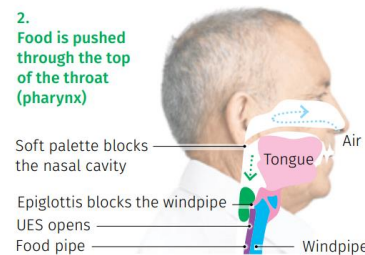
A dietitian can help you make changes to your diet if needed.

Eating and swallowing food involves several stages:

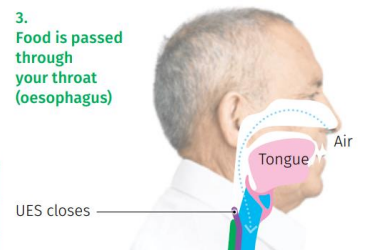
1. Food is chewed into a ball to prepare for swallowing



2. Food is pushed through the top of the throat (pharynx)



3. Food is passed through your throat (oesophagus)



Cognition

Changes to cognition as you age with a traumatic brain injury

The term cognition means 'thinking skills'. It is normal for some parts of your cognition to get a little worse with age, particularly after 65 years of age. However, changes to your cognition that are a normal part of ageing are usually small and shouldn't make it harder for you to do things you are already doing on your own.

You may also notice changes to your cognitive skills after your brain injury. A brain injury can also make cognitive decline, that is a normal part of ageing, happen sooner or faster. But a brain injury itself does not always cause cognitive decline.

What are some strategies that might help with certain cognitive skills as we age?

Some areas of your cognition may be affected by a brain injury and may also get worse with age:

Speed of thinking

You may not be able to process information and give a response as quickly as you used to. You may also need to take more time to complete simple tasks.

Strategies you can try:

- Allow more time to complete tasks and respond in conversation.
- Allow yourself time to prepare for meetings and appointments by writing lists of the things you would like to discuss.
- When seeing a health professional ask for longer appointment times.

Attention and concentration

- You may have trouble filtering out irrelevant information
- You may find it more difficult to multi-task than you used to
- You may notice yourself forgetting names or losing your train of thought

Strategies you can try:

- Minimise nearby distractions
- Break information/tasks into smaller parts and focus on one at a time
- Don't try to do more than one thing at a time

Language and word-finding

You may have trouble finding the right words to say (feeling like the word is "on the tip of the tongue").

Strategies you can try:

- Describing the meaning of the word
- Visualise spelling the word – run through the letters of the alphabet to try to work out what it starts with

I'd never heard of a neuropsychologist (before)... and they were just such a big change in my life. They helped me make decisions myself and laid out a few ideas on how to deal with different situations and then work on which one's the best for me. That was very helpful.

Raylene, lived experience of traumatic brain injury



Tools for ageing well with TBI

Part 6

Getting organised

You may need to think ahead and make plans for the future, just in case there are changes in your health status or care arrangements. While facing these issues can be tough, having a plan in place can provide reassurance and peace of mind, rather than worrying about the 'what ifs?'

[Download PDF \(0.22MB\)](#)



Contents

- Legal options
- Power of Attorney, Guardianship, and advance care planning
- Accessing extra support
- Travel concessions

Part 8

Tools and skills

This section of the resource is designed to help you to begin to think about your health issues. It includes templates that you can print and use to help monitor your health and keep track of your goals.

[Download PDF \(0.67MB\)](#)



Contents

- Planning
- Goal setting to help you age well
- Health diaries
- Fatigue management
- Apps and other tools

Part 7

For carers

This section may be helpful to people, including family members and partners, who provide paid or unpaid care and support to a person ageing with a brain injury.

[Download PDF \(0.30MB\)](#)



Contents

- What it might mean to care for someone ageing with a brain injury
- Caring for yourself as a carer
- Respite care or short-term accommodation

Part 9

Where to get help

As you get older, you may start seeing different types of health professionals for help with new issues. This section explains what different health professionals do, and includes example questions that you might find helpful when you have an appointment.

[Download PDF \(0.19MB\)](#)



Contents

- Questions for your health professional
- Telehealth
- Health professionals who can help to treat health issues associated with brain injury
- Other professionals who may be helpful to you
- Organisations providing funding, care and support to people with traumatic brain injury

Case study – Mrs K, age 74

- How best to help Mrs K and her family?
 - Education
 - Practical support
 - Appropriate services
 - Effectively manage other illnesses
 - Link with general practitioner
 - Anticipate issues (where possible)
 -



Case study – Mrs K, age 74

6. Getting organised

Legal options – Power of Attorney, Guardianship, and advance care planning

Accessing extra support

Travel concessions

The aged care system can provide a range of support from:



i) support at home (via the Commonwealth Home Support Program),



ii) higher levels of care at home (the Home Care Packages Program, and



iii) when living at home is no longer an option, moving into residential aged care (like a nursing home).

Case study – Mrs K, age 74

- What happened?
 - Went home
 - Daughters (local and helped a lot)
 - Husband had own health problems
 - Level 4 Home Care Package
 - Fell at home and had hip fracture
 - Mobility impaired after hip fracture
 - Home again
 - Later Mrs K and husband went to RACF



Tools for ageing well with TBI





Thank you

