

## The Brain Injury Cheat Sheet

*This pamphlet has been created by five people who are in the same situation as you. Everyone's experience is different, but here are some things we found useful.*

*We have made this for you and your family to help ease the transition to your new reality.*



**REMEMBER** – *You can do almost anything that you used to  
It's just going to take more time and effort.*

***Think Smarter NOT Harder***

# Physical

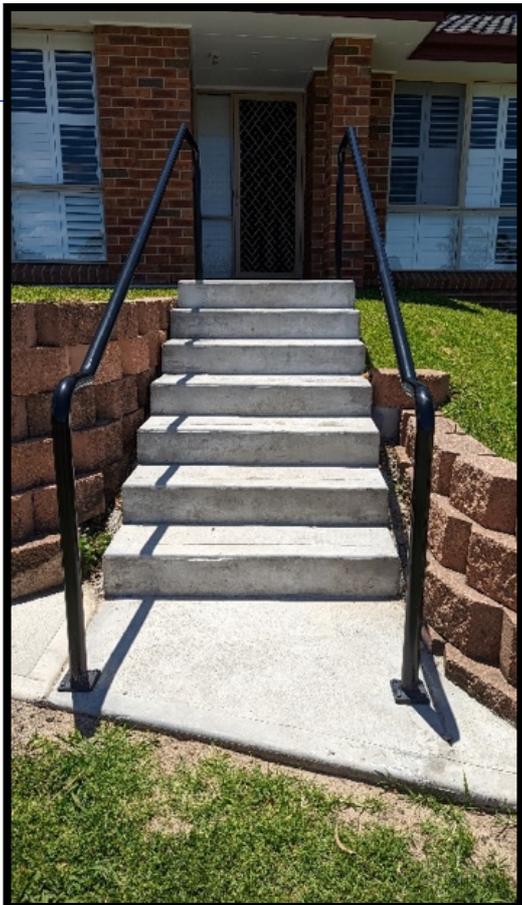
This is a list of some of the difficulties we encountered after our injuries and how we overcame them.

Difficulties	Our Solutions
<p><i>Reading &amp; Writing</i></p>	<ul style="list-style-type: none"> <li>• <i>Access Speech Pathology (SP) services for assessment and therapy</i></li> <li>• <i>Audiobooks</i></li> <li>• <i>Voice to Text</i></li> </ul>
<p><i>Loss of licence Independence of travel</i></p>	<ul style="list-style-type: none"> <li>• <i>Try to find people who you can rely on.</i></li> <li>• <i>Find alternative transport e.g., scooters, electric bikes, push bike</i></li> <li>• <i>Emphasise a return to driving in your recovery path</i></li> </ul>
<p><i>Toileting &amp; self-hygiene</i></p>	<ul style="list-style-type: none"> <li>• <i>Occupational Therapy (OT) services</i></li> <li>• <i>OT equipment and training</i></li> <li>• <i>Find equipment that can help e.g., shower chair, long handled scrubber</i></li> <li>• <i>Get creative – repurpose household items, if it works for you then it is the right equipment</i></li> </ul>
<p><i>Manual labour &amp; Work (cleaning areas that require a ladder or changing light bulbs or fire alarms)</i></p>	<ul style="list-style-type: none"> <li>• <i>Calling a tradesman or friend to help</i></li> <li>• <i>Use your support worker</i></li> <li>• <i>Look at equipment or appliances that can help for easy access, e.g. double draw dishwasher, stick vacuum or robot vacuums</i></li> <li>• <i>Use leaver door handles instead of round</i></li> </ul>

# Physical

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Modify your space to suit your needs!



Alter your access!



## Memory

We have difficulties remembering faces, names, and specific words. At times we need to describe things, and this can get frustrating.

### Faces and names

- Have patience with yourself and loved ones.
- Have pictures of people and places on your phone.
- Repetition, repetition, repetition!

### Remembering things, dates, times

- Making a list will help you remember, then set an alarm to look at it. e.g., going to the shops, getting the washing done.
- Calendars are great particularly electronic ones. You can add in the time, address, and a description of what you have to do.



### When to take medication

Have someone to remind you, have alarms on your phone, organise a Webster pack, have a routine.

- WARNING – Sometimes things go wrong and if you forget to take medication you may not notice until you start feeling sick.

### Remembering to turn on/off appliances

- Have someone there while you're cooking.
- Have post-it notes on appliances to remember to turn them off.



### Using technology

Technology can be hard to set up, but it can be a great help and improve your safety. **An OT can help organise this.** We have used voice-activated software to do things like; Turn on/off lights and air-conditioning, make emergency calls and operate doorbells or cameras

## Social

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***Your life and relationships are going to change completely.***

We found that many things changed - our interactions, how others spoke to us, our ability to handle some situations. It is important to stay connected and reengage with the world.

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### Intimate Partners

**You have changed!** These changes can be quite dramatic, physically and mentally. You may worry about how your partner feels about the changes. All five of us have

- Yes, your partner is also worried, nervous, and unsure
- Sex will change and things will be awkward
- Your partner won't understand what you are going through
- It will be harder to communicate your needs

**You must face the challenges.** These are our best solutions.

- Seek medical advice, doctors may be able to help.
- Relationship therapy to discuss the changes.
- Be sensitive to your partners situation, their lives have changed too.
- Partners can access services too - encourage them to see a psychologist.
- Your relationship can develop and grow based on the circumstances.

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### Family and Friends

As it is difficult for you to come to terms with the new you, it is also difficult for your family and friends.

We have found the following to be the most important.

- Friends will come and visit you in hospital but may not at home.
- Know that everyone else's life will move on.
- It's harder to look after young kids or grandkids.
- The roles might change with your older kids looking after you.
- Friends might feel uncomfortable to talk with you.

This can be confronting and uncomfortable, but here are some solutions.

- Know that you can find new friends.
- There are support groups.
- Speak to someone about communication partner training.
- Ask for help when looking after young kids.
- Accept the help from your older kids. They are helping because they want to.

## **Your Wellbeing**

**It is very important to get out there and interact with people after your injury.** You can talk to friends and family and access other services. Here are some services we used during our recovery.

- Psychology services (1: 1 therapy)
- NSW Brain Injury Rehabilitation Program
- Vocational Intervention Program
- TBI Express and TBIconneCT (Sydney University)
- Recovery groups
- Get social supports (e.g. carers)

These services helped us and our families come to terms with some of the challenges we face each day.



# Independence

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When we had our brain injuries, we each experienced a loss of independence, everything was different.

You might;

- Not be able to work long, which means less money.
- Lose your licence. You can't go where you need to go, visit friends or family. This is the single biggest blow.
- Have difficulty communicating what you want and need.

These things might make you;

- Feel useless.
- Lose your sense of self.
- your identity.

You must acknowledge your skills have changed. You must learn to work around this new standard and try to find other ways to do things.

We found these things helpful.

- Don't be afraid to rely on your loved ones.
- Volunteer, it can be rewarding and keeps you busy.
- Do physical activities, keeping fit helps you mentally as well.
- Talk to your friends.
- Get a Support Worker who can take you places.

## A Brain Injury comes with lots of Admin!

Here are some tips we found very helpful during recovery.

### Understand the services available to you.

- **NDIS** - National Disability Insurance Scheme. This is available for a person under the age of 65 with a disability. You may request a support coordinator to help you organise supports.
- **iCare and Lifetime care** - Available for people who have been severely injured in a motor vehicle accident or received an injury at work. You will be given a case manager to help you organise supports.
- **Medicare** – Medicare is the publicly-funded universal health care insurance scheme in Australia.
- **Aged Care Package** – Provides funding for people over the age of 65 with complex needs to help them stay at home. This is means tested.

### Keep Copies of EVERYTHING – At minimum, key documentation such as:

- Discharge Reports
- Specialist reports
- All NDIS Assessment documents

Know who can help you. You might have a partner or family member to help with paperwork. If you don't or something happens to your partner, you can get an **advocate**.

An advocate can help you sort out a problem, or do other things such as:

- Help write letters
- Help make phone calls
- Go to meetings with you or on your behalf.

During recovery your needs will change, so it is important to know that you can request a reassessment.

## THANK YOU FOR READING!

Here is some advice we wish we heard after our injuries.

- Things will change. Things will get better.
- There is a time and place for a hill to die on. Fight the battles you can but ask for help when you need it.
- We think it's important to take control recovery journey.
- Get therapists to assess your needs, so you can access available technology that will help.
- **Accept that some things will be too challenging to do now.**
- Expect a grieving period, but it's up to you to motivate change.
- It can be easy to dump your paperwork off to others but try not to. Don't let services dictate the pace of your life.
- Get a dog!



**This pamphlet was created by these five guys. Each has a type of brain injury, caused by an accident, a stroke or dementia. Mark, Dom, Peter, Voytek and Niko (left to right) wanted to share their advice for anyone going through a similar experience.**