

July 2022



BRAIN INJURY MATTERS

NEWSLETTER

Meet Matthew Dykes

1. How long ago did you acquire your injury?

31 July 2009.

2. What is your greatest achievement since your injury?

Being able to walk with my Zimmer frame.

3. What do you want to achieve in the near future?

Increasing my physical recovery and better walking - it's great for my self-esteem. It reinforces that everything is possible and repetition is the key.

4. What do you find your biggest challenge?

Fatigue. Energy seems to reduce the older I get, but I need to find ways around it. So, for example, being in big groups of people is draining.

5. What is your favourite food?

LOBSTER (rarely!!!!!!), Steak (frequently): rump or porterhouse, served medium-rare.

6. What is your favourite movie?

The Road Warrior - Mad Max II. The stunts are much better than Mad Max, the first movie.

7. What is your favourite hobby?

Watching music. My favourite band is the Stone Temple Pilots.

8. What do you want to achieve through Brain Injury Matters?

I lost social conditioning and I want to get it back. So, chit-chatting with people is great. BIM is enabling that.

9. What advice would you give to a person with a new brain injury?

Try to talk to others about your brain injury, like meeting and talking with people at BIM. Asking questions and listening to others and their experience.

10. What does Brain Injury Matters mean to you?

I struck gold with BIM. I thought I was the only person! For example, hearing that other people with an ABI got fixated on things was reassuring.



REGULAR THINGS HAPPENING AT BIM:

Online Coffee Mornings

Mondays at 11am

Open to anyone with a brain injury.

A fun way to start the week includes jokes, quizzes, and conversation starters.

Contact office@braininjurymatters.org to receive the Zoom link.



Peer Support Groups

Small groups of people with brain injury meet weekly to catch up, learn from each other and have some fun.

Current groups:

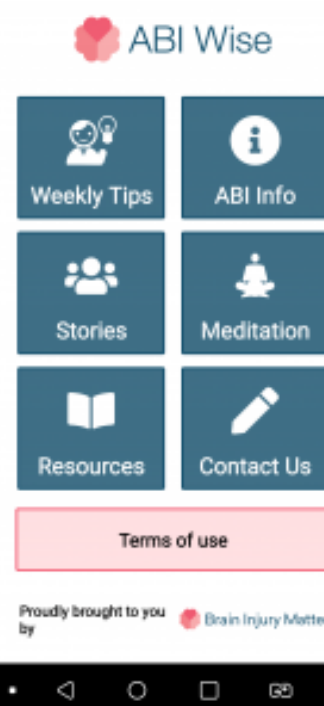
- **Northcote** - Tuesdays at 10am
- **Frankston** - Tuesday at 10am
- **Online only** - Wednesdays at 10am
- **Ringwood** - Thursdays at 10:30am
- **Footscray** - Thursdays at 10am
- **Gisborne** - Last Wednesday of the month

Contact office@braininjurymatters.org if you are interested in joining a group.

Check out our Website, ABI Wise App, Facebook and Instagram

<https://www.braininjurymatters.org>

ABIWise App is free to download from GooglePlay and the App Store



Updates

Committee of Management (CoM) Report

Right at the last moment, BIM received some good news – six months funding for the peer support program until 31 December 2022. We had been hoping for a 2-year extension, but the incoming Government have decided to review the ILC program. The details of this ILC review are not clear, so we are seeking information.

The hunt for funds from other sources continues, with several submissions, either being lodged, or in train.

On behalf of BIM, I presented a paper at the Brain Injury Australia conference in the last week of June. The paper was on our peer support group program. The paper was very well received, but I did raise with the conference organisers it would be great to have self-advocate's presentations in better time slots. My feedback was well-received.

Cheers,

Brent

Brent Alford

Chairperson

Project Report

As Brent mentioned in the CoM report, we had great news about project. The six-month funding extension is great, but we hope there will be more secure longer-term funding commencing in 2023!

Unfortunately, one of our team has left us. Sonia, one of our wonderful peer coordinators has left us. We will really miss her, as will the people who come along to the peer support groups that she was pivotal in setting up. Best wishes from us all Sonia!

The peer support groups all continued to meet face-to-face and on-line. Some of the activities included the Aquarium, the IMAX cinema, Bowling and karaoke, a favourite song session and guest speaker Joy Ward, a neuro-physio. As always, all the activities are suggested and chosen by group members.

Talk to you next month.

Fiona, Fraser, Peter, Sally, and Yannick

Report from the Office - Lauren

Working at BIM it is great to be reminded daily about why we are here. Each new project and activity must align with our organisational vision, which is *'People with Acquired Brain Injury lead dignified and meaningful lives in an inclusive community'*.

BIM is here to support and empower people to advocate for themselves and enhance the lives of other people with Acquired Brain Injury.

BIM has many supporters and partners who share our principles and values, working collaboratively with us, towards our common goals.

Peninsula Community Legal Centre have offered to partner with us on several ventures. In person events are being planned.

The first collaboration will be a Webinar run by lawyer, Will Young.

The topic is Wills, Power of Attorney and Advanced Care directives.

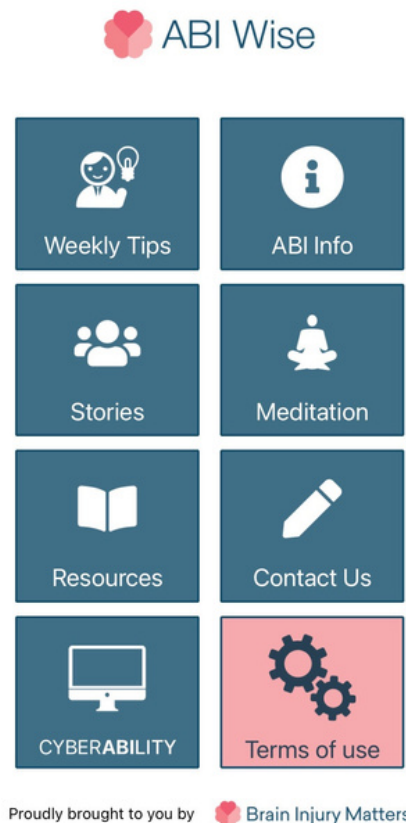
The Webinar will be tailored specifically with the needs of people with ABI in mind. Members have been consulted about the content and the format. Funding is being applied for to have the Webinar content put on the BIM ABI Wise App. The recording will also go on the BIM website.

Please have a look at PCLC website <https://pclc.org.au/>. You will receive an invitation to the Webinar, to run on the 6th of September at 11am.

Another great partner of BIM is Monash University. The Cyber**AB**ility program, about how not to get scammed, was developed by Monash and BIM. This great information to ensure cyber safety is now available on the ABI Wise App. Further additions to the App are material tailored for people with ABI in emergency situations, like fires and floods. The resource has essential information and includes how to make a 'Personal Emergency Response Plan'.

Report from the Office continued

I downloaded my new version of the BIM ABI Wise mobile phone App today and it is brilliant! It now looks like this.



Please download yours at the App store for Apple or get the Android version. Both are free. If you already have the App, you may need to refresh it by deleting and reloading it. Please call us at the BIM office if you need help.

More good news, Adam Bandt MP, the leader of the Australian Greens and Federal member for the seat of Melbourne, is visiting the BIM office next month. We will be showing Adam the new computers purchased through the grant he supported. If you would like to meet Adam, please let me know. We hope he has time to stay for a cuppa with members. We want to introduce Adam to lots of people with the lived experience of an ABI. He will meet with BIM self-advocates, whose actions enhance the lives of other people with Acquired Brain Injury and themselves by working together.



Seeking people with a traumatic brain injury (TBI) for their thoughts on potential treatments that could improve long-term social outcomes

Researchers from Monash University are seeking people who have had a traumatic brain injury (TBI), more than 2 years prior, and are interested in talking about hypothetical new treatments with the potential to change outcomes after a brain injury, such as new medications and rehabilitation programs.



This research project, entitled *Patient and Family Attitudes Towards Potential Treatments After Traumatic Brain Injury*, aims to understand the perceptions and attitudes of those with lived experience of TBI, towards hypothetical new treatments that could alter outcomes (particularly, social functioning) in the years after a TBI.

Findings from this project are anticipated to influence the design and development of new treatments for chronic problems after a TBI by understanding and taking into account patient perspectives and concerns.

Participating in this project will involve completing a single videoconference or telephone interview, which will take approximately 30 mins. Your next of kin or caregiver is also welcome to join the interview.

Participation in this research is voluntary. You will be provided with a \$50 gift card following interview completion, to thank you for your time.

If you are interested in being a part of this study, please contact **Nadia Moore** on nadia.moore@monash.edu or call **0447 083874** you with further details or answer any questions that you might have.

Note: This is not an intervention study, and involves discussion about hypothetical, potential future treatments

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Cyber safety tips from Col

The 16 best password managers in 2022

Creating and remembering passwords is a necessary evil of life on the Internet. With just about every web site requiring a new and individual password, remembering the passwords has become very demanding. This is where password managers come in. This list provided [here](#) is of free password managers on the [Android Police](#) web site. Just because they are free, don't think that they are easy to crack. All offer good security, most usually with a password that is required to gain access to the app.

The one that I use is [Keepass](#), in the list at number 7. This is available for both Android and Apple devices and you can store the password list on a cloud server.

Read through the list and find one that you prefer and try it. Some of the password managers in the list have a small fee attached, but most are free.

If you have been using a password manager and have a recommendation, let me know at vicechair@braininjurymatters.org

ABI Wise app update

For those people with an Apple iPhone, we are awaiting Apple to process the update to the app. You will then have access to the Cyber**AB**ility and Emergency Response modules, which were recently uploaded to the app.

How to block spam messages on your Android phone or your iPhone: A step-by-step guide

<https://www.xda-developers.com/how-to-block-spam-messages-on-your-phone/>

If you are getting spam messages on your smartphone, take a look at the guide above.

Travellers Aid

For more than 100 years Travellers Aid has been assisting people to get to where they need to be. Started by a group of pioneering women who believed that everyone had the right to feel safe while travelling into the city, today we offer a wide range of services that allow you to connect, engage and participate in your community safely and independently.

Some of the ways we can help:

Our **Time Out** program seeks to provide respite for unpaid carers who look after family members, including adult children, partners, and parents. This respite allows carers to have some “Time Out”, either to attend to their own personal needs, or to enjoy an activity with their loved one - without having to act as their carer.

The Travellers Aid **Companion Service** is a free service available to any person travelling to, from or within Melbourne, Seymour and the surrounding areas. If you are attending an essential appointment, we can provide trained volunteers who will assist you along the way.

Events can provide enjoyable moments and life-long memories. Our service users agree. We work with event organisers to provide assistance at public transport hubs and major events, ensuring our service users feel supported and comfortable to get to - and around - events.

We provide our services at **Seymour, Flinders Street and Southern Cross** railway stations for any mobility and assistance needs you have.

These Include:

- Buggy Transfer Service (Seymour and Southern Cross Stations)
- Participation Assistance (Companion and the Time Out Carer Respite Services)
- Personal Care
- Mobility Equipment Hire
- Crisis Travel
- Travellers Aid Lounges
- Training and Education Services

Travellers Aid continued

Travellers Aid proudly provides not-for-profit services to anyone who needs them. The provision of these services is made possible by the kindness and generosity of our supporters, volunteers and donors. For further information or to make a booking, call us on **03 9654 2600** or visit travellersaid.org.au

Travellers Aid Southern Cross Station

Opening hours:

6:30am to 9.30pm, 7 days a week

Phone: (03) 9670 2072

Email: scs@travellersaid.org.au

99 Spencer Street, Docklands VIC 3008

Travellers Aid Southern Cross Lounge is located opposite the Luggage Hall on the main concourse

Travellers Aid Flinders Street Station

Opening hours:

8:00am to 7:00pm, 7 days a week

Phone: (03) 9068 8187

Email: scs@travellersaid.org.au

Corner Flinders & Swanston Streets, Melbourne VIC 3000

Travellers Aid Lounge is located on the main concourse near the escalators between platforms 9 and 10

Travellers Aid Seymour Station

Opening hours:

8:30am to 6:30pm, Monday - Friday

Phone: (03) 5793 6210

Email: seymour@travellersaid.org.au

Station Street, Seymour VIC 3660

Travellers can use the V/Line lounge room at the station



Flinders Street Site



Over 200,000 instances of assistance to people from all walks of life



Over 28,000 courtesy buggy rides

Spotlight on Pets

Delia and Molly

Delia is 68 years old and has had her brain injury since 1986.

In 2012, Delia met Molly - a Cairn Terrier, aged 6.

They have been companions ever since. Delia had previously had another Cairn terrier for 7 years.

When asked about the benefits of having a dog, Delia says she loves the constant company and unconditional love. She also says that having a dog makes you not look so mad when you're talking to the bed! Dogs are also great conversation starters with other people.



Delia gets around in an electric wheelchair and Molly has always known how to get out of the way of the chair and had no problem being taken anywhere. Delia often tells others that Molly has kept her sane while she lives in an aged care facility.

Sadly, Delia has recently had to give Molly up, because in her old age, she became deaf, partly blind, and incontinent. Her breeder has taken her back to care for her in her old age. Delia misses her like mad and is considering whether or not to get another assistance dog.

Brainstormers - Karaoke and Bowling



The following is a monologue which was written and performed by Sonia Marcon. It is a letter to the golf-ball sized section of brain damage as a result of Multiple Sclerosis. Sonia shared this with our Brainwave peer support group who found it helpful.

Dear golf ball,

Are you well? I'm not. It's not your fault. It's not mine, either. Neither of us put you there but there you are.

I've never met you. I've seen your photograph, though. You're like the world's strangest celebrity. Especially seeing that your photo got taken to a convention in the US. My photo didn't but yours did.

I guess that's what happens when you're famous to a select few.

I just thought I'd drop you a line and let you know how the one who's keeping you is going seeing that it's been, what, more that fifteen years since you moved in.

To be honest, I'm tired. Not for the reasons of how and why you're there but more for the reasons of how I'm treated because you're there.

I have you, a golf ball sized lump of dead brain in my head and people usually expect those with that to be lolling around in bed getting sponge baths and pissing through a tube. Sometimes I wish for that. God, it would be easy. No job. No Centrelink. No selfish f***s on a train who won't give up a seat even when you have a walking stick because of said golf ball.

Unfortunately, the expectations are ten-fold when you're not bed ridden. 'You look fine. You look great! You're doing so well. It makes me so happy to see you out and about.'

If only the people saying that had a single clue of what my reality is.

There is so much that I have tried. So much that I have wished for. But the treatment I get for the reason you're there does nothing to heal you so all I get is the vacuous support and the vile misunderstanding.

'Stop using your disability as an excuse! You're not that bad! Everyone has problems.'

I know you don't understand what I'm saying but if you did, would it make a difference? You are dead after all.

New Resources

The National Assistance Card

The National Assistance Card is now available for people in Australia living with brain injury.

The National Assistance Card Service hope that, in the future, the National Assistance Card will be available to all Australian's living with disability and/or health conditions.

The National Assistance Card can:

- help cardholders communicate their unique areas of difficulty and the assistance they may need.
- give cardholders greater independence.
- assist cardholders to feel more confident in everyday social situations.
- provide peace of mind for families and carers.
- enhance community understanding of disability and health conditions.
- support positive community interaction with cardholders.

Every National Assistance Card is personalised.

The Card includes a cardholders:

- first and last name
- photo
- date of birth
- nominated contact person's name and phone number
- (A cardholder can choose if this person is contacted)

Also printed on the Card:

- up to five areas of difficulty chosen by the cardholder
- (for example: communication, fatigue, memory, processing information)
- a QR (Quick Response) Code providing access to additional written information (written or personalised video) that the cardholder has chosen to include.
- the Police Assistance Line phone number.

To apply for a National Assistance Card please visit:

www.nationalassistancecard.com.au/apply

Click on the **Apply Online Now** button to access the online application.

To help you with your application we recommend you:

Read one of the How to Apply Guides available at the link above.

You can refer to these Guides while you complete your application.

Watch the 'How to' videos included in the application, such as the overview video. Here is the link- <https://www.youtube.com/watch?v=ZW4DmfiDwEo&t=8s>

Ask a family member, friend or support worker to help you.

If you have any questions about the National Assistance Card, please:

- Visit the National Assistance Card Website, you may find the answer you need on the Frequently Asked Questions page:

www.nationalassistancecard.com.au/frequently-asked-questions

- Contact the National Assistance Card Team via:

- Email: info@nationalassistancecard.com.au or

- Phone: freecall 1300 242 827



**NATIONAL
ASSISTANCE
CARD**

Newsletter Contributions Welcome

Contributions by BIM members to our newsletter are always welcome. If you have any tips, stories or experiences that would be of interest to

others, please contact office@braininjurymatters.org

**Ross House, Level 4/247 Flinders Lane
Melbourne, Vic. 3000
email: office@braininjurymatters.org
www.braininjurymatters.org (03) 9639 7222**