



Brain Injury Matters Newsletter

Issue 1 February 2015

Wise Words for a Back Bending Life

A hearty welcome from our newsletter team to our latest edition! – and welcome to all of our new readers who have joined us since our last issue!

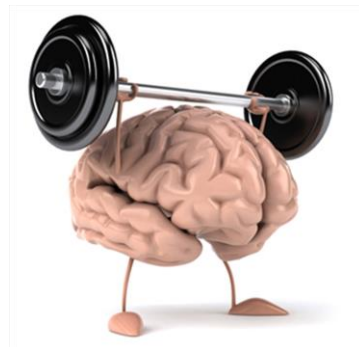
We have news in abundance in this issue, including:



Also in this issue, we have included a special publication ***“2014 – A Year in Review”*** which features some key news items from 2014, as well as:

- A report about the 2014 ‘*Acquired Brain Injury National Conference*’
- A Q&A with our Vice President, Lisa Brumtis
- Details of an exhibition of Larissa MacFarlane’s etchings
- A report on the opening of Caulfield Hospital’s new ABI Unit
- ABI in the media, and –
- much more!

Don’t forget that everyone is welcome to make contributions, so please send in your stories, news, poems, artworks, photographs, whatever! We’d love to hear from you!



Brain Injury Matters facilitates self-advocacy and community education for people living with an Acquired Brain Injury. Our aim is to help people living with ABI to realise potential for a full life within a supportive community and increase community awareness about ABI.

<http://www.braininjurymatters.org> Ph: (03) 9639 7222

Brain Injury Awareness Week – 11-17 August 2014

A significant event held in Bendigo during this year's Brain Injury Awareness Week, was the '**Acquired Brain Injury National Conference**'. It was staged by Loddon Mallee Acquired Brain Injury Network (LMABIN) in collaboration with Bendigo Health. The information presented was designed to be relevant to health professionals, community service providers, researchers, people with an ABI and their carers. Presentations and keynote speakers aimed to explore four key streams:

- Sex and sexuality
- Restorative justice
- Belonging to Community
- Meaning and identity



The keynote speakers were: Dr Sally Cockburn ('Dr Feelgood') GP; Tim Feeney, Neurobehavioural Specialist; and Nick Rushworth, Executive Officer, Brain Injury Australia.

Held on the 11th and 12th of August, there were over 30 presentations and workshops spread over the two days. BIM's involvement included Larissa MacFarlane's *Book Making Workshops*, and a joint presentation by Peta Ferguson, Lisa Brumtis, and Neil Cameron entitled 'My Changed Brain'. Peta, Lisa, and Neil spoke of personal experiences as well as BIM's activities, and also the production of two kits – the '*Speaker's Kit*' and '*A Hitchhikers Guide Through The Brain Maze*' and featured a prototype of the latter for audience perusal.

ABI in the Media

A posting by Clare Rawlinson on the ABC News website on August 13, 2014 spoke of a clubhouse in Fitzroy which has become a "*social hub for an eclectic mix of members, all bound by one thing: acquired brain injuries.*" It's called the '*Compass Clubhouse*' and is a Melbourne City Mission initiative which aims to provide a launching pad for people adjusting to life with an ABI. Importantly, it is governed and staffed by people with ABI's.

Viron Koukoravas, one of the three staff at the clubhouse, astutely states: "You've seen one acquired brain injury, you've really just seen one." Clubhouse members Erin Davis and Peter Manolopoulos are both quoted as saying that they feel they have a 'family of friends' since becoming involved with the clubhouse. For more information about Compass Clubhouse, go to: <http://www.melbournecitymission.org.au/services/disability-services/living-with-an-abi/program-detail/compass-clubhouse>

Alesha Capone writes in the Brimbank Leader on August 11, 2014 that the group '*LifeMoves*' aims to connect people who have acquired brain injuries as well as degenerative brain conditions, and improve their quality of life. The program is an initiative of the Victorian-based service *Brainlink*. The program is a peer support program that is participant-directed and involves eight weekly sessions where participants can talk about the challenges they face inclusive of physical difficulties, relationship changes, and acceptance of their changed lives. More details about LifeMoves can be found at: <http://www.brainlink.org.au/events>

*******Peta and Jan: would you be able to add here the BIM criteria for becoming a Committee member?**

Lisa Brumtis

To become a member of the BIM committee you must have an ABI.

Art Installation - ABI and public transport

Early in 2014, I made some artwork for the window gallery at 50 Orr St Carlton (*PS50Gallery*).

It was a collection of small etchings, resembling Metro train signs, installed within a box that was covered with black and white pixelated images of trains and train stations. The work was inspired by the difficulties that I encounter when travelling upon Melbourne's trains. As we all know, public transport can be very difficult and sometimes impossible for many people with disabilities. The signs focus on my own experiences of ABI induced noise, light, and touch sensitivity, but they also draw on the experiences of my peers.



The etchings take the form of real METRO train signs, with fictitious but relevant warnings of the situations that we may encounter on trains as people with different needs and abilities. For example, one sign warns us of the presence of fluorescent lighting, and its potential to induce migraines and epilepsy. Several 'signs' explore the vexed issue of how to claim your right to use a seat on an overcrowded train when you do not look disabled. Indeed, 90% of all disabilities are invisible. Have you ever tried to ask for a seat knowing that you 'look fine'?

Another sign highlights the safety features of train stations whilst acknowledging the dangers of extensive EMF. Another records a long list of symptoms (that resemble those found on a medication information sheet) that train travel may induce.

A further issue explored is the difficulties you may face if you are not able to use stairs and require a lift. As we know, lifts at train stations are often broken, leaving you stranded where the only option is to travel to the next station (where you may of course face the same situation), where you must then find an appropriate taxi to take you to your destination and later engage in a lengthy, bureaucratic process to be refunded.

Another sign warns us that if you have a disability you cannot expect to ever be on time whilst using public transport! I also touch on some of the issues that those with mental illness face when using public transport. And of course, the signs emphasise that Metro takes no responsibility for any negative outcomes of train travel.

The whole artwork is a little tongue in cheek, but hopefully still highlights the seriousness of the discrimination that many people with disabilities face when using public transport. As always it is hard to depict this sort of art installation in photos but I hope that some of the accompanying images can convey to you a sense of this artwork. I also hope to be able to show this work again in another exhibition. If you have any ideas, please let me know.

Larissa MacFarlane

Caulfield Hospital opens dedicated ABI Unit

The Caulfield Hospital's new Acquired Brain Injury Rehabilitation Centre was officially opened on Friday 5th September 2014 by Health Minister David Davis. The 42 bed facility and the nearby off-site four bed transitional living facility was built at a cost of \$36 million. Work began in January 2013. [*Caulfield Hospital is managed by Alfred Health.*]

Health Minister, David Davis, stated *"The Caulfield Hospital ABI Rehabilitation Centre will provide a specialist rehabilitation service accessible to brain injury patients across Victoria and will be complementary to other statewide specialist rehabilitation services."* The Acquired Brain Injury Rehabilitation Centre is jointly funded by the Australian Government, Victorian Department of Health and the Victorian Transport Accident Commission (TAC). The centre will treat patients from the early stages of injury, through to rehabilitation and recovery.

Mr Davis was also quoted as saying *"Apart from the physical and emotional distress, a severe ABI can cost about \$2.2 million in care over a lifetime."* (The Health Minister did **not** state, however, where he obtained his figures from!)

The Transitional Living Centre (TLS) attached to the unit is described as being a homely four bedroom residence designed to help return ABI patients to daily activities following rehabilitation. *"Patients who graduate from the rehabilitation centre, in need of further skill development, will receive residential rehabilitation in this facility to build greater skills in independent living in a home-like environment before re-entering the community"* according to Alfred Health's website. Dr Mithu Palit is the Head of Neurological Rehabilitation at Caulfield Hospital. He said they would admit five patients on Monday,



*Caulfield Hospital patient Anj Barker, front, with (from left) Dr Mithu Palit, Jacqui Morarty and Katrina Neave. **Picture: Valeriu Campan***

with more patients added in stages as their medical staff built in numbers. Alfred Health chief executive Associate Professor Andrew Way said the new centre would see eligible patients leaving acute hospitals sooner to continue their treatment in this specialist setting.

Sources:

- <http://www.alfredhealth.org.au/bettercare#1>
- <http://www.premier.vic.gov.au/media-centre/media-releases/10858-caulfield-s-36-million-rehabilitation-centre-opens.html>

BIM Committee of Management – working hard for Victorians with ABI

June

- 6th June 2014
- 'Brain Strength' group, Doveton

BIM attended the Doveton group of 'Brain Strength' and talked to the group about self-advocacy as well as BIM.

July

- 31st July 2014
- Department of Justice

BIM consulted with the Department of Justice about the Victorian *Guardianship and Administration Bill*.

August

- 25th August 2014
- Judicial College

BIM met with officers of the Judicial College of Victoria. We hope to present at one of the college courses.

The Judicial College of Victoria website states that the College "... provides education for judges, magistrates and VCAT members." (VCAT is the Victorian Civil and Administrative Tribunal.) "We keep judicial officers abreast of developments in the law and social issues, and help them build and maintain the skills they need to perform their roles with rigour. Maintaining the community's confidence in judicial officers is essential to the rule of law. Judicial education and ongoing professional development are powerful agents to support and reinforce cultural change within the justice system."

September

- 12th September 2014
- Tim Wilson, Australia's Human Rights Commissioner

Tim Wilson attended BIM's office and met with members of BIM's committee of management as well as the president of Reinforce, Susan Arthur. The primary objective of meeting with Mr Wilson was to inform him about ABI as well as discussing the rights of people with an intellectual disability and also the rights of parents living with a disability

- 19th September 2014
- Acquired Brain Injury Global Picnic

BIM attended an Acquired Brain Injury Global Picnic event in Doveton.

Public Transport Ombudsman (PTO)

- *Visits to ABI groups*

BIM is continuing to meet with ABI support groups within metropolitan Melbourne as well as in regional areas of Victoria.

- *Melbourne City Council*

BIM's ongoing partnership with the Melbourne City Council is, and continues to be, very successful.

- *Peer-to-peer support*

BIM, with SARU, is involved with the process of the hoped-for development of an ABI self-advocacy group in Beaumaris.

- *19th September 2014*

- *Acquired Brain Injury Global Picnic*

BIM attended an *Acquired Brain Injury Global Picnic* event in Doveton.

High Numbers of Offenders in Victoria's Prison with an ABI

In an article appearing in 'The Age' newspaper on June 30, 2014 titled *"Fixing The Trouble Inside"*, journalist Julia May states that *"...in Victoria's male prisons, at least 42 per cent of inmates are affected"* by acquired brain injury; this is according to a 2011 report by Corrections Victoria, Arbias, and LaTrobe University. In the general prison population *"...about 2 per cent of people have an acquired brain injury."* She goes on to say that

"...men imprisoned for committing an offence are at least 20 times more likely to have sustained damage to the brain causing cognitive, physical or emotional dysfunction – or a combination of all three. Female prisoners are at least 15 times more likely."

She asserts that, statistically, links between brain injury and crime are compelling, and that *"medics, mental health advocates and criminal justice experts"* describe this as *"...a hidden epidemic."* She also reports

"John Eyre is the chief executive of Arbias, which provides support services and has developed a well-regarded diagnostic tool for people with an ABI, a condition he describes as 'insidious'. We call it a silent disability because by the time a person has even a mild one, they have a disability but they don't know it."

In regards to Victoria's prisons, Ms May quotes a spokesman for Corrections Victoria as saying

"...the state's prisons use the Arbias screening tool when assessing new prisoners and provide treatment programs in prisons and community corrections. Prisoners identified as potentially having an acquired brain injury are then referred to a specialist clinician for a full clinical assessment. If a prisoner's ABI impacts on their ability to participate in mainstream programs they will be referred to a specialist disability stream, which provides tailored programs."

Additionally, she reports this spokesman as advising that both Port Phillip and Loddon prisons have programs delivered by

"specialist staff, who receive ongoing clinical training in treating offenders with ABI" and that "general prison staff also receive training in how to identify signs of acquired brain injury, the differences between ABI and intellectual disability and strategies for working with people with ABI."

Ms May observes that Arbias' John Eyre is sceptical about this and she quotes him as saying

"I'm not confident that [state run prisons] are using [the screening tool] to the level that they should. I suspect because of time and resources that they don't screen as much as they could or should... Just like any area of business, they have a turnover of staff. For that screening tool to be accurate, the prison staff has to be trained, and the last time we trained any staff in using our tool was in 2006."

Ms May also reports Nick Rushworth, the executive director of Brain Injury Australia, as stating

"Awareness about brain injury lags about 30 years behind other disabilities. You'll find no end of services for intellectual disability and psychosocial disorders in the corrections systems, but next to nothing for brain injury."

This news article sheds light on many of the challenges of working with offenders within the prison system. However, there is much work to be done in many sectors of the community in terms of educating relevant staff as well as management personnel in various institutions and service providers about the impacts of ABI on behaviour and lifestyle. BIM is one of the key organisations which are prominent in both educating and awareness-raising about ABI – BIM's mission statement being;

Diary dates!

September 2014

Brain Injury Australia's – 'Sidetember'

'A fun initiative running for the month formerly known as September to help raise funds for people living with acquired brain injuries (ABIs) and their incredible carers.'

For more information, and to register, go to www.sidetember.com

Get Involved!

Murdoch Children's Research Institute is seeking input into developing guidelines for '***Communication and Swallowing Disorders Following Traumatic Brain Injury***'. ***They are specifically looking for:***

- Adolescents and young adults who have experienced communication or swallowing difficulties following traumatic brain injury.
- Parents who have a child who experienced communication or swallowing difficulties following traumatic brain injury.

For further details, go to:

<http://www.braininjuryaustralia.org.au/docs/TBI%20Guidelines%20Flyer.pdf>

To find out more about Melbourne City Mission's 'Compass Clubhouse', visit:

<http://www.melbournecitymission.org.au/services/disability-services/living-with-an-abi/program-detail/compass-clubhouse>

To find out more about Brainlink's '*LifeMoves*' peer support group, go to:

<http://www.brainlink.org.au/events>

Further Reading...

'Bridge': a quarterly (Australian) magazine about brain injury that is free to all people with an ABI. Contact them to get on their mailing list... **www.synapse.org.au/shop/magazines**

Useful websites...

www.unitedbrains.org.au

www.brainlink.org.au

www.braininjuryaustralia.org.au

For details on Caulfield Hospital's new ABI Unit,
go to:

<http://www.alfredhealth.org.au/bettercare#1>

In attempt to reduce our environmental impact
and save money we would prefer to send our
newsletter via email. Please contact us at BIM let
us know your preference for the newsletter in
future. Thank you!

Sender

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