

THINK!

THE HEAD INJURY NETWORK FOR KIWIS

Oct – Dec
2016

One moment can
change a day, one
day can change a life
and one life can
change the world.
Gautama Buddha

The voice of those affected by head injury

Te reo o nga tangata i pangia i te mate mahunga

My Brain Injury'

Anon

This constant companion
More than anything
An Invisible
Inner reality
Those close to me witness
Yet struggle to understand

Appearing
As many different things
Its a package deal
With an open ended time
frame
I didn't want to buy

The way the pressure builds
Blocking my intelligence
Rendering me a zombie
In my own skin
The way I must monitor
Everything I do
Before the fatigue sets in

Unable to turn the volume
down
To the outside world
Or the pain that comes and
goes in my head
My brain cells don't retrieve
What I used to know
What I want to remember

More than anything
It is about accepting
This strange place
I now navigate
Is the new me



MISSION STATEMENT

We empower people affected by head injury through the provision of information, education and advocacy support and raise awareness and prevention of head injury in the community.

“Bringing together those in need with those who wish to give”

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Your contributions help to impact lives

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THINKHeadInjuryAwareness
NZ

Research Report



Dr Alice Theadom, Senior Lecturer, Department of Psychology. Deputy Director, National Institute of Stroke and Applied Neurosciences, Auckland University of Technology

The experiences of recovery & adaption after brain injury

A study conducted by a team of researchers at Auckland University of Technology has provided evidence about the impact of brain injury on the lives of people in New Zealand.

The study which was funded by the Health Research Council of New Zealand aimed to find out what areas of life people felt had changed most since their brain injury and the things they have found most helpful or unhelpful in managing the effects of the brain injury.

A total of 201 interviews were

carried out during the study. Participants were 53 people who had a brain injury and 37 of their 'significant others' (close family or friends).

Participants were interviewed up to three times – at 6-9 months, 1 year and 2 years after the injury.

The overall themes from the interviews showed that participants experienced challenges in keeping up with life and in understanding and dealing with what brain injury meant for them and their life.

During the first months after their injury, many people experienced significant disruptions in the daily processes that made up their life (e.g. family, work, leisure activities) and also highly valued connections to other people and to what matters to them in life.

People described how in the recovery process they needed to actively change some aspects of life, and yet also 'allow' or accept that other changes happen. This was quite a difficult balance for many people.

Valued supports for this process included being heard and believed; being looked out for; having someone help drive the recovery process; and services and supports that go beyond planning and avoid assumptions about who

or what matters most. These findings have real potential for helping services improve the way they work with people in the first year after injury.

As time moved on after the injury, people described realising that recovery takes time, and that life experiences, life roles, spirituality and sense of self all contributed to how they managed the disruption to their lives caused by the brain injury.

The research confirmed the difficulties people experience after a brain injury (much of which we know from earlier research). But importantly – the study provided new insights into how people make sense of life after brain injury, and the complexity of that process.

For more information about the study please contact:
Dr Alice Theadom email: alice.theadom@aut.ac.nz
Tel: 09 921 9999 x7805

END OF YEAR BBQ

Our end of year BBQ is coming up. **Put this date in your diary.** Flyers will be distributed closer to the time.

When: 29 November 2016
Where: THINK! office, 11 Somerset Street, Frankton.
Time: 11:30am

Report from headquarters

by Marion

Greetings everybody

Welcome to our last newsletter for 2016. I know it's become a cliché, but, how did that happen so quickly! We have not been idle.

Brain Injury draws the short straw in terms of recognition in many areas, but awareness is growing. The team of researchers from AUT National Institute for Stroke and Applied Neuroscience and the Waikato University BIONIC and subsequent studies, have valuable findings that cannot be ignored, and I am sure there will be more to come. People who are dedicated to finding out the long term effects of brain injury using recognised methodology are very important.

One of them, Alice Theadom, spoke at our Conference in June for Health Providers and some of you came to hear Alice talk on sleep issues and the sleep programme through AUT last year. Kelly Jones who is based at Waikato University and also one of our Board members, has a specific focus on the impact of brain injury on children. We are very fortunate to have such good people working alongside us who are always willing to share their expertise.

Meanwhile, we continue to do our best to assist our clients and to provide a link in the community in a range of ways,

whether it is the important task of assisting people in navigating systems such as ACC or Work and Income, attend appointments with people for support, or provide options not previously known or considered; to name a few.

Support groups are an opportunity for people to meet others who understand and it is really nice to see connections and a kind regard for people develop in the group. Our Tokoroa and Cambridge group are such groups, and we are currently working on building numbers for our newly established Huntly group. Te Aroha is looking promising for a Support Group meeting with clients from surrounding areas.

Education Sessions continue to be well attended. The "My Memory App" session was great with a lot of people showing interest in being part of another proposed study through the Waikato University. A special thanks to Laima who shared her personal experience of being part of the previous study and the difference it made in her life. The App is currently only for Android phones and the researchers are following up the needed funding to get this underway. The App uses a range of methods to store, retrieve and prompt memory so that important information can be easily accessed. It works to both refresh and train memory using texts, colour

coding, and photo cues which have particular power to assist memory training.

We look forward to two more interesting topics still coming this year including a Neuro-physiotherapist and 'Be Active & Well'.

I have provided a summary of the Gil Newburn Seminar (Page 5), held at our office for clients and family members recently, for those who were unable to attend.

Recently Ella and I attend the Brain Injury Association Conference in Auckland. It was a good opportunity to meet up with others across the country who do the same work and hear a range of relevant speakers. As an outcome of new move to form a National body with the Brain Injury Association, my title will be Liaison Officer which in many ways is more descriptive of what we do in our region and the current title in other regions.

Congratulations to Carl McElhinney who is the winner of the mystery prize draw for paying a membership fee.

Best wishes for a safe and fruitful Spring and Summer season.

Marion

The office will be closed from 22 December 2016 and reopen on 11 January 2017.



What people don't understand

By Janice Tindle

You take for granted that when you wake up, you will go to sleep that night as the same person you were when you began your day. You thought the same thoughts, had the same feelings, dreams, goals and abilities as you did the day before. You expect that the next day you will still look at yourself in the mirror and recognize your face, body and voice as yours.

You know yourself. Whether or not you like yourself, you have full recognition of your body, mind and spirit. You are comfortable in your own skin. You may not be content or satisfied with who you've become, but you understand how you got that way and you understand what you need to do to change, grow and progress.

Now, imagine waking up one day and within the course of your normal activities, a blow to the head removes all that. Imagine your sense of yourself disappearing like a document in your computer that you forgot to save. You remember that it's there. You search for it, you know it's there, somewhere, but no matter how hard you search, you just can't find it.

So you try to make a new one, as close to the old one as possible, but all the subtle nuances and specific details,

are gone. All you can do is try to make a copy of the "you" that used to be, but you feel like an imposter. You feel like you're living someone else's life, but it's your life. You're lonely for yourself. You feel completely lost.

Things that were so important before, now have no meaning. Relationships that you once treasured, you find difficult to connect with. You understand the meaning of the lyrics in Gordon Lightfoot's song, "If You Could Read My Mind" because you walk around like a ghost in your own life "with chains around your feet" agonizing because "the feeling's gone and you just can't get it back."



If that is too hard to understand, try to imagine it this way: Picture yourself getting into your car that only you drive, and suddenly, the seat is in the wrong position. You try to adjust it back to where you've always had it, but your most comfortable setting is gone. The steering wheel won't tilt into place, and the climate control system no longer has your temperature of choice.

The radio has been reprogrammed without any stations that you recognize. The wipers stick and squeak. The defroster only defrosts one side of the window. The gas tank is on the other side.

You try to drive it anyway, but no matter how hard you try, you just can't get the speed up to normal. You can't see, your back hurts, it's either too hot or too cold, the music is too loud, and the wipers are driving you crazy.

You feel like you're living someone else's life, but it's your life.

You are so frustrated by everyone honking at you that you just pull over, put your head in your hands and cry. Now imagine that car is your brain. That's TBI (traumatic brain injury).

Janice Tindle is a freelance writer and brain injury survivor. (Taken from June 2016 TBI HOPE AND INSPIRATION p22-23)

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www.facebook.com/THINKHeadInjuryAwarenessNZ

<https://givealittle.co.nz/donate/Organisation/whis>

Emotional Volatility and rage after brain injury

Below is a summary from a recent workshop with Dr Gil Newburn, Neuropsychiatrist. Emotional volatility following a brain injury could result in one of the following:

- The right emotion but too much of it
- Emotion that is not expected
- No emotion when some is expected
- The wrong type of emotion

Registering, monitoring and responding to emotions uses 20% - 25% of total body energy per day. Emotions arise from stimuli and our responses to it. Brain injury can cause perception and awareness to be impaired. As a result the person may not know how to respond, or their judgement is impaired & they don't attach any importance to it. Conversely they overreact by not being able to control the response.

They may lack an ability to read a situation or register another person's feelings or expressions. The ability to respond may also be affected by depression and causing altered facial expression. A failure to experience a range of emotions can inhibit the ability to detect the feelings of others.

Depression is found in 70% of cases following a brain injury.

Manic episodes are also noted. Where PTSD (Post Traumatic Stress Disorder) exists there may be reactions to past stimuli which are internalised and replayed with triggers. A third of people will experience anxiety and PTSD following a brain injury. Obsessive Compulsive Disorder is 3 times more common, with difficulty in shifting mental set. The person becomes fixated on a topic which they repeat.

Depression is found in 70% of cases following a brain injury.

Many emotional responses come from a "fight or flight" which is an automatic fear response to a perceived threat, and becomes the dominant way of responding to external stimuli. It may be an inappropriate response to the circumstances. There is a physiological basis to these responses. Damage to pathways messaging specific centres of the brain alters any interception of fight/ flight reactions. Key areas involved are within the Limbic system including the Insula, Hippocampus, and the Amygdala. Parts of the Insula give us a "gut response" to external triggers, the Hippocampus is a memory bank and gives context and relevance to a situation. The Amygdala triggers the fight or flight reaction.

If there is damage to the systems that assess, then send messages to say "don't do anything now" or "this is ok", there is no threat; the fight/flight mode will be activated. Rage is part of the fight response.

Management:

- Recognise situations where emotional issues arise
- Avoid stimulus overload
- Manage fatigue. Be aware of signs and stop before reaching limit. Do not push yourself.
- Treat specific disorders such as depression and PTSD through a health professional.
- Build up an alternative psychological back up or script which you can draw on; such as "It's ok I can manage this" to retrain or intercept the response. Repeat this on a frequent basis.
- Regular daily exercise of 30 minutes stimulates an important component in brain health which builds connections in the brain called BDNF (brain derived neurotrophic factor)
- It is important that exercise is anaerobic and increases heart rate but is not too demanding.
- Impulse control disorders and episodic dyscontrol may respond to medication such as SSRS (Antidepressants) or anticonvulsants that have dual use and treat moods.

THINK! SUPPORT GROUP MEETINGS



Huntly

1st Friday of every second month at 10:30am at Friendship House, 22 William Street, Huntly.

Tokoroa

2nd Thursday of each month at 10:30am at Tolloch House, Gate One, Maraetai Road, Tokoroa

Cambridge

3rd Tuesday of each month at 10:30am at Cambridge Community House, 193 Shakespeare Street, Cambridge

Kirikiri

Last Tuesday of each month at 10:30am at THINK! office, 11 Somerset Street, Frankton, Hamilton

Horsebirds over Waikato

A social group for women who have had a brain injury and a love of horses in common. They meet once a month on the last Saturday of the month.

Please contact the office for more information, or to add you to our mailing list.

Education sessions with Healthcare Rehabilitation Ltd

Sessions for clients, families, carers, & anyone interested in the topic of brain injury. Sessions are on the **2nd Wednesday** of the month at **10:30am** at the THINK! office.

October: Wednesday, 12th

Topic: Role of Neuro Physiotherapist

Laura Bloomfield, Neuro-physio will talk about her role in helping the brain to form new pathways & improving symptoms such as difficulties with loss of balance

November: Wednesday, 9th

Topic: Be Active and Well

Chloe Stevens, Active & Well Coordinator from Sport Waikato will be talking about the effects of regular exercise which will answer the who, what, when, where, and how.

Information about these sessions will be on our website www.thinknz.org.nz
Sessions will resume in February 2017

Head Injury Advocates

Only THINK! staff members are advocates for THINK!. No one else can represent THINK! in an advocacy role or use the name of THINK! for other purposes not approved by the Board. Consultation with THINK! staff is recommended for any suggestions made by other head injured people for treatment for a head injury.

Fundraising

Give a Little

We are registered with givealittle. Support our work www.givealittle.co.nz/org/whis/donate



Why not consider donating through payroll giving? Your employer deducts a set amount from your wages and it gets paid directly to us. My **sincere thanks** to people who are currently donating this way.

First Aid Kits



77 Piece first aid kit - \$39.95

Order your kit today from THINK!. We get \$12 for each kit sold. The kit has transparent fold-out compartments that contains 77 items including a digital thermometer and instant ice pack. The kit is CE approved and follows Worksafe NZ guidelines. View this first aid kit at the office, or online at www.fundraisingfirstaid.co.nz

Disclaimer

All care has been taken in the preparation of this newsletter; THINK! disclaims any liability for information contained within. It is of a general nature and to be used as a guide only.

Suicide Prevention

The Waikato District Health Board (WDHB), along with many organisations and agencies, want to ensure that everyone has the greatest opportunity for wellness and wellbeing and has access to helpful support. The DHB has a Suicide Prevention and Postvention Plan and part of the plan is having a suicide prevention coordinator.

Support services

If you or someone you know is experiencing feelings of sadness, despair, anger or confusion and these feelings stop you from being able to do things that you would normally be able to manage, we encourage you to talk to your General Practitioner. For urgent help, please contact:

- The Crisis and Home Treatment team on 0800 50 50 50
- Lifeline 0800 543 354
- The suicide crisis line 0508 TAUTOKO (828 865)
- Samaritans: 0800 726 666

If there is any threat to your or anyone else's life, please call 111 immediately and ask for police.

FEEDBACK & SUGGESTIONS

We welcome your suggestions and/or feedback. We want this organisation to work for you. Please forward your feedback to Ella at admin@thinknz.org.nz

Bereavement support

If you know of someone who is experiencing grief as a result of a suicide, you may wish to consider bereavement support. For more information, please go to <http://www.waikatodhb.health.nz/public-health-advice/suicide-prevention/>.

The recent television broadcast, [The Hard Stuff with Nigel Latta – Let's Talk About Suicide - Safely](#) gives us all clear advice on what to say if we are worried about someone and how to keep them safe before we get them good help.

Information kindly provided by Clare Simcock, Suicide Prevention and Postvention Coordinator, WDHB

BIWAP Wānanga weekend in November

The Brain Injury Whānau Action Project (BIWAP) held a most successful two day wānanga at Weraroa Marae last year. They plan to hold this free event for families again this year.

When: 19-20 November

Guest speakers: **Barry Willer** - rehabilitation & community re-integration,

Hinemoa Elder - child brain injury

Clare Wall - nutrition and the brain

Rosamund Hill - the functioning of the brain plus more.

To see what the wānanga is all about, watch this short clip: <https://www.youtube.com/channel/UCzsaQ712noe8C9ReGO7mgCw>

Contact BIWAP on facebook <https://www.facebook.com/search/top/?q=brain%20injury%20whanau%20action%20project>

Our SINCERE THANKS to all our funders and supporters



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THINK!

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CC 23785

NEW MEMBERSHIP / RENEWAL

We invite you to become a member and support the work of THINK!

We empower people affected by brain injury, to make informed choices in ways that create a long-term and sustainable difference in their lives through the provision of information, education and advocacy support. We raise awareness and prevention of brain injury in the community

I wish to become a member \$ 10 (Students, beneficiaries, seniors)

I wish to become a member \$ 50 (individuals waged)

I wish to give a donation \$10 \$20 \$30 \$ ___ (other)

Payment can be made by Direct Deposit into SBS bank account no 03-1355-0691730-00. Please use your name as reference or phone the office for a reference number.

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YOUR MEMBERSHIP AND DONATION MAKES A DIFFERENCE IN THE LIVES OF PEOPLE WE SUPPORT