IN THIS ISSUE:
DisabilityCare Australia
Brain Injury Awareness Week 12th - 18th August
INDEX

03 A Better Deal?
05 Answering The Urgent Need
07 Strategies For Coping
09 Problems With Vision
11 Mopy Dick?
13 My World After Brain Injury
15 Travel Tips For The Post ABI Journey
17 Substitute Decision Making
19 Locked In Syndrome
20 Back To Normal
23 Coming To Terms With Loss
25 The Big Bad Wolf
27 Loosing Friends
28 Keeping Friends
29 General legal issues

DisabilityCare - an excerpt
Why DisabilityCare is needed now
Hemiplegia & hemiparesis
Strategies and therapies to assist
Don’t let words govern your life
Ann Wood talks about her life
Travel slowly...
Tough Decisions Ahead
Dream It To Do It
A challenge for family life
The long journey to acceptance
Strategies for living with ABI
A Personal Account Post ABI
Useful communication tips
Legal issues and disability

A step closer to a fair go for all

Imagine if you were part of a group responsible for planning a just and equitable society. Some of the ingredients would no doubt include democracy, an impartial legal system and education. Now imagine that you, and everyone in this group each have a disability in this new society; a brain injury, an intellectual disability, schizophrenia and quadriplegia among others. No doubt you would suddenly be paying a lot more attention to how people with a disability would be treated. Australia has only provided very basic support for people with a disability, a situation that would change dramatically if the policy makers all had a disability themselves! That will now change with the new National Disability Insurance Scheme (NDIS), recently branded as ‘DisabilityCare Australia’. This is a positive step toward providing the supports that will ensure a fair go for anyone with a disability.

Both of the major political parties have agreed that DisabilityCare is needed — the key will be to ensure that the necessary funds are there despite tough economic times and budget deficits. It is also good to see that Indigenous Australians will be getting a fair go as well. In May 2013 the Gillard government announced $900,000 over three years for services to assist Indigenous Australians to understand and access support from DisabilityCare Australia. “We know the prevalence of severe or profound disability among Indigenous people is around twice the rate for non-Indigenous Australians” said Minister for Indigenous Affairs Jenny Macklin. “Unfortunately, many Indigenous people are reluctant to identify themselves as a person with disability and often do not seek help with disability services.”

In the mean time, Synapse and other Brain Injury Associations across the country are raising funds to make a difference for the 1.6 million Australians affected by Acquired Brain Injury (ABI). The BANGONABEANIE campaign encourages people to buy a blue beanie in support of Brain Injury Awareness Week from the 12th to 18th August 2013. All profits from BANGONABEANIE will go toward improving essential and much needed services, including accommodation, support and resources. There are plenty of things you can do too. Visit BANGONABEANIE.COM to buy a beanie, make a donation, download free resources or visit our Facebook page. Whether you realise it or not, we all know someone affected by ABI they contribute to our community and deserve our support.
A better deal

An excerpt of Brain Injury Australia’s recommendations for DisabilityCare

DisabilityCare, the new name for the National Disability Insurance Scheme (NDIS), aims to provide long-term person-centred care and support to all Australians with a significant and ongoing disability. It also has the potential to meet the support needs of many Australians who have an Acquired Brain Injury (ABI).

However, the experience of Brain Injury Australia (BIA) and its member organisations is that the needs of people living with an ABI are often overlooked and misunderstood. Telling decision-makers what’s needed by disability services, health professionals and ABI are often overlooked and misunderstood is that the needs of people living with an

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care and support to all

person-centred care and support to all
government’s planning around
DisabilityCare. 

The present report is in response to proposed
the NDIS Rules. It provides an analysis and
record of the views of key stakeholders across
Australia on the “National Disability Insurance
Scheme Rules Consultation Paper”. This is
only an abridged excerpt from the report — the
entire report can be downloaded from the links
at the end of this article.

The aim of BIA’s response is to ensure that
the NDIS takes into account the needs of
people living with an Acquired Brain Injury (ABI),
together with their families and carers.

These recommendations are based upon the
results of a three week national consultation.

A complete record of these outcomes and
a list of the contributors can be found in the
appendices of the full report.

Key topics

• Disability requirements
• Early intervention requirements
• Reasonable and necessary support
• Management of plans
• Supporting decision-making

Example of recommendations made

The following is an illustrative sample of

• Ensure that knowledge of specialist services is
• Assess the scope of a person with ABI’s
• Hold both regular assessments and a mandatory
• Assess the scope of a person with ABI’s
capacity to make decisions in their best
interests on a regular basis
reasonableness and necessity for
people with ABI and their carers, and why.
Their responses, in general terms, included:
• respite for carers
• social and relationship support
• specialist healthcare, aids and equipment
• access to mainstream services
• transport funding
• psychological support
• focussed cognitive support (e.g. for
decision-making)
• specialist ABI training (e.g. for carers,
nominees, support workers, Agency staff)
• support for independent living.

Brain Injury Australia and its member
organisations are available to discuss or
clarify this report and have further input into
the government’s planning around

DisabilityCare.

This is an excerpt from “Brain Injury Australia – National
NDIS Consultation Report (2013)”. You can download the
full report from http://tinyurl.com/cmb2w4k for a PDF or
http://tinyurl.com/cpbzlmq for a Word document. Brain
Injury Australia is the peak advocacy body working at
a national level to meet the needs of people with an
Acquired Brain Injury, their families and carers. Call 1800
272 465 or visit www.bra.org.au

WHICH COUNTRY EXPECTS A CHILD TO WAIT MORE THAN 2 YEARS FOR A WHEELCHAIR?

DisabilityCare action so far . . .

10 August 2011: The Productivity commission’s final report into disability care and support is released.

An NDIS Advisory Group is also announced by the Prime Minister.

19 August 2011: The Council of Australian Governments agreed on the need for major reform of disability services in Australia through an NDIS.

26 November 2012: Australian Government released the draft NDIS Bill.

21 March 2013: The NDIS Bill is passed by Parliament.

Anticipated in the near future are:

July 2013: First stage of the NDIS in South Australia, Tasmania, the Hunter in New South Wales, and the Barwon area of Victoria.

July 2014: First stage of the NDIS in the Australian Capital Territory.

For anyone unfamiliar with the term National Disability Insurance Scheme, it is a completely new way to provide disability services.

So what is wrong with the way things have been done in the past? Currently, it is a matter of luck on whether people receive enough funding to meet their needs. It is well known that most people with disabilities receive inadequate funding, and the levels vary greatly depending on where they live, what disability they have, and how they attained that disability.

A Productivity Commission in 2011 found that none of the States of Australia were successfully meeting the needs of people with disabilities overall, despite successes in some areas.

An NDIS aims to not just respond to crisis situations, but accurately assess needs and take a lifetime approach to providing care and support. An example of this is making suitable investments up front, such as funding for home modifications that will lead to a better quality of life.

DisabilityCare is the name of Australia’s NDIS.

3 / BRIDGE MAGAZINE

Er, remind me what an NDIS is?

Every Australian Counts

NDIS = revolutionising disability services

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Case studies from the Brain Injury Australia’s recent report provide a timely reminder of what life is like for people who have acquired a brain injury, as well as their family and carers.

A three-week national consultation resulted in 19 sessions involving a total of 235 people. This included 34 people with a brain injury and at least 28 family members and/or carers of people with a brain injury. The case studies focused on what kind of supports are reasonable and necessary for people with ABI. These are excerpts from the report; the full report can be downloaded from the Brain Injury Australia Website.

Case studies by people with ABI

**Transport:** “I need cab fares – so to go to pay bills, to go to employment, etc. Catching a bus is too hard.

**Focussed cognitive support:** “I need support to go sailing. I couldn’t sail if I didn’t have this support (because I don’t have balance anymore). And sailing is my life. I have a group of friends who also sail who have stuck with me and so this is part of my social life. And my family are not close, and have not taken an interest in helping me.”

**People with ABI need support to reduce their social isolation — like groups or ‘buddies’ that can motivate you and take you to mainstream activities (e.g. learning how to surf, going for a coffee or to the movies, or shopping). This is because a lot of people don’t understand ABI. For example, they think that because I can talk and communicate, I am fine. (Some even deny that I have a brain injury). More broadly, social isolation can contribute to mental health issues and substance misuse — including the abuse of medication; and mainstream supports are often not suitable (e.g. hours are not flexible, lifetime has no idea about brain injury, etc.).”

**Independent living support:** “Day-to-day support for living, a home to live in, with toilet and shower facilities. These are necessary and reasonable all the time, every day due to my physical constraints.”

“Normally, I am fine. But first, there are episodes when I experience the impact of my ABI, and need personal care 24/7 during these times (e.g. being showered, taken to the toilet, brushing my teeth) . . . The system needs to recognise that my condition is permanent, but episodic.”

“I need support with caring for myself, going shopping, etc. I don’t want to impose on my family or be a burden on them — they have family of their own, or are living somewhere else, or the support that they can provide is too limited.”

**Accommodation:** “I live in my own home, and rent the front property out to Headway. I receive 20 hours of support, and my mum plays an active role in helping to pay bills, etc. But I do my own shopping, and I live fairly independently. There was a big cost-benefit in moving out of a residential facility into my own home, but I couldn’t have done this without funded support. And I am now far more independent than I used to be”.

**Specialist healthcare:** “I need support to fund a physio in the community who can give me continuous help and practice in walking. Being in a wheelchair I have the capacity to walk, but I only get 6s of physio a year. But with an ABI you need continuous repetition to help you undertake a task.”

Social and economic participation support:

**First,** I need a life-style support person to go back to education — someone who was suitably (i.e. academically) qualified to be able to support me (e.g. who knew enough about the topic). Second, I don’t have support to help me with difficult family members — e.g. when they have a mental illness themselves or they don’t understand the results of ABI, or they do understand the impact of ABI and use it to their advantage. Third, I am aiming to use my degree to start up a business that can help other people with a disability (i.e. a paraplegic employment service to produce niche furniture). . . With regard to the support I need to start up a business, this is because I want a role. I want to feel like I am achieving something in life. I need to (and I have a right to) have a purpose and to feel valued in life.

**Case Studies by carers of people with ABI**

“**My son needs support to live a normal life** — to get back into the workforce, transport training to his workplace, assistance with public transport, social activities, independent living support (which uses a personal assistant). Due to the ABI, he has short-term memory loss, and so cannot plan ahead or for himself, he has no initiative so needs prompting, he needs to repeat things over and over again to learn things, and he has seizures, he gets too tired to do anything in the afternoons, he also suffers from depression and loneliness, lack of motivation and initiative, and lack of concentration.”

“I need carers to be able to take my son out to do things. He has a cognitive impairment and so is vulnerable and needs assistance with doing things.”

“My wife can’t look after him for more than two to five hours at a time because he can become too aggressive. So at the moment we need enough support in the home, community based access, sufficient respite for us as carers, and emergency care when this is not covered by mainstream services. In the long term, we want to have fully supported 24/7 (i.e. in a facility which is age appropriate, where all his needs are met, where he has full access to the community and his own child, where he has as much independence and control over his life as possible). We need these immediate supports in order to keep him at home and out of nursing home. We need the long-term supports so that, as we age, we can know that he will be fully cared for.”

“Our son still has seizures, so he needs to be with a carer to go on public transport or to the shops. And he needs (carers to help him with) tending to the plants, and to be with him when he is using high-speed tools during sculpting. In the long-term, he would need to have support at the home, visits every day, help with transport to shopping, and someone to meet with.”

**Currently school funding for disability support (e.g. one-on-one teacher’s aide) is inadequate, so we would hope to get additional funding to supplement what the school provides. We also need innovative and flexible approaches to support (e.g. paying a university student to provide engaging support and assistance).”**

“**I want to be confident that if I am not there his needs will be met.”**

“The current level of ABI training is insufficient (e.g. they can be extremely negative when it comes to setting goals for my son, minutes during meetings are inaccurate, being referred by a GP to a specialist in a distant location when there is one locally, case managers who don’t understand the specific needs of people with ABI).”

“My son has both ABI and a physical disability, so we need equipment, mobility options to access everyday life, home and vehicle modifications (so he can own his own car) and technology for augmented communication and access. From a personal support perspective, he needs assistance for personal care, including feeding. We would like him to be supported for post-secondary education and open employment support, and living in his own home with other people of his choosing, and by people who respect and support his own vision for his life. These things mean that he can live his life, i.e. enabling him to have a job and income and independence.”

“My daughter (9 years old) has ABI, epilepsy, anxiety and oppositional defiant disorder. We are the primary carers, but eventually she will need a carer, ongoing support and guidance, if she will allow this.”

“**Why DisabilityCare is needed**

Case studies highlight the urgent need for a National Disability Insurance Scheme to help rebuild lives after a brain injury

Case studies by people with ABI

**Transport:** “I need cab fares – so to go to pay bills, to go to employment, etc. Catching a bus is too hard.

**Focussed cognitive support:** “I need support to enable me to go back to school or TAFE. Due to issues with organisation skills and memory loss, I am scared that I won’t be able to cope with (a) learning in the classroom, (b) getting the assignments in on time, and so on. If I don’t cope I will go into meltdown, and everything will come to a stop”.

**Social participation support:** “I need assistance to have a productive social life and be able to contribute to community. I can get there on my own but I have lost the motivation to get out and do things socially. I become too tired, and feel that I have to explain certain problems or mistakes I am making”.

“I need support to go sailing. I couldn’t sail if I didn’t have this support (because I don’t have balance anymore). And sailing is my life. I have a group of friends who also sail who have stuck with me and so this is part of my social life. And my family are not close, and have not taken an interest in helping me”.

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“I need carers to be able to take my son out to do things. He has a cognitive impairment and so is vulnerable and needs assistance with doing things”.

“My wife and I look after our son. But, due to his ABI, his behaviour is such that...}
Coping with hemiplegia & hemiparesis

Hemiplegia (paralysis of one side of the body) and hemiparesis (weakness of one side of the body) can often occur following brain injuries, particularly strokes. These conditions can make everyday tasks extremely challenging for the injured person. Here are some strategies to cope with these common problems due to hemiplegia and hemiparesis.

Parallelism of arms or hands

If an arm or hand is paralysed, it is important to try to improve its function by treating it as normally as possible and not neglecting it. Place the limb in positions that were typically used before the brain injury, and place it where it can be seen. This is particularly important if the person lacks awareness of the affected limb.

One approach is to open the hand out flat and rest it, palm down, on the lap or table. Ask the physiotherapist if the hand and arm would benefit from lots of sensory stimulation, such as massaging the skin, rubbing briskly with a wet cloth, rubbing the hands together, kneading and rolling dough, etc.

Conventional wheelchairs can be very difficult to use one-handed and many people use powered wheelchairs instead. However, these are expensive, heavy and lack portability. One strategy is to use a weighted chair to reduce the weight being carried by the hand and arm, and to use an electric shaver, preferably a straight shaver, with a safety guard to prevent cuts and burns. Small simple mechanical choppers or electric mixers are available.

Sensory problems

Although life with hemiplegia or hemiparesis is inevitably difficult, there are many ways to make it easier using some of these strategies. Despite these challenges, there are many great resources available for free download.

TIPS FOR DRESSING

Personal hygiene

Toileting: Suction cup bath mats are available, working in a similarly to the suction nailbrush.

Dentures: Hands-free toothpaste dispensers are available.

Cutting: Experiment with different toothpaste dispensers.

Cleaning: Cut and paste guides are available for clipping onto the side of a cooker to hold pan handles minimal handling. Proper microwave cookware, which is designed to absorb less of the cooking heat, will be cooler to handle.

Eating and drinking

Serve food: Microwaving, chopping, grating and mixing:

Food processors, blenders and juicers can be very useful.

Peanuts: 'Rex' peelers have broader handles which can be used as a fine grater.

Shoveling: Interlaced toilet tissue (as often used in pub and restaurant toiler) is easier to use, as tearing off tissue is difficult using one hand.

Handling: Use an electric shaver, preferably a straight shaver, with a safety guard to prevent cuts and burns.

Elimination: Use an electric shaver, preferably a straight shaver, with a safety guard to prevent cuts and burns.

Shaving: Use an electric shaver, preferably a straight shaver, with a safety guard to prevent cuts and burns.

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Cutting: 'Rex' peelers have broader handles which can be used as a fine grater.
• Install window guards to keep young children from falling out of open windows and use safety gates at the top and bottom of stairs.

• Install handrails on stairways.

• Use a step stool or reach-high shelves.

• Assist the person from the non-seeing side, or encourage the person to turn their head to you when talking to them.

• Approach the person from the non-seeing side by drawing attention to objects or activities on the affected (non-seeing) side.

• Skilled therapists can teach people to maintain their balance and gait. A person will work through these problems with a rehabilitation team appointed at the time of diagnosis or assessment. Rehabilitation therapists can develop helpful strategies to manage many vision problems. For example, an occupational therapist can teach people how to use what vision they have to scan the environment, enabling safety and independence with tasks such as food preparation and dressing.

• A person can also be taught how to read labels and recognise signs more effectively.

• Loss of vision can affect a person’s ability to maintain their balance and gait. A physiotherapist can teach them how to use their remaining vision to scan the environment, without losing their balance.

Vision problems

How a brain injury can affect a person’s vision and some strategies and therapies to assist

Our ability to see and to understand what we see relies not only on our eyes, but on many parts of our brain. Damage to a particular part of the brain or the optic nerves (the nerves that connect the eyes to the brain) can affect our vision in many different ways.

Some possible problems include partial vision, seeing double, hazy or blurred vision, an inability to recognize or interpret what you see, being able to see only one side of your surroundings, tunnel vision (as if looking down a tunnel), trouble seeing in dim or glary light.

Hemianopia, visual neglect and visual agnosia are three common problems that may occur after a brain injury, stroke or brain tumour.

Hemianopia

Hemianopia (hem-i-an-o-pia) is a type of blindness. It affects the same half of each eye, either the left half or the right half; or a person may have a hemianopia of one eye only dependent on the lesion site. It occurs as a result of damage to the optic tracts and wiring of the visual system of the brain.

In medical terms, the person loses half the visual field (sometimes less) of their “visual field”. It’s like losing a wedge of sight or a portion of your vision. People with hemianopia can be affected in various ways, and in varying degrees; they may bump into things on one side, knock over drinks on one side and can be startled by objects that “suddenly appear” on their affected side.

Reading can be difficult, as one side of the page may be unseen unless the head is turned.

Support strategies: Usually the person has an understanding or insight into their sight difficulty, and some people learn to compensate well for these difficulties. You can help a great deal by drawing attention to objects or activities on the affected (non-seeing) side.

Approach the person from the non-seeing side, or encourage the person to turn their head to you when talking to them.

Reading and writing are easier if there is a clear edge down the affected side of the page — a ruled black or red line or a brightly coloured strip of cardboard might help to direct attention to the start or end of a line of text.

Compensation strategies include teaching the person to turn their head to scan the environment, and place objects within sight.

If the neurological condition advances, or the brain damage is significant, you may need to approach your family member only on their non-affected side. Assist when needed with activities such as dressing on their affected side.

Visual neglect

While hemianopia is a sensory loss of vision to one side, visual neglect is a loss of attention to one side of the body e.g. a person with visual neglect may not share one side of their face or not eat the food on one side of the plate.

It is a spatial disorientation disorder, usually caused by damage to the parietal lobe of the brain, which deals with spatial awareness and the perception of sensations — the person may not have an insight into the problem.

Support strategies: It is more difficult to overcome the effects of visual neglect because the person is able to perceive that part of their world has been damaged. They usually need persistent prompting to attend to all things on their affected side. The person may sit slumped towards their good side. With permission, encourage and assist them to sit up straight.

Visual agnosia

Visual agnosia is when someone is unable to recognize things. While their eyes still “see” the world, their brain is not able to interpret the information sent from the eyes. It is a processing problem.

A person may look at a cup but have no idea what it is. If they pick it up however, their fingers may recognize it. They may have trouble identifying objects in a cluttered pantry or on a supermarket shelf. For some, pictures or faces may become meaningless or unrecognizable.

Visual agnosia can be very frightening because the person’s world no longer makes sense to them. Activities we take for granted like crossing the road or catching public transport may become terrifying to them.

Support strategies: You can help — recognise the problem and reassure the person they are not going mad! You can gradually help them to recognise objects again. Encourage the use of other senses, such as sound and touch, to make sense of visual information. When moving about, encourage the person to set orientation landmarks that are meaningful to them.

Don’t automatically assume they are coping, especially in busy environments. Ask if they would like physical guidance and then offer your arm — don’t take theirs — and link arms if they need a stronger grip.

Therapies: Ideally, your family member will work through these problems with a rehabilitation team appointed at the time of their diagnosis or assessment. Rehabilitation therapists can develop helpful strategies to manage many vision problems. For example, an occupational therapist can teach people how to use what vision they have to scan the environment, enabling safety and independence with tasks such as food preparation and dressing.

A person can also be taught how to read labels and recognise signs more effectively.

Loss of vision can affect a person’s ability to maintain their balance and gait. A physiotherapist can teach them how to use their remaining vision to scan the environment, without losing their balance.

This article is reproduced from “Those who care” published by BrainLink, a Victorian-based service that is dedicated to improving the quality of life of people affected by acquired disorders of the brain.

Visit their site at www.brainlink.org.au
Confusion

Normally, people use their planning and organizing skills to work their way through confusion. However, because Acquired Brain Injury often results in some loss of these skills, it may be difficult to deal with confusion. Confusion usually comes about through:

- Irrational self-expectations e.g. memory of achievement is inconsistent with current ability
- Inability to recognize that a disability exists
- Others having too high an expectation
- Attempts to achieve too much at once
- Intermittencies, noise, clutter or visual misuse

So many instructions being given all at once. Cpn and family members can go along way to reducing the impact of these factors. Gently support the person with a brain injury to come to terms with their abilities and deficits. Allow room for them to discover these by making mistakes as well.

Make sure tasks and information are in bite-size pieces, with processes broken down into achievable steps. Write these on a whiteboard, or at least a piece of paper.

Keep the home environment tidy and quiet. Remember that places like supermarkets may be overwhelming with all their visual and auditory stimulation.

A brain injury often leads to fatigue and limited amounts of energy available for the day. Daily tasks should be limited to avoid confusion and becoming too tired.

Night owl or a morning person?

We’re long known that many people fall broadly into these two categories. Research indicates that there will be better times to undertake certain kinds of tasks. If you have acquired a brain injury, you have probably discovered the benefits of writing down a daily plan of activities. If you fit into the ‘morning person’ or ‘night owl’ category, try scheduling your activities around these suggested times and see if you notice any improvement. Remember not to overload it though, and take all the rest breaks you need to avoid fatigue!

Mopy Dick by Rick Bowie

An English musical comedy team from the late 1950s, Hlanders and Swans, sang a song about a whale called “Mopy Dick”.

The first lines of the song go:

The bottle nosed whale is a bowling long
And he sings this very lugubrious song
As he sails through the great Arctic Ocean Blue.

Maybe its because of my brain injury that the words “headstrong strong” have stayed with me for many years.

I’ve never really thought about being head strong. I think it probably is a great way to be, even though it can also be a way of describing an unruly child (or even stubborn adult)? as well!

I’ve always wanted my children to be strong enough to stand up for the right to “know” and “believe” within their thoughts, that they feel good about themselves and are content with the direction in which their lives are going.

Our language is overlaid with negative words — words which limit us in so many ways. How many aspects of our lives are governed by words like “can’t”, “don’t” and “won’t”, as well as “should” and “ought”? Words like this weaken us considerably, and part of the problem is that these words also sabotage any sense of fulfillment in our lives.

Part of the problem is that these words also come up in our negative “self-talk”, and we use them to wallow ourselves into accepting the lesser instead of the more! The result is that our lives become progressively poorer.

These words are like a kind of automatic reminder service on our phones, and they tend to be generated by some deep beliefs we have about ourselves.

Many of these beliefs are left-over material from growing up. “Always do what your father tells you.” “Don’t walk over the road without daddy being with you.” “No, you can’t go swimming in the river! It’s too dangerous and you never know what is under the water.” And so on.

Confusion

It needn’t be like this you know.

I want you to notice what this voice, or these voices are like. Think of one of these negative inner voices now, and become aware of where it is located in space. Is it in front of you? Or behind you? Is it to your left? Or to your right?

Simply become aware of how it speaks to you. How does it sound? What are the qualities of the voice? Is it fast speech or slow? Is a deep voice? How loud is it?

By becoming aware of these qualities you can discover a way to de-power them. These qualities (whether the voice is high or low, quick or slow, soft or loud and so on) are what makes the pattern powerful for you. They are the glue which, together, keep them stuck inside our heads.

The fun part comes next when we interrupt the pattern and sabotage it – melting or weakening the glue, in essence.

Have a go at this: listen to one of your inner voices. How loud is it? How far away is it located in space. Is it in front of you, or behind you, or to your left, or to your right?

By changing the way we talk to ourselves we can interrupt and change our thinking patterns.

Now listen to it again and turn the volume down. It doesn’t sound quite so loud. Perhaps it’s stopped speaking to you.

Better to be thought a fool...
My world after a brain injury

Ann Wood talks about the massive disruption a brain injury caused in her life

I liken my brain injury to an earthquake in my brain. Just as in an earthquake, roads and bridges and railway lines are broken and you can’t get to where you want to go — so after a brain injury the brain wants to find/restore process information and it can’t use the normal pathways, because they are not there — they have been broken. Before the accident, I saw and heard the world around me. I had to go out to a quiet place several times during the dinner to cope with the stress it caused me. I had difficulty even being out socially with a group of friends, because I used to get tired from the concentration of following conversations for any length of time, and dealing with multiple conversations.

I found it difficult to be in small groups. At dinner to cope with the stress it caused me. I had difficulty even being out socially with a group of friends, because I used to get tired from the concentration of following conversations for any length of time, and dealing with multiple conversations.

I had difficulty coping with multiple auditory inputs. I could not go to restaurants and hear what was going on, because I was finding it hard to make sense of the information on the plate. I couldn’t cope with the movement of the person sitting opposite me, and I couldn’t cope with the movement of the person sitting opposite me.

I had difficulty with making sense of visual inputs. I could not go to restaurants and hear what was going on, because I was finding it hard to make sense of the information on the plate. I couldn’t cope with the movement of the person sitting opposite me, and I couldn’t cope with the movement of the person sitting opposite me.

I had difficulty understanding what was going on, because I was finding it hard to understand myself, and make sense of my world, and operate in this strange, new world around me. Not only was I dealing with all of this — but my world now looked different, but also sounded different to before.

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Travel tips for the post ABI journey

At the age of 16 (18 years ago) I was involved in a motorcycle accident that resulted in severe brain injury. After four weeks in a coma, I was unable to walk, talk, and my body was unable to control autonomic functions such as my body temperature or hunger awareness, amongst other things.

The power of positive thinking

Like a lot of people with acquired brain injury, I experienced loss of friendships, short-term memory and concentration problems, fatigue, epilepsy and suicidal thoughts. I am extremely fortunate to have had one very significant person on my side throughout all of this – my mother. She never stopped believing in me, and believing I was capable of achieving more than the doctors were telling us. I can’t possibly overestimate the value of having someone believe in you. Believing in someone does not mean pushing them to do the things you want them to do, but it is listening to their issues, and believing I was capable of achieving more than the doctors were telling us. I can’t possibly overestimate the value of having someone believe in you.

Setting achievable goals

One of the first steps to help with my memory and concentration was attending an introductory computer course which was developed specifically for people with acquired brain injury. The course was held over 12 weeks, just a couple of hours a day, and this assisted me in not only learning computer skills, but the processes involved in short-term memory and concentration. The course helped my self esteem, and I saw an improvement in my concentration and memory.

Study and work

Four years after my accident I applied to study a diploma of Beauty Therapy, and 14 months later I began working as a Beauty Therapist. Five years after gaining my Diploma I did part of an Associate Diploma in Business Management, and I am currently at university full-time, studying Rehabilitation Counselling and working as a support worker for Synapse. As someone who does not have any obvious physical impairment, it is difficult for people to even consider the possibility of an invisible disability such as brain injury, and the associated difficulties with learning.

Using resources

If you are negotiating the thought of studying, or are studying, never be ashamed to ask for help. Most universities have a Disability Support and Services division which will help adjust the system to your needs. Examples of this are things like planning around your fatigue. By the afternoon I am usually not at my peak condition, so the university has arranged for me to sit my exams in the morning. Sometimes this means sitting the exam before my fellow students, and I need to sign a Statutory Declaration which states that I will not tell any of the other students what is in the exam. In my second year of University I had to take intensive medication for six months and this made my concentration even worse, so the University also arranged for me to sit exams in a room on my own. These are just a few of the services available to assist in achieving goals, but there are many more if you ask.

To summarise, if you keep organised, practise using repetition and ‘tricks’ to help you remember, and use the resources available to you, you may discover that with hard work you too can achieve your goals.

Nicole

A brief history of the brain

A mix of nonsense, occasional accuracy and the downright bizarre

From mere stuffing for the skull to the most complex system in the known universe, our insights into our own minds have been riddled with mistakes, guesswork and experiments.

Mere stuffing for the head?

Early Egyptian views on the brain saw it as a form of cranial stuffing. The brain was removed when preparing mummies, as they thought the heart was the seat of intelligence and essence of life itself. However, an ancient Egyptian record does contain the first written account of the anatomy of the brain. It documents 26 cases of brain injury and treatment recommendations, and describes the cranial suture, the meninges (the external surface of the brain) and cerebrospinal fluid.

Beware of Greeks bearing ideas

Alcmaeon, an early Greek physician, conducted the first recorded dissection of the brain. He believed that the brain was the central organ of sensation and thought, but unfortunately this idea did not catch on. People preferred Aristotle’s belief that the brain only cools blood from the heart, leaving the heart as the seat of the soul still. He did get some things right though — Aristotle correctly believed that the processes involved in short-term memory differ distinctly from those for long-term memory.

The four humours (not a comedy group)

Galen was a physician to Roman gladiators, and had plenty of opportunities to see inside human bodies after the fights. He believed that a person’s temperament and body functions were directly affected by the balance of ‘humours’. For example, excess of black bile caused a melancholy temperament, while too much blood made someone overwrought. He did have some accurate ideas as he believed that memory, emotions and the senses were located in the ventricles of the brain. Galen’s theory of humors was the dominant theory for more than twelve hundred years. The Catholic Church’s bans during the Middle Ages on dissection helped, as this prevented any scientific exploration of the brain. Primitive brain surgery was performed by enterprising barber’s who offered to remove the ‘source of madness’ from the skulls of the mentally ill.

Post-renaissance

Following the Renaissance and the Reformation, the church lost much of its power which allowed dissection, free thought and the development of the scientific approach. René Descartes, the French philosopher, claimed that the nerves are filled with “animal spirits” that carry matter and sensory information to the ventricles of the brain, much in the same way that hydraulic fluid travels through machines.

Lumps and bumps on the head

Strange ideas with little basis in fact continued to emerge. Phrenology was invented by Franz Joseph Gall in the 19th century. He believed the brain had 31 personality organs, each with a specific mental function. Gall felt the heads of people from the extremes of society such as criminals or clergymen. He concluded that various lumps on the head could determine the personality and integrity of everyone. At the height of the phrenology craze, it was suggested that politicians be chosen based on the shape of their skulls.

Evolution of the brain

Charles Darwin met with much resistance from the churches and the establishment, but played a major role in studies of the brain. Huxley was a 19th Century biologist and disciple of Charles Darwin who argued that the mind was simply a result of events in the brain. This view was reinforced by the steady expansion of knowledge about the functions of the human brain.

In the 19th century no one knew exactly how the brain carried out such functions as memory, emotion and perception, so metaphysical theories continued to flourish. But better technology and rigorous study of the brain during the 20th century made it increasingly clear that all components of the mind have their origins in the brain.

Body, soul and mind

The debate about the nature of the mind is relevant to the development of artificial intelligence. If the mind is indeed a thing separate from or higher than the functioning of the brain, then presumably it will not be possible for any machine, no matter how sophisticated, to duplicate it. However, if the mind is no more than all the functions of the brain, then it would be theoretically possible to create a machine with a mind.

Perhaps we do have an identity and consciousness that exists apart from our body, but is one of the great mysteries of life that won’t be definitely answered until that final day...
Substitute decision making

In addition to the medical consequences arising from acquiring a brain injury, a person with brain injury and their family may be confronted with a variety of legal issues. Because every person’s situation is unique, and because the law is different in each State, it is important to consult a solicitor to obtain legal advice that relates to your particular circumstances. The following is a general guide to the legal issues surrounding acquired brain injury. Please note that this fact sheet is relevant to Queensland. For accurate legal guidelines in other areas, please contact your local Brain Injury Association.

All Australians have the right to make decisions about their personal, financial and health-related affairs if they are over 18 years of age and are mentally able to understand the nature of, and foresee the effect of, a particular decision. They must also be able to do so freely and voluntarily and be able to communicate that decision in some way.

If, as a result of a brain injury, a person has lost the capacity to make some or all decisions for themselves, there are some important legal considerations of which they, family members and close friends must be aware.

Legislation, terminology and processes regarding substitute decision making in Australia, may vary between States. Readers are advised to consult the Brain Injury Association of their particular State to clarify local variations. However, the general philosophies within Australia are consistent with the following sections.

APPOINTING SOMEONE ELSE TO MAKE DECISIONS

Power of Attorney

A Power of Attorney is a document that appoints someone to act as an agent on your behalf. This may be required if for some reason you are not going to be able to act personally (e.g. being overseas).

A General Power of Attorney unfortunately has limitations as a device for the future planning of our affairs. If you were to incur some illness or injury that deprived you of the capacity to manage your financial affairs, this type of Power of Attorney is not of much assistance as it is automatically revoked because of your incapacity to give instructions to the Attorney.

An Enduring Power of Attorney continues in force after the principal has become mentally incapable of understanding the nature and effect of decisions about a financial matter or a personal matter as the case may be. The appointment of an Attorney under the Enduring Power of Attorney must be made while the principal is still capable of understanding the nature and effect of the document.

All States have Guardianship Tribunals with power to appoint a guardian (for personal matters) or an administrator (for financial matters). All have requirements about the adults having impaired capacity and for there to be a need for decisions to be made on the adults behalf.

Medical Directives and Attorneys

One of the greatest challenges to assisted decision making is the question of what happens if a person loses capacity and there are no prior arrangements about health care. All States appear to agree on the common principles of this issue but terminology, and the extent of directions that can be given vary significantly.

For up-to-date information relating to a particular State, contact your local Brain Injury Association.

A Statutory Health Attorney in Queensland is someone close to the adult who can give consent to health care, where there is no enduring attorney or enduring guardian, or guardian appointed by the tribunal. Formal appointment is not necessary in some States, since their authority comes from their relationship to the patient with impaired capacity.

An Advance Health Directive enables an adult to make arrangements regarding the type of future health care they desire (or do not desired should they become incapable of making decisions. An Advance Health Directive may also include the name of an appointed person to assist with determining the principal’s wishes. However, an Advance Health Directive can only be made by a person while they have the mental capacity to do so and comes into effect only after the person has lost that capacity.

A “Ulysses Agreement” enables a person with an episodic mental illness to give directions (including the use of restraint) so that a treated person or persons can arrange for psychiatric treatment when specified symptoms or behaviour become apparent. Where an Advance Health Directive conflicts with the type of treatment that can be carried out under the Mental Health Act, the terms of the Advance Health Directive must be followed as closely as is possible.

INTERSTATE RECOGNITION

An Enduring Power of Attorney or Enduring Guardianship document made in another State is recognised in Queensland. This means that if an adults with impaired capacity moves to Queensland, their enduring attorney or enduring guardian will be able to continue to act for them. All other States are currently considering changing their laws to recognise the authority of enduring attorneys or enduring guardians from another State.

If you would like to contact them for more information, call their freecall number on 13 11 99 or contact Shine Lawyers.

Auditory agnosia

A brain injury can damage both mechanical and neurologic processes and result in a variety of hearing difficulties. Auditory agnosia is impaired recognition of nonverbal sounds but intact language function. This rare outcome is normally from damage to the temporal-parietal region of the brain which interferes with the cognitive process of hearing. There may be an inability to understand spoken language while the ability to speak is preserved. Auditory agnosia often gradually worsens over time.

If you are experiencing auditory problems, see your doctor, as there may be a treatable medical cause. A referral may be needed to have your hearing checked by an audiologist (hearing scientist) or you may be referred to an ENT (ear nose throat) specialist. Some audiologists run specialist clinics to help manage some conditions and they fit hearing aids and/or therapeutic noise generators if needed.

There are practical steps you can take to lessen many hearing problems:

• Avoid noisy environments where possible
• Tell others of your difficulty
• Use gentle music or “white noise” recordings to cover constant noise if you experience tinnitus
• Try to sleep well and avoid stressful situations
• Cut down on salt if your problem involves fluid pressure in the ear
• Stop using drugs such as coffee, cigarettes and alcohol.
Kristy’s accident in 1990 transformed a bright, energetic, articulate and outgoing young lady into someone who was trapped in a body that no longer worked for her. She even lost her ability to speak. Over the next five and a half years until she died, I could only imagine but never truly comprehend the horror of what this must have been like for her.

If her accident had occurred 10 to 15 years ago, if she had even survived Kristy would no doubt have been placed in a nursing home with little chance of doing anything other than existing in what would most likely have been termed as a persistent vegetative state. Because of the emergence and existence of assistive technology and the realisation that many persons, like Kristy, are “locked in” – her life after her brain injury was not merely an existence – it was lived and it was lived well and to its fullest potential.

A new voice

Kristy taught us all that you do not have to be a physically able, speaking person in order to be intelligent. She demonstrated to all of us that we must concentrate on a person’s ability, not their disability. Through the use of assistive technology, Kristy was able to return to high school and graduate with honors – even though her death came before her long awaited graduation day. Kristy amazed educators by taking the same tests, exams, and end-of-grade testing that non-disabled students took, and many times outscored the majority of students. Kristy also did things that she enjoyed at home through the use of assistive technology such as cooking, baking, playing with her cats and her dog, and controlling her environment (turning on/off her TV, stereo, VCR, lights, ceiling fan, etc). Assistive technology helped her share her love and her wonderful sense of humour with those that took the time to learn how to communicate and interact with her.

Trying to find meaning after death

As her mother, I have grieved deeply since her death. I have no doubt that I will continue to grieve for a long time to come, if not for the remainder of my life. Kristy was my strength and determination. I now search for my path in life without her. There were many days in the months after her death when I struggled with why she survived the accident to then lose her life five and a half years later. What lesson of life was I supposed to learn through this journey? On bad days, I must admit, the answer often eluded me. But on those days when things look clearer, I realize that had Kristy not survived her accident, there are many, many people whose lives she would have not touched and that would have been a bigger tragedy.

Years ago, while Kristy remained in a five month long coma, I cross-stitched a phrase for my brave beautiful daughter. I think it puts into words what Kristy lived in her all too short twenty-one year life. . . “Kristy, if you can dream it, you can do it.”

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Your family is probably not exactly the same as it was before the injury. However, your family life can still be pleasant; it will just be different. Here are some common changes, and what you can do to help adjust to them.

Changing roles
You may not have thought about it before the injury, but everybody in your family probably had a special role that they filled. Some worked and earned money; some took care of the house, and some made financial decisions. Other roles may have been more emotional in nature. For example, someone may have been the person who made everyone else laugh in hard times. Someone else may have been the “rock” in the family, who everybody turned to in times of trouble.

It’s likely the injury has changed a lot of these roles. Your family member who was injured may no longer be able to fill the same roles. Other family members may try to take over those roles. Many times this leads to role strain, which means that each person in the family is trying to fill too many roles.

Family members can become overwhelmed and can become sick, either physically or mentally.

What to do about changing roles: Accept that roles must change after the injury. Get your whole family together. Discuss what needs to be done and how things can be divided up. Be sure to involve your injured family member in the conversation, and have them take on some responsibilities. They need to continue to make a positive contribution to the family.

Problems communicating with each other
Things have probably been so hectic since the injury that there is very little time to talk to each other. Often, it seems that everything is about the injury now, and family members may not know what else is going on in each other’s lives. Everyone may have similar feelings about the injury and what has happened, but they may feel alone in these feelings. Some family members may feel that it’s not okay to talk about the injury. Even small children in the family will have feelings about what has happened and they need to feel understood.

Sometimes the person with injury has problems that may make it hard for them to communicate with other family members.

How to improve communication: Set aside times when family members can get together and share what’s been going on in their lives. For example, you can schedule a sit-down dinner together once a week. This will let you enjoy each other’s company as a family again. Let all family members know that it’s okay to talk about the injury, even if some of their feelings are negative. Find new ways to communicate with the injured family member that get around any problems they have. For example, if they have trouble speaking, have them write down what they want to say.

Less affection among family members
This problem may be related to communication problems. Family members have less time to spend together and talk to each other. This may show affection for each other less. Sometimes family members may feel less affection for the person with injury because of physical or emotional changes. For example, if the person with injury is verbally/physically aggressive, then other family members may feel less affection for them.

How to increase affection in the family: The same suggestions for improving communication can work here. Set aside some time to spend with your family members doing things not related to the injury. A fun activity is to get some old picture albums out and look at them. This will allow you to remember the fun times you’ve shared as a family. Accept that it is normal to not feel affection for the person with injury at times. That doesn’t mean that you love them any less.

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Coming to terms with loss

**THE LONG JOURNEY TO ACCEPTANCE**

Psychologists have proposed models to help explain the various emotions and stages we are likely to move through. A common model of the grieving process has five stages: denial, anger, bargaining, despair and acceptance. We have added confusion as this quite applicable to situations involving Acquired Brain Injury. This is a rough guide on what to expect on the road to recovery, as we may skip some steps, or occasionally revisit some at a later point.

**LOSS**

For the person with the brain injury, life can change dramatically and they may report that their life or a part of themselves is lost. This loss may be felt in many ways over time, as there is a gradual awareness of what has been lost in terms of skills, health, abilities and opportunities. If their self-awareness has been affected, it may take them some time to gradually realise the extent of what they have lost. For some, this may be strongest two years after the injury, when their brain's limited ability to heal itself is over. The impact of a brain injury is often likened to the ripples in a pond when a stone is thrown in — those closest to the survivor are affected most, but the effects continue onward to extended family, friends, employers and the wider community.

Families also experience loss. Faced by personality changes, they may feel as if their loved one has gone in a sense. Grief is a normal emotion when confronted by these losses, and each person will have their own way of gradually dealing with it. Ideally, everyone should have an understanding and acceptance of the grieving process to help them move through this difficult time.

**Grief**

Signs of grief can include anxiety, depression, guilt, restlessness, disturbed sleep, a sense of unreality and breathlessness. Our ability to work through grief is influenced by a number of factors, which may include how much support is available, our intelligence, personality type, beliefs and motivations.

Some people tend to have a positive outlook on life. They are more likely to respond positively to grief by eventually converting the loss into a gain i.e. "this brain injury has made me work on self-development and being a better person". Other people may have trouble moving beyond the initial stages of grief. Kieran walked past a pub and was suddenly beset by memories of his past. He is extremely bitter about these males who left him in a coma, and were never caught.

Bargaining may also be something that is done secretly, which means that it often goes unnoticed. People with religious beliefs may attempt to strike a bargain with God — perhaps a promise to be a better person or to church every week for the rest of their lives, in return for a full recovery. More recognisable signs come in the form of less drastic comments such as, "If I did anything to have my life back". The best support is continuing to be patient and positive by acknowledging how the person feels, and by forgoing positive suggestions and encouragement about the present and near future.

**CONFUSION**

Commonly called post-traumatic amnesia (PTA), this stage means the person with a brain injury may be very disorientated, not recognising family members, or becoming sad or angry very easily. It can be very distressing and it can last for a temporary stage. For family members, it can be a feeling of unrealness, overwhelmed by the enormity of a loved one’s injury.

Often the first reaction to loss, denial acts as a buffer to protect against being overwhelmed by strong emotions such as anxiety and fear. Without a period of denial, the shock of acquiring a brain injury could prove too much for some to endure. Time is usually one of the best remedies. A good line for the injured to say is, "Sometimes laughing helps me to keep my life back."

For the survivor, anger and aggression can develop as a direct result of the brain injury. It can also be a reaction to how life has changed, and family may be targeted. The difficulty in assisting people through the anger stage is that to agree with what they are saying may reinforce their negative thoughts, while to disagree may turn their anger against the person trying to help. It is generally recommended to only agree with what is believed to be true, and to offer a second truth to challenge the statements that are considered false. Another way of coping with the person's anger is to give them some personal space, but not avoid them. Encourage them to minimise stress in their life, without cutting out personally meaningful activities. Avoid critical comments or pointing out how they have changed.

**DENIAL**

As the acceptance of the effects of the injury begins to sink in, with a brain injury will often feel a sense of tremendous loss. Depression and self-blame may build to create a sense of hopelessness. Families and friends can help by watching the person sink deeper into depression. Focusing on positive facts might help, such as the skills and abilities that remain, the loving family, the improvement to be expected in the first few years, and being alive against the odds. The added danger of the despair stage is that it if continues for too long, there is a risk of the person developing chronic depression or contemplating suicide. At any hint of this, professional help should be sought.

**ANGER**

Bargaining may be an indication that the person is beginning to realize the extent of the injury. However, it also indicates that they are not yet ready to accept it. Bargaining may also be something that is done secretely, which means that it often goes unnoticed. People with religious beliefs may attempt to strike a bargain with God — perhaps a promise to be a better person or to church every week for the rest of their lives, in return for a full recovery. More recognisable signs come in the form of less drastic comments such as, "If I did anything to have my life back." The best support is continuing to be patient and positive by acknowledging how the person feels, and by forgoing positive suggestions and encouragement about the present and near future.

**BARGAINING**

For some people, it is coming to terms with the pleasureable and beautiful things in life again. Acceptance also means going with the flow — experiencing a range of emotional reactions, both highs and lows, as 'normal' and understandable reactions to daily events. This goes hand-in-hand with feeling a greater sense of control of events and pursuing goals and challenges. We all grieve differently, and we all walk our own path toward acceptance: 

> “... all this led me to understand that the universe is a godless expanse full of random, unplanned processes, completely oblivious to human existence. It had me depressed and angry for a while, but now it is strangely liberating. I make the most of each day, knowing I’m lucky to still be alive and it’s up to me what I do with the rest of my life. We only live once, with this one life we have...”

“My son’s injury really challenged my faith. How does a loving God allow such a horrendous thing to happen? I haven’t got the answer to that one, but it has deepened my faith and got me thinking about my priorities — family, relationships and friends on the one hand — versus career, possessions and pursuit of the almighty dollar on the other...”

**DESPAIR**

People who go to support groups often get a lot of positive feeling from being with others who have brain injuries. They tend to openly talk about their frustrations, fatigue or poor memories. These people may also say that some days they feel like giving up, but then they manage to keep it all inside. You can contact your local Brain Injury Association and see if there is a support group in your area, either for survivors or carers.

**ACCEPTANCE**

As the acceptance of the effects of the injury begins to sink in, with a brain injury will often feel a sense of tremendous loss. Depression and self-blame may build to create a sense of hopelessness. Families and friends can help by watching the person sink deeper into depression. Focusing on positive facts might help, such as the skills and abilities that remain, the loving family, the improvement to be expected in the first few years, and being alive against the odds. The added danger of the despair stage is that it if continues for too long, there is a risk of the person developing chronic depression or contemplating suicide. At any hint of this happening, professional help should be sought.

The acceptance stage is a period of reconciling the loss and preparing for the future with a renewed sense of wellbeing. However, while this may be the final stage of grief and loss, there is still a long way to go. To assume that all will be well may encourage false expectations. The person may require guidance to understand the impact of the brain injury, and to develop strategies to compensate for any problems that have developed as a result. Support groups can be a great help, for both the survivor and family members.
Warning: fragile!

The big bad wolf
by Anne Gianni

Have you ever had to be firm with someone, yet continue to smile to not make it seem so harsh? If so, perhaps you, too, have played the role of The Big Bad Wolf. Those of you who read my article, We Breathe the picture and explain that it still wasn’t time doing behind the wheel.

Three years ago, I will never forget the first days it is a bit more difficult. In the long run it is to protect the best interests of our loved ones. My advice is to have an exact permission from www.lapublishing.com/blog explanation as to why you are setting these parameters. “Just because” is not a good enough reason. Tell them why, as this is how they learn. Eventually, they may come to realise that everything you did was for their own well-being.

As horrible as it felt, I had to say no. I told him that he should not purchase these items until he was hired. I had to take into consideration his financial control and that he “needs” something. Someday I hope to have Paul re-enrolled in a driving course. However, I feel it is imperative that a doctor ride in our passenger seat next time.

Driving the car anymore was asking too much for Paul and he was trying to be very careful, it could tell he was trying to be very careful, it, and eventually he agreed with me. Though he kept his driver’s license, he stopped driving. Then came the evening that we picked up our new car at the dealership. Feeling that it was unfair to not even let him try out the car that both of our names were going on. I asked if he would drive from the supermarket back to our home. Two years on, I could see that his road perception hadn’t changed. Though I could tell he was trying to be very careful, it just wasn’t working for me. He still didn’t give me the feeling that he knew exactly what he was doing behind the wheel.

At this point, the Big Bad Wolf had to come into the picture and explain that it still wasn’t time yet. Someday I hope to have Paul re-enrolled in a driving course. However, I feel it is imperative that a doctor ride in our passenger seat next time. 

Handling money

Finances are another issue in our home where I have had to assume my Big Bad Wolf role. I have been in charge of our finances since I saw Paul bounce cheque after cheque while we were dining. Bills would come in the mail and he would toss them aside, not even opening them. I knew that if I was to marry this man and combine our finances, then I had to take the reigns.

Since then I have managed our checking account and all our bills. We have no debt and it feels good that way. Though Paul knows the picture and explain that it still wasn’t time yet. Someday I hope to have Paul re-enrolled in a driving course. However, I feel it is imperative that a doctor ride in our passenger seat next time.

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Losing friends
A personal story on losing friends after acquiring a brain injury

I read an article about happiness the other day. It seems all the latest scientific research confirms what many of us know already — the main key to happiness is the people we know, such as partners, children, friends, relatives and parents. We may desire power, sex, status and the latest mobile phone that doubles as a microscope, but these do little to provide lasting happiness.

About two years after my brain injury, I realised I had lost many of these connections with people, and my level of happiness had dropped accordingly. Why? I was one of the fortunate ones in that I did not have a raging personality to deal with that issue before she brought the next one up.

Five years down the track and I still haven’t regained many of those lost friendships. But I am less bitter now. What if the situation was reversed? What if a close mate had completely changed after an accident? What if he or she now moody, demanding, never listened to me, rambled on about himself in a confusing way and had essentially become a different person? I know I would have hung around for a while as a strong friendship demanded, but eventually I would have given up and concentrated on friendships which had more give-and-take. And of course this is precisely how my closest friends did react. So I’d be a hypocrite if I held bitterness against them for too long.

Unpleasant feedback

These problems were only the tip of the iceberg. Thankfully, my better half is quite sensitive, and she gradually revealed the many ways I had changed. Even so, I was angry as I thought she was simply criticising me for the sake of it. However, with time I had to acknowledge she was right, then I would try to deal with that issue before she brought the next one up.

Frustration down the track and I still haven’t regained many of those lost friendships. But I am less bitter now. What if the situation was reversed? What if a close mate had completely changed after an accident? What if he or she now moody, demanding, never listened to me, rambled on about himself in a confusing way and had essentially become a different person? I know I would have hung around for a while as a strong friendship demanded, but eventually I would have given up and concentrated on friendships which had more give-and-take. And of course this is precisely how my closest friends did react. So I’d be a hypocrite if I held bitterness against them for too long.

Any answers?

I’m in a support group now. Most of us agree that the first stage is bitterness against friends who have deserted us. Then there is the long process of realising how much we have changed and how it affected our relationships. The toughest part is usually making the decision to do something about it. I know some who have chosen to stay with self-pity, alcohol to numb the pain, anger against the world or hating themselves. I don’t blame them. Unless you’ve had a brain injury, you simply can’t grasp how demoralising and terrible it can be. It takes a truly heroic effort to lift yourself up and commit to truly living again.

Happy endings?

I’ve got some of the old me back. It’s been bloody hard, but slowly I am learning how to interact with others again in a way that doesn’t demand to be driven away. There are still days when the constant fatigue gets to me, and I fall back into old patterns. I don’t think there is a happy ending as such, but I can choose to keep moving forward, or simply stop and slide backwards. It is a tough journey, but worth striving for.

Keeping friends
Useful communication tips for retaining old friendships and making new ones

Think of the people you most like being around. Chances are they have good listening skills. When somebody really listens to you, you feel understood, appreciated and worthwhile. When somebody just raves on about themselves constantly, you are inclined to see them as boring, arrogant or self-centred.

A brain injury can lead to a loss of listening skills. Why? We are born selfish. Growing up is a long process of learning to balance our needs with the other seven billion people living on the planet, but particularly those closest to us. A brain injury can disrupt much of this hard-won experience, and we can revert to our earlier basic patterns. Speaking about ourselves is a much easier skill than listening, so you may be more inclined to talk about yourself.

The problem is you may now have trouble organising your thoughts into compact, structured sentences for others, so you may tend to ramble on and on. The next problem is you may have lost the ability to pick up non-verbal cues from others. You may not be able to interpret the signs of boredom — the other person does not keep eye contact, keeps looking at their watch, or looks frustrated at not being able to get a word in. When your social skills have been disrupted, you will need to begin the slow process of reconnecting these skills. One of the most important is learning to listen to others, as this is perhaps the most crucial skill for keeping old relationships and beginning new ones.

Ask questions

People love to feel you are interested in them. Instead of trying to talk about yourself, focus on the other person. Get interested in what they are talking about. Ask plenty of questions but make sure they aren’t too personal. If you have trouble with disinhibition, you may be inclined to ask offensive questions about their sex life or how much they earn. Be appropriate!

Balance the conversation

Try to keep an idea of how much ‘air space’ you are hogging. You should be letting the other person talk at least half of the time. The more you let them speak, the more they will appreciate the conversation.

Look out for social cues

Many of our communication is non-verbal. You know the person is probably not enjoying the conversation when they don’t keep eye contact, turn away from you, look at their watch or stop smiling. These may be an indication you have talked too long, or on a topic they don’t find interesting. Of course, they might just be depressed themselves, or need to be somewhere else. Non-verbal cues are tricky to read at the best of times — where possible, get feedback later from a friend without a brain injury on how you went in conversations with others.

Limit interesting

Asking questions is only part of good listening. It helps if you smile, nod and laugh in the right places. This is hard if you are depressed or nervous, but practise anyway.

To tell or not to tell

Think about their friends and how it affected our relationships. The process of realising how much we have changed and how it affected our relationships. The toughest part is usually making the decision to do something about it. I know some who have chosen to stay with self-pity, alcohol to numb the pain, anger against the world or hating themselves. I don’t blame them. Unless you’ve had a brain injury, you simply can’t grasp how demoralising and terrible it can be. It takes a truly heroic effort to lift yourself up and commit to truly living again.

Happy endings?

I’ve got some of the old me back. It’s been bloody hard, but slowly I am learning how to interact with others again in a way that doesn’t demand to be driven away. There are still days when the constant fatigue gets to me, and I fall back into old patterns. I don’t think there is a happy ending as such, but I can choose to keep moving forward, or simply stop and slide backwards. It is a tough journey, but worth striving for.

Avoid alcohol and drugs. Plenty of our social interaction revolves around alcohol. Remember it will only amplify your tendency to rave on, say inappropriate things, or be unable to listen effectively. Stick with the orange juice and work with your social skills instead.
General legal issues

In addition to the medical consequences arising from acquiring a brain injury, a person with brain injury and their family may be confronted with a variety of legal issues. Because every person’s situation is unique, and because the law is different in each State, it is important to consult a solicitor to obtain legal advice that relates to your particular circumstances. The following is a general guide to the legal issues surrounding acquired brain injury. Please note that this fact sheet is relevant to Queensland. For accurate legal guidelines in other areas, please contact your local Brain Injury Association.

MAKING A WILL

Along with the Enduring Power of Attorney, a Will is amongst the most important documents most of us will ever sign. Anyone can make a Will, as long as they are over eighteen years of age and have testamentary capacity at the time. It is recommended that a Will be prepared through a professional service, as a Will produced contrary to the requirements of law may lead to lengthy court proceedings and may be ineffective. The Executor of a Will is the person appointed to attend to the administration of the estate. They should have the necessary knowledge, experience and judgment to perform the task.

MARRIAGE

A person with a disability is subject to the same marriage laws as any other person. A person can marry provided that they have the ability to understand the nature and effect of the marriage ceremony at the time of the ceremony.

VOTING

The law states that a person who is incapable of understanding the nature and significance of enrolment and voting is not entitled to vote. In reality, a person’s eligibility to vote is unlikely to be questioned when they enrol. If an objection is raised regarding a person’s eligibility, the Divisional Returning Officer is then subject to appeal.

ENTERING A CONTRACT

A person entering into a contract must have the ability to comprehend the nature of the agreement being entered into. If a person with a brain injury has a cognitive disability and enters into a contract, the obligations entered into in the contract may be questioned. Whether or not the contract is enforceable will depend upon a variety of factors:

- Whether the other party knew or ought to have known of the person’s disability.
- If the subject of the contract was not an essential item, such as food.
- If the person was subject to a protection order at the time of entering into the contract.
- If an innocent third party acquired an interest in the subject matter of the contract.
- If substantial resolution is possible.
- If the contractual document was signed with a mistaken belief regarding the subject matter or the nature of the document.

Any queries regarding the nature of a contract or a person’s rights concerning a signed contract should be taken up with a solicitor or other legal professional.

SPECIFIC LAWS AND PEOPLE WITH A DISABILITY

The law is a set of principles and guidelines designed to protect and give all Australians the freedom to live without fear of intrusion by others. People with a disability are no different. Laws are as applicable to people with a disability as they are for everyone else. However, legislation has been passed through parliament, which is specifically designed to cater for the additional needs of people with a disability.

The Disabilities Services Act 1986 gives people with disabilities the right to:

- Receive respect for their human worth and dignity as individuals.
- Realise their capacities for physical, social, emotional and intellectual development.
- Access services that support obtaining a reasonable quality of life in a way that supports their family unit and their full participation in society.
- A grant of financial assistance to ensure that a minimum quality of life is attainable.

Each Australian State has additional legislation that supports and enhances the above points, for example the Anti-Discrimination Act aims to prevent a person being discriminated against because of their disability. Any concerns can be forwarded to the Anti-Discrimination Commission.

Opportunity policy is to identify key minority target groups and to set guidelines to help ensure that their opportunities for employment are no different to those of other people. These laws have made it illegal for an employer to discriminate against people with a disability, whether it be in choosing someone for a job, the way an employee is treated, or the dismissal of an employee. Any issue relating to possible violations of these laws can be forwarded to the Anti-Discrimination Commission.

CRIMINAL LAW AND PEOPLE WITH DISABILITIES

A person with an Acquired Brain Injury has the same rights as any other person under criminal law. They have the right to remain silent and the right to obtain legal representation. They also have the right to apply for legal help from the Legal Aid Office. A person with an Acquired Brain Injury who has committed an indictable offence must be placed for a committal hearing at the earliest available time. The mental capacity of the person will be assessed in order to identify their capacity to stand for criminal trial. Any queries regarding this should be directed to the Legal Aid Office or to an independent legal representative. If a person with a brain injury is to be interviewed by the police regarding a criminal matter, a third independent person must accompany them; usually a Justice of the Peace, solicitor or parent. Their job is to be present during the interview to protect the rights of both the person with the brain injury and the investigating officers.

This information was published thanks to Shine Lawyers. For more information they can be contacted by phone on 13 11 99.
Personal Injuries Law

- Motor Vehicle Accidents
- Workers’ Compensation
- Medical Negligence
- Public Liability
- Asbestos Related Diseases
- Claims for Nervous Shock
- Claims for Death Dependency
- Superannuation and Disability Insurance
- Professional Negligence
- Criminal Compensation
- Guardianship and Administration Applications
- Industrial Relations
- Product Liability
- Claims for Injuries Caused by Dog Bites
- Claims for Stress

Wills and Estates Law

- Wills, Enduring Powers of Attorney and Advance Health Directives
- Administration of Estates
- Contesting a Will
- Estate Litigation
- Family Provision Applications
- Superannuation Death Benefit Disputes

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