The Courage to Care

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“Nothing in the world can take the place of persistence. Talent will not; nothing is more common than unsuccessful men with talent. Genius will not; unrewarded genius is almost a proverb. Education will not; the world is full of educated derelicts. Persistence and determination alone are omnipotent. The slogan ‘press on’ has solved and always will solve the problems of the human race.”

President Coolidge
– US President 1923-1929
Author’s Introduction

“My name is Cheryl Koenig and I have a son who has a Brain Injury.”

When introducing myself in a support group meeting for parents of children with disabilities, about one year after my son Jonathan’s horrific accident, I could not bring myself to say those very words. Speaking them aloud would turn my unspoken denial into reality. And instead, as if watching myself from a distance, I heard a trembling voice quietly utter,

“My name is Cheryl Koenig and I have a son who has had an accident.”

For some reason admitting my son had severely damaged his brain, were words that would not flow from my lips. Perhaps their very connotation and the subsequent social stigma I perceived would be attached, was the reason for my reluctance. You see, for twelve blessed years I was fortunate to be the parent of two very bright, active and ‘normal’ boys. Suddenly, our perfect little world was turned upside-down - in a split second we almost lost our cherished first born son. That was horrific enough, but then we were told that he had an extremely severe brain injury and a very poor prognosis. Doctors were not sure what, if any function, he would ever regain. It was like the falling of a guillotine, severing what little hope we had left in our already crushed hearts. After weeks of further emotional anguish, sitting helplessly by his side as he clung to life on a ventilator, watching with horror as numbers plummeted and alarms shrilled, we thought our prayers were finally answered as he defied the odds to survive. Only then were we confronted with the daunting realisation that not one muscle in his entire body functioned; his eyes were fixed to the right, he couldn’t walk, talk, or even swallow - his head hung forward and dribble poured from his mouth. The first few weeks and months were a nightmare. Somehow we stumbled through them, coping only because we knew we had no other choice, until the point when he was pronounced “medically stable”. With that knowledge came overwhelming feelings of relief; but what we didn’t know then was that we were in for a marathon - years and years of intensive daily therapy.
At first it was thoroughly distressing to observe Jonathan struggle through each day of his rehabilitation programme. The tone in his muscles was so tight, he would moan in pain whenever we tried to stretch his arms or legs. To us it seemed like one step forward and two steps back the next day. But, as the weeks turned into months, ever so slowly the single step forward turned into two, and the steps backwards became less frequent. Little by little some physical function and mental capacity began to return. With his improvement, our emotional stability also returned, but we were soon to discover we were not out of the woods in that department either.

After five months in hospital we went home. Yes it was “home” – but we very soon realised that home would never be the same again. Life would never be the same again. We threw ourselves into the mammoth task of rehabilitating our son. For most of the first year at home we had no time at all to deal with feelings of grief or loss. As Jonathan’s condition improved he gradually resumed his place in the community, returning to his former high school and participating in more activities outside the family home. With this progress came the realisation that for us to survive and function in the community as a family, we had to find a new foothold in a very different world to the one we had previously enjoyed. This was a world filled with adversity, inequity and unexpected confrontations and hurdles. We had to accept that precious dreams had been lost and press on regardless. On top of that we also had to deal with the attitudes of the ignorant. The largest burden came not from the six-hours-a-day of home-based therapy programme, nor from the countless hours of physical care and assistance that Jonathan required; instead it came from the weight of insensitive remarks and preconceived notions of others. So for several years following the accident life was a huge challenge for our little family and for me personally. The change was pervasive and overwhelming, partly because I was reluctant to relinquish my attachment to the ‘perfect’ life we had once shared as a family.
Today however, some ten years later, I have accepted this new reality. We are once again a happy family having adapted, albeit slowly, to our new lives. From a personal perspective, I have been enriched and enlightened and have grown spiritually as a direct result of caring for my son and dealing with his residual disabilities on a day to day basis. Yes, I am a ‘Carer’, and my son has a brain injury sustained when crossing the road as a pedestrian and hit by a car at the tender age of 12. Our son’s incredible courage led us on a special journey of discovery and healing. Writing a book of our family’s determination and struggle to overcome the hand that fate dealt us, has helped me reach a place of peace and understanding. The book, although not yet published, has offered hope and inspiration to many people in similar situations and this has given my life new meaning and purpose.

My role has changed over the last ten years in parallel with Jonathan’s needs as he continues his relentless quest for physical improvement. I wear many hats, as do most people who find themselves in the role of Carer. At home I am his physical trainer, speech therapist, social secretary, tutor, counsellor, personal-care attendant etc. etc. Outside the home I am his mode of transport, his aide in educational courses, and by and large his navigator and assistant – both literally and figuratively. Beyond all of these roles, I am his mother and he is my best friend.

I am not alone and my situation is far from unique. There are an extraordinarily large number of caring individuals who take on the huge responsibility of looking after a loved one. They are usually, but not always, family members who are unexpectedly thrown into this challenging role. The role can be very physically and emotionally demanding and at times extremely draining and frustrating. But it can also be uniquely rewarding and fulfilling for both the care-giver and recipient. Carers play a critical role in enhancing the health, happiness and general well being of those they care for. Enhancing the quality of life for someone you love is very worthwhile.

PAPER CRANES – A Mother’s story of Hope & Determination' Exisle Publishing (due for release March 2008)
The stories you are about to read are all true accounts of the extraordinary lives of every day people, who find themselves caring for someone who has suffered a brain injury. Celebrity biographies are a feature in any bookstore and stories of heroism abound in the daily media, but if we took the time to look behind closed doors in almost one in every five Australian homes², we would find the real ‘heroes’ – the Carers in our society. The life of a Carer is rarely glamorous, it often requires patience and perseverance just to make it through the day. A Carer with a positive attitude and an optimistic perspective on life however, can make a huge difference. Treasure those small unexpected ‘light-bulb-moments’ that sometimes happen when interacting with the one you love, a moment that you both learn from and grow through together. These moments cannot always be defined with spoken words, but they can be all you need to keep you going when you’re feeling tired or stressed. Such moments and memories sculpt who you are and who you are becoming, giving you purpose and direction. Precious moments forge bonds that unite you in a unique and rewarding relationship.

The individual life journeys and inside stories of the challenges and obstacles Carers face living with and caring for a person with a traumatic brain injury that follow, will hopefully help you to recognise how love and optimism can strengthen the human spirit. Most Carers keep their cards close to their chests when the chips are down and maintain brave façades, so getting them to tell their ‘real’ stories was not easy. They rarely let their guard down about how they were actually feeling or coping if they were feeling low. My own experience helped me to read between the lines.

At the end of each account, I asked three pertinent questions to give each Carer an opportunity to detail the key issues which would improve the situation that they faced, both initially and on a continual daily basis. The main purpose in writing these very private accounts of life as a Carer was to reach out to others in similar circumstances and let them know that they are not alone – that others are experiencing the same emotional ups and downs. Relating to the personal experiences others face can help us to grow and move forward.

² Supplied by Carers NSW
If you are reading this and are not a Carer, I hope it might help you to take the time to listen, support and encourage someone who is – who may be carrying an enormous emotional and physical load. See them for who they really are; ordinary people doing extraordinary things. They are Carers in every sense of the word; pressing on quietly, seeking no recognition, except perhaps acknowledgement and validation of their role in society. From those that I have met, and from my own personal experience, often the only reward for being a Carer comes from the heart and is reflected in the eyes of the loved one for whom we care.

Cheryl Koenig.
Ten years ago I nearly died, but Mum never left my side. She retaught me how to walk and talk, not once, but twice, she gave me life.

So thanks Mum for caring for me. For being my eyes when I couldn’t see. For being my voice when I couldn’t speak. For being my strength, when I felt too weak.

Thanks Mum for loving me!

By Jonathan Koenig
(author’s son, aged 22)
A Message from Nick Rushworth – President, NSW Brain Injury Association

Carers probably don’t like to think of it as a ‘burden’. But governments, who never like looking beyond the horizon of the next election, must think of care that way. A recent study by the National Centre for Social and Economic Modelling (NATSEM) predicts that the demand for care over the next twenty-five years – as the number of elderly disabled rise by 150% and the number of younger people with disabilities rises by 25% - will outstrip its supply. I still think that NATSEM’s accounting on the supply side is generous. Broader social trends – historically low fertility rates, the sharp increase in single person households, the increase in the participation of women (the mainstays of care) in the workforce and high levels of geographical mobility – will mean that those able to take on a carer role, where they are available, may not have the energy or be able to spare the time. And while generalizations about generations are always risky, it’s hard to imagine that generations “X”, “Y”, “Z” etc. or our ageing baby boomers are going to be as self-sacrificing as boomer parents were, are.

Though it’s never been the case that care for the disabled generally - let alone for people with an acquired brain injury specifically - has ever been over-serviced, it’s still stunning to think on how well governments have privatized, have domesticated care. And how much money they have saved in the process: according to the Australian Institute of Health and Welfare (AIHW), if carers were to be paid “industry” rates, they’d cost the economy some $19 billion per year. Access Economics (2005) estimated that if all hours of informal care were replaced with services purchased from formal care providers and provided in the home, the replacement value would be over $30 billion.
As the “burden” of that care increases, it may fall most heavily on those who care for a person with an acquired brain injury. I’ve said elsewhere that one of the biggest lies perpetrated on the Australian public is the notion that the tide of the road toll is somehow being turned back. While the overall trend might be towards fewer fatalities, any of the recent annual reports of the NSW Institute of Trauma and Injury Management tell a very different story. While death rates are indeed falling, admissions to the state’s hospital trauma units – most due to motor vehicle accidents – are up by around 15% per annum. It can only mean that more severely injured people are surviving. And some of the best evidence points to acquired brain injury producing, on average, three times the level of disability as spinal injury. If you look at the recent analysis of a decade’s worth of admissions to the Brain Injury Unit of the Sydney’s Royal Rehabilitation Centre – 480 out of the 600 were young men - they came largely from living at home and overwhelmingly returned home on discharge, and to the care of their mothers, girlfriends or wives.
Carers: Facts & Figures

The following is statistical information taken from Carers: Facts and Figures\(^3\) which highlights the number, and some of the characteristics, of Carers across Australia. These figures represent all Carers – those who care for the frail, disabled or mentally ill.

- There are approximately 2.6 million Carers across Australia.
- There are approximately 1 million in NSW alone.
- 73% of primary Carers are women.
- 79% of primary Carers live with the person they care for. Of this group, 44% report that they provide, on average, 40 hours or more of care per week.
- Primary Carers are most commonly in the age range of 35 - 64 (3% are aged 18-24, 10% aged 25-34, 19% aged 35-44, 25% aged 45-54, 19% aged 55-64, 13% aged 65-74 and 10% aged 75 and over, with the remainder less than 18 years).
- Primary Carers’ main source of income is as follows: for 56% of primary Carers, a government pension or allowance; for 29%, wages or salary; for 8% their own business, partnership or other private income; and for the remaining 7% unknown.
- 61% of primary Carers are not in the labour force and 4% are unemployed. Only 36% of primary Carers are employed, and of this group, 57% work part time\(^*\)

Secondary Carers (numbering more than 635,000) also contribute to the person’s care and support, however are less likely to live with a person needing care. 53% of secondary Carers are female and 47% are male.

\(^3\) www.carersnsw.asn.au

\(^*\) Figures do not add up to 100 due to rounding. Figures accurate as of 2006
Carers are a diverse population. All caring situations are different and may vary according to the –

- age of the person receiving care;
- nature of their disability or illness;
- length of time care is provided (one-off, weeks, months, years);
- kinds of care activities provided;
- cultural background of the carer and person receiving care; and
- frequency and intensity of care activities.

There are also many people who provide assistance to a close family member and see their role as a ‘natural’ extension of other family roles such as spouse/partner, parent or sibling. As such many do not identify themselves as ‘Carers’; hence the number of Carers is probably even more than stated above.

**Common Issues and Emotions Carers of people with a Traumatic Brain Injury may experience:**

There are often personality/behavioural changes, lack of self awareness/social skills, impaired control of verbal and or physical aggression, mood swings/depression, impatience, frustration, self-centredness, memory deficits, lack of motivation/initiation skills, fatigue issues, as well as physical, sensory and perceptual losses, in a person who has sustained a traumatic brain injury (TBI). A common grievance amongst Carers is their struggle to come to terms with this ‘new person’. Very often too, isolation plays a key role in feelings of confusion or depression, as friends all too often drift away from the family, due to a lack of understanding of what the Carer and the person with the brain injury is really going through. Many Carers also admit to being shocked and overwhelmed, when they realise the impact of the life-long changes that caring will have on their lives. There are no right or wrong emotions; the following feelings are all a normal reaction to caring for a person with a TBI.
Grief: Mourning for the loved one that has been lost. Mourning for life as it once was prior to the injury.

Anger: Frustration with the person being cared for, due to tiredness from the increased workload, or stress from the cumulative physical and mental effects of caring – especially when support services do not provide adequate assistance.

Guilt: A Carer may experience guilt for many reasons, such as taking a break or using respite services. Losing their temper; blaming the person for their loss of freedom; or having to place the person in a residential centre or nursing home.

Depression: Feelings of worthlessness or agitation, of no control over your own life, or difficulty in making decisions are common.

Resentment: Lack of support from friends who stop making regular contact can lead to isolation and feelings of resentment.

Fear: Fear of the unknown, your future and/or the future of your loved one, should something happen to you, are common concerns.

Thankfully today there are good support services available for Carers. For further information relating to services and/or support groups contact your State’s Brain Injury Association, or ring the Commonwealth Carer Resource Centre on 1800 242 636.
"...The more I give to thee
    The more I have,
    for both are infinite."

Juliet in Shakespeare’s Romeo and Juliet
In a quaint little house situated on a busy thoroughfare in Enfield, a suburb in south west Sydney, Irene greets me at the door with a friendly smile and welcomes me into her home to be interviewed about her life as a Carer of a person with a TBI (traumatic brain injury). It is a cold winter’s day and the rain is unrelenting, but as I step through the doorway I am immediately made to feel at home, as Irene puts the kettle on for a cup of tea with our chat. Irene, who is 60 next year, not only cares for her disabled son Michael, who is now 28, but also for her frail mother who is aged 87. She has another daughter, Leanne, who is married with a 2½ year old child and expecting another baby around Christmas time. Sadly, Irene is a widow. Her beloved husband, Rowley, died suddenly from a heart attack only 11 weeks after Michael’s tragic accident. It is generally agreed by all that the severity of Michael’s injuries, as well as the sudden upheaval in their once happy lives, were contributing factors in his death.

“That must have been just so difficult for you,” I say, the shock obvious in my voice. “I can’t imagine how you coped with both tragedies…”

“I had to - I had to keep going. I just kept putting one foot in front of the other,” Irene says stoically, not wanting to elaborate further.

Michael was 22 when his accident occurred on the 27th June 2000. He was enjoying a night out with some friends at a club in the city. Apparently he was walking along a dimly lit corridor, head turned sideways looking at something other than where he was walking, when he suddenly toppled head first over a balcony, falling approximately seven metres to the ground. He spent the next two weeks being kept alive by a ventilator in the critical care unit of Royal Prince Alfred Hospital. There were medical setbacks with his progress initially, when complications including pneumonia arose. However, once medically
stable he was transferred to the high dependency ward for a further two months. This was followed by over a year of specialised rehabilitation at Royal Ryde Rehabilitation Centre. As well as a severe TBI with skull fractures in six places, his other injuries included six broken ribs, punctured lung, cracked vertebrae, dislocated hips, cracked collarbone and a broken wrist.

“I honestly believe he pulled through those early weeks because he was such a keen sportsman and was extremely fit. He played representative cricket, soccer, loved swimming and running, and used to go in the ‘City to Surf’ each year. His room is full of trophies!” Irene says proudly, going on to tell me of his high academic achievements as well. “He went to Balmain High until year 10 then St. Mary’s Cathedral College in the city. He got lots of awards and at the time of his accident he was going to the Australian Catholic University and was studying for a degree in Human Movement. He also worked part time at Leichhardt Aquatic Centre as a Lifeguard, which he loved. On the day of his accident he had gone to soccer training, after a shift at the Aquatic Centre, then straight into the city…”

Michael couldn’t talk for approximately seven months, and when the tube inserted into his trachea to assist his breathing came out, Irene recalls having great difficulty understanding him. It took almost one year of physiotherapy for his balance to be good enough for him to get out of his wheelchair. Michael was keen to participate in his therapies at first as he detested his wheelchair, but as time went on he often became frustrated and less obliging with the therapists, and his mother. Naturally these were arduous times for Irene, but what she recalls as the most distressing was training him to eat again. Even today, Michael’s issues with food are still problematic for her to handle.
“We started with pureed food and it was a very slow progression to a soft food diet. Even today he still has swallowing problems.” Irene says. “Though the main problem we face today is his insistence on eating sweet soft foods, like those he was fed in hospital; things like custards and desserts; it’s almost an addiction and it’s probably what we argue the most about, as I am concerned about his weight ballooning out of control.”

Michael also has some challenging behaviour due to the frontal-lobe damage to his brain. Having personally met Michael a few times in a group situation with my own son, I was impressed with his politeness and concern for others’ needs. However Irene reluctantly points out that he is not always so polite and at times can be verbally aggressive, especially when something frustrates him. Irene finds it difficult coping with Michael’s physical needs as his build is large. Though he still requires assistance with his personal care, he resists Irene’s help and regularly argues with her over these issues. Michael’s ability to plan and organise himself is also severely affected and Irene finds it very frustrating to watch him procrastinate over simple matters.

“He has OCD (Obsessive Compulsive Disorder). For example, he must always sit in the same seat at the table and eat his meals in a specific order.”

Michael spends most of his week attending ‘Headway’, which is a community recreational program for adults with a brain injury. He loves his bowling and other activities such as relaxation classes. From time to time Irene receives respite when Michael attends Gem Hill Cottage at Castle Hill, for an occasional week-end away. Other than that, Irene keeps herself busy as a ‘Carer Representative’ for the Headway organisation, which involves attending meetings and the occasional conference. When asked about her social life and support from family and friends, Irene is reserved in her answer, acknowledging that although family and friends visit now and then, they are not used to dealing with someone with a brain injury. When asked about how she copes with her current situation, she briefly lets her guard down and the smile disappears, as she admits she copes on a day-by-day basis.
“What can you do? You have to cope, don’t you, you have no other choice.” After a few moments the smile reappears, as she adds, “But Michael has a great sense of humour, and we quite often have a good laugh together. It helps to see the funny side of things, for instance often he can be talking about one thing and go straight on to something entirely different. In one minute he can be talking about bowling, then asking what’s for dinner, then asking to see his nephew, Ethan. I have a quiet chuckle to myself when he gets up from an afternoon nap and thinks that it’s morning!”

What worries Irene the most is the very same fear that I, and most likely all other Carers harbour – the future. The dread about ‘what happens when we are not around to look after our loved ones’. We share this moment quietly, as neither one of us has the answer.

When asked if there was a stand-out issue that she faced during the early months following Michael’s accident, that could have been improved, Irene replies:

“The doctors and nurses should have warned me about his compulsive behaviour and how to handle it. I wish they had not fed him up on custards and sweets, as he is now obsessed with sweets!”

When asked about now – what is the most important issue she currently faces? Irene replies:

“His weight! It’s ballooning out of control. I can’t do simple things like take him shopping with me as he is obsessed with buying only sweet things.”

And to the final question of – “What is the one message you would like people to know about life as a Carer?”

“There is no time for yourself – your life is not your own any longer. But you can still have fun – it’s not all bad!”

If you were to cross paths with Irene in the street, you would never know the depths of sorrow she has experienced. She has the strength of character to manage and come through smiling!
“The Audience” By Rebecca Gentz

Rebecca now 33 sustained an Acquired Brain Injury in 1998. She finished an Arts degree in 1997 and since then has been creating beautiful and thought-provoking art work. She is currently a facilitator of ‘Art as therapy’ with groups of people with diverse disabilities.
In the ideal portrait of the Blazevic family, the wheelchair which temporarily frames the restricted ability of the eldest son Adrian, would fade into the background and the love of his devoted parents Diana and Ivan, and younger brother Nathan, would come to the fore and take on a prominent hue in the canvas. Most family portraits of similar ill-fated journeys would be drawn with dark traces of sadness, tinted with grey shades of sorrow. But not so the Blazevic family portrait; it would be filled with colours of joy and radiate the brightness of a family filled with happiness and passion for all that life has to offer.

Adrian, or ‘Age’, as his family and close friends call him, is now 21 years old. His destiny was tragically altered three years ago when he fell 30 metres down the steep rock face of a cliff, at a beach in Newcastle. Amongst other injuries he sustained a severe traumatic brain injury. He was in ICU on life-support for two weeks and a further one month in the high dependency ward of John Hunter Hospital, before being transferred to Liverpool Brain Injury Unit, where he would spend the next 15 months of his life.

“He was your typical 18 year-old,” reflects his mum, Diana. “He was working in his Dad’s building company and studying Project Management at TAFE. He was full of life; full of love; had a wonderful group of friends. He enjoyed sports; played soccer early on, but then found his passion for wakeboarding. I remember the last time I saw him before his accident. He bounced in the door happy and energetic, grabbed what he needed before saying, ‘Bye Mum. I love you’. A few hours later he sent me an SMS to say he’d arrived safely. That was the last time…” Her voice falters as she wipes a tear from her eye. So we decide not to go there… especially in front of Adrian, who although unable to speak, has full comprehension of what is being said. Diana has always maintained an extremely positive aura around Adrian and this has reflected on her amazing younger son, Nathan.
Both admit that when the accident occurred the family had little knowledge of the devastating consequences of brain injury, and even when the enormity of the situation was realised, each of them, including Adrian's wonderful friends who had rallied around to support them, would never let go of their deep optimism and hope.

Nathan recounts; “We camped out in an empty room that was about to be renovated at the end of the corridor of the hospital ward. We found unused blankets and mattresses. Adrian's best friends stayed with us and each of us took turns to maintain a 24 hour vigil by his bed. We tried to keep the situation light and positive; for instance it was common knowledge how much Adrian liked his sleep, so we made bets on when he’d ‘wake up’. Aside from that we'd play board games and did our best to keep our spirits high. I remember one particular day a security guard actually asked us if we were homeless! After that we spent the rest of the time in a nearby hotel.”

This inspirational carer's story could be told by any one of Adrian's immediate family members. They share an equal passion and dedication in caring for Adrian's daily physical needs and providing him with unconditional love and emotional support. They have spared no expense in improving his quality of life at home. But I have chosen to write of Nathan, who is now 19, as he shares an extraordinary bond with his brother; a bond of such magnitude that it will be difficult to capture with mere words. For the 15 months Adrian was in Liverpool Brain Injury Unit, Nathan rarely missed a day's visit. Each afternoon after school, he would take the train to see his brother. He managed to cope amazingly well through his senior years of high school, but admits that there were times when focusing on his assignments or studying for exams was very difficult. To witness the connection Nathan has with Adrian, who is for now unable to use words to communicate, turns your heart inside-out. In fact they don't need words to communicate – they share an antenna invisible to the human eye, but on the same wave length. When Nathan speaks – Adrian’s eyes light up and look in his direction. And when Nathan shares some precious childhood memories of life with his brother, Adrian's face dances with emotion. His smile reaches out to the corners of your soul.
They connect not only on a spiritual level, but also physically as well. Nathan frequently displays his love for his brother, either by kissing his forehead, wiping his hair from his eyes, or just reaching for his brother’s hand as we chat.

When I ask Nathan about the emotional impact on him, regarding his brother’s accident three years ago, he answers with a profound insight for one so young;

“Life is still good – I love life with Adrian. He has lit a light for me to follow and made me realise that there’s nothing more beautiful than life, because without life we have nothing. If we never were, then we’d never know what is.”

Currently Nathan is attending University, studying for a Business degree, 2½ days a week. “Mum takes most of the load of Adrian’s care, with Dad and I taking turns to be home to assist.” Nathan also confesses that it is his mother who carries them all without even knowing it. “We get our vibe from her.” he says.

On his free days Nathan loves nothing more than to take his brother out to music festivals, friend’s houses, parties, or even simply taking him for a walk on the beach. “Adrian is a chic magnet”, he laughs. “People come up to us all the time to tell us how inspired they feel to see us out and about and enjoying life.”

When asked to look back to the time of the accident, and whether there was a stand out issue that they feel could have been improved, Nathan says;

“Apart from not getting enough good therapy, due to limited resources and the inexperience of some therapists, what upset me the most was the lack of regard for Adrian’s comprehension. When I spoke up or voiced my concern about some inadequate handling of Adrian, I got into trouble for being ‘an insolent 16 year old!’”

When asked about now – what is the most important issue you currently face, Nathan replies,

“There are no real issues we can’t handle now. We are a lot stronger from what we have been through. The chain of events that led us to where we are now has helped sculpt us into the family we are, and I wouldn’t change that.”
Finally, when asked about his message to others facing similar challenges in life, “It’s only hard if you make it hard. You can take it two ways – either get sad and depressed, or take it head on. Learn from your experiences and share them with others!”

Nathan has revealed himself as an outstanding young man, with extraordinary humanity and insight for his young years. Ivan and Diana must feel extremely proud of the person he has become. On Adrian’s recent 21st birthday Nathan made the speech which follows – between the lines of brotherly mockery, the heartbeat of an angel is exposed…

“And now onto the man of the hour… Adrian Blaz! I don’t know if anyone has noticed this, but Adrian has this remarkable talent of prolonging, extending and emphasising anything that will benefit him in any way. Perfect example, three months on from his actual birthday and here we all are still celebrating it. Another one was when Adrian broke his knee wakeboarding and fair enough, yeah it’s broken while it’s in the cast, but for the next 4-5 months after it had healed, it was all we heard about in our house. Mum would say something like ‘Adrian, take the garbage out’, and sprint would turn into hobble, the arm would go to the knee and we would hear, ‘I can't, my knee!’ I think we all just got sick of hearing it and started not even bothering to ask him.

His ability to palm things off on to me surpassed just chores and even went into punishments! When we were little around five and seven, I don’t know why, but Adrian used to bite down hard on his arm, making sure to leave red raw teeth marks and then run to mum and dad screaming ‘Nathan bit me. Nathan bit me!’ Mind you, this all came to a crashing halt when Adrian had lost his front tooth, bit his arm, ran to mum and dad with the usual deal, only for them to notice a missing tooth in the pattern of teeth embedded in his arm!

Adrian has always been the perfect older brother to me, always there to give me advice and constantly leading me in the RIGHT direction. Or so I thought! One day when we were on holidays on a cruise, as the little brother does, he follows his older brother like cat and mouse. It was his wise idea to enter the
first ‘STAFF ONLY’ door we saw and see how far into the depths of the ship we could get. We got so far into the ship that one door we opened actually had the captain of the boat standing there holding a meeting with some high-ranking crew members. Hearts racing and flushed we ran as quickly as we could out of there. But with Adrian in the lead and me in tow, this was not the end of our adventure. As we were running we came across a room that had what looked like the ship’s bar supplies – alcohol and cartons of cigarettes. My heart racing and convinced someone was around the next turn - I paused and pleaded with Adrian to get me the hell out of there. His reply was a swift, ‘Nathan, don’t do this to me right now – do you know how much money I can make?’

Adrian, looking back on it all, you have always led me on the best adventures and journeys – the biggest and best one – LIFE. You have always been ahead of me in everything we do and lit the light on the way. It’s hard for a younger brother to say, but I honour and look up to you so much. Your courage, persistence and patience has always pulled you out and put you on top of every situation. I admire you day in and day out - for the person you are and the life experiences you have been through. It never ceases to amaze me that you have come out of it all smiling! You have the ability to put a smile on all our faces. I don’t think one day has gone by where you haven’t made being around you a fun occasion. You should be extremely proud of yourself and how far you have come, because I can safely say we are all amazed and will continue to be, every step of the way.

I’d like to make a toast, To Adrian – for 21 beautiful and full years of life. I love you Age!”
“Christmas Drawing” by Rebecca Gentz
Genevieve Kavanagh  
– A Lifetime of Life’s Hardest Lessons

Try to imagine, if you possibly can, receiving the call that two of your sons were involved in a very serious car accident, twelve hours away from home. Then try to imagine the horrendous shock and unbearable pain of learning that one of them had died, before you reached them. Unimaginable? Unbelievable? Unfortunately for the Kavanagh family, true.

When Genevieve and John Kavanagh immigrated to Australia from London, on the 12th of April 1968 for a better climate, never could they have imagined the great pain and heartbreaking loss that lay ahead for them in the country that beckoned them with promises of blue skies and warm tomorrows.

When they first arrived in Sydney that Friday (Good Friday!), they stayed for a short while in a hostel located in Bunnerong Road, Matraville. From there they moved to Malabar, then some time later, finally purchased their first family home in Barton Street, Kogarah. John worked hard in those early years as a Gent’s Measure Cutter, in the tailoring industry. But changing times meant that John became redundant. Being handy with tools and keen to work, he decided to start his own fencing business. Genevieve dedicated herself to raising their six children. At the time of the tragic accident on New Year’s Day 1982, the children’s ages were as follows: Diarmuid the eldest son, 22 years; John, whose life was sadly cut short was just 21 years; Anthony whose massive injuries devastatingly altered his destiny at 18 years; Helen 17 years; Brian 15 and the youngest Christine, 13 years.
At 18 Anthony had the world at his feet. He was achieving great things as an athlete, playing representative AFL (Australian Football League) for St. George, and even greater accomplishments in his chosen work career as an Electrical Fitter Mechanic, winning ‘Apprentice of the Year - 1981’, and attending a special function to receive his award from the then Premier of NSW, Neville Wran, shortly before his life took a tragic turn.

On Boxing Day 1981, the two young brothers aged 18 and 21, set out on what was then and still is now, almost a ritual for young men - the long drive north up from Sydney to Queensland. Being sensible young men, they took their time, stopping a few times overnight along the way. Things were going fine until John began to experience car trouble as they got close to the northern NSW town of Bendemeer where they were forced to leave their car. They continued the journey in the back seat of a car belonging to a friend with whom they were travelling. Tragedy struck near Kingscliffe in the small township of Chinderah. Apparently the driver of the car they were travelling in fell asleep at the wheel. The car veered off the road, flipped over, and John and Anthony were both thrown from the back seat of the car to the roadside. The driver and the other friend in the front passenger seat were both amazingly unscathed, apart from a few cuts and bruises.

Genevieve and John had spent New Year’s Eve at a friend’s house in Mount Druitt and to avoid the one hour’s drive back to their home in Kogarah, they had decided to stay overnight. When the local police came to their Kogarah home to tell them about the accident, and were unable to locate them. Neighbours had to enter their home to try to work out where they might be. Without the benefit of mobile phones, they set about telephoning everyone listed in their phone teledex, until they located them at Mount Druitt. Genevieve and John then had to drive the one hour back home to meet the local police who advised them to quickly pack what they needed and organise a flight to Coolangatta, Queensland, as they had initially been told their sons had been taken to Tweed Heads Hospital. Somehow during their frantic packing and planning, they learnt that due to the serious nature of both their sons’ injuries, the boys had been transferred to a Brisbane hospital. They needed to change their flight.
destination to Brisbane, which regrettably caused further delay. When Genevieve and John finally arrived at Brisbane airport, there were more frustrating delays. Faced with a long queue for a taxi they decided to make a quick call to the Hospital from a public phone to inform staff that they were now in Brisbane and would shortly be at the hospital, only to be told the tragic news that one of their sons had died. Mistakenly, they were informed that it was Anthony who had died! They were overwhelmed with shock and not able to take it all in. They were frantic to get to the hospital. Finally they were able to get a taxi and Genevieve asked the female driver how long it would take to get to the hospital. Genevieve can still recall the rudeness of the reply. Disregarding her passenger’s obvious distress, the driver said:

“I am not going any faster than this, I don’t want to have an accident – you’ll get there when you get there!”

When they arrived at the hospital they learnt that it was their older son, John, who had died from his massive injuries. The Intensive Care doctor began to explain why they had been unable to save John’s life and inform them about Anthony’s devastating injuries, when the police arrived and asked them to go and identify John’s body in the morgue.

“The sad part was that we couldn’t even get close to John to touch him; we had to identify him through a glass wall. That was difficult enough but we also had to deal with learning that Anthony had severe brain damage – 9 skull fractures, broken facial bones that needed rewiring and cuts and gashes to his body. It was 25 years ago, but I remember every word the doctor said – ‘If he survives, take him home and love him – his eyes will be okay, but he’ll have behaviour and memory problems and will be objectionable to society’.”

This story could be about Anthony’s remarkable survival, which involves all the love and support of his entire family, but instead, it is the story of Genevieve, an incredibly dedicated and strong willed mother who, with the odds always stacked against her, never gave up. Faced with one battle after another, she refused to submit to hospital administrators and doctors, in her struggle to have her son treated with the dignity and respect he deserved, all the while trying to deal with the insurmountable pain of burying their cherished son, John.
“I flew back for John’s funeral, not wanting to leave Anthony, who was clinging to life by a thread. I remember feeling numb – like a zombie – at his funeral.”

Twenty five years ago little was known about rehabilitation and recovery from brain injury, though Genevieve recalls the initial period in the Intensive Care Unit, the medical treatment provided was of a very high standard. Even when Anthony was transferred to the high-dependency ward, the standards of care were still very good, but after major surgery to reconstruct his entire face, a major setback occurred when he contracted golden staph infection during the operation. Anthony was then transferred to an old part of the hospital that had just been reopened.

“I had to complain to the assistant superintendent that the old bed they put him on, which came from a basement somewhere below the hospital, was not fit for him to lie on. The assistant superintendent had to speak to the staff to get another proper bed for him.”

The standard medical opinion of that era was that rehabilitation from brain injury cost too much in time and money with little hope of any recovery. He therefore received virtually no physiotherapy. It was Genevieve who set about getting him up out of bed, firstly by herself with Anthony leaning on her and then enlisting the aid of an agency nurse. She basically taught Anthony to walk again little by little, all by herself. Anthony would lean on the nurse or use a corridor railing for support and Genevieve would bend down and place herself at his feet, lifting his legs and placing one foot in front of the other.

Genevieve had no access to a Social Worker to help her cope with the emotional trauma of losing a son. She stayed by Anthony’s side and cared for him around the clock – from rubbing his legs with cream to advocating on his behalf for the provision of basic personal hygiene. All this whilst trying to keep tabs on what was happening at home 1000 kilometres away, with her other four children. Her deepest regret when she talks of her other children is that she agreed to send her youngest daughter Christine, who was only 13, to her close friend’s home in Melbourne for a holiday. She thought it was the best solution for Christine at the time, but in hindsight regrets sending her away from the rest
of the family who were all going through the same emotional turbulence and providing support to each other that only a family can, in such devastating times. “All the kids were badly affected, but they learnt to hide their pain and feelings over the years, probably to protect me.”

Anthony and Genevieve spent four difficult months in a hospital in Brisbane, dealing with one battle after another. John flew back and forward, but steadfastly supported Genevieve in her quest for basic treatment, even phoning and persuading the doctor who, despite Anthony displaying alarming deterioration in his eyesight, refused Genevieve’s pleas for assistance with basic eye examinations. Genevieve’s battles did not end with Anthony’s transfer from Brisbane to Sydney. In fact, the transfer itself was nothing short of disastrous. Genevieve was not allowed to travel with Anthony and had to take a separate flight to Sydney. She was assured that his ‘care flight’ and subsequent transfer to home, would be well coordinated, but after hours of waiting at home she phoned the Brisbane hospital only to be informed that the care flight team had refused to take Anthony for fear there was still some golden staph infection in his eye, and the patient transport vehicle had had to turn around and take him back to Brisbane. Unfortunately, another flight could not be arranged until after the following weekend! Even upon their return to Sydney and subsequent visits to the main rehabilitation facility at that time, there were unnecessarily frustrating encounters with medical professionals who often treated the Kavanaghs with disdain.

So, with little or no support from the public health system, when Genevieve got her family back together and her son home after four long months away, Genevieve set out to help him recover the most function he possibly could. This was no easy task 25 years ago, as there was no internet to bring the world within reach of her fingertips. In her search for answers, she came across the teachings of Maxwell Britt and Dr. Ian Hunter and ‘Friends of the Brain Injured’. Under their guidance, Genevieve placed an ad in the local newspaper asking for assistance from the community in developing a home-based therapy programme for Anthony, and was amazed when she had 50 replies from caring individuals.
The programme was developed, monitored and changed according to Anthony’s improvements over some years, and Genevieve is convinced that this type of therapy is responsible for the outstanding physical gains Anthony has made. Basically, this therapy is not unlike that used today by Occupational Therapists in Brain Injury wards around the country, to stimulate the brain and encourage function – only it is done more frequently and intensively, and usually in a home-environment with community and/or family involvement, due to the limited resources of the public hospital system. The theory behind it is simple (yet too complex to describe in detail here). It involves taking the brain back through the childhood stages of development – for example, retraining the patient to crawl before walking is seen as crucial to developing a correct cross patterning movement. (Interestingly, similar therapies are now widely recognised as being beneficial in early intervention with children diagnosed with Autism.)

After Ian Hunter had taken Anthony as far as he could, Genevieve tried to get Anthony rehabilitation and recreation through community networks and joined a group called ‘Cerebration’ through Prince Henry Hospital. The group comprised mainly parents searching for something for their brain injured children, even just by way of recreational activities.

Despite seeking many specialised opinions, including that of Dr. Fred Hollows, and providing many hours of work and stimulation, unfortunately Anthony’s eyesight never returned. Anthony’s only other residual physical disability is some mild left-sided weakness. He does exhibit some challenging behaviours from time to time, especially in his desire to constantly eat sweet things. Genevieve has to lock the kitchen cupboards, otherwise it is not uncommon for him to raid the pantry during the night! Anthony communicates well, though sometimes speaks a little too fast. He has a wonderful sense of humour and often uses appropriate cartoon voices for different situations; he even gives people nicknames from cartoon characters or television series actors (like characters from MASH and Dr. Who) - those whom he remembers well from television that he watched prior to his accident.
The principal difficulty Genevieve that has endured for 25 years and disappointingly still endures today, is a lack of services to cater for Anthony’s recreational, social/independent living skills and employment needs. Unfortunately as Anthony is both blind and has a TBI, he doesn’t fit neatly into the required criteria in either area, and Genevieve has spent relentless hours pursuing this.

“Anthony currently attends some disability services such as DSA Caringbah on Thursdays and every second Tuesday. On Mondays he attends recreational activities provided by the Pole Depot Penshurst, but most of the activities are not suitable for the blind. Despite years of searching for somewhere for him to fit in, the sad reality is that he only fits into the too-hard-basket.”

Genevieve has a room full of filing cabinets dedicated to all the research and information she has gathered in her 25-year investigation into all areas of brain injury. She has led a pro-active life, never resting in her search for a better life for her son, nor in the quest for improvement in services delivered to all those affected by brain injury. In the past she was actively involved in community organisations such as ‘Cerebration’ (which is now known as Headway) and has written many letters to local members of parliament, to government and non-government bodies. Recently, Genevieve and John were featured in the local newspaper having their first week of respite in 25 years. This, paradoxically, not only exemplifies their dedication as carers, but highlights the lack of suitable respite care for people like Anthony. Recently, Genevieve’s brother passed away in Ireland. Her restrictive life as Anthony’s main carer meant that Genevieve could not attend the funeral.

“Times like this cause me sadness and I still get upset on the 13th September, as that was John’s birthday. Anthony still misses John terribly, only today he asked me if I miss John as much as he does.” Genevieve says with a tear in her eye.

As we go on to discuss the sorrow of painful anniversaries, Genevieve reveals a moving anecdote from when Anthony first began to understand that his brother was not coming home…
“One day, some months after the accident, we were sitting at home and Anthony asked me, ‘Where is John?’ He had asked about him before, but it was always ‘How is John?’ At those times I usually told him that John was hurt far more than he was and he had accepted that. So this day I replied ‘John is in Heaven. He is in Heaven praying for you.’ Anthony then said, ‘Mum, you’re not serious – is my brother dead?’ And I said ‘Yes Anthony’. He then said ‘But I didn’t go to the funeral.’ And I had to tell him that he was in a coma in the hospital when John’s funeral was held.”

Genevieve did her best to explain to him, but Anthony wasn’t convinced. He kept asking all his sisters and brothers as they arrived home at various times throughout that day, if John had actually died. To help himself believe or accept what he was hearing, Anthony then asked to visit the cemetery where John was buried, so that he could feel the outline of the grave with his hands. For some time this became an almost daily ritual, with Genevieve often driving to the cemetery up to three times in one day!

When asked about her life now - after 25 years, and about the most important issue she currently faces, Genevieve replies;

“The same issue that it’s always been – somewhere for Anthony to fit in. He could have benefited so much from retraining of his social and behavioural skills, but there has never been any consistency.”

When asked about the message she would like people to know about life as a carer, Genevieve says;

“You have to find everything out for yourself. There is a definite lack of support for people like Anthony. Your time is tied to the clock. You don’t have time to be sick! Having a good family has helped get us through, along with Anthony’s wonderful sense of humour!”
Amazingly at 70 years of age, Genevieve exudes an aura of energy and dedication to her son's ongoing dependence that has not diminished over 25 years of caring. The constancy of her courage and devotion, despite facing almost insurmountable challenges, confirmed my own philosophy; that being - it is not about the victory, it is about the fight! It is not important where you finish, it is important that you try! Genevieve and John can rest assured in the knowledge that they have done everything possible for their son – providing never less than unconditional parental love. Both epitomize the true role of ‘Carers.’
A human head collides with a tree at 140km/hr. Memories are erased by the impact.

These prints represent my experience of the Traumatic Brain Injury (TBI) I suffered in a high-speed motorcycle accident. Using items salvaged from the crash and hospital scenes, I created templates for acid-etching into copper, emulating the way the crash has been engraved into my mind. I now use the printmaking process in a cathartic manner on my road to recovery, while working to heighten public awareness of the challenges associated with TBI. I also run workshops at Willowbank Studio for survivors of acquired brain injury.

Scott Trevelyan
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A closer look at Scott Trevelyan’s imagery from the previous page.
My Boyfriend’s Motorbike Accident: A Haiku Sequence

tall grasses
a wheel spins above
buckled handlebars

ventilator vigil
the robotic rise and fall
of his chest

moonless sky
heart monitors blink
in the dark ward

near the top of the waste bin a man-sized nappy

first light
the spoonful of baby food
at his lips

nurses ask
where all the coconut comes from ...
lamingtons in bed

his memory of it
picking up the bike,
riding away

By Sharon Trevelyan Dean

(Previously published in Yellow Moon Issue 18, Summer 2005, and ‘commended’ in the magazine’s ‘Seed Pearls’ haiku sequence competition, Summer 2005.)
I first met Marie at a Carer Support Group meeting south of Sydney, where I had been asked to come and speak about the first booklet in this series called ‘There’s always Hope...just alter the Dreams’ (NSW Health 2006). She was the ‘group leader’ and from my earlier telephone conversations with her and from watching her talk to her contemporaries on this particular day, she struck me as having just the right mixture of leadership/communication skills and empathy for her fellow carers. She appeared to have everything under control even demonstrating exceptional patience and tolerance listening to other people’s current problems. There was no hint that behind her friendly smile and composed façade there lay a tragic story of human suffering - one of the saddest and most disturbing tales I had ever heard.

Marie was reluctant at first to share her story, as she was well aware that retracing the tragic events of the past would be painful for her and confronting for others. She chose to go on with the project for the sole reason that by exposing the reality of how mental health issues and brain injury cross over on many levels, she may in turn help others dealing with similar circumstances. For anyone familiar with brain injury, it is widely recognised that mental health issues, such as depression are quite common in the months and years following the injury. A variety of reasons may contribute, among them, social isolation. Peter’s situation reflects the reverse; that is, he had mental health issues which directly led to his self-inflicted brain injury.

*Names changed for privacy reasons*
Pete and Marie met online some time late in 2003. They are now married. Marie has three children from a previous relationship. Prior to Pete’s injury Marie was a Bank Manager, having managed some of the biggest branches of one of Australia’s leading four banks in Sydney’s eastern suburbs. She had also previously worked in commercial and mortgage lending, which, she said she enjoyed much more as she was able to offer people much more significant assistance.

At the beginning of their relationship Marie admits that she had no idea of the true extent of Pete’s inner torment. However, as time went on it became increasingly apparent, that the combination of the very public humiliation caused by his first wife having an affair, and the subsequent breakdown of his marriage, which in turn led to some very self-destructive lifestyle choices, were contributing to a progressively downward emotional spiral.

Over the ensuing 18 months, a lot of personal ‘tight-rope-walking’ went on between Marie and Pete. I will let Marie tell the story in her own words, so as not to detract from her raw and compelling journey…

My (now husband, but then ‘sort of partner’) Pete had his fourth failed suicide attempt in as many months on the 20th April 2005. This suicide attempt was way more serious than any of the others and as it turned out, was to have a devastating effect on his life and ours as well. The injuries sustained were the result of a gruesome self-inflicted penetrating injury to the right side of his head. Resulting from a right-hemisphere injury, Pete has left-sided deficits. His disabilities are similar to those who suffer a right-hemisphere stroke. Pete had a PTA (Post Traumatic Amnesia) of 61 days (though, as with much of the ‘care’ that he was given whilst an inpatient at a leading Sydney Brain Injury Unit, I have reason to question the validity of this result.)

Before his injury, Pete was a self-employed motor mechanic with a passion for all things mechanical and technical and a certain ‘knack’ for figuring out stuff that even now, baffles me. He was never a bright student as far as school was concerned. He was successful in getting an apprenticeship as a motor mechanic two weeks after he had begun Year 11, so his parents allowed him to leave school and follow his dreams.
As a child, Pete was always a loner and did not really have any special friends. He was a likeable enough sort of a person and had a calm and easy going nature about him that I have struggled to find in anybody before or since. The calm exterior did much to veil the torment and raging torrent of deep-seated and un-addressed emotional issues inside him.

In 2000, Pete married his former defacto wife of nine years, and in September 2003, she announced that she was leaving him to be with someone she had met while she was at a (swingers) party. Pete had regarded her as his princess and had given her everything that she wanted and then a hell of a lot more! It seems that each time Pete gave her what she wanted, she moved the goal posts and made more and more demands.

There are many issues regarding Pete's mental state which I can only attribute to the torment that he must have felt at his ex-wife's “betrayal”, but most of these issues went unaddressed as she refused to support Pete in his attempts to gain professional help for them.

I remember finding Pete on the night of April 20th 2005. I will never be able to erase the night from my mind. (I guess I should put the whole story down on paper as it is rather a long tale and to tell one part or another would likely put things out of context.)

Pete's family is not now nor have they ever been exceptionally close. Pete went there if he had a problem and they would give him their take on events and his sister-in-law (self appointed matriarch of the family) would give him instructions on what she thought he should do. They never really understood Pete's mental health issues and didn't really take them seriously. They certainly made everything a lot harder than it had to be. I would like to say that they were well-meaning and that they were trying their utmost to reach out, but in all honesty, I cannot even give them that much credit.
Pete’s earlier suicide attempt(s) are ones which I had handled by myself and not worried about getting his family involved in as the more people were involved, the more complicated things seemed to become. But the ‘big’ one was not something that I was prepared for, nor was I equipped to handle it on my own. It was gruesome and I had no idea how to deal with the blood and the dark side of Pete’s illness.

So I called Pete’s brother Tom to come over and to stay with me while I waited for the ambulance to come and do what they had to do. I do not know how long it took for Tom to arrive, but I know that he left when the ambulance did and told me to call him when I heard anything. The ambulance people took Pete in one ambulance and me in another. I made a phone call from the ambulance telling my kids that Pete had had a small car accident and that he was going to be all right. I do not know whether or not I said this to them to convince them or to convince myself that he would be ok.

I got out of the ambulance at the hospital and they took Pete inside and started working on him. I remember feeling frustrated because they would not let me go in with him while he was treated. They had allowed me to be present the last time so I was starting to have an inkling that this was not as straight forward as the previous time that he had attempted suicide.

I sat in the waiting room at the emergency department of Wollongong Hospital and all I could see was blood. Lots and lots of blood. My mind kept on playing the picture of the dark red blood over and over and my mind then multiplied it and multiplied it some more and it occurred to me that he could be dead and the doctors were waiting on the other side of the door to come and tell me that he had died and there would be nothing that I could then do to save him from himself.

I started to sob and kept sobbing. It was weird…I wanted to stop and get a grip of myself but it seemed that there was a river flowing from deep inside me and the reality of losing him was just more than I could cope with. I felt people staring at me and though I was trying to stop myself from crying, I just couldn’t. I got up and went outside and I sat there - crying my eyes out and just feeling wretched inside - not for anything that I could or should have done, but with the first pangs of grief kicking in at possibly losing the one man in my life that I had truly loved.
Maybe it was self pity - who knows, but I know I felt sad. I tried to overcome the tears and to work my thoughts through, but nothing worked. I looked around and tried to focus on something - anything that might take my mind away from Pete. I see myself sitting in Wollongong - which I wouldn't be doing had it not been for Pete. Everything that I thought of to divert my attention brought me right back to Pete.

It was cold in an eerie sort of a way. It was moderately cold I guess and I remember my body feeling kind of awful. It was then that I saw the Police car. They drove in and waited for the boom gate to open. It was only as this boom gate started to rise that I started to experience paranoia. I can look back now and identify it as paranoia but then it was oh so real. It occurred to me that they were at the hospital to charge me for doing this to Pete. That they would think that I had done this and that if Pete died, there wouldn't be a soul in the world who could tell them otherwise. My mind was racing; I was frantic to think of what I could do and/or say to make them see differently.

The fear that ran through me as I sat there was such that I found myself wetting myself and without the Police even having spoken to me. I was horrified that my kids would be on their own if they decided to take me to jail.

As I thought of what I could do, I figured that if I went back into that crowd of people in the waiting room, the police would not make a scene in there and I would be able to deal with it a little bit better. As I sat there, there was no doubt in my mind that the police were there to see me, and not to see any one of the other thirty or so other people present in the waiting room that night. So I sat there, off to the side, my elbows resting on my knees, feet apart, and looking at the floor - waiting for the hammer to fall. All my concentration was on not starting to sob again when the boots appeared.

Two pairs of boots - black ankle boots attached to navy blue pants appeared there and the footing seemed to be uncomfortable. They said “Are you Marie?” I said, “You think I did it, don't you?”
Then I burst into tears again. This time, I was just empty - scared and empty. Scared that Pete would die and that I would not have him around anymore and scared that I might go to jail and that my kids would be on their own and scared that then, things might happen to them and no one would be there to protect them like I could.

To my surprise the police went and asked a nurse if there was somewhere that I could go where it was a bit more private than in the waiting room. They took me around to the room at the back of the emergency section and there I sat for some time. The police were wonderful in their approach to me and sometimes, even now I see the male police officer around and smile, thinking that his kindness and compassion was and I imagine still is, outstanding. The police did ask me however if they could have the keys to Pete’s house so that they could go and take a look and make sure that everything was as it should be as far as this being a suicide attempt and nothing more. They were good about it, but I explained to them that I was now the only person with keys to Pete’s house and that I was unable to give them to anyone. I said that I would take them there and let them in so they could look around, but that I could not just hand over the keys. They agreed to this and arranged to get a highway patrol car to come and pick me up. They also said that they would be able to help me clean the blood up as I had explained that I was not good with blood.

When we got to the house, the police officers were of the opinion that it was definitely a suicide attempt, as the amount of blood was well contained and confined to the bath, but they wanted to call in their supervisor for a second opinion. The supervisor arrived and was of the same opinion, though he asked me about Pete’s frame of mind on the morning of the incident. The supervisor left. When the other two police officers were about to leave I asked them if they would be able to help me clean up the blood. They said that they couldn’t because they were not equipped for this and told me to leave it and come back in the morning and do it. As trivial as it may seem, I was really angry at this - they had said that they would help me and then didn’t. I did not think that I would have the strength to clean his blood out of the bath tub. However, eventually I did it, though a lot of it had stuck to the tub and wouldn’t come off, so I had to scrub
and scrub to get it off. Finally with the bath clean, I felt really dirty myself and so decided to throw out all the towels that were used to clean it up and also the clothes I was wearing and the clothes that Pete was wearing, I wanted to erase all memories of that night from my mind.

Things from here went along in a blurry fashion. I remember all too well the precise happenings of that night and the days that followed, but to go into them at length opens up a wound that is best left shut for now.

I know I was frustrated at the hospital for not looking into his mental health issues enough and I know that when I was around, even though Pete was somewhere between unconscious and semi-conscious, I always got a squeeze of the hand or something from him that showed me that he could hear me and that he was hanging in there.

I could not get the ICU staff to listen regarding Pete’s mental health medications and I knew that part of the issue with his system was that he was feeling anxious. Pete has a bowel problem that can raise its ugly head when he is stressed. I was torn between not wanting to tick the hospital staff off, but also wanting the very best for Pete, so after meetings with this doctor and that one, I finally went up to the mental health unit to see them and ask them to intervene.

They too were reluctant to become involved, so I went to see a former client of Pete’s - a psychiatrist who had visiting rights at Shellharbour Hospital. He looked in on Pete and then told me that he could not prescribe anything for Pete’s anxiety issues while the neurologists were unsure about what Pete’s brain injury was doing.

In the meantime, Pete’s diarrhoea got worse and worse. The ICU doctor’s response was to tube him for that as well!!! Pete now had tubes in every orifice of his body with the exception of his ears. None of the veins in either of his arms could have the cannula inserted, so they had cut a direct line to his heart and sutured the device to his upper left chest.

It was horrifying to watch him waste away and to see the amount of drugs that they were pumping through him and to then have them tell me that his liver was shutting down due to the amount of Panadol that they had administered to
stabilise his temperature. It was around this time that the doctors told me
that they thought Pete had meningitis because of his uncontrollable temperature.
This news was the straw that broke the camel's back. I was horrified to think that
there was so much guess-work involved in his treatment. Some doctors were saying
that he might be developing an allergy to the antibiotics being pumped through the
drip and others were saying the meningitis thing due to the fact that he had had
steel introduced into his brain and it was no longer a sterile environment.

I became angry at this and begged them to stop everything that was going
through his IV line and then to reintroduce it all one at a time to see what was
causing the problems. By this time, Pete was covered in an angry looking red rash
over most of his body which was attributed to his high temperature. They stopped
the drugs running through the IV and within two hours, Pete’s fever was back to
a normal level and even though he was semi-conscious, he was more responsive
than he had been previously. It turned out that Pete was allergic to one of the
drugs in the cocktail and when it was removed, he started to improve.

Fortunately for us, there was someone who came into hospital that was deemed
to be sicker than Pete and they moved him to ward C4 at Wollongong Hospital
where he started to become human again. I remember the first morning that he
was moved, they got him out of bed and showered him and used copious amounts
of baby powder and eucalyptus and almost got the ‘smell of death’ off him. They dressed
him in a white hospital gown and asked me to bring some clothes in for him to wear
and told me that I could bring things in that he liked so that he could have the room
decorated in a way that he found comforting.

Pete’s family were initially fairly supportive in their response, but after the initial
three to four weeks, their support began to wane and I knew that to make it,
I would have to fight this battle for Pete largely on my own. Having said this,
Pete’s father was absolutely fantastic in his support of me and his concern for Pete.
As an 81 year old man, he felt helpless in knowing what to do for Pete, so he just
helped me as much as he could. For me, that old man was an absolute godsend!!!
Pete's father, Alex, and I were getting the house ready to go on the market as we knew that Pete couldn't afford to keep the house now that he was facing uncertainty regarding his ability to work etc. Alex and I were working from 9:00am to 5:00pm every day painting and making sure the house was well maintained and fixing the things up that were desperately crying out for attention. Some days Alex and I would spend all our time talking to each other about every little thing - other days, we were just content in the knowledge that the other was there. Every day, I would get out of my painting clothes at 11am and go to the hospital to feed Pete his lunch (though before he was allowed to eat, I would just sit with him, get him relaxed and massage his feet until he fell asleep). A couple times a week, Alex would give me money and get me to order three pizzas on the way home - one for Alex and I for lunch and two for the kids and myself for dinner that night.

Alex was so considerate and kind in his own way. He allowed me to be angry if I needed to be, sad when I needed to be and would express his own fears to me in the best way that he could.

We were in the ICU and then high dependency unit, then ward C4 of Wollongong Hospital for around six weeks before being transferred to a leading Brain Injury Unit in Sydney.

I make sure that I have no regrets with any situation that I find myself in. Making decisions about Pete's care was no exception to this, but if there were ONE THING That I TOTALLY REGRET, it would be sending him to that brain injury unit. All I can say without going into too much detail, is that the medical professionals involved in Pete's care behaved like a team of 'superior God-squads'. They treated me and Pete, in a condescending and at times inconsiderate manner, showing little respect for my knowledge of Pete's situation and his likes and dislikes, even in basic matters such as food. The whole problem we encountered with lack of individual patient-orientated care, is one that unfortunately is still occurring all the time.
Today, as far as Pete's ongoing daily needs go, I try to stand back and help as little as I possibly can - to develop his level of independence. Sometimes mental illness issues complicate the picture.

Most brain injured people have mental illness because of the brain injury, but Pete has the brain injury because of mental illness.

We are extremely fortunate in that Pete is able to shower and toilet himself and is largely independent with everyday living. I provide emotional support and encouragement more than physical help. Though I do have to keep Pete's appointments for him and remind him of the things he has to get done as the time arrives for him to do them.

Pete's father Alex is still very supportive of what I am doing and I am grateful for this. Pete's family has never been a close one, and while this tragedy has brought his father closer to me, nothing much has changed as far as the rest of the family is concerned. Unfortunately during Pete's hospitalisation his Dad was diagnosed with Bowel Cancer and had to undergo major surgery to remove and repair his bowel. Pete has two older brothers who at one time or another showed some vague interest in Pete and his rehab process, but beyond doing token things to ease their conscience, they have done nothing to REALLY help. I feel pretty jaded regarding his brothers' contributions as I have a VERY black and white view about family – you’re either there or you’re not. You either care or you don’t…not just at Christmas, Easter and birthdays. To me, ‘playing families’ is the ultimate act of hypocrisy. I struggle every Christmas, Easter and birthday to deal with it.

I did not speak to my own family at all for a long period as they basically ordered me to leave Pete and run away (not walk!) when Pete went into hospital with these injuries. They told me that I was not doing the best thing by the kids or by myself by staying with him and seeing him through this. Shortly after that I told them that I had made my choice and that Pete was it and that I wanted nothing further to do with them. It was on this day I believe that I became an adult and started to become the person that has ultimately coped with way more than the average person would in three lifetimes!
When asked if was there a stand out issue Marie faced that could have been improved – and what could have been done to help her cope better – Marie says;

I made a decision early in the piece to never have regrets about anything that I had done or was doing. As long as I was doing everything that I possibly could to further Pete’s interests then I would face whatever had to be faced and if something did not turn out as I had planned, then I could only learn from it and move on.

I do not suffer from guilt in relation to things with Pete or his injuries as growing up in the Catholic religion gave me more than my fair share of the whole guilt thing. I had decided a couple of years before Pete’s injuries that I would no longer harbour unpleasantness within by feeling guilty about things that I could not change anyway.

My feelings on this are such that if Pete were to attempt suicide again, I would ask that they not try to revive him this time as it would be very clear that he no longer wished to continue in this life after so many attempts to end it. At the end of the day I guess my way of coping should Pete try suicide again is that there is nothing anyone can do or say that would change that in him and if he REALLY wants to die then it will happen. (Having said that, I make sure that Pete gets every bit of help and support that he can get for his mental wellbeing as well as his physical rehab and I am also very aware that his psychologist has not yet taken him back through the events that led up to the awful night of April 20, 2005.) Pete has promised me faithfully that he will never attempt suicide again and so I have to take him at his word on this and I try not to think of it any more than I have to.

When asked about now – what the most important issue is that she currently faces and what are the life messages she would like people to know about her personal experience as a carer, Marie says;

I HATE gossip!!!!! My lot as a carer could and certainly should have been made a hell of a lot easier if there had been much less gossip than there was surrounding Pete and his hospitalisation. At the time I felt, and certainly to an extent I still feel now that I am under a microscope with (medical) people constantly watching for signs of stress or for me to jump through the right hoops and come up with the right display or the right answer to this one or that one’s probing.
With the exception of what Pete actually did to himself, (though I never lie about what Pete did, but we made a conscious decision not to tell people other than those in the medical arena what Pete did – most people without medical backgrounds cannot prepare themselves for the severity of it and are shocked beyond belief, so I do not allow myself to get drawn into answering that particular question.) I am open and honest with people about our situation and if people want to know about things I prefer them not to speculate behind my back, but come to me and ask questions.

The kids are now aged 15, 12, and 10 – so they were young at the time of the incident, but certainly they were my rock. I was away looking out for Pete a lot of the time and they were able to get along relatively well and coped admirably for such youngsters. I think Pete’s situation has helped them to experience empathy in the true sense of the word and it is my hope that rather than remembering the detrimental parts of this journey, they will ultimately become better people for having traveled this road.

I have just started talking to my family again and they now accept the situation that we face and can see that as a family unit, we are successful and happy and we are starting to spend more and more time with them.

I have started selling Tupperware to allow me a social outlet and Pete is very supportive of this, in that he stamps all my books and will be able to help me pack orders, check lists off etc. It gives me the flexibility of not having to work in a 9 – 5 job and contact with other adults in a non threatening environment that was not designed for my kids or my husband but for me to nurture and to grow.

To do this, we agreed that Pete would go to another activity one more day a week. So now he goes to woodwork on either a Monday or Wednesday morning, Tuesday morning is also woodwork and Tuesday afternoon, Pete’s carer picks him up and takes him out for lunch. Thursday around lunchtime is Social Club at Headway which he looks forward to and is participating in happily.
I am heavily involved in Junior Soccer and have just accepted the role as Treasurer for the region’s Junior Soccer Association.

Marie exemplifies the meaning of ‘pressing on against the odds’. The depth of her resilience and ability to forge ahead in her personal life are truly awe-inspiring. She is one of the most strong-minded and courageous people I have had the good fortune to cross paths with!
Spirits

Just as the seasons have to change,
Nothing in life remains the same.
Just as the sun each day must set,
Few of us live without regret.
One year as the amber leaves did fall,
My precious son heard God’s call.
So dark, so sad, so near the end,
‘You can’t have him Lord, he is mine to tend.’

Through months of angst and years of rain,
We prayed for the warmth of the sun again.
As glimmers of hope flickered radiance,
Our spirits lifted and our hearts danced.
We used to question this destiny,
The hardship of living with brain injury.
The answer is found in his deep blue eyes,
He is the love and pure joy of our lives!

Anonymous
John Fenwick
– “I am not going anywhere”

The soothing tones of John Fenwick’s voice of experience and wisdom, match the tranquillity and peaceful surrounds of the five acre property he shares with his brother Robert, on the outskirts of south western Sydney. The atmosphere in this exceptionally tidy and well kept house is quiet and serene, matching the personality of its occupants. The view from the rear of the house takes the eye over pastel green shades of undulating hills, framed by golden bushes and grey gum trees, directly into the heart of the Sydney CBD which is outlined by miniaturised scattered buildings. The stillness of the morning is only broken by the melody of colourful birds and the calmness of John’s voice as he proudly shows off his beautiful surroundings.

In the nine years since Robert’s tragic accident, John has been his sole carer. Listening to John speak about this life altering experience, one can only be inspired by his courage, touched by his plight, and fulfilled by his dedication and love for his only brother. John is 59 and Robert is 58. Neither brother is married. Both their parents have passed away and there are no other close relatives. This was not the life they had planned when they set about establishing themselves in business together some 32 years ago…

“Robert and I started our transport business in 1966. We had purchased a retail milk run and in our spare time we delivered groceries for Woolworths and Coles. As we got older the trucks got bigger until we had a fleet of six semi-trailers transporting pre-assembled house frames and roof trusses. In some way I see my role as full time Carer for Robert as an extension of that business relationship. The main difference being that now, I am the only one able to contribute to the day-to-day running of the business. But I am sure that if the situation was reversed, Robert would have done exactly the same as I have done for him.”
On the 24th November 1997, Robert was tying down the load of packs of steel on his truck with chains. The mechanics of tightening the chains is something that we had done countless times before. On this occasion, however, something went terribly wrong. He was struck on the side of the head by the steel pipe that was used to tighten the chain. He then crashed head first to the ground, suffering fractures to both sides of his head. Later in the day and again the following day, his brain haemorrhaged, which resulted in an extremely severe brain injury. He was in ICU for 10 days before being moved to the neurological ward for another 20 days and was finally moved to the brain injury rehabilitation unit on Christmas Eve 1997, where he spent the next 10 months. His prognosis was very poor. The Rehabilitation Specialist informed John that his brother was unlikely to ever walk, talk, eat or swallow again. John readily admits he was in denial about this advice, but fortunately for Robert, John realised that if Robert could learn to walk independently then he might just come home, and not live in a nursing home (as was the medical opinion). With this thought in mind, and with much persuasion of a physiotherapist, John helped bring about the major accomplishment of Robert’s independent walking. Robert finally left the Brain Injury Unit on 22nd September 1998.

“They wanted to admit him to a nursing home, but I had made up my mind that I could muster the strength to look after him – I knew that if he was to go to a nursing home, he would just shrivel on a vine.”

Things were not easy when Robert first came home. He was unable to eat or drink properly and still had a peg tube inserted into his stomach for nourishment. He was also incontinent and needed full assistance with all his personal hygiene requirements.

“I am sure that being in familiar surroundings greatly enhanced Robert’s recovery. I had no help from anyone. Did it all on my own – apart from our close friend Frank, whose support has been invaluable. We made up the rules as we went along. The district nurse called a couple of times, but said that she thought that I was on the right track. She also said she was loaded with cases that required her services more than we did. She left me with her phone number, should I get into trouble.”
According to John, Robert’s condition still continues to improve to this day, some 9 years out from his accident. Despite having no speech, as he does not have the ability to process sound, John has recently discovered that Robert has visual processing skills for the written word, and they are now communicating, in a simplistic fashion, via a white board. Surprisingly however, over the years there has been the odd occasion when Robert has suddenly and spontaneously verbalised a thought or question, which continues to amaze his brother.

On the morning of our meeting for this interview, Robert was ‘out-of-sorts’ as he could tell that something out of the ordinary was going to take place. Just before my arrival he suddenly asked his brother, “Where are you going?” John responded by telling him what was going to happen and to help him further comprehend, he wrote on the white board “I AM NOT GOING ANYWHERE”. This simple sentence, full of meaning, lay in plain view on the table as the interview progressed. The total reliance Robert had on his brother John, for his every move, mood and even existence, both on an emotional and physical level, made an unforgettably poignant picture. John said he had had no regrets about his decision made about five years ago to sell his successful transport business, retire and devote himself fully to caring for Robert and enhancing the quality of his days.

“On occasions during the night I will hear Robert call out for me. I go into his room and turn on the light, only to find his foot sticking out from under the blanket with a request to scratch a certain itchy spot! You can see the funny side of it! One day a young fellow asked why I devoted all my time to looking after Robert. He suggested that that was what nursing homes are for. After I told him that I was doing what I could for Robert because he needed me and I was happy to do so, he must have had second thoughts and proceeded to apologise for his remarks.”
John has been able to provide Robert with a good weekly routine, which helps Robert keep track of the days of the week. Once a week they are now utilising the services of a Carer provided by Community Connect Respite Services. The service is provided through Home Care NSW with the aim of providing an outing or centre-based activity for clients. Because Robert would not go to the centre, they provide an in-home service for five hours each Wednesday. Up until recently Robert was not happy having a stranger in his home and would spend the entire time in his room. John was tempted to cancel the service, but was persuaded to persevere by the centre’s administration staff. Fortunately he took their advice, as Robert is now going out nearly every week with the carer for lunch. She has succeeded in getting him to pay with his own money for the hamburger, and has also been successful in getting him to play darts, draughts, quoits, dominos and card games. This has been a huge leap forward for Robert and has been extremely rewarding for both John and the Agency Carer. Most of Robert and John’s other outside activities revolve around going for long drives. These bring great pleasure to Robert who was, and still is, passionate about trucks and driving. It is clear that John has a very positive outlook on life and providence has helped him to meet the unending demands and challenges that a full time Carer faces.

“At times it can be difficult to deal with the different changes that you see in the person you care for. Sometimes it is like looking after a small child and then, in a matter of moments, you have your 58-year-old brother back again. Robert reminds me so much of our late father. The way he walks, the way he puts his handkerchief in his pocket – it’s dad all over!”

John readily admits that his faith took a battering following Robert’s tragic accident.

“A girl once told me that is was God’s way of telling Robert that he needed to take a different path in life. I am sure that God never lived with any one that had suffered a brain injury, because if He did, He would go out of His way to ensure that no one ever suffered from a brain injury ever again!”

When asked about his experience with the public health system over the years, if there was a stand-out issue he faced and what could be done to improve services, John replied;
“Apart from having to deal with an arrogant Neurosurgeon, the rest of the hospital care, and rehabilitation staff were all very good. The Rehabilitation Specialist developed a good rapport with both Robert and I, and became a good judge of Robert’s character. Coming home from hospital was a different experience. We were virtually left alone – promises of help never eventuated. I was fortunate to have maintained a good circle of friends and some relatives who have provided me with a shoulder to cry on in my times of need.”

When asked about now – what is the most important issue he currently faces, John replies;

“The difficulty of not being able to communicate fully with my brother is a huge problem. I think my main concern, and that of all Carers, is the issue of what happens to the person that I care for should something happen to me? One special friend has promised to take over the role of carer should something happen to me, which is very reassuring.”

John’s final message of what life is like as a full time Carer is uplifting and effectively conveys the meaning and purpose of this booklet;

“Life can still be very rewarding – I get a ‘buzz’ out of seeing him enjoy something that I have done for him. You can’t change what’s happened and blaming others is a waste of energy. You have to think positive or you’ll go under. You simply have to ‘hang in there’!”

From a personal point of view, I came away from that meeting having felt the warmth of the flame of a truly compassionate and unselfish human spirit. It was indeed a great pleasure to meet such a unique Carer.
Sometimes I have to trust the winds
To find the course to take,
To push me on, or steer me right,
To accelerate or brake.

It isn’t always where I go
Or where I think I’m headed.
Sometimes I just need to know
The trajectory I’m getting.

I make my body work and sweat
Through sunshine, rain and snow.
The end result is worth the work
When I trust the winds that blow.

There will be ups. There will be downs.
There will be better times to find.
I need to do it by myself
When I’ve left the wind behind.

No one knows how hard it is
To struggle day to day.
Remembering and forgetting
As I go about my way.

But, one day, I’ll venture forth
And blaze a solo track,
Because I learned to trust the winds
To take me there and back.

\[\text{Trusting the Wind}\]

5 ‘In Search of Wings – A journey back from \textit{Traumatic Brain Injury} by Beverley Bryant
– Wings Publishing (ME) 1992
Robyn Hosking

“If you know you’ve lost your abilities – You know you’ve lost yourself”

From first observation, Robyn Hosking is a picture of health and vitality. She dresses stylishly and presents immaculately – both herself and her home! She has a vibrant and outgoing personality and it’s not hard to imagine that she once ran her own Management Consultancy company, which specialised in organisational change. However, these days Robyn is far from functioning at an executive level. In 1999 she fell down 18 stairs in her home and sustained a mild to moderate brain injury. Following her accident Robyn was cared for by her dedicated mother Gwen. Where this story differs from others in the book is, that through the hand of fate, Robyn has now undergone a ‘role-reversal’ and is now caring for her beloved mum.

On admission to hospital, Robyn had a GCS (Glasgow Coma Score) of 8 and PTA (Post Traumatic Amnesia) of approximately 1 day. Robyn has no memory of her fall and only some vague memories of her five days in hospital. It took some time for her to come to the realisation that she had substantial deficits in her memory, balance, cognitive and visual processing and higher order executive functions. At first, due to a lack of understanding, she didn’t listen to the doctors and cancelled appointments, thinking that she could get her life back on track by herself. Unfortunately this was not to be the case and after undertaking a Neuro-psychology assessment, Robyn was told her prognosis for a full recovery was poor. She was told if she wanted to give herself the best chance of recovery to take a prolonged rest and let the body heal itself.
She spent several years suffering from severe depression and much to her
dismay, despite making good, albeit slow progress, her residual disabilities
have left her unable to return to work at all.

“Mild to moderate brain injury can be almost as debilitating as severe brain
injury, but in different ways. Losing yourself, and having the insight to know that
you have, is very hard to bear!” Robyn says. “I wasn’t very well for a long time.
Mum and my sisters Gaye and Joy were wonderful; they wouldn’t let me give up.”

In 2001, just two years after Robyn’s accident, Gwen who was then aged 71,
took a trip to Cairns to visit relatives. Whilst she was there she had a stroke and
spent six weeks in hospital. Gwen lost her speech and strength in her right side.
When she finally was well enough to come home, she had to undertake many
months of rehabilitation. On top of that over the last six years she has had
numerous other health problems that have contributed to her incapacitation.
She underwent heart surgery and had a pacemaker inserted and has suffered
several mini strokes. Gwen has endured many illnesses throughout her life
including both a shoulder and knee reconstruction. Unfortunately since the stroke
both her shoulder and knee replacements have gone backwards. Her mobility
is limited. She uses a walker at home and for outings, a wheelchair.

Robyn is not the sole carer for her mother. Her sister Joy also lives with them
and shares this responsibility; however Joy works full-time in her own Project
Marketing Company. The sisters have gone to great lengths to enhance the
quality of life for their mother at home. They have, at great personal expense,
installed an automatic stair/chair lift, as well as other medical equipment,
including electronic tilt bed and chairs. The sisters ensure that Gwen gets
to the hairdresser every week, attends hydrotherapy, goes shopping and
participates in other family events. Gwen keeps her mind sharp with writing
letters and telephoning friends.
Caring for someone can be difficult enough for those who are themselves fit and healthy. In Robyn’s case, this is what makes her contribution even more extraordinary. Her load is made lighter by what she calls her “sacred circle” – Joy, Gaye, Joan (an Aunt) and the invaluable support of a wonderful Clinical Psychologist named Heidi. Heidi has given Robyn the tools she needs to manage on a day to day basis – such as making use of a weekly planner/scheduler and a white board to keep on top of appointments and social events. Robyn still suffers from multi-sensory overload and has admitted to getting frustrated at times with the demands of meeting her mum’s requirements as quickly as her mother desires. Without the help of a cleaner, someone to look after the lawn and a general handyman, Robyn wouldn’t have the capacity to look after her mother as she does. When out together, Robyn says that she is much better off managing her mum alone, without input from others, because although well-meaning, their assistance alters her routine and causes her some degree of anxiety. Robyn and Gwen both suffer from fatigue.

“At times it feels we are like two trains on the same track, heading in the one direction; on course for a head-on collision!”

Despite having a full load on her plate, caring for her mother and the ongoing demands of trying to get on top of her own impairments, Robyn has managed to find meaning and purpose in her life. She has written a book entitled “In Search of Meaning”, which she says accurately reflects her journey of healing and discovery over three different stages. The first stage, the first four to five years after her accident, she describes as her ‘lost years’. In the second stage, the next one year period, she writes about life as it really happened. And finally in the third stage she finds herself reconnecting to life and finding her ‘new self’. As well as this Robyn, with enormous help from Heidi, Joy and Gaye, has been able to redesign several programs (she conducted before her accident) into programs for Carers and their families. Robyn and her ‘sacred circle’ hope the programs will provide Carers with the skills they require to cope, but more importantly, that they empower people with strategies such as ‘Mindfulness Meditation’ and ‘Positive Psychology’.
“In life people usually try to get away from pain and are always hoping for happiness. But as a Carer you can’t always do that. Carers, more than anyone else, need strategies to know how to move forward, to solve problems and most importantly to engage in life. We used a lot of complementary therapies in both the rehab programs for Mum and me, so our family hopes that our work may build a bridge between complementary medicine, business practices and mainstream medicine. My family and friends will end up doing more than I will, but that's okay.”

Her sister Gaye adds, “Without Robyn’s sheer determination and abilities, she wouldn’t have achieved what she has today.”

When asked if there was a stand-out issue she initially faced that could have been improved following her accident, Robyn says,

”Mild and moderate brain injury causes many hidden disabilities and I didn’t realise the extent of my problems. Without the support of my family and wonderful medical team, I would have been totally lost. We have conducted our own self-funded rehab program. Without all the help I receive I wouldn’t have the energy to help take care of Mum now.”

When asked about now – what is the most important issue she currently faces as a Carer, Robyn says,

“I isolation is a huge issue. Life can become very empty. Mum has lost herself too and we don’t talk about what the person we care for loses – their independence, their identity etc. You have to make the decision that you won’t go under. It is important to find something you like to do to fulfil yourself – to give purpose and meaning to your life.”

And the message Robyn would like others to know about life as a Carer –

“Friends can become very scarce when you are a Carer. If you have friends or family who are Carers, I’m sure they would appreciate your friendship and support. Carers often get put into situations they don’t have the skills to handle and they need all the help you can give them.”
Robyn’s biggest critic is herself; but that has probably helped make her such an inspiring person. She continues to exude enthusiasm and belief in her family’s ability to implement much needed programmes for Carers. There is no doubt in my mind that with her passion for this quest, she will one day achieve it.
Lie still, don’t move, don’t feel
The pain might disappear.
   No, it won’t, it’s real,
   Its intensity I fear.

Morning takes forever,
   Sleep is not my friend.
My legs, my arms, please sever,
   And then the pain may end.

For years and years I suffer,
   They say there is no cure.
The pain may still get tougher,
   Not sure I can endure.

But wait, the sun begins to rise,
   My son will call my name.
   It’s not hard to realise,
   My love is worth the pain.

Anonymous
An Insight from a ‘Professional Carer’

Julie⁵ is a young attractive woman with a two year old daughter and a baby on the way. She currently works for an Agency that supplies carers/personal attendants to clients whose brain injury has left them in need of assistance in performing daily living skills. Julie’s many years of experience in the field of disability combined with her friendly and vibrant approach make her a valuable asset to those in need of her services.

Julie became a carer approximately 15 years ago. She was studying for an Associate Diploma in Recreation and a requirement of the course was a practical component in the welfare field. She found herself a job in a ‘Group Home’ as a Recreation Officer and worked mainly with the intellectually impaired and those with Downs Syndrome. After about a year in that role, she was asked to provide support in the ‘workshop’ area and assist with centre-based activities. Julie acknowledges that this initiation in the area of disability gave her an in-depth education and sound knowledge on how best to work with the disabled.

“15 years ago the direction in the Group Homes was very different – unlike today, the focus was more on centre-based activities than living skills”, Julie reflects.

About three years ago Julie started work in an Agency as a personal attendant, as she found this gave her more flexibility to combine caring for others as well as her own newly started family. She presently cares for an 18 year old boy who suffered a traumatic brain injury as a passenger in a car accident. The left side of the car he was travelling in was totally wrecked and as well as a severe brain injury, he sustained terrible injuries to his left leg and foot. Julie describes her current role as more of a ‘social educator’. Although she transports James* to all his various appointments and other activities, and assists him at home with his physiotherapy programme of general strengthening exercises, she sees her main role as assisting him relearn his social skills and aiding him cognitively, specifically with problems associated with his short term memory.

⁵ Name changed for privacy reasons
“I enjoy the work I do, though what I find personally difficult is knowing when to give assistance if my client is faced with a challenging situation, and when to sit back and let them persevere – it can be a very fine line!”

When asked why she chooses to work in the field of caring for the disabled or mentally impaired, Julie says,

“Sometimes I myself wonder why I chose to work in the personal hygiene area, it can be very testing. But I enjoy challenges and I especially enjoy helping people less fortunate than myself.”

I asked her about what aspects of her job she finds the most difficult to handle, she said,

“Where do I start – I’ve had knives pulled on me; chairs thrown; been chased down the street… How do I handle these situations? Well the time that I was actually chased down the street, I ran about a hundred metres before I thought ‘hey, wait a minute, I’m not going to let him scare me!’ So I stopped in my tracks, turned around and let him know what he was doing was unacceptable! It worked that time, but I think the most important thing is to know your clients really well, and know what works best with them. However in saying that, no matter how well you think you know someone, there is always a little percentage that you can never really know!”

When asked if there were any issues pertaining to her field of work with the disabled that could be improved with training, Julie definitely feels that there is a need for greater education for both the professional and non-professional carer in the area of handling challenging behaviour.

“There is very little done in the way of formal training on how to deal with challenging behaviour, though these days most agencies have Guidelines in place. I find consistency is a problem – by that I mean that I may deal with the unwanted behaviour in a certain manner and the next carer may handle it differently, which is giving mixed signals to the client.”
Julie obviously has the right combination of enthusiasm and optimism to work with the disabled, as reflected in her comments below. “It can be very worthwhile doing something that actually helps people either physically or emotionally. I find motivating my clients to do something that they have not done before, extremely rewarding. Despite the obstacles I’m faced with from time to time, the gratification of helping those in need and their families, definitely outweighs the challenges!”