

There's always HOPE just alter the DEGAUS

#### Acknowledgement

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# Foreword

Thousands of Australian families each year receive that phone call or that knock on the door that foreshadows the upheaval of traumatic brain injury. For the injured person and his or her family, life changes in an instant. The routine of their day is thrown into the horror and chaos of pain, confusion, and despair at not knowing. There is hope that the loved one will live, sometimes vacillating with the unspoken hope that they will die and end the pain; questions – what are hospital staff talking about, what do I do now, what's going to happen? For rural-based people there is an added dimension, the logistics of how to manage a household or property perhaps hundreds of kilometres away and remain with their child or spouse – attached to tubes and wires and simply needing a hand to hold; how to attend to the needs of the other members of the family; how to manage the costs associated with all of this, and usually on a reduced income.

Families need to contend with often difficult and mystifying changes that follow an injury to the brain. These changes can be clearly visible or they can be maddeningly subtle. Some of the more obvious **physical** effects of brain injury include changes in mobility; speech; reduced strength in arms or legs or both; problems in sexual functioning; and often, greatly increased fatigue. There are also changes that are not so obvious and these may be more confusing for the person with the brain injury and family members. These include the effects of brain injury on **cognitive** skills such as paying attention, memory, understanding and processing visual information, and executive skills such as organization of information and being able to sequence the steps of a task correctly, the ability to learn new material, and to switch back and forth between tasks. People after a brain injury are often slower to process information. They may have word-finding difficulties and basic skills such as arithmetic may be affected. Families usually say that by far the most challenging changes though are seen in the **behaviour** of the person with a brain injury. The brain has highly developed structures involved in controlling and moderating behaviour, particularly the more refined aspects. When these more recent evolutionary developments of the brain are damaged, the person with an injury may find that their levels of emotional control are altered. For example, after a brain injury a person may develop a "short fuse" and become irritable, snappy, or at times outright aggressive. Being able to initiate and maintain an activity can be affected, which is often mislabelled as laziness. Others may develop a degree of disinhibition or change in control of socially appropriate behaviour. Further, because of organic injury, a person's lack of insight may mean that they have little or no appreciation of the nature of their own changes, which makes it harder to adjust to the feedback of family and professionals. All this can lead to the exasperated outcry from a partner that, "S/he is no longer the person I knew".

A most important consideration for the person with the brain injury is the reaction to being told that they can no longer do what they did before, such as drive, enjoy a drink, or play their contact sport. These losses too can affect a person's behaviour as they grapple with the enormity of these changes that may have taken only a microsecond to create, and may not have been their fault anyway.

One of the most significant changes to be endured is the response of the community to brain injury in the family. A fundamental truth is that the community at large knows very little about brain injury, and even less about how to respond to the trauma of it. Invariably this leads to a sense in the person with the brain injury and his or her family members that the community is more distant, less accommodating than one hoped for, and often very much less supportive. It can be a confusing and hurtful time, a slap in the face when understanding was most needed. This lack of understanding can cement a very real sense of isolation from those whose support was taken for granted in better times. This can include everyone from close friends, to associates in sports clubs, to well-known faces about town or the shopkeeper you see every day in the street.

Even more disconcertingly, it can also extend to the family GP, the hospital Emergency Department, and other professionals such as the local health centre and Police – those on whom families often rely in times of need. It is where the reality of brain injury as a "hidden injury" becomes apparent, as community members see a person who is recovering physically but can't see the scramble inside the skull. Constant questions about why they are not back at work, and opinions expressed about how they "should be over it by now" can be difficult to endure.

For the family, coping with these issues is by no means a straight-forward process, it doesn't always get easier with time. In the journals and textbooks about family responses to brain injury the emphasis seems to be on the percentages of those carers that find this experience overwhelming and develop clinical depression or family dysfunction. However the flip-side is also clear, while a certain percentage may indeed develop depression and overwhelming distress, *the vast majority of families cope successfully with the hugely varied and complex challenges and issues that they face every day.* These ordinary people become the extraordinary, and learn to manage the substantial demands of a person with a brain injury in sometimes ingenious and thought-provoking ways. I have never failed to be awed by the resilience of family members and their means of adapting to exceptional circumstances, often with grace, humour, and an inspiring wisdom. None of them will tell you it's easy, but they will always tell you it's possible.

#### So what works?

Families often describe the benefits of taking **one day at a time**, while acknowledging that the good days will often be peppered with the bad. All families are different and each family member, including the youngest child, is going to have his or her own way of managing the changes happening around them. Much of this will be based on the nature of the family prior to having brain injury enter into the equation. It is well recognised that those families that were close-knit, open in their communication with each other, and practical in their approach to general problems prior to this trauma, are likely to better manage the issues associated with brain injury as they arise. There is often a storm of confusing emotions associated with severe trauma, particularly when suffered by children. These include guilt; blame; anger towards self or close others; powerlessness and perhaps anger in the face of so many professionals and strangers and the often-conflicting information being circulated; and the need to protect the injured person from further harm, whether this is appropriate – or even possible – or not. These are difficult concepts that most families face after such a grievous trauma. And despite the enormous sense of being alone in harbouring this hurt and confusion, the undeniable truth is that there are many, many families dealing with much the same sorts of issues in their own ways.

**Talking to people helps**. Certainly there are professionals who are knowledgeable about brain injury and the myriad effects it has on the injured person and his or her family. Finding one or a select few professionals you can trust can be very rewarding. Talking to friends is not always easy, particularly if, despite their well-intentioned advice, they clearly don't understand. The sad reality is that many of these friends will slip away as they struggle to comprehend the life-changing issues associated with brain injury. For a long time the group of families of people with a brain injury debated whether this was because these issues were so alien to them or whether in fact they were all too close, and were overwhelmed by the thought that "there but for the grace go 1 ...". But families have highlighted the sense of satisfaction they get when those friends who do remain connected start to glean some understanding of not only what they have been through and what they face, but where this can lead, and where they as friends fit into the picture and how they can help.

**Finding out information helps**, in the right measure. Families often say that in the early stages after an injury they are bombarded with information that doesn't sink in right away, but does prove useful later on. Again, the right brain injury health professional can steer you towards information that might be helpful at the different stages it is needed.

Having said this, all the information in the world isn't going to tell you everything about your family member who has sustained a brain injury. S/he is a unique person who will change in ways that no-one will able to foresee. Even the best doctors try and give definitive answers to the urgent questions about what happens next. As flippant as it sounds, the truth really is that only time will tell. We have been fortunate to witness improvements that defy everyone's best knowledge, to meet people sometimes many years after their brain injury and to be awed by their achievements.

**Provide information to those who obviously need it**. Families often say that one of the most effective means of combating the lack of knowledge in their community is to be *active* in facilitating knowledge about what it means to experience brain injury as an individual and as a family member. They talk about the need to *actively* counter the confusion that exists between brain injury and mental illness, *actively* educate the shopkeeper who hurtfully quips about the behaviour of a person with a brain injury, and *actively* inform the health professional who has demonstrated limited knowledge of the realities of the situation. This takes patience and perseverance, but some families have described this action as one of the most important factors that helps them to deal with their extraordinary experiences with the grace, humour and wisdom.

One of the most effective strategies that families talk about is recognising that *they have needs too*. Family members need at some stage to resume the activities in their lives that are important to them – to maintain the activities that make life fun and interesting. This cannot be overstated. Families that fare better in the long term are those which have established definite boundaries for how they support their family member, and how they support themselves.

The stories of courage, adjustment, and positive adaptation that follow are duplicated thousands of times in countless variations across the country. This booklet taps into the rich resource of strategies, anecdotes, stories, and techniques that individuals with a brain injury and their family members have devised in circumstances that to many are hard to contemplate. Although there are few family support groups available at this time, there is certainly scope for developing networks of whole families and exploring more fully how families successfully manage the complexities of supporting a brain injured person in their lives. It has been a humbling experience to bear witness to some of these stories, through which one can draw encouragement and inspiration.

#### Jim Huntley

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# Author's Introduction

The stories you are about to read have been narrated to me through a series of personal interviews. They are, I believe, extraordinary stories of how courage, determination, love and support are an omnipotent force when combined with progressive and ongoing medical treatment. More significantly however, these stories highlight the importance of having a positive attitude in the face of adversity. Despite the fact that traumatic brain injury in all its varying degrees of severity and resultant disablement, is a devastating blow for those afflicted as well as their families and friends, maintaining a positive attitude during the long haul of rehabilitation, can make a huge difference in encouraging recovery.

I have endeavoured to retell each client's personal experience of dealing with their injury and prognosis, in a positive and inspiring way that will hopefully enable those experiencing similar tragedies to look within themselves and find the courage and vision they need to overcome their individual misfortunes. As dark as times may be, if you look hard enough, there is usually a small ray of hope lying just beneath the surface of your suffering, waiting to be illuminated with just the smallest dose of determination.

How do I know this? My own son is the very definition of persistence and determination. In May 1997 Jonathan, who was then only 12 years old, was hit by a car whilst crossing the road not far from home. Initially he had a Glasgow Coma Score (GCS) of 3 and we were told many times not to expect him to live through the night during the ensuing three weeks in Intensive Care on life support. He was in a coma for approximately six weeks and was in post-traumatic-amnesia (PTA) for about 10 months. We were told he may never walk, talk or even eat again, and were given a very

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poor long-term prognosis. But due to his relentless drive and a wellcoordinated holistic programme of rehabilitation, he has defied the odds – going back to school to get his Higher School Certificate, working part-time and even learning to drive! He can not only walk independently, but has recently begun to run! He plays tennis, swims laps, plays the piano and can even snow-ski! All this through sheer hard work and a never-say-die attitude.

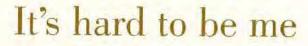
It goes without saying that surviving the early impact of the realisation that you or your loved one has suffered a brain injury is extremely difficult. When you first come out of the devastating shock and the enraged denial, the real pain and heartache are enough to threaten your very existence, and if you let it, the resentment can destroy your soul. The sudden change in life as it once was, and the partial loss of the very essence of yourself or your loved one, is very, very significant. What can you do? You have only two choices – you can spend your life mourning the fact that your dreams are now shattered, or – you can do whatever is within your power and capability to do and change what can be changed , without forsaking the insight to accept what cannot be changed. The choice is yours to determine how you respond to your suffering – it can be your undoing, or something you can create meaning and purpose from.

Our family was able to carry on by taking one day at a time and looking to find something *positive* from each day. The fact that we still had our son in our lives was the main source from which we drew our strength. Even now we still find it best to live our lives one day at a time, enabling us to concentrate on small pleasures; things that in a normal life would be taken for granted, now add richness and colour to our lives. Even though the past eight years have been very physically demanding and at times an emotional rollercoaster ride, caring for Jonathan and his ever-changing needs has brought us closer together as a family unit and enriched our lives in many unexpected ways.

Despite living in a society that values status, production and competition Jonathan, who was once top of his class academically, could play the piano, clarinet and guitar with exceptional ability and who could run like the wind, has through his boundless courage and strength of character, taught us that personal credibility doesn't come in the form of I.Q. numbers, degrees or sporting trophies. He has revealed the importance of validating and accepting individuals for who they are and whatever contribution they make to society. He has learnt to not only live with his disabilities, but to teach those around him to do the same. Of all the knowledge we have gained during our journey of hope, discovery and healing, one important fact stands out – human development cannot be accurately determined by science, nor can potential be predicted, or spirit measured.

Enthusiasm and motivation too, are vital ingredients which you will find lie beneath the positive outcomes of the following stories. Enthusiasm can drive us to reach what some may see as improbable dreams. Hopefully these extraordinary people will enlighten you and enable you to see how when we adopt an optimistic and enthusiastic attitude, we can define our own quality of life; or perhaps even alter a destiny that fate may have indiscriminately carved in our paths.

Cheryl Koenig.



It's hard to be me For no one can see Who I am, What I feel, What it's like to be me.

See me.....hear me.....watch me try..... See me.....hear me....watch me cry.....

> It's hard to be me, For I used to run Just like you, Like the wind, Now what can I do?

See me.....hear me.....watch me try..... See me.....hear me.....watch me cry.....

> It's hard to be me. I want my old body back. I want to live Just like you. Just like you.

See me.....hear me.....watch me try..... See me.....hear me.....one day I'll fly!

By Jonathan Koenig

### Where has Lily gone?

Her name was *Lily*. However everything about *Lily*, including her name, dramatically changed on the 11th July, 1994. From that fateful day, unbeknownst to Lily who lay comatose and close to death, she became known as '*Laya*' – meaning 'Matriarch of the Jewish Religion'.

Up until July 1994, Lily had enjoyed a normal teenage life in the beachside suburb of Bondi. She worked full time as a waitress/supervisor in a Coffee Shop located in trendy Double Bay. She was very proud of her independence; driving a Mazda 121 and living in a flat by herself, though readily admitted that her Dad was always there if she needed him – financially as well as emotionally.

Lily was a beautiful young girl, with the world at her feet. She was very athletic, playing many sports, her favourite being netball! Her team was called "Pretty Girls", and she played in the position of Goal Attack. Lily enjoyed being part of the "Pretty Girls" and relished the many social benefits that accompanied the sport. Now, 11 years after her horrific motor vehicle accident, Laya struggles to walk with the aid of a push-walker. The left side of her body is somewhat weaker than her right, and even though she does have function of both hands, there is a noticeable generalised ataxic tremor (a tremor which arises or is intensified when a voluntary, coordinated movement is attempted) more predominant on her right side. She speaks softly but clearly and is obviously very intelligent and perceptive. However there is an aura of despondency conveyed by Laya, as she reflects about her life, and compares her physical appearance now with that before the accident;

"Just the other day I looked in the mirror and thought 'who am I – where has Lily gone?' The Lily I knew was fun, pretty, cool! Now I look old and fat and not so pretty... I think I was robbed of my attributes..." To the observer however, it is not hard to see past the physical disabilities that Laya struggles with today. These disabilities have not detracted from her still captivating dark beauty. Nor is it difficult to see inside her now disillusioned eyes; eyes that reflect a profound longing for the life that she once knew. No, it is not difficult to envisage the beautiful and vivacious Lily of bygone days...

"My story for survival began early Monday morning at about 3:00am. My parents were awoken by a knock at the door. It was the police. They informed my father that his daughter was involved in a motor vehicle accident and that she was dead. My father was shocked by this news, especially at three in the morning woken from a deep sleep. He immediately phoned my uncle and told him to come to the hospital with him as he feared seeing me. He didn't tell my mother what had occurred, as he knew that she would be frantic. He came to the hospital and was informed on arrival that there was a misunderstanding and that it was the driver, my friend Alex, who had died (although this was wrong as well; Alex had been revived several times and was also alive). My father was then informed that I had sustained a severe head injury. My father's mobile phone kept ringing, it was my mother; she knew something terrible had happened. My father explained what had occurred as well as my injury. Apparently it was a shock for everyone involved as nobody had ever heard of Brain Injury before. The shock waves were felt by everyone who knew me; like a set of dominoes falling!"

Neither Laya, nor the other people involved in the motor vehicle accident, have any memory of the crash itself. Laya can recall certain details leading up to that point in time, however Alex the driver of the car, sustained an extremely severe brain injury and has been left with profound physical and mental disabilities. There was also a girlfriend of Laya's in the back seat who had been asleep at the time of the crash, and fortunately only sustained a broken tail-bone. Laya was initially taken to Prince Henry Hospital and it was here that her parents were told by the attending Neurosurgeon to unplug her life support. Even if she somehow survived, they were told, she would remain in a vegetative state. Fortunately for Laya, her parents held true to their strong Jewish beliefs that promote *healing* life – not *ending* it. And so they gave her the name of 'Laya' believing it would empower her with the strength needed to survive.

After many weeks Laya slowly regained consciousness. She was transferred to Prince of Wales Hospital, then Lidcombe Brain Injury Unit and finally Liverpool Brain Injury Unit, where most of her rehabilitation took place. She was unable to speak for two months and when her speech returned it was almost instantaneous, although very slow and not much louder than a whisper. She was in post traumatic amnesia for 3 1/2 months and says that she finally began to understand what had happened to her after 4 months. As well as her brain injury, she sustained internal injuries. She had two major operations; part of her bowel was removed because of damage done by the seatbelt, and a pin was inserted through her pelvis and hip.

"When I went in for the operation on my bowel both my parents were so scared as the Doctor's informed them that I may not come out of it alive. My mother placed a picture of the Rebbe beside me. He is known as one of the holiest men of our generation, according to Hebrew traditions. To a person who believes in the strength of the Jewish faith like me, all I had to get me through this terrifying ordeal was my faith and hope."

Eventually Laya spent enough time conscious to enable her to commence a programme of rehabilitation which involved Physiotherapy, Speech Therapy, Occupational Therapy and Psychological Counselling.

"My gains in Speech have been very slow. When I first started speaking, my voice started off as a whisper, and then gradually I got louder and louder. What I have realised is that you have to pace yourself; you can't expect to climb every mountain all at once. No one can do the work for you – you have to take the responsibility into your own hands. My Physiotherapist Carmel, reassured me not to expect miracles overnight. But with hard work and motivation you can expect results. I was initially bed-ridden and the only way I could be transferred was with the use of a hoist. With the help of good physiotherapy I was eventually able to stand – 1 minute at first and gradually this increased. I began walking with the use of a pick-up frame. It was a very slow process, but after being on the pick-up frame for some time, I moved to a walker. By the time this happened 16 months had elapsed since my accident."

Laya made slow but steady progress in all areas of her intense programme of rehabilitation. Despite her own admissions of frustration at times, at the slow rate of improvement, Laya recounts her time in Liverpool Brain Injury Unit as an environment where she felt fully supported and constantly encouraged by all the staff and therapists.

"I was very fortunate as I had a good Doctor looking after my Rehabilitation; she was the Rehabilitation Unit Manager. Her name was Doctor H. and she gave me a lot of encouragement. One thing that has stuck in my mind to this very day is her saying, "Laya your mind is a very powerful thing, it controls everything; it's all in the mind!" I enjoyed my conversations with her."

Eventually Laya was transferred to a Transitional Living Unit where she spent six months regaining some form of independence. She recalls her time there favourably; wishing she could go back, as the Carers were fun people and the outings were great, "I had friends there – people to talk to – not like now!"

Unfortunately these days Laya longs for company. Her friends have stopped visiting and she feels lonely and bored. She is unable to work – her only experience with work placement she likened to that of a 'sheltered workshop', which due to her mental capabilities, she found frustrating and depressing. Regrettably, despite overcoming huge adversities along her journey of recovery, and achieving more than most people ever would in a lifetime, today she portrays a picture of social isolation.

"Nobody comes around anymore – nobody cares. People move on with their own lives. A few weeks ago I came across my old best friend, whom I hadn't seen for about 8 years. We talked and she gave me her business card and said to call her at work and we could arrange something. Well I called her a couple of days later – she said she was busy and would call me back later. I'm still waiting, but I know she won't call."

Laya still works hard towards walking without her frame. She has

hydrotherapy and goes to the gym each week. She relates her recovery to that of being at the bottom of a ladder and climbing up one step at a time. Undoubtedly her optimism and commitment, especially during her early years of rehabilitation, combined with continuing family support, have contributed to her positive outcome to date. Her outlook on her life today is perhaps less confident, but she has the ability to reflect philosophically about life in general, with the realisation that considering the severity of her injuries, she is indeed fortunate to be where she is today.

"You can't reverse time or change circumstances. I consider myself lucky that I can walk and talk!"

Finally, I finished our conversation with three questions that I asked each interviewee for this project:

Looking back – what is the single most important issue you faced during your recovery?

"Making old friends stay around - I need friends more than anything in the world."

What about now - what is the most important issue you face now?

"Now? The same - friends!"

What is the one message you would like everyone to know about what you have been through and what you are still going through?

"I would like to create more community awareness – to educate the community to have more patience and understanding of people with a brain injury. My Speech Therapist Is training me to do public speaking at schools – but she says I need to increase the volume of my speech a little more. What do you think – how do I sound to you?"

So I tell her, "Laya you sound just fine to me! Maybe I could become your friend...."



"Deep in thought" by Peter Upton

# Acquired Brain Injury

Do you have a brain injury just like me? All those problems that no one can see. My emotions go crazy and I don't know why, So I find an empty room and have a good cry. I have exploded once again, I'm like an old time bomb, Who is this new person? Where did he come from? I forget how to dress and I often get dizzy, I want to tell my doctor but he's always too busy. Sometimes he hears me out while reading my thick file, But all I get from him is a patronising smile. Old friends say "Hi", then hurry on their way, I don't get angry anymore, there's nothing much to say. Emotions are confusing, there is no one to blame, I'm a different person now, I am NOT the same.

It took a while to realise that I'm happier now, That doesn't sound right, happier – How? You see I should have died on that dirty floor, But fate has decreed that I do an encore. I have told you the lows, now listen to the highs, How I cherish every day as I watch the sun rise. The solemn awe I feel is hard to disguise, When gazing at the stars in the night skies. Don't look back as you march ahead, There is victory in every step that you tread. For us going forward is the only way, Let tenacity have the final say.

By P.M. Harrington

# Brett Lawrence Stanford – A young man to admire

On meeting Brett Stanford, one cannot help but immediately take a liking to this well presented and affable young man from the southern suburbs of Sydney. Brett, who was one minute your average 26 year old guy from the surfside suburb of Caringbah; working hard through the week and playing and partying just as hard at weekends, talented surfer, representative cricket player and keen skateboarder, has also had to fight his way back from death's door. Over the last 5 years he has faced and overcome one medical battle after another, one operation after another, in all totalling 17, along his arduous rehabilitation from an accident which left him with severe traumatic brain injury. And just when he thought life had dealt him its worst hand, fate tragically struck again, stealing from him his treasured mother, whom he attributes as the one person who helped him more than any other in getting him back to where he is today.

On the 7th December 2000, Brett was travelling by skateboard to work in the city as an office cleaner. Brett had held down some interesting jobs over the years, working as a bartender in the city during the Olympic Games and working as a wardsman in a busy Public Hospital. He recalls each job with particular pride and reminisces about happier times; the many friends he once made so easily; his love of playing sports like cricket and rugby league; girlfriends; driving; going out to nightclubs with friends – a normal young man's life. His memory of his old life is clear and intact. Not so however from the morning of his accident, the only thing he remembers about that day was making his way to work down George Street. He says he was walking along with his skateboard under his arm, but he doesn't remember being on it, and despite the fact that the streets were laden with pedestrians, no one questioned at the time remembered seeing him on it. In fact, no one heard or witnessed anything. All that is known is that Brett

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was found lying unconscious in the gutter of George Street, with a blow to the side of his head. It is thought that he must have stepped down into the gutter about to cross the road and been struck in the side of his head by the side mirror of a large vehicle; most likely a bus.

Fortunately for Brett a doctor was quickly on the scene, and despite having no obvious physical injuries, the doctor suspected a brain injury from his dilated pupils. His correct diagnosis and immediate response were probably what saved Brett's life that day. Brett was rushed to Royal Prince Alfred Hospital in Camperdown where they operated immediately, removing part of his skull to allow for swelling of the brain. He remained in a coma for 4 weeks and underwent several subsequent brain surgeries, removal of part of his damaged right temporal lobe and insertions of various shunts to drain excess fluid. Unfortunately for Brett he had to fight off difficult infections from these shunt operations and this was a stormy period for him during his six-month stay in RPA. He was unable to eat orally for almost a year; for 5 months being fed by a tube through the nose, and then by a tube into the stomach for a further 6 months. After this it was a long, slow process of learning how to eat normal food again. When he was more stable Brett was transferred to Liverpool Brain Injury Unit, where an extensive period of concentrated rehabilitation began and lasted for almost 18 months. All in all he was in hospital 10 days short of 2 years; with his devoted mother Beverly missing only 5 days of visits. Initially both Brett's arms and hands were flexed and inverted from severe spasticity and his legs were rigidly extended with loes pointing towards the ground. He was told he would be confined to a wheelchair, probably for life, unless he underwent tendon-release operations to correct his deviated ankles and feet. Similar orthopaedic operations were performed on his contracted fingers and wrists and botox injections were used to relax the tone in his upper arm muscles. The success of these procedures is evident in the way in which Brett now walks independently and has almost full use of both hands. Naturally this success was not brought about without follow up physiotherapy; months of pain and hard work from a rigorous programme. Brett underwent intensive speech therapy, as well as occupational therapy,

and as he speaks of this time he does so with fondness for all the therapists and nurses with whom he spent such a long period of his life.

"Sue, Noeline, Sandra, Ron - they were great to me, helped me a lot."

These days Brett lives comfortably at home with his Dad Max, sister Kirsty and dog Milo. A young male Carer/companion named Cheyne, whom Brett describes as his best friend, comes daily to assist Brett with everyday living skills and transport him to appointments. Max is almost of retiring age but takes great pride in his ability to still put in a hard day's work as a sawmiller, and it is obvious from whom Brett gets his solid work ethic. The weathered lines etched deep on Max's face belie the outwardly tough-asnails appearance he portrays. There is a deep sense of loss as he speaks of the past, especially of his beloved wife Beverly, and what a fighter she was right up until the very end.

"57 she was" he says solemnly, "too young to go ... "

He relates with pride how she was continually by Brett's side, encouraging him; advocating for him; and even once insisting on a second doctor's opinion that ultimately saved his life! The house is full of pictures and mementos of her that depict a loving wife and dedicated mother whom I am told had everything in place for the ongoing care of Brett, before she passed. When he speaks of his mum, Brett who is clearly well spoken, despite his voice being just a little slow and monotone, loses even more shades of intonation and his eyes become distant,

"I know she's watching me - she got me where I am - 1 ... miss ... her."

Despite his natural grief for his mother, Brett continues on with his home based physiotherapy sessions, determined to improve his walking skills, and also attends the local leisure centre at Sutherland for aqua aerobics once a week. He enjoys playing ten-pin bowling on Mondays and participates in an adult development programme called 'Headway' where he has been trained to take part in the Community Education Program. So rather than mulling idly about, feeling resentful for his lot in life, he chooses to be proactive and gains purpose and meaning out of his unfortunate accident by speaking publicly in High Schools to educate, highlight and hopefully prevent the high incidence of brain injury in the younger generation. He says his memory and planning ability have been affected, but he recites for me,his 15 minute presentation, word-for-word, almost without pausing for breath!

Brett Stanford is a young man from whom we could all learn. His insightfulness about his circumstances and his ability to move on with his life despite the recent loss of his mother who was not only everything a mother should be, but his main carer, is inspiring and indicative of his inner strength. Not too far below his rather impassive facial expressions, common to many with brain injury, there also lies a guy with a great sense of humour. As Max relates how he and Brett have taken up making wooden chopping boards down in the back shed, a wry smile lifts the corner of Brett's mouth,

"Yeah Dad does most of the work, I am just the sandman, aren't I Dad?" he says. "And when we finish the hair of the sandman is just about the same colour as yours Dad, isn't it!"

And so I end our afternoon talk with my three usual questions;

Looking back – what is the single most important issue faced during your recovery?

"My need to walk again – that was the hardest and most important thing for me to do."

What about now - what is the most important issue you face now?

"Missing my friends and social life – they have all forgotten about me. And my Mum...I miss my Mum."

What is the one message you would like everyone to know about what you have been through and what you are still going through?

"It takes just a split second to change someone's life – so please take care! If you ride a bike, skate board or scooter, please wear a helmet. The last few years have been the hardest – lots of pain and suffering – but I'm happy to be where I am now, doing things that I never thought I would."

> "If I can't be good - I'll be good at it. If I can't be good at it - I can still enjoy it."

> > Brett Lawrence

I am sure Brett's mum would be very proud of her son.





Emerging back from brain injury The first thing I came to see Was my mother standing quiet and still Despite the fact that I was very ill

She had waited so long for the 'Sign of Hope' My open eyes made it easier to cope. From critical times to PTA My will and body fought to stay.

Depression remains on constant threat However, I'm protected by my confidence met. Parts of my memory are lost like tears in the rain But I continually hope again and again

That I'll remember them like yesterday And all the things I used to say. I'm only starting to realise the truth That faced with this injury while still in my youth.

The quoted saying 'how could this happen to me' Is beginning to subside as I'm starting to see The progress that I'm starting to make Is slowly but surely about to remake

The person that I used to be The definite and undisputed key. And while I still have the factors that restrict and all The underdog can always prevail.

By Craig Anderson

# Julian Dennis – "I Can Do It!"

In June 2001 Julian Dennis and his wife Jan arrived home by taxi following a pleasant night celebrating a farewell party in the suburb of Balmain. Julian had had a few drinks, but was definitely far from inebriated, which was confirmed by a blood alcohol test taken later that night. Julian says,

"As I was walking up the stairs to our front door, I stopped, and then suddenly passed out and fell (like a tall tree chopped down at the base) head first and backwards down the stairs onto sandstone pavers. I was knocked out, unconscious, bleeding from the back of the head!"

Jan recalls her husband, who was then aged 43, falling asleep in the back seat of the taxi on their way home to the northern Sydney suburb of Harbord, and remembers him looking a little pale. She asked him if he was feeling okay, and he replied, "Not really."

Feeling a little concerned she hurried up the stairs in front of him to unlock the front door – she had no idea that the events that were about to unravel would throw them into an emergency situation; hurling their immediate lives into a tailspin and ultimately resulting in far-reaching changes to the comfortable lifestyle they had once so blissfully enjoyed.

Prior to that night in June 2001, Julian led a rewarding and busy life. He had a very contented home life with wife Jan and daughters Emma 2 and Kara 8 (his daughter from a previous marriage). He worked in a demanding profession as Project Manager of a leading investment company; managed to include a very full regime of weekly exercise, running over 65kms a week in training for his first marathon; as well as undertaking renovations to his home at Harbord. Julian's story is different from the usual way in which traumatic brain injury occurs, in that it wasn't related to a motor vehicle accident. However it is indicative of the significant life-long changes brain injury can bring about and highlights the need for adapting to these changes realistically and more importantly moving on with your new life in a positive way.

As Julian lay bleeding and unconscious at the bottom of the stairs, Jan immediately called an ambulance which came and took Julian to Royal North Shore Hospital, where he remained in Intensive Care on life support for 12 days. Julian has virtually no recollection of his time in Royal North Shore Hospital, but mentions vague memories of visitors, routines, friends coming and going, though he does recall a feeling of being surrounded by an aura of tremendous concern from family and friends.

"What I remember most clearly whilst at North Shore, were the problems I gave them. Fighting against the medications, the drips etc. All I wanted was to get on my feet and move around. That was taboo but I still tried! The doctors and nurses were terrific – very caring, professional, and oh so BUSY! Just too many patients to care for."

"When Julian first opened his eyes" Jan reflects, "he was in this permanently jovial mood – his jokes and comments were hysterical! Initially he was able to talk and hear normally, but suddenly after 3 days he began shouting very loudly, which was very confusing. Tests were done which determined he had completely lost his sense of hearing!"

Some weeks later, Julian was transferred to Royal Rehab Centre at Ryde to begin an intensive programme of rehabilitation which was to last over two months.

"Whilst at Ryde I received a huge level of rehab care that covered memory, diet and exercise. They gave me confidence, encouraged me, and gave me tasks to do which taught me some independence. I think I challenged them a bit, as I was so keen to get out, get on and do things! Personally, I don't think they were used to having a patient who got well so fast (I was not that badly injured compared to most other patients there), asked so many questions and was not tolerant enough to just stay in bed and wait!"

Initially after discharge, despite problems with cognition and memory, Julian was able to get himself around Sydney using ferries and buses, but his independence really surged when he was able to get his driver's licence reinstated. After spending some time with CRS (Commonwealth Rehabilitation Service) he returned to work, although not in his old job role. However he soon had to concede that even the 24 hours or so a week he was working was too much for him to handle, so his working hours were reduced to 15 per week.

"I was very unrealistic about what I thought I was going to be able to do. The reality of just how limited I was in what I could do in the workforce was a big shock and one that I am still coming to grips with. Returning to my old job and resuming my previous weekly physical exercise regime are two glaring examples of the gap between what I wanted to do and what I was actually able to do. Yes there were (and still are) memory problems, primarily in relation to my short term memory. Also I was much less patient with people and most things. I used to get so angry and frustrated that I would yell or swear much more than I ever used to, which has been very hard on Jan."

In response to this, Jan tries to explain in her own words to Julian, what she actually went through; her message is compelling to all those working in the field of brain injury:

"I think it's fair to say that no-one made it clear to me in the early stages how critically injured you were. Likewise there was little clear communication about your likely recovery. I wish someone had sat me down and said ... "Look, Julian has lost about x% of his brain tissue in this area and that area which means he will never be the same again. He will probably have on-going difficulties with A, B and C. Recovery from this sort of injury varies dramatically so it's difficult for us to say how he will recover. Some people redevelop the ability to A and B over time, others don't. Recovery is slow and painful for everyone – the person who has sustained the injury and their friends/family/carers. Most people with brain injuries continue to improve over time, others reach a point where their recovery seems to stall or plateau. You will have access to on-going support from the Community Rehabilitation Team and to A, B & C resources."

But they didn't. No one for instance told me meningitis, epilepsy and infection/abscesses are some of the side-effects of this injury that might be a factor. You ended up having all three and each time it felt like such a frightening setback.

The other thing I found frustrating was that many medical people left it up to me to explain things to you – to give you the bad news. This meant you started resenting me and what I was saying – the old "shoot the messenger syndrome". It would have been much better if someone else had told you everything – particularly things like what you can't/shouldn't do. You ended up calling me "handbrake" when I was just passing on the opinion of the medical experts."

Despite putting an enormous amount of effort into returning to work, Julian was retrenched which was a severe blow to his confidence and self esteem. According to Jan, the support they received from the Community Rehab Team from the Royal Rehab Centre at Ryde was fantastic.

"The recovery process seems to be a continuous process of taking three steps forwards, then one giant leap back. Whenever there was a setback (like his retrenchment) to overcome, we had access to our own Case Worker, who knew Julian and was a trained Occupational Therapist. I just couldn't have managed him and his reactions to things by myself." she says. I'm just not trained to deal with someone who isn't able to see things logically or clearly – it takes a special type of skill and patience. Besides, I was trying to adjust to the shift in roles since his accident. It's hard to draw a line between caring and becoming paranoid. Julian really objected to being wrapped in cotton wool and I wanted to return to being his wife and partner. Without the Community Rehab Team I would have been forced into some sort of healthcare role which would have placed even more stress on our relationship." As it happened, life then took an unexpected but providential turn when family friends bought a nursery in Dunbogan, near Port Macquarie and offered Julian a job. The family made the huge decision of selling their Sydney home and relocating to the screnity of coastal Lake Cathie and Julian undertook a TAFE course in Horticulture Certificate II. Jan believes that this was the best decision that they could have made in regard to adapting to their altered lifestyle since Julian's accident. She felt that in Sydney they were in a 'negative-holding-pattern', and since the move north things have been a lot easier to handle in many unexpected ways. Her personal philosophy in coping is to be admired,

"We had to be able to say goodbye to the old plans to make room for the new ones," she says reflectively, "by moving to a completely new place, we were able to leave our old dreams in our old house!"

From all view points, Julian has made a remarkable overall recovery. He can now run, and although he suffers from some balance problems, he competes each year in the Manly Soft Sand Classic 9km run, which is a huge achievement! Unfortunately he requires daily medication for Epilepsy. He also suffers from depression for which he also takes daily medication. He believes that he has gradually come to accept that there are some things we will not be able to do without supervision, and emphasises the importance of establishing routines to help lessen the anxiety associated with short term memory problems. In 2002 he had a cochlear implant and now wears a hearing aid. This has provided the biggest single improvement to his overall rehabilitation and well-being – without the implant he could not hear anything at all.

Although Jan and Julian miss the support and advice of their Case Worker from Ryde, they have found a local GP who provides excellent support. They also have access to the North Coast Head Injury Service, although their staff are stretched to limit, so one-to-one care is pretty much reserved for those with more severe head injuries. When asked about the most important issue faced during his recovery, he says,

"I am still going through recovery. I don't think it stops once your bones mend and you get discharged from hospital. For me it will be with me for life. Acceptance is an important issue for me. By that I mean accepting that as a result of this accident I am a different person."

When asked about now – what is the single most important issue he currently faces? He says,

"Finding a balance in my life. There are so many things that I want to do, both ongoing and one-off events that I can't fit into my daily life. I have to decide what I really want to do. The biggest problem is my procrastination – I put things off until either it's too late or I run out of time to do them properly. It's killing me this frustration about the fact that I can't or don't start things, let alone finish them!"

What is the one message you would like everyone to know about what you have been through and what you are still going through?

"I don't want sympathy. Patience and understanding would be much more appreciated!

My approach is – no matter what happens (to a person) **"I can do it!"** By that I mean, as long as I have the limbs and senses needed, (e.g. vision) I can do anything. I don't think I can't do it; I turn it over and say **"I can do it."** Whether it be to run a marathon, compete in the Hawaii iron man event, or a kayaking race down the Hawkesbury River. When the going gets tough, the pain or tiredness is very high and you want to stop/rest/quit – DON'T – because, **"I can do it!"** 

And of course my other message to people is: I ain't finished yet!"



"Rebirth" by Rebecca Gentz

# Head Injury Ward

Shower chairs, wheel chairs Shaven heads, vacant stares Apathy rules, nobody cares, Common sense very scarce.

Sterile doctors stiff and bleak Read our charts, will not speak Wonder what they really think While I drown in ambivalence creek.

Overweight domestics move like hearses Vitals checked by starched faced nurses They ignore the patients curses We resist while they coerce us.

> Blood taken don't know why When they go I'll have a cry Days are low, days are high All in all my life's awry.

Cotton buds up the nostril Golden staph in the hospital How the hell is that possible? Did the staff make it plausible? Physio arrives with her ready smile Says I'll walk but it will take a while A few nervous steps feels like a mile Slow progress written in my file.

But enough of negative looking back Persistence helped keep me on track So a future that seemed oh so black Was avoided by taking a positive tack.

Don't smile, shake your head and think It will never get better for me, Because negative is the trap And positive will set you free!

By P.M. Harrington.



# Gregory Ross Brown "Don't think you know,..."

Sometimes, when you're least expecting it, you meet someone who leaves an indelible imprint in the softness of your thoughts. Greg Brown is one such person. Finding the right adjectives to adequately describe the injustice of what happened to Greg 18 years ago is not easy. When Greg was just 18 years old with the world at his feet, tragedy literally struck in the form of human hands. For most people it is hard enough to come to terms with senseless accidents, be they motor vehicle related or otherwise, but when your destiny is altered and your life catastrophically changed forever by brutal thugs, in a scenario that equates to the lowest form of humanity, this can be much more difficult to accept. However despite this, or perhaps in spite of this, Greg has had the fortitude to move on. The significant physical and cognitive impairments that are obvious upon meeting this young man somehow fade into the background and what emerges to the forefront and overrides the picture of a body wracked with spasticity and paralysis and framed by a wheelchair, is the good natured outlook on life he demonstrates and his wonderful humorous spirit. These are the images that take a more prominent hue on the canvas that depicts the story of Gregory Ross Brown.

In 1988 Greg had everything going right for him. He had finished school and found himself a job in the automotive industry as an Automotive Dismantler (or "car-wrecker" as Greg puts it) in the Sydney suburb of Greenacre. He loved all sports and used to play cricket, baseball, soccer, squash and ten-pin bowling. He was also in the Army Reserves, which was fortunate for him, as being extremely fit probably contributed to saving his life. But above all else was his passion for cars. He had worked his way up as a driver in the elite field of Touring Car racing. He drove a Falcon GL 500, and as any car enthusiast would know, this was the car of the 1980's. "I drove once at Amaroo, twice at Oran Park, and had qualified for the James Hardie 1000. But I got bashed two days before my big race!" Greg says in a voice that struggles to be audible due to significant dysarthria.

The biggest race of all, the fight to get back into the driver's seat of his own life, began for Greg when he was attacked by five hooligans on the train coming home from work. He was bashed senseless, for reasons unknown, and thrown off the train near Campsie railway station. He lay on the side of the tracks, undiscovered and close to death, for 26 hours! It was the glimpse of army boots protruding from the long grass that caught the eye of a passing train driver, who then signalled for help, which saved him from certain death.

Greg has little memory of the event, but has what is known as 'flashes of memory', which he aptly explains as,

"I see some pictures in my head, but it's not running on movie reel yet!"

He was initially taken to Canterbury Hospital, being the nearest hospital to where he was found, but due to the massive insult to his brain, combined with fractures to his skull and cervical spine, he was immediately transferred to Royal Prince Alfred Hospital in Camperdown, where emergency surgery to save his life was performed. His parents were told he had just 5% chance of survival, and had to contemplate the awful decision of whether or not to keep him alive on life support. Their decision meant he spent the next 18 months in RPA, in an unresponsive state, emerging from a prolonged coma. Eventually when he was in a suitable condition to begin rehabilitation, he was transferred to Lidcombe Brain Injury Unit.

"I have memory of that time" he says with a mischievous glint in his eye. "Ward 33 – was built back in World War I and hasn't changed since! I remember the hard time we used to give the physios – four of us guys used to be placed on tilt tables at the same time every morning, and we used to scream in pain at the physios, calling them 'physio-torturers' instead of 'physiotherapists'!" Greg spent several years at Lidcombe, before being sent to live in a Nursing Home. It took three long and stressful court battles over 15 years, to enable him to finally get his own place and be cared for around-the-clock by privately hired Carers.

"Greg has 24 hour care, provided 7 days a week by rotating carers" said the young female Carer attending Greg. "At home he is very independent. He is strong-minded and very determined to do things – he knows what he wants. He is intelligent and very funny too!"

Today Greg still has significant physical impairments, but he is determined to keep up his daily routine of exercises at home to bring about any improvement he can. He is partially blind and has significant tone in his limbs, particularly the left side, for which he has had a Baclofen pump inserted under the skin on his stomach. He is well aware of his limitations and disabilities and flippantly remarks,

"But hey – I kept my good looks, didn't I! And now I speak two languages – good English and bad!" Then he adds more seriously, "I may now be in a wheelchair – but I still sleep, still wake up – still laugh."

Greg is also involved in 'Headway' which is an organisation that provides development programs to assist adults with brain injury live within the community. He regularly plays ten-pin bowling and participates in a community awareness program, which involves public speaking at local schools.

When asked about the most important issues he faced during his recovery, he appeared lost in thought for some time, then finally said,

"There were so many issues really; lack of support from family and friends; lack of physiotherapy treatment; lack of help communicating. I was pissed-off at the world because no-one could understand – all the world could do was laugh at my funny gestures. But I got used to doing sign language and found a way to tell people 'where to go'!" When asked about the issues that concern him now, in particular in regard to the point he previously mentioned about lack of support from friends, he replied,

"What was that word? Friends? Don't know what that word means! What matters to me most now is to keep recovering!"

Finally it was time to end the interview as Greg grew noticeably tired, and his speech became laboured. Despite the reduced clarity in intelligibility, Greg's profound message was quite clear in meaning,

"Don't think you know... you can't know... But I live life... and I love life... for now... because right now... I am the best that I can be!

# **Crackpot Friends**

"A water bearer in China had two large pots, each hung on the ends of a pole which he carried across his neck. One of the pots had a crack in it, while the other pot was perfect.

At the end of the long walk from the stream to the house, the cracked pot was always half empty. For two years this went on, with the bearer delivering only one and a half pots full of water to his house. The perfect pot was proud of its accomplishments but the poor cracked pot was miserable that it was able to accomplish only half of what it had been made to do.

After two years of what it perceived to be a bitter failure, it spoke to the water bearer one day by the stream,

"I am ashamed of myself, because this crack in my side causes water to leak out all the way back to your house."

The bearer said to the pot, "Did you notice that there were flowers only on your side of the path, but not on the other pot's side? That's because I have always known about your flaw, and I planted flower seeds on your side of the path, and every day while we walk back, you've watered them."

"For two years I have been able to pick these beautiful flowers to decorate the table. Without you being just the way you are, there would not be this beauty to grace the house."

Moral: Each of us has our own unique flaws. We are all cracked pots. But it's the flaws we have that make our lives together so very interesting and rewarding. You've just got to take each person for what they are, and look for the good in them."

Taken from Synapse - Autumn 2005 Edition The Official Journal of Brain Injury Associations of Australia

# Paul Raciborski – "Not time to go!"

December 22nd, 2003 could well have been Paul Raciborski's last day. Whilst on a family holiday near Mt. Cook on New Zealand's south island, Paul was out walking in the mountains with his twin 16 year old sons, when a large rock fell on his chest, knocking him over and sending him tumbling down a mountain a further 15–20 metres, resulting in shocking injuries that should have proved fatal. As fate would have it, it was not Paul's time to go.

Nearby happened to be another mountaineer who immediately came to assist and who was proficient in first aid. He kept Paul alive while a tourist helicopter was summoned to fly him down to the valley. From there the Westpac rescue helicopter met him and paramedics continued the life saving treatment whilst Paul was flown to the casualty department at Christchurch Hospital.

At the time of his accident Paul was 43 years old, happily married to wife Julie of 20 years and the proud father of 4 children; Alexa 17, twins Ted and Joe 16, and Francis 8. He was in the prime of his life professionally, working in a senior executive position as Project Manager for British American Tobacco Australia, which often involved him travelling overseas for business. He was also a capable mountaineer, having plenty of experience climbing and walking in varied terrains over the last 30 years and always using the correct equipment.

Paul has no memory of the day of the accident or of the following seven weeks, apart from some blurred recollections of preparations for the walk prior to setting out that day. He was to spend the next 10 days in a coma on life support in the Intensive Care Unit of Christchurch Hospital, after which he was transferred to the Neuro Ward for 5 days. Initially his wife Julie was told he had a 2% chance of survival, and if he did survive he would most probably end up vegetative. However Julie, who describes herself as the 'eternal optimist' refused to accept this and despite what she was told, never gave up the belief that her husband's strength of character and fierce determination in all he did in life, would carry him through.

Paul's injuries included a skull fracture, a shearing brain injury, fractured left eye socket, fracture of three vertebrae, compound fracture to the lower right leg, damage to his right finger tendons, as well as serious cuts and abrasions to various parts of his body. Julie's devotion and optimistic attitude when faced with such a devastating scenario, combined with truly amazing support from the company for whom Paul worked, were undoubtedly a very real force in Paul's astounding recovery. His company not only paid for all of Paul's overseas medical expenses, but also incredibly flew his father out from England to New Zealand to be with him. However their support didn't end there, when Paul was medically stable, they repatriated him back to Australia, sending a doctor and nurse to fly back with him. They have met his every need, both financially and spiritually, keeping him on full wages, and welcoming him back to take up his previous position, when he was ready to do so.

"All we ask of you Julie, is that you help him get better." Julie recalls Paul's boss saying to her in the early days, when she expressed her gratitude for their extraordinary support.

When he arrived back in Sydney on January 8th 2004, Paul was taken to Royal Prince Alfred Hospital where he stayed until the 27th. He was then transferred to Royal Ryde Rehabilitation Centre where he began a rigorous programme of inpatient therapy, eventually leaving after a relatively short period on April 1st 2004. His discharge probably came earlier than expected, as physically he was still in need of intense rehabilitation, but the tentacles of depression were beginning to take hold and the decision was made to seek alternative management. It was during this time in RRRC, after about 5–6 weeks, that he began to emerge from post traumatic amnesia. Reflecting on that confusing period Paul says,

"For a long time I thought I was having a dream and I was looking for that 'something' inside my hazy mind that would confirm for me that it was a dream, and that I would wake up if I tried to. My body, my surroundings and my experiences were so changed I did not believe it was all real for a while. When the impact hit home that it wasn't a bad dream, I initially had difficulty coming to terms with the new reality, but thanks to support from my family and help from rehab, I learnt to accept what had happened and was able to move forwards. During my rehab at Ryde one of the therapists told me that I was very goal driven, and I believe that this is one of the reasons behind my positive outcome. I think you need to believe you will get better and really want it to happen. I am constantly amazed by the devotion of those close to me. In many ways I think I had the easier experience when you compare it to what Julie and the children had to cope with as I was not the easiest person to be around."

Due to Paul and Julie becoming frustrated with the lack of individualised rehab needs often available in the public health system, and with the very real threat of this causing Paul to become depressed, they left RRRC and opted for private outpatient therapy at Metropolitan Rehab Centre, not far from the family home in Stanmore, where he attended  $3^{\frac{1}{2}}$  days a week up until November 2004. Julie, who has vast experience in the area of disabilities being a Special Education Teacher and previously working in the field of Autism, explained the need to opt for private therapy this way.

"Unfortunately potential to recover can be limited by some professionals who try to fit a square peg into a round hole! Every person with or without a brain injury is different and as such has different interests or needs. As well, we all come from diverse family situations and relationships vary within each household. These things need to be considered and therapy should be adapted according to individual needs." Paul started back to work around mid April, only going in for about half a day a week, and gradually increasing this time each fortnight. In mid September 2004 he got his driver's licence reinstated, which naturally increased his independence. Paul's career didn't suffer any setbacks because of his accident, in fact if anything it has blossomed;

"If anything this has helped my career; it has given me more perspective and balance in my approach." Paul says.

Paul's recovery to date is nothing less than astonishing considering the shocking injuries he sustained during his fall. What stands out as even more amazing however, is the fast rate at which he has achieved his goals. When this is suggested to him he modestly replies,

"Yeah, I am doing pretty well. Each week gets better. My broken leg doesn't work as well as it used to – the flexibility has gone, which causes me to limp a little. But intellectually I feel I am back to about 98% and emotionally I am even better than I used to be before the accident; I am less driven now. For me the greatest learning has been around the phrase 'is it life or death?' It has given me some real perspective on whether something is really important, because 'life or death' for me has real meaning!"

When asked about the most important issue he faced during his recovery, Paul replied that not a lot frustrated him initially, due to ignorance of his situation. However as his cognition progressed and understanding improved, he found the inflexibility of his rehab programme caused him some angst.

"Everybody is individual – you can't pigeon hole a patient or family. None of the fellow patients were the same and professionals need to understand individual needs.

Not so long ago I went through a phase of 'self-doubt'- I questioned my own take on my actual recovery – was I as good as I thought I was – would anyone tell me if I wasn't. It was an unusual period for me and hard to put into words, but fortunately it didn't last long."

When asked about the most important issue he faces now he says they are probably not brain injury related,

"My goals and interests have moved on from my injury to those of a typical husband, father and working person."

Finally, when asked about the message he would like to give to others, he says,

"My advice for others is give it time, be patient and flexible. Just like the body, the brain too needs to be exercised, and I have found doing crosswords every day very beneficial. I also discovered that sometimes just talking to others in similar situations can be more beneficial than exercising. I have been lucky. I stayed positive and goal focused throughout. I continue to receive tremendous support and encouragement from all those around me, and this combined with my own motivation to get better, have been integral parts of the matrix of my successful outcome. After a traumatic experience like mine, you have a greater appreciation of life and don't take a moment for granted!"

Looking at Paul Raciborski, you would never guess what he has been through. But listening to him, an emotional intelligence and insightfulness is revealed, because of what he has been through.



If you think you are beaten – you are. If you think you dare not – you don't. If you'd like to win, but you think you can't it's almost a cinch that you won't.

If you think you'll lose – you've lost. For out in the world you'll find, success begins with a fellow's will. It's all in the state of mind.

If you think you're outclassed – you are. You've got to think high to rise. You've got to be sure of yourself, before you can ever win a prize.

Life's battle doesn't always go To the swifter or faster man, but sooner or later, the man who wins is the man who thinks he can.

Author Unknown

### Peter Bons – "The sky is the limit"

Turning into the long gravel drive lined with pink flowering blossom trees, there is an atmosphere of tranquillity that is as welcoming as the smile on Peter Bon's face, as he awaits our arrival at the bottom of the steps that lead to the wide front veranda of his charming country style home. Peter and his wife Carol live on acreage in a semi rural town south west of Sydney, and their property backs onto the local airport. Inside the open-planned house of mostly timber décor, there is an air of rustic peace that is also warm and inviting. The timber walls are filled with cheerful family photos depicting a close knit family unit and the Bons are happy to elaborate on their cherished memories from the past. Amongst this strong sense of family, it is easy to feel relaxed and comfortable.

Despite our conversation being constantly interrupted by the noise and display of close flying light aircraft, this does not concern the Bons at all, in fact they enjoy it – especially Peter. You see, prior to his accident in 1997 Peter had been a pilot, flying civil, military and commercial airlines since 1969. So one of the foremost reasons for the recent purchase of this property adjacent to an airport, was the fact that he would be able to observe with great pleasure all the landings, take-offs and aerial acrobatics, he desired – as unfortunately due to a freakish accident which resulted in traumatic brain injury, he is not allowed to fly an aeroplane ever again.

On the 2nd August 1997 Peter, who was then aged 47 and whose hobby was building and flying radio control model aeroplanes, was standing in the car park of a designated flying field, chatting to a friend in a car, when an out of control model aeroplane struck him on the side of his head, knocking him unconscious. An ambulance was immediately summoned and he was transported to Campbelltown Hospital. From there he was airlifted with 'Care Flight' to Concord Hospital for immediate neurosurgery to the right temporal lobe region, where the engine and propeller of the plane had struck him.

Carol had been at home on that fateful day, watching another tragic event unfold on television – the devastating landslide at Thredbo and the saga of rescuers trying to save Stuart Diver. She had never in her wildest dreams anticipated that that day would also deliver the shattering news of what had happened to Peter, the subsequent impact on the whole family, and more significantly, the life-long consequences it resulted in; all from just standing in the right place at the wrong time.

Their three daughters, Sarah then aged 22 and just married; Tammy aged 19 and at university studying teaching; Jemma 14 and still at school; were all naturally extremely distraught and significantly affected by the sudden change in the essence of the wonderful father they knew. But their son Travis, who was then aged only 15, was with his father that day and witnessed the entire horrific ordeal – one can only imagine the impact of these memories on a life so young and vulnerable.

Peter spent two weeks in a coma in Concord Hospital and was there for a further six weeks. He has no actual memory of his accident, only that told to him by witnesses and friends. However during what he describes as 'surfacing from his coma' he recalls the presence of family and friends around him. He also has vague memories of doctors and nurses in the intensive care unit and of being aware of some tubes down his throat, which he detested and desperately wanted to pull out.

"Family and friends are great as a draw-card back to life. I can tell you there were some people who left with pretty sore hands from asking me to 'squeeze their hand if I could hear them', because I sure squeezed them hard!"

After six weeks at Concord Hospital, when it was evident that he was medically stable, he was transferred to Liverpool Brain Injury Unit (BIU), where he spent a month in rehabilitation. He found all the therapists at Liverpool to be very encouraging and helpful, and equates his stay there as a very comfortable and positive time; *"like a 'security blanket' toward some sort of future."* 

Carol recalls that at first she thought the occupational therapists were a bit tough on Peter, but it didn't take long for her to realise that they had to be cruel to be kind.

"I remember feeling shocked when watching Peter learning to dress himself all over again, and thinking to myself 'my God, he can't even tie his shoc laces!' But I soon learnt that this was part of his post traumatic amnesia."

Peter made a remarkably quick recovery at Liverpool BIU and after one month was discharged to go home, where he was monitored by case managers that visited regularly. He says that this provided him with a vital connection to the 'medical world' which was of great assistance during those early weeks at home, as they helped put together so many pieces of the puzzle that was his new life.

"At first during your recovery you go from feeling lost in a strange world unknown to you; to that of mixed emotions of anger, anxiousness, and fear about the future. Then on top of that you have to try to deal with outside conflicts brought on to you by the heartless legal/insurance conglomerate, which are a manufacturing industry to themselves. They have no empathy that you are in the unknown, fighting for the unknown, in an unexplained period, made worse with nothing to live on except for the social security disability support pension.

Only time helps you cope better with your emotions. Family life and support is everything. Being involved in personal pursuits, goals, as well as eventually getting back to some casual work does much to normalise your life. You must have things to look forward to."

One of the highlights of Peter's stay in hospital that helped lift his spirits, in what was naturally a very distressing period of his life, was the day the nurse

wheeled him out on to the balcony of the hospital ward. Peter recounts this moment fondly,

"The nurse suggested I get some fresh air out on the balcony. Always looking in the sky, I looked up this day and remarked "If I'm not mistaken, that's a DASH-8 – I used to fly them!" Unbeknownst to me an arranged flypast took place on one of our Sydney to Canberra services. The skipper explained on the ground to all the 36 passengers, the plight of their colleague who was recovering in Concord Hospital. The aircraft was flown low for the remaining commentary and viewing during the flypast. My nurse, who was still on the balcony with me, remarked "You know, it's not a coincidence that we are out here, and your DASH-8 flew past!" I couldn't figure out what she meant until much later from another visiting pilot colleague who told me it was all rigged! WOW – it sure lifted my spirits!"

Over the ensuing years Peter adapted to and restructured his new life. Pursuing old interests and hobbies meant a great deal to him now that he was unable to fly due to loss of peripheral vision, headaches and the threat of epilepsy.

"Subsequent years found myself and dependent family lost in a strange new unfamiliar world, having lost all of my qualifications (flying and driving). I was unsuitable for labour orientated work, due to moderate risk of fits, and office work was conducive to eye strain and headaches. So it was that I wanted to pursue a hobby business already started prior to my accident. For this I needed product publications and plan drawing capabilities. I was computer illiterate and sought training in Computer skills to accomplish Desktop publishing (DTP) capability, and CAD at a later date. 'Head2Work', which is affiliated with Liverpool Brain Injury Unit, provides vocational rehabilitation and steered me in the TAFE direction. I was relieved that disability training was available through TAFE and because of my memory problems, eye strain and headaches, I was able to receive one-on-one assistance with a specialist disability teacher. I successfully completed a basic computer course and desktop publishing using MS Publisher and Adobe Photoshop. It was a most rewarding and satisfying experience to be finally useful at something again. It wasn't flying, but this computer stuff felt good under the circumstances, overcoming my feelings of worthlessness."

In 2004 Peter was offered a casual job with a Hobby Wholesaler within the local community. His duties are mainly warehouse functions, including filling orders and packing goods for shipment.

When asked about the single most important issue he faced during his recovery, he says without doubt that it was the insensitivity and singlemindedness of the insurance company and inequitable legal system. When questioned regarding the most important issues he currently faces he says,

"Rebuilding and restructuring my new life to secure the future. Pursuing interests. Finishing off a long term aircraft project in a hobby business. Retraining myself in flying radio control model aircraft as part of my hobby business. All this takes time, but it restores confidence."

The message that Peter Bons would like to leave people with in respect to what he has been through is,

"While the circumstances of my accident seem a little freakish and uncommon, I recall the plight of so many with me in the brain injury unit. All victims of everyday accidents, familiar to us all. Of the many patients there, most were from car accidents, some were from skate boards, others horse riding, falls and assault. One of the latter was only a kid who was senselessly bashed unconscious for his new pair of shoes. My point here is this – it can happen to any one of us, at any age. What will happen to you tomorrow or next week? I certainly did not expect the events of 2nd August 1997. Having said that, once the immediate aspects of your injury are behind you, such as medical and legal issues – accept, adapt and move on. Pursue old interests where possible. Time does heal wounds, emotions and anger. Let go and move on, you'll accept and adapt better. Above all else NEVER EVER GIVE UP!" Peter attributes his survival and amazing recovery to the brilliance of NSW Ambulance, Campbelltown Hospital, Care Flight, Concord Hospital, Liverpool Brain Injury Unit and naturally to the love and support of his family and friends.

From the writer's point of view, Peter and Carol Bons are an extraordinary couple. Despite all that they have been through they are amazingly happy and kind spirited people. Peter's positive attitude and buoyant spirit has undoubtedly helped him in his incredible recovery; it is infectious and lifts the mood of those around him – proving that you don't need wings to soar above the clouds.



A jar of secrets is her life, And all she goes through is pain and strife. She stands alone as the people go by, And as she remembers, she wipes that tear from her eye. She tries to remember what happened six years ago, But alas, she can only remember what they already know. She finds it difficult to adjust, To her new weight, facial complexion and the size of her bust. And her life. Well, it is free, but it's just not how it used to be. Everyone just looks and stares, But in the long run who really cares? No matter how hard she tries to please, All people can do is tease. They say some things which she can't stand, There is only one girl who really understands. She is really very shy, And is in fear of showing her feelings for 'that guy'. It is hard for her to comprehend, For she has only one true friend.

> By Karolina Mazurkiewicz (Aged 14)

#### ASPECTS

Some of my friends were embarrassed for others it was fear why is this happening to my dad and I wiped away more tears he would roll across the carpet crying then laughing my special cuddles proved in vain. It was an aspect of his damaged brain.

Mum would take him to physio next day the O.T. smiling, he went through the motions but it's purpose he couldn't see "Why for am 1 do that"? was his child-like refrain. It was another aspect of his damaged brain.

Because I had just turned 8. "why won't daddy talk any more? Why did they shave his head? Why does he stare at the floor? Look, he's crying again, What's wrong mummy, is he in pain"? It was another aspect of his damaged brand

"Aspects - word on paper" by Peter Harrington

When I was about eleven Mum explained about depression and the realities he would to face the torment and confusion of trying to find his new place I also noticed in mum the despair and the strain. It was another aspect of his damaged brain.

#### I'm fifteen now

some days he's good, others bad and I want you all to know that I never stopped loving my dad. Today is his birthday so we celebrate once again. That can also be an aspect of a damaged brain.

P.M. Harrington 2004

## Karolina Mazurkiewicz – "My life is different – and that's okay"

Karolina Mazurkiewicz was only 9 years old when her young, free and innocent life, with all its promise for tomorrow, was tragically altered by fate's cruel hand. Karolina and her mother Maria had only been in Australia for 5 years, emigrating from Poland with the hope of a better life with greater opportunities. Despite being a qualified teacher in Poland, the language barrier prevented Maria from teaching here and she took a job in a hotel. Through connections and support from the local Polish Community of south western Sydney, they were assimilating and adapting well to their new surroundings. Settling into a new culture and learning to speak a new language were difficult enough, but little did they know just how difficult life would prove to be, and the physical pain and emotional struggle that little Karolina would have to face.

On the 27th May 1995, as the greyness of dusk embraced the late afternoon, little Karolina had just finished her Polish Dancing and was being driven to her friend's house in the friend's family car. With Karolina being an only child, Maria understood how much she wanted to travel with her friend so she followed their car to meet them at the friend's house. The car Karolina was travelling in stopped on a main road in Hoxton Park across the road from their destination and all the children alighted. No one is sure just how or why Karolina crossed the road at the time she did, and Karolina herself has no memory of that afternoon's events. All that Maria can say is that when she arrived on the scene some 5 to 10 minutes later she was shocked to find her precious daughter lying crumpled like a rag doll on the road, with people gathered around her, and one of the parents she knew giving first aid. As she speaks of this scene her eyes fill with tears and her pain is obvious,

"She had no skin left on her body, it was bloodied and blackened with tar from the road. At the hospital the doctors told me she had very serious injuries including a broken left leg, broken ribs, a hole in her left side, broken pelvis, damaged liver and damaged spleen. They said that due to her brain injury she might not live, and if she did she might not ever walk or talk again!"

Initially the ambulance took Karolina to Liverpool Hospital and at around midnight she was transferred to Westmead Children's Hospital. Despite having such a long list of ghastly injuries, Karolina desperately clung to life for the next 12 days on life support. She spent 21 days in the Intensive Care Unit after which she was transferred to the ward and her care was taken over by the brain injury rehabilitation team. Being only 9 years old Karolina does not have much memory of her time in hospital, but she does recall some instances such as a nurse named Connie who braided her hair. She was in the Children's Hospital for four months with Maria by her side every single day, at first only able to hold her by her foot due to her extensive skin abrasions and physical injuries, and to talk to her of Karolina's favourite things. As time went on she began to stimulate her with massage and touch, and advocate on her behalf for as much therapy and assistance as she knew her daughter needed to get better.

"I had to always push for everything and always felt that some of the medical team wouldn't listen to me or believe me. They need to realise that parents have better intuition than anyone else. I believe that the special connection I had with my daughter was very important; and to touch and massage is very important as well."

Maria relates a time when Karolina was emerging from coma, still unable to speak, when she had to leave her for a short while to visit a relative. She normally would not have left Karolina's side, but as it was her own birthday she thought she would go and told Karolina she would be back in one hour. Time got away and when she returned to the hospital Karolina defiantly held up two fingers to her mother, indicating the time she had actually been away!

Karolina had many friends and visitors during her stay in hospital, which helped make her time there happy and positive. However in the months following her discharge she was unprepared for the emotional impact that her physical and cognitive disabilities from her brain injury brought about, and found it very difficult to understand why she couldn't do the things she once did with ease. Prior to the accident she was an extremely high achiever and academically placed at the top of her year 4 class. She was a beautiful ballet and Polish dancer and was socially very popular, having many friends both at primary school and at the Polish school she attended every Saturday.

All this changed for Karolina after her accident. When she returned to school on a part time basis she was desperate to be accepted as the 'old' Karolina, but unfortunately due to her disabilities and the associated stigma of brain injury, she was treated very poorly by most of her peers at school, and her needs also went unrecognised within the Polish community due to the lack of appreciation of the significant impact brain injury has on families as well as the victim. People's lack of empathy and acceptance affected Karolina psychologically, making her very self-conscious, and even more desperate to appear 'normal'. She struggled on through school amid constant phases of rejection and thoughts of inadequacy through primary school and the transition to high school. This latter transition was extremely difficult, and eventually Karolina and Maria made the decision to change high schools in the middle of year 9, switching to a Catholic College, believing she would be more readily accepted. However, this transition was not an easy one either. Karolina refused to tell anyone about her accident in the hope that she would be treated normally, she even rejected any type of assistance or educational aide that would make her stand out from her peers.

So Karolina's time at school was a difficult period and the emotional strain of not being accepted there or within the Polish community, placed an even heavier burden on Maria, who herself was struggling to come to terms with Karolina's lack of insight, fatigue and problems with thinking and processing. Eventually Maria was forced to go on anti-depressants to help her cope and fortunately the medication, combined with the emotional strength she gained from watching Karolina's fierce determination to improve herself, motivated her to carry on day after day.

With continual love, support and assistance from her mother, Karolina pushed herself relentlessly with her studies, and was able to make remarkable progress academically and especially with extra-curricula activities, though always high on her agenda was her refusal to be treated differently. She continued with her dancing until year 9 when she took up drama at Kid's Casting Agency, which led her into appearing as an extra in a short film.

"Drama lessons improved my self-confidence and really helped me develop socially." Karolina says.

At the end of year 10 her Karolina got herself a part time job in a retail shop at Westfield Shopping Centre in Liverpool. With her confidence slowly returning she joined Liverpool Youth Media Team which led on to her becoming a representative on Liverpool Youth Council. In 2002 she was selected to participate in the National Youth Round Table (NYRT), through which she worked on a project to address her concern about the negative portrayal of young people by the media. She did this by successfully establishing a student-run school based radio station at Freeman. The NYRT involved working on her chosen year long project, travelling to Tweed Heads and Canberra, where she met and was photographed with Prime Minister John Howard. To be nominated to represent the voice of young people in Australia was an outstanding feat, and a great tribute to her courage and determination to be treated equally amongst her peers. Her efforts in her project, and the project outcome were shown on a segment of the television show 'Totally Wild'. The developmental opportunities of her NYRT project were a stepping stone for her involvement in radio. Currently she is a co-producer of the Youth Style Art program, that is aired on Wednesdays from 5:00pm to 6:00pm on her local community radio station, 2GLF 89.3.

"I know what it is like to have no one to hang around with, and I feel radio fills this void of loneliness" Karolina says profoundly.

Karolina proudly displays a photo album filled with various newspaper pictures and articles on her amazing achievements at school and within the local community. Ironically at the end of her school life she was voted 'most likely to be the next Wendy Harmer' (successful radio personality). "In the end I really felt like I left my mark on that school!"

Currently she attends the Australian Catholic University and is studying for a Diploma of Habilitation. Habilitation involves supporting people with disabilities, and as part of the course she had to complete a field placement which she did at Community Access Service Liverpool, the Spastic Centre of NSW. However she has since decided to volunteer her assistance there and is gaining great satisfaction in teaching a lady who has cerebral palsy how to knit with more independence.

"Going there has taught me a lot about interacting with other people at all levels" she says.

When asked about the most important issue she faced and continues to face she simply states,

"Making friends."

And her message to others,

"I encourage everyone to learn about brain injury. Gaining an understanding of brain injury and its affect on me, has given me something that I didn't initially have – control over my situation. Accepting my brain injury has been the hardest transition of my life, but it is worth it. Through self discovery I have found my new identity, I am a different person now, I am special and my life is different, and that's okay too!"

Karolina is indeed different; she has more humanity, humility and insight into the things that really matter in life, than most girls her age. With her special qualities and enthusiasm in all she does, her future is limitless.

# My Wish

My wish is to be beautiful, to exist in everyone's space To have the latest clothes, and a perfect face.

To be accepted for who I am and receive everything I'd ever want To have no trouble in fitting in and have feelings that I belong. A life of happiness, acceptance and possibility, A life worth writing about, about what to write a song.

To have a chance, a chance to make it and be somebody true, To start off as someone else, and to be somebody new.

In my life I confess, all I want to be is your little princess, With emerald sea and turquoise sky, To wish my wish ... I only try.

> To not be 'that girl' they push and shove, But to be that angel, that they all love. Not be that person whom they tease, But be the person they wish to please.

> My thoughts are sad and filled with pain, And tragic memories I wish to drain. The pain I feel makes me sick, Too sick to cry, too sick to speak.

> > By Karolina Mazurkiewicz. (Aged 16)

### Susanna Greig – A second chance at life

In 1996 Susanna Greig was 22 years old, had completed at degree in Science, was living in the peaceful NSW country town of Narrabri, and had an interesting and enjoyable job working for an Agronomist. She loved her life and her work which was predominantly physical, bug checking and examining cotton crops.

Life was progressing well for young Susanna, until Christmas Eve 1996. As she was driving home from work that afternoon, fate took an abrupt turn, stopping just short of a 'dead-end'. Susanna has no memory of what happened – perhaps she was adjusting the radio or possibly even fatigued from a long day at work – but somehow her car veered off the isolated country road and smashed into the trunk of a large tree. She was found bleeding and unconscious inside her car, which had been drastically compressed in size from the impact. A heavy tree branch lay on top of the car.

Fortunately for Susanna not much time had elapsed before a father and son who were driving to Gunnedah, found her and immediately called for help. She was taken by ambulance to Narrabri Hospital, and due to her severe head injury, once she was stabilised she was transferred by air ambulance to RPA in Sydney. As well as the traumatic brain injury, she suffered a broken jaw and nasty gash to her right knee. She was in a coma in the Intensive Care Unit of RPA for approximately three weeks and her parents were told she had serious injuries that suggested a poor prognosis.

Once conscious and medically stable, she was transferred to Royal Ryde Rehabilitation Centre where she began an intense program of therapy for approximately four months. She has very positive memories of her time there and says the therapists who worked with her were all fantastic.

"I will always remember the support of my physiotherapist Joan," she says, "and the doctors and nurses provided excellent support and advice. I also had amazing support from family and friends, which I believe was my key to motivating myself to recover and get back to living my life as closely as possible to how it was before the accident."

After discharge Susanna continued to work hard towards her goals, although she readily admits that this transition period was very tough, "My personal expectations were quite different from reality."

However about a year after her accident she amazed everyone by going back to University and completing a Graduate Diploma in Education. She subsequently became a teacher in a NSW country school for three years where she was the only science and agricultural teacher in the school. This was probably the toughest period in Susanna's life. She had to confront the realities of her life after the accident, but it forced her to develop the organisational and planning skills that are often impaired with traumatic brain injury. Susanna currently resides in Armidale, where she is an Educational Officer for the cooperative research centre for Australian Weed Management, in the School of Rural Science and Agriculture at the University of New England. She has no problem living independently or getting herself around, and amongst other things is a keen bike rider and bushwalker. She finds she is still slightly weaker in her left leg and arm, but this does not stop her participating in the activities she enjoys. She admits that her emotions have been affected since her accident, and has noticed that coping with excitement or downtimes are somewhat difficult. She also recognises that fatigue is still a problem for her, sometimes causing her vision to blur or double, and that she requires lots of sleep. Although her speech carries traces of dysarthria (Imperfect articulation of speech due to disturbances of muscular control), it is articulate and intelligible.

"I am extremely fortunate to be able to do the things I enjoy. Every Tuesday and Thursday morning I ride 18 kilometres before work on my bike; I am a member of the local bushwalking club, and have played hockey and touch football since the accident."

In an amazing twist of fate, a few years after her accident whilst she was visiting Sydney and waiting for a train at the busy inner city train station of Central, she noticed a young man staring at her. Naturally she felt a little disconcerted but the young man explained he recognised her and asked if she was in a car accident near Narrabri in 1996. When she replied in the affirmative, he informed her that he and his father were the ones who had found her and called the ambulance! Destiny is indeed strange – in a city of approximately four million people this young man just happened to be at the station at the very same time as Susanna – *and had he not been travelling to Gunnedah at that very time on Christmas Eve 1996* ...

When asked about the single most important issued faced during her recovery, she related that dealing with the changes in her life and adapting to her new life was a challenge. Fatigue was and still is, an issue. Just as important to her was her need to get back to work.

"While adapting to the changes in my life has been helpful, this is a long process which I think I am still doing in many ways."

When asked about the most important issues she currently faces, she says,

"My concentration still needs work. I still have to work on my weak areas and see a physiotherapist regularly to improve my physical problems. And of course, wanting to do too much!"

Susanna's passionate message to others going through similar struggles is powerful;

"Recovery and rehabilitation is jolly hard work! But the best way to have a win is to be motivated and work at it bit by bit. Improving myself is still the number one thing in my life 9 years after my accident. I want to work hard to become the best person I can! There is a way forward – you have been given a second chance at life – your mind has to become strong enough to value it!"

Susanna's profound message has conveyed the tone of each the stories you have just read, and therein the purpose of writing this book.

