The importance of passion

The theme of this issue of empower is passion. It’s so important for people with (and without) disabilities to be passionate about something in their lives. It could be an ideal or cause. It could be family, friends, art, gardening, sports, travel, pets or cooking. Whatever it is, passion makes life worthwhile and helps people achieve great things! In this edition we meet six inspirational people who refuse to let their disabilities stop them from pursuing their passion. Their stories reinforce the importance of getting out there, pursuing your hobbies, fighting for your beliefs and following your dreams!

Vicky’s cause

By Dr Bronwyn Morkham, National Director of the Young People In Nursing Homes National Alliance

Through my work I’ve met some pretty amazing and passionate people. I work for the Young People In Nursing Homes (YPINH) alliance which aims to raise awareness of the plight of over 6,500 young Australians with high and complex support needs living in aged care nursing homes because they have nowhere else to go.

Take Vicky for instance. Vicky is one inspiring and remarkable person. Now 35, Vicky was injured in a car accident when she was just 16 and has spent more than half her adult life in a nursing home because there has been nowhere else to live. Yet Vicky’s passion and determination to make sure that young people like her have the chance to live in the community has seen her achieve some amazing things. She has, for example, run a one woman campaign from her nursing home that has raised awareness of the YPINH issue in the regional town in which she lives and demanded action. She has written numerous letters to politicians and is well known for speaking about the inequity of the YPINH issue on local TV, radio and newspapers. She has appeared before senate inquiries and met with state and federal ministers.

But it isn’t only the big picture issues that concern Vicky. She became aware that many elderly nursing home residents were keen to go shopping at the mall next door. Vicky successfully lobbied the local council to cut a gateway in the boundary fence between the nursing home and the mall and lay a concrete path that was safe for residents to use. Now elderly residents can be seen following Vicky as she leads them across the car park to the shops in her electric wheelchair.

Vicky’s passion has allowed her to change government policy and attitudes towards the care and support of people with high and complex needs. Powerful passion indeed!
An Acquired Brain Injury hasn’t stopped Bianca Palamara from pursuing her passion for poetry and singing.

A bitterly cold morning on 18 August 1999 changed my life forever. On that morning, I was on my way to complete a hang-gliding course in Birchip, just outside Ballarat. I had taken up hang-gliding after going through my marriage break-up, and had decided to take a few risks. I had no idea that it would be the roads, not the skies, which would almost take my life.

I lost control of my car on an icy road and slid into a tree. I don’t remember anything after that but my parents told me that when they arrived at the hospital, I was a battered and broken mess. My face was full of blood, my nostrils were full of blood and my ears were full of blood. I suffered a severe brain injury, my kidneys had failed and I was paralysed on the left side. Although I was hooked to various machines to keep me alive, I was not expected to survive.

My injuries were so severe that it is a true blessing for me to be able to write this here now.

Days later I was given my last rites by a priest and nine days after the accident, on August 26, my mother and father were asked to make a decision no parent should – whether to turn off my life support. As fate would have it, it was the same day thirty-one years earlier Mum had lost her father in a car-accident.

Mum and Dad refused to turn off the life support.

To the amazement of doctors, my kidneys began to function again and after four and a half weeks, I was transferred from intensive care. It really was a miracle!

In total, I spent seven weeks at the Alfred hospital. But then began the hard part – my rehabilitation. Eighteen months of intensive therapy followed at Ivanhoe Manor Rehabilitation Hospital. After that I continued with my rehabilitation at home, gradually learning how to walk and talk again. It was really difficult at times, but I was determined not to give in.

After four years in a wheelchair, today I walk with a splint and sometimes even use a walking stick – not bad for someone who was totally paralysed down her left side.

As I continue with my treatment and recovery, the one thing that keeps me going is my love of poetry and writing. I cannot recall exactly when this passion for words was born, but I’ve always derived such pleasure from creating images through words. I’m very grateful that I still have my writing gift, after such a severe accident. Sure, it’s harder to unscramble my thoughts now, because of my brain injury. But there is no way I’m letting this stop me! If I ever feel down expressing myself through poetry is sometimes the best medicine.

I still like to try new things and take on new challenges. Recently I began singing and belly dancing. I’m not the greatest belly dancer in the world but it’s a lot of fun. Who knew the belly could move in so many ways? And singing has given me a new lease on life...IT’S SO FUN! I sing in class with others who have sustained a brain injury and I also get private tuition. I’ve even started writing my own songs for our class to sing! And I also edit other class members’ songs. My singing coach helps put our words to music. And I feel very proud when the class sings the songs which I’ve helped edit.

Recently our church held a concert in front of a large group of people. Despite our nerves, the audience enjoyed our performance and we received a warm round of applause, although I don’t think the Three Tenors have anything to worry about!

My injuries were so severe that it is a true blessing for me to be able to write this here now. And with the joint care of the loving people around me, I can continue with my celebration of life:

CELEBRATION OF LIFE

Bianca Palamara – 22.10.06

I’ll battle through my pains
Till no grief remains:
Again I walk
And once more I talk
And the best thing Is now, I can sing
And yes, I’ve taken the chance Where I now also belly dance
I have battled through all kinds of strife
So I may continue in this celebration of life...

I’d just like to leave it here where I give thanks to God for my second chance at life. And to all the doctors, nurses, carers and therapists and to all the loving people that have helped me.

The Road Trauma Support team provides support, information and counselling to people whose lives have been affected by road trauma. You can call their helpline on 1300 367 797 or visit their website at www.rtstv.org.au
After a serious car accident, Andrew ‘Nicko’ Nicholson is passionate about spreading the road safety message to students.

G’day my name is Andrew, ‘Nicko’ to my mates. On the first day of 1986, I was drinking and driving and looking at this scantily clad young lady riding a horse down the side of the Hamilton Highway. I hit a bridge and 10 weeks later woke up in hospital. It was then I found out that it was not a nightmare, my friends had given me a heart massage and mouth to mouth while waiting for the police and ambulance. First time a bloke with a moustache has ever kissed me. And the last time I hope!

I wouldn’t let the words ‘can not’ enter my vocab.

Seriously though, the accident cost me my sight, my right arm and put me in a wheelchair. It was a life sentence for an action that took seconds. It was bloody tough, I was 30 and I’d gone from an independent yobbo with a good job, mortgage and money to spend living in the fast lane to totally dependent on others for even the most basic needs. I needed around the clock care. I couldn’t get myself a drink of water. I couldn’t go to the toilet by myself. The only thing I could do for myself was talk. My fiancé was pregnant at the time and it perhaps the cruelest blow of all knowing that I could not witness the birth of my son Thomas five months after my accident.

I spent the next 12 months in a rehab hospital. My fiancé and I went our separate ways and there were times when I thought I’d never leave the hospital. But I was determined to get back home, see my friends and resume my life as a farmer.

I was also determined to prove my doubters wrong. Some people looked at me and thought I should be put in an institution for the rest of my life.

It’s not all serious when I talk. I crack a few jokes to make the kids feel comfortable because they’re more likely to understand my message when they’re relaxed. I rely on my sense of humour, although I’m a bit dark on Steady Eddy because he stole a lot of my jokes!

These days I’m no longer farming but I still like to keep myself (and my carers!) busy. Apart from my guest speaking roles at schools and clubs, I have been secretary of my local Lions Club. I am a member of various disability groups including the Geelong Rural Access Group, the Barwon Ability Alliance, Bacchus Marsh disability forum, ParaQuad and AQA. I am also a citizens’ advocate for various organisations such as Limbs 4 Life and I write articles for local, regional and state newsletters.

I still catch up with my friends and family, especially my son on a regular basis. I’m the biggest ‘sticky beak’ west of Melbourne with a keen interest in people and current events. I spend up to forty hours a week listening to talking books, the radio and talking on the phone in the company of my dog.

I think life is actually mind over matter. People like me are in a ‘dead end street’ if we let it become that. You either do it, and get on with life, or you don’t. If you decide to ‘do it’ things just start to happen and that motivates you for other things to happen. Just look ahead. There’s always a bit of hill to climb but once you get to the top, you can get to the other side really easy.

Attention companion card holders!
If you catch public transport a companion card now allows your friend or carer to travel for free.
To find out if you are eligible for a companion card please call 1800 650 611 or visit www.companioncard.org
Passion pushes my buttons!

Chris Durham’s passion is to tell the world what life with an Acquired Brain Injury (ABI) is really like.

Recently I climbed a hill. Half way up I stopped to catch my breath and I watched two full moons rise above the banks of clouds (yes, double vision is still a problem because of my brain injury). Raindrops glistened like diamonds on the gum leaves and I thought ‘I wouldn’t be dead for quids!’ Suddenly it struck me. The 16 year anniversary of my car accident had slipped quietly by and I hadn’t given it a second thought. Amazing! The anniversary had been such a big deal until now.

I reached the top of the hill and thought of the long journey I’d made from those nightmarish years after my car accident. On that day I was driving to uni when bang! Suddenly my car was flying out of control, spinning round. There was a huge explosion. Flashes of bright, piercing, white light, pain, strange sounds of clattering metal, choking, floating, agony, hell. Then blackness.

Much, much later I learnt that a car had sped out of a side street, hit the road to get a quote to have his car fixed. The driver of the other car left the scene, and I thought ‘I wouldn’t be dead for quids!’ Suddenly it struck me. The 16 year anniversary of my car accident had slipped quietly by and I hadn’t given it a second thought. Amazing! The anniversary had been such a big deal until now.

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I feel as frightened, lost and cut off from the world as I was. Months passed. I had no energy. I couldn’t even be thankful for the kindness of family and friends.

Then one day I noticed that the symbolism doesn’t push my buttons anymore. I’ve discovered that passion = enthusiasm + energy + imagination and that triumph = try + umph! It’s far better that I’ve ‘buttoned’ myself up (put my life together), and ‘unbuttoned my lips’ (to try to help and support others) rather than be a whiz at doing up my shirt buttons!

I discovered that being happy doesn’t depend on everything being perfect (after all I couldn’t walk, talk or speak properly) it depends on having hope. Now I’m writing another book about all the adventures that have happened because of the book and my speaking activities.

I’ve discovered so many things about living with a brain injury. I’ve never had a drop of alcohol in my life yet it’s like I’m drunk all the time. People look weird, distorted. Getting dressed is easier said than done and setting the table is a challenging multi-tasking job. I still sometimes catch sight of myself in a shop window with my buttons done up incorrectly! Although the goal of doing up my buttons set me on the path to where I am now, the symbolism doesn’t push my buttons anymore. I’ve discovered more important things.

‘So what!’ I say to myself. I’ve discovered that passion = enthusiasm + energy + imagination and that triumph = try + umph! It’s far better that I’ve ‘buttoned’ myself up (put my life together), and ‘unbuttoned my lips’ (to try to help and support others) rather than be a whiz at doing up my shirt buttons!

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Empower

After acquiring a brain injury, Ronnie Telfer has a lot of free time. He fills his days with things he is passionate about. He prefers to think of his cup as half full, not half empty.

What do you do when you have lots of time?

First, look at what you have got, not what you haven’t.

Second, set up goals based on your loves and divide and conquer so that inch by inch, anything’s a cinch.

Third, be organised. I’ve had big problems with this after being critically injured with an ABI 17 years ago. Writing in a diary and looking at it is essential here. It also helps to write tasks on note-pads and tick each of them off one by one.

In organisation, I have learnt not to be overly ambitious but be simple.

Fourth, bring balance to your life. I love going to classical music concerts. With balance comes diet, good medicine and a minimum of 30 minutes exercise a day.

Fifth, find good causes to support. You can’t just be a consumer, we’ve got to feel like contributors in some way. I’ll never have any children but I’ve got ‘my child’ in India with World Vision. I have felt really discouraged and low at times but Pushpa has at times been a great reason for living.

Sixth, always be positive in every movement, thought or deed. You will become a success story when you’re enthusiastic about whatever you’re doing.

Well, this essay is a summary for all of us about living a successful life. If I didn’t have ABI I couldn’t have written it.

I know, you hiccup and get frustrated along the way. I know, I haven’t been healed. I know, I struggle to play the piano. I know, my injured ankle hurts. I know, my brain roars in agony. I know, I’m indoors most hours. I know, I’ve had chronic fatigue syndrome for four years. I know, I don’t see the answer to my prayers. I know, millions of people go to bed hungry.

But we don’t go to a footy game to see the final score, we go to see the struggles, fights, team effort, thrills, tensions, problems, battles, and difficulties. It’s the journey which counts, not the destination.
Wheelchair dancing all the rage

Queensland amputee Scott Kenney’s passion for dance has helped him have heaps of fun and make some great friends.

I’ve always loved to dance. I’ve always loved to perform. Last year I discovered a stage on which I can do both…Wheelchair Dancesport.

In January 2006 I found out about a group of wheelchair dancers that meet at Morayfield (north of Brisbane) every Saturday. That day I enrolled in the very next class.

Saturday 28 January 2006 is a day I’ll never forget. I arrived at the class early, which is typical of me when nervous. I didn’t know what wheelchair dancing involved. The class was held at Morayfield Park Leisure which was well set up for wheelchair access, with ample level parking, no stairs and fully accessible toilets. I sat patiently in the foyer area and soon wheelchair dancers started arriving.

I’d been out social dancing before, in nightclubs etc. But rarely did I see anyone else in wheelchairs. So to see one, then two, then four, then ten wheelchair dancers come through the door blew my mind. I couldn’t wait to see how they danced.

My coach Lynette and the whole group welcomed me and invited me to watch their first dance. The music started. Then the dancing. Oh my God this was beautiful. I remember having goosebumps and shedding a few private tears of joy. I’d finally discovered what felt like home…people of all differing abilities sharing a love for music and movement.

I was invited to learn my first ever ballroom dance. So much smiling, so much laughter, so much fun. I met everybody that day, a group whom I now consider wonderful friends. And since I started, more people have joined.

For those who are interested, there are competitions to enter. You see, wheelchair dancing is a sport practised in more than 20 countries worldwide. Holland, the birthplace of the sport, just celebrated their 25th anniversary of dancing. And it was at this very celebration that Australia took its first steps onto the world stage of competition Wheelchair Dancesport.

Over Easter 2006, a team of ten Australians flew to Holland and danced. I was a member of that team and it was a trip of a lifetime. So that’s my diary from my first three months of dancing. Since then I’ve continued to dance and made more new friends and had more fun. The true beauty of the sport is that anyone can participate, no matter what their level of ability. You can learn ballroom, you can learn latin, you can have the time of your life. At the very least you’ll make new friends and dance to beautiful music.

Where is wheelchair dancing available? There are very few qualified wheelchair dance instructors in Australia. Lynette Gordon-Smith is the current National Coach and she may know of some instructors based in Victoria. You can contact her by ringing 0434 921 012 or emailing info@wheelchairdancesport.com.au

In April 2006, I moved to Byron Bay where there are no wheelchair-specific dance instructors or classes. So I took a proactive approach and introduced myself to able-bodied professional dancers. I asked these professionals, who normally teach able-bodied clients to dance, to adapt their teaching to incorporate my wheelchair. The results have been amazing!

My advice to anyone wanting to dance in the absence of any formal wheelchair dance instructor, is to approach your local ballroom/tap/ rock n roll/ballet/latin/hip hop etc. dance instructor and challenge them to think outside the square and incorporate your wheels with their steps. It blends so beautifully and reinforces a strong message of integration of the ‘disabled’ with the ‘abled’ – a message so vital for our society to see and hear.

Feel like boogying the night way? Club Wild organises regular dance parties for people with disabilities. Based in Melbourne, Club Wild can be contacted on (03) 9326 9970 or www.clubwild.net. Be warned: these dance parties are seriously fun and funky!