

POETIC LICENCE



Shelagh Brennand

54, Author, Stroke Safe Speaker, Motivational Speaker,
(former UK Detective Inspector and PI in Australia)

At 49, I was living the dream. I was a successful private investigator on the Sunshine Coast with good management of workload and family life. On the 15th of April 2013, I was gardening on a hot day with my son Patrick, who was 11, and came inside for some water as I felt hot and nauseous. I put my head into the toilet to be sick and blood burst through the basilar artery in my neck and into my brain and knocked me out. Patrick found me collapsed and drifting in and out of consciousness, unable to speak, as I had no voice, and unable to move my right side. A friend came by unexpectedly and they called 000. I was blue-lighted by ambulance to Nambour General Hospital. My husband was working away but he was contacted by the friend and told I may have suffered a stroke. The paramedics were excellent, but I couldn't communicate and felt scared, confused and helpless. I was scared of being disabled. We arrived at accident and emergency and the junior stroke doctor spoke with my sister but didn't include me in the conversation. I could understand but

not talk. I felt frightened and upset and excluded from potential decision-making but was then asked to sign a form consenting to the clot-busting drug – which had risks of death and severe disability. It was very frightening. Stroke physician Dr Rohan Grimley attended to me and didn't believe I needed the clot-busting drug, which meant no surgery. I felt safe once he arrived and he took care of me throughout the MRIs and CT scans, which were all very noisy and scary.

My husband, David, flew back from work in Arcadia Valley, near Roma, thinking I may be dead! He was frightened I would die. Patrick and David visited me that night and Patrick was scared he would lose me too or that I would be disabled. My sister Patricia was the height of professionalism and practicality as usual.

I only spent two days in hospital and my voice returned after a week. I was walking slowly, but after few sessions of OT in Caloundra Hospital, I was good again. I felt I had recovered quickly and in June flew to the UK to see my nephew get married. In July I flew to Melbourne with David to celebrate my 50th birthday.

Once my birthday festivities were over, I realised that there was nothing to look forward to. I could not see any useful purpose in my life, although I spoke little about my depression and tried to soldier on, thinking I would snap out of it. I wrote sad/dark poetry because my brain would only work in rhyme and I stayed in bed for days because I felt fatigued. I began to cry as I did not know how to get better. Good friends took Patrick to school, so I had all day to stay in bed and cry. Patrick looked after me when he got home and never left the house, which wasn't good for him. My sister booked me a doctor's appointment, where I was given medication, which helped to relieve some of the sadness, but I still felt 'flat' and worthless.

The turning point came in February 2014, when I began exercise/fitness training with a local PT I knew, Melinda Bingley. I'd gained nine kilos and wanted to lose that weight, so I joined a 10-week mind and body challenge she was hosting. I began to realise and was taught: 'Focus on what you CAN do, not what you can't' and I learned to be grateful for what I have and not what I have not. I was already sharing my poetry with other stroke survivors on Facebook and through the Stroke Foundation newsletters and knew survivors were getting better by reading my poetry. What I had to say resonated with them and helped them to feel less alone. I knew I had to publish my book to help others.

The first thing I did towards making the book happen was to consult the lovely Alex – an editor Melinda had recommended. I popped along to listen to her talk at a network event, as Alex had her own history of pulling through, and we met, spoke and connected immediately. In August, I attended two of Alex's book workshops (one where I slept for an hour during an activity because I was fatigued) and I felt that Alex understood me. She just knew what I wanted to do and why I wanted to do it and could see my vision, both in words and the reason I needed to share my experience with the world.

A Stroke of Poetry is literally 'my heart and soul' in a book. When my close friends read it, even they said they had not appreciated how depressed I had been and how much my stroke had affected my outlook on life. I had fatigue most days during the three-month timeline I gave myself from the end of the last book workshop until publication. It hurt my brain a lot but I was still motivated to keep going – helped, I think, by adrenaline.

Alex took the 'hard work' out of it. Sometimes there were days when I just could not answer her queries but she just seemed to understand and made it all okay. She was soon able to gauge my fatigue levels by the words in my emails and she helped me to move forward with each step, guiding me through the process as she'd promised. I cried on the phone several times and she didn't care – I felt she knew how I felt. We knew there was a bond between us and a great friendship in the making, which is true to this day.

Life now is totally different to the way it was before my stroke. My brain doesn't work the same, so I know I can't go back to the investigation work I loved.

Since we worked together, Alex has suffered an accident that resulted in her own brain injury. I'd like to think that it has helped to create even deeper understanding between us and that her understanding of her own brain injury has been helped by my advice and own recovery. Alex has understood that it is a slow process and tried to manage her limitations and she knows the need for rest.

Life now is totally different to the way it was before my stroke. My brain doesn't work the same, so I know I can't go back to the investigation work I loved. I suffer horrible fatigue and if I spend too long on the computer or trying to do anything logical using my brain, my brain packs up. Fatigue can hit unexpectedly and there's

no option but to go to bed and rest – your whole body aches and you cannot function. But I have the luxury of not having to get up each day and go to 'work' in the sense of being in employment. I tend to know how to self-manage my fatigue and still run, cycle, climb, play tennis and walk. My life is fulfilling every day and I am grateful for the smallest thing to the largest, making the most of each day. I thoroughly love speaking to others about my journey, stroke and it genuinely fills my heart with good feelings. At a recent Young Stroke Survivors Stroke Forum stroke education seminar at Townsville Hospital, where I was invited as a guest speaker to talk about my

emotional experience as a stroke survivor, the audience applauded me and some of the OTs walked up to me in tears and shook my hand and hugged me. They said that they would now deal with stroke survivors differently in the future and not just focus on their physical restrictions. That just cemented why I do what I do and I have many other moments like that where people say: "I get it!"

I feel this was always my vocation and am truly blessed to have met some amazing, honest, loving people since my stroke. Without that, I would never have met Alex, who I know will be a lifelong friend. I believe that I was meant to have my stroke so I could educate others, help others and make a difference, however small that may be. It has made me a better person. I no longer look back to my 'old life', as I call it, but look at the tremendous joy I get out of my new one. Life is good.

Now my mission is to advocate for government funding to help people receive critical care in the case of a stroke. Federal government funding is a huge issue as so little gets given to the Stroke Foundation from government. The 'No Postcode Untouched' campaign tries to focus on those living in rural areas as they are 19 per cent more likely to suffer a stroke and quick diagnosis and treatment are essential since there is only a 4.5-hour window for the clot-busting drug. I encourage MPs to share the stroke messages, even by leading a healthy life, so that risk of stroke can be reduced.



Alex Fullerton

51, Self-publishing Consultant

Working with someone who had had a stroke at such an early age was confronting. The author/consultant role is very close, and working with someone my age who had had such a busy career, then been affected by something so random, was thought provoking.

Shelagh's idea was to create more than a book of poetry, and this fitted well with my ideas as a consultant. Readers want more than a passive experience; they want to interact, and to feel that they are being understood. Together we brainstormed the concepts, the content and the reality of publishing, and found a way to bring her ideas to life.

Shelagh was so down to earth. Her Northern English sense of humour, and her detective's pragmatism, made her so easy to work with professionally. However, I soon came up against the legacy of her stroke, and started to learn how long she could focus for, how far I could push her, and how written follow-up and step-by-step instructions were so important. After our meetings, I'd race off to do the rest of my 10-hour work day, and she'd have to go have a lie down. I wasn't to know how that insight into brain fatigue would help me.

Shelagh has a naturally giving personality. Because she can no longer work in a 'day job', she threw herself into other projects and had the time and focus to foster a friendship and create opportunities to strengthen it. I first met Shelagh at one of the writers' workshops I ran twice every year, and she used her special charms to pull all the attendees that day into her inner circle. We worked on charity projects together and attended events. Then when I had my accident, she was right there beside me, using that same irreverent sense of humour and can-do attitude that we both share to help me find my way through the mess.

On the day of my accident, I was an ordinary working mum, running my self-publishing business, as well as a not-for-profit organisation that helped women entrepreneurs. I'd raised my kids on my own while I built my business and the Women Entrepreneurs organisation. I'd remarried a year before, so we have a blended family of seven kids, with two still living at home, one in another house on the farm, and the other four off to university. My husband is a farmer, so he works seven days a week. I spent one week a month flying to Sydney to care for my parents, who were struggling to remain independent. By strange coincidence, they finally gave in and moved closer to me only a month after the accident!

After a few weeks I realised my lack of concentration and balance were more than just shock and whiplash. The diagnosis process from there took a year all up.

My husband and I were both constantly being told to slow down, take a break, you can't keep going at that pace. We were juggling like mad trying to fit relaxation and 'couple time' into our hectic schedules. That day we were doing as recommended, taking a day out for ourselves. We hopped on his Harley and rode out into the hills for breakfast. We decided to come the long way home, up the beautiful winding road through the hills to Montville. We stopped there and bought a couple of pairs of shoes (my secret love) and then had a Devonshire tea (his secret love) before heading home in time to collect the kids.

We were coming around a blind corner, on the crest of a hill in an 80km zone, when a lost tourist did a sudden U-turn in front of us. We didn't stand a chance.

My husband cut his foot in half taking the front bumper off the tourist's car. I was thrown from the bike and woke up in the middle of the road. I suddenly realised I was facing into the oncoming traffic. I knew enough about people being run over after bike accidents for the survival instinct to kick in. I tried to get up but quickly realised my legs didn't work, so got up on my elbows and shuffled to the side of the road.

At first the physical injuries we sustained meant I didn't know I had a brain injury. My husband was in and out of hospital having his foot rebuilt, and my foot was broken in a couple of places, plus I had neck and shoulder injuries from landing on my face, so we were both in coping mode and trying to hold

everything together, with surgery, work, kids, parents and the whole hospital scene.

After a few weeks I realised my lack of concentration and balance were more than just shock and whiplash. The diagnosis process from there took a year all up. Each specialist referred me to another and each came up with another diagnosis. It was overwhelming and I didn't know who to trust or what to believe. In the end, unfortunately they were all right. I had ligament damage, nerve damage, a frontal and temporal lobe brain injury and BPPV, which is an inner ear injury that affects my balance. I was sleeping 20 hours a day and could only focus on anything for a few minutes. I had to hold on to the wall to walk around a corner, and could only drive the car on good days.

I kept thinking I'd snap out of it. I'd survived a cancer scare, an abusive marriage and the Boxing Day tsunami. Surely a bump on the head wasn't going to get me.

The first six months were a blur of hospitals and specialists, plus the awful legal process that goes with a road accident. My GP was amazing and still is. He knew what to look out for as far as the lows and highs of recovery go, and was ready with understanding and patience.



As a natural carer and nurturer, I don't accept help very well. In the first weeks after the accident, with both of us having foot injuries, I had to learn to take help because the most basic things were a bit tricky. People you'd never expect would pop up out of nowhere with an offer to drive the kids to school, or bring a meal over. Others stayed away, unsure what to do, like they wanted me to ask them for help. I was in shock and had an undiagnosed brain injury, so I was using all my energy to do the basics. For once in my life, managing how other people were coping wasn't my main focus!

When people realised I wasn't back at my usual pace, they asked if my broken foot was giving me grief. It was a confusing time because I didn't know what was wrong with me and no one understood why I didn't bounce back. I had quite a big profile in my local community, but the news kept getting worse, and there was never the right time to tell the world something was seriously wrong, so I didn't.

My husband was using a wheelchair for the first few months, and it took about nine months before he could put shoes on. As a farmer, that makes things difficult. For the first six months I cared for him, just bumbling along doing my best, and then as he recovered, my head injury had time to show itself. Some days I was okay, some days I couldn't drive, some days I couldn't even get out of bed.

I was attending medical specialists three times a week, and because of where we live, this usually took a half day per visit. Plus there were my husband's medical appointments, plus the legal stuff, so it became a full-time job. Of course I still had the kids and my parents to look after.

For the first year I focussed on restructuring my business so that I could keep the doors open. I couldn't work for more than an hour a day, so I hired a structural editor, a copy editor and a graphic designer and streamlined the printing process so that I was free to be the face of the business and just do the project management and client consults.

When I got the final diagnosis a year after the accident, I had a strange sense of relief. I'd battled against my limitations for so long and was so tired that to find out there was actually something broken, and no way to fix it was just what I needed at the time. It allowed me to come to terms with my 'new normal', and begin to build a new life. I had to accept that my old life was not coming back, and that my job now was to design a new life based on what was most important to me. Because I had so few useable hours in a day, I was in the strangely empowering position of paring back

anything that wasn't essential. Focussing on my family was the thing that had to stay top of the to-do pile. So I had to let go of my public roles. I couldn't manage both anymore. After almost 12 years, I closed the not-for-profit organisation I ran. We had over 2500 members, all women who I helped find their way through the minefield of business. I also came to terms with the fact that the restructure of my business was permanent. It really was the silver lining to this experience, to have the opportunity to look at my life and choose only the parts I wanted to take into the new, scaled-down phase.

As my head injury symptoms became clearer, I couldn't help relating them back to what I'd learned from Shelagh. The brain fatigue, lack of concentration, losing words, running out of steam half-way through meetings (or even sentences!), these were all things I'd seen Shelagh experience, and manage with grace and poise. I never thought I'd be doing them myself! And yet I was so lucky I'd had such a good role model, watching firsthand how Shelagh put people at ease by being honest and self-deprecating. These were both qualities we shared, so I modelled all my coping skills on her!

My relationship with Shelagh started out with me as the teacher and her as the student, learning how to write and publish her first book and build a career as a speaker. Now, it's the other way around! Shelagh has taught me how to live gracefully with a permanent head injury, and to focus on what I can do rather than what I can't.

These days I still go at a hundred miles an hour every day, but my days are much shorter. Once I've slept (I'm down to 14 hours a day now), done my exercises and seen whichever doctor is on the week's schedule, I just have enough time left to check in on clients before focussing on caring for my husband, kids and parents. My husband continues to have health issues, my parents' care needs increase all the time and the kids will always need their mumma, so there's always someone to care for. I have good days and bad days, and on a bad day Shelagh has taught me the best thing you can do is just go to bed. It's hard to do but when it happens there isn't much choice. My body just packs it in and I need to lie down till it's ready to go again. ■