FINDING YOURSELF AFTER STROKE

COMPILED BY LETISHA LIVING

Finding Yourself After Stroke

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Further to this, some of the stories might cause distress to the reader due to the nature of the content in each of the authors' stories, including descriptions of physical and emotional distress.

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INTRODUCTION

I remember being in the stroke ward at hospital thinking to myself that this can't be right. I couldn't have had a stroke. I am a young person and young people don't have strokes…do they?

It was a somewhat shameful feeling coming to terms with the fact that I had suffered and survived a massive stroke.

One minute I am confident and full of dreams for the future and the next I am a young person with disabilities, full of uncertainty.

I didn't know of any other young person that this had happened to. The information that I was given in hospital had elderly people's faces on it, and the stroke ward was full of elderly people. I wasn't discriminating against them with my thoughts and feelings (my heart felt for them), I just couldn't relate to my surroundings or my experience. Because of this I felt incredibly isolated.

Leaving hospital felt like leaving a giant security blanket behind. If anything were to go wrong, if I were to have another stroke, then at least I felt like I was in the right place, even if I preferred not to be there.

It took me quite some time to accept my stroke. My body changed, my relationships changed, my job and financial status changed, and my independence status changed.

I was not prepared for neuro-fatigue, cognitive changes, parenting issues, identity challenges as well as adjusting to a body that wasn't the same as it used to be. All these things were affecting my mental and emotional well-being.

I felt alone after leaving hospital and returning home. There weren't any support groups, and to be honest, in those early days, pride probably wouldn't have allowed me to participate in them anyway. I tried counselling but I didn't feel it was helping me with my acceptance or filling the emotional gaps that I now had.

After feeling alone for quite some time and not knowing where to turn for validation, I eventually found some Social Media groups full of people just like me.

Finally, I wasn't alone in my experience anymore. Finally, I was connecting with other people who just "get it". They get the neuro-fatigue, they get the independence issues, they get the little things that most people take for granted.

Finally, I felt relatable, accepted, and connected.

Being an introvert, it took me a little while to open up, but I am so glad that I did, as I have now met amazing people all over the world who continue to inspire me on a daily basis.

It made a massive difference to my stroke recovery and to my emotional wellbeing to connect with other working-aged stroke survivors.

And that's the thing about recovery…It doesn't have a timeline. No matter how long ago your stroke was, improvements can happen.

When I look at the circumstances surrounding my own stroke and those of each contributing author in this book, I wonder how much can be done for stroke prevention; for most of the young people I have come across that have had a stroke, the underlying causes are due to biological events, not just lifestyle factors such as smoking, alcohol, poor diet, and stress. All these strokes happened suddenly, unexpectedly and without warning.

We also need to take a closer look at how stroke presents in younger people. Not everyone presents in the same 'typical' way. It took days for my stroke to be diagnosed and I often wonder if my post-stroke disabilities may not have been permanent if I received care and treatment sooner.

Life after stroke for working-aged stroke survivors is something I am passionate about. Young survivors deal with a different kind of grief and loss of our own lives, pregnancy, parenting, relationships, intimacy, identity, and much, much more.

To everyone who is impacted by stroke, *Finding Yourself After Stroke* is dedicated to you.

May these living experiences of each young stroke author within these chapters bring you relatability, connection, inspiration, and hope.

Live
Life
Laughter

This is my story

By Anton van Niekerk

I am Anton van Niekerk. I was born on 28 January 1972 and am 50 years old. I grew up in the Kruger National Park and I live in Johannesburg, South Africa. I am a stroke survivor since 22 February 2015.

“A day without laughter is a day wasted”

On 22 February 2015, at the age of 43, I had a massive aneurism and an arterio-venous malformation (AVM) rupture in the frontal lobe of my brain, causing a haemorrhagic stroke.

On that Saturday, I decided to try and catch up on some pressing work I had not had the opportunity to do previously. I was working until about 12.30 and because I did not want to disturb my wife, I decided to sleep in the spare bedroom. I could not fall sleep, so I was watching YouTube videos on my tablet when I experienced a strange sensation spreading from my toes upward. When it reached my torso, I lost consciousness. I think it happened about 1am in the morning. When I regained consciousness, it was about 3am. I realized I was in trouble because I could not hear, see, move or speak.

I forced air over my vocal cords and tried to shout “HELP ME” but only a faint whisper came out. My cat heard me and made enough of a ruckus to wake my wife up. When she heard the faint “help me” coming down the passage, she knew something was wrong and rushed to the spare room where she found me almost paralysed, deaf and blind. She asked what was wrong and I told her I had a splitting headache, but she could see that there was more going on and called an ambulance.

The paramedics arrived and did a quick assessment on me confirming that I’d suffered a stroke.

After stabilising me they took me to the nearest hospital. At the hospital the ER doctor who treated me conducted various malaria tests (as I had been in a malaria area the month before) and called for a CT scan after conducting a lumbar puncture and finding blood in the lumbar fluid.

The CT scan confirmed I was bleeding in two places in my brain. I had an arterio-venous malformation (AVM), and an aneurism in the frontal lobe of the brain that ruptured. It also showed a possible second aneurism to be focused on later, but that was not considered an immediate threat.

They transferred me to the Krugersdorp Netcare Hospital's ICU immediately, as it was the closest Hospital with a Neurosurgeon on duty. I spent a total of 4 weeks in ICU before going to the Netcare Rehabilitation Hospital in Auckland Park. All I can remember from that stay in the ICU are the hallucinations and the "vampires" that drew blood twice a day.

When I woke up in the hospital, I thought to myself that I would never again return to my workplace, as I was extremely unhappy with my high-pressure job. At the time, I was the Corporate Services Director for the Financial and Fiscal Commission, a Constitutional entity that supported, advised and made recommendations to the three spheres of Government (Local, Provincial and National). I also realized I had been having headaches from about six months prior to having had the stroke but thought I would have it checked out the next time I went for my full medical examination that April.

The Neurosurgeon stopped the bleeding in my brain and then sent me for a second opinion to the Netcare Unitas Hospital in Centurion. There they have a specialised intervention unit that can treat aneurisms much less invasively via an angiogram. The team examined me and determined that they could not assist me and that I should undergo a craniotomy.

I had the craniotomy on Friday 05 March 2015. The surgeon removed the AVM and successfully clipped the aneurism, then on Thursday 17 March, I was transferred to the Netcare Rehabilitation Hospital in Auckland Park where the therapists determined that I would require approximately eight weeks of rehabilitation.

I did not know I’d had a stroke until I arrived at the rehab hospital where they had posters on the wall.

I didn’t accept that I’d had a stroke until about four and a half years into my recovery as I had a very negative connotation of stroke.

I was wheeled into the rehab hospital in a wheelchair, I wore a nappy and couldn’t wash or feed myself. I had intensive Psych, Physio, Speech and Occupational therapies while in hospital. They discharged me from the hospital on Friday 24 April 2015 after 5 weeks, rehabilitation goals achieved. I could walk, talk, wash and feed myself and perform my ablutions.

At the rehab hospital, they had weekly family meetings where the therapists and a social worker would discuss my progress with my family. My father attended one of these meetings and never again. He never accepted my condition and wanted to know why this happened to me. The more I told him “why not” the less he wanted to do with me. I also lost a lot of my friends along the way. People who I thought were close friends just stayed away and eventually disappeared completely. There were a few people who I never expected anything from who stuck by my side throughout.

I was told that I should attend outpatient rehab twice a week for six months focussing on occupational and speech therapy. I also elected to see a psychologist as part of my therapy. The rehab team wrote a motivation to my medical aid with the request. My medical aid approved three months at that time.

On Friday 22 May 2015 I went back to my surgeon for a check-up. They did another CT scan and confirmed there was another aneurism in the frontal lobe of my brain. I was sent back to Unitas, and the intervention team there successfully coiled the aneurism, so I didn’t have to have another craniotomy and all the rehab again. I went in on the Thursday and was discharged on the Friday.

My neurosurgeon said that my recovery should take approximately two years, and anything not recovered would probably never come back. I have experienced it differently. Because of neuroplasticity (neurons that fire together, wire together), you can still recover years after your initial insult. I am still improving, and it has been seven years already.

After my discharge on 24 April 2015, I was concerned about my hearing, as I was sensitive to sounds like radio, tv etc. for months, so I had tests for any nerve damage. None was diagnosed. I also had my eyes tested for possible nerve damage as I was extremely light sensitive (I still wear sunglasses whenever I go outside) and they were also perfect. At that moment I was inactive and dependant on others for transporting me around. I was not allowed to drive my own car yet and appointed a caregiver with a driver’s licence to drive me everywhere. After successfully completing a stroke driver’s assessment, I was allowed to drive again after 14 frustrating months.

Through the rehab hospital I heard of a brain injury association called Headway Gauteng. I approached them for group therapy and once they approved me, I immediately started therapy sessions with them twice a week. The therapy consisted of group Biokinetics, Psych, Speech and Occupational Therapy. I am still attending at present, although the sessions are online now, and will probably continue participating for the foreseeable future.

After being absent from work for 18 months, my then employer wrote me a letter requesting that I give them written reasons why they should not terminate my employment. After an intense discussion at their offices, it was agreed that I would start a 6-week reintegration process at work.

The 6 weeks turned into 6 months whereafter my neurologist wrote a letter to my employer, stating that I was taking strain at work, as I had sustained frontal lobe damage which affected my executive functioning. I could no longer plan or make decisions.

My employer agreed that I was struggling and we discussed the process of putting me on permanent medical disability.

I immediately started attending Headway again, as I had not attended for the 6 months while I was working. With nothing to keep me occupied for most of that time, I approached a biokineticist friend of mine and asked if I could do volunteer work at his organisation. I started immediately doing some admin in his office. I worked for him for about 2 years until he automated all the work I was doing. I then approached Headway for volunteer work, and they gave me basically the same work to do.

As part of my rehab, I have a personal trainer come to my house once a week for exercise and I see a biokineticist once a week for stretching. I also play golf once a month, which helps with concentration and balance.

The only real deficit I have now is executive functioning like planning, problem solving, decision making, headaches, emotional numbness and minor short term memory loss. My personality has also changed, but for the better.

I truly believe the stroke was the best thing that ever happened to me. For the first time, my eyes opened to the world around me, and I could stand back, observe and enjoy what was happening to and around me.

At one point I decided that “from now on I am only going to be happy and positive”, and my life turned around. I now live in the moment with no worries about the future and no regrets about the past. I am just thankful that regardless of what happened to me, I did not lose my sense of humour.

My motto now is: “A day without laughter, is a day wasted”.

My life partner was amazing during this whole time. She researched every piece of information the doctors gave us to fully understand what was happening. She visited me every day, some days she visited twice if I’d forgotten she’d been there already and asked for her. She was with me throughout my rehab in hospital, coming every day to follow my progress. When they set me free from the hospital, she took care of me because I was still wearing nappies and had to take medication every three hours.

Through this whole process we found that a strict routine works best. I keep my diary religiously and make lists for everything I want to do. I also take my daily medication at specific times and include a lot of supplements like Magnesium, turmeric, multivitamins, Omega 3, Probiotics, etc.

My routine further includes household chores like doing the laundry, feeding the cats at night and doing most of the grocery shopping.

I also found a very good brain training game called Lumosity that I play twice daily and try and further my best scores as it keeps track of my progress. I also keep myself busy on Facebook and every morning I started posting a motivational meme and a motivational quote that I get from my diary.

Whenever I get out of routine, like when we go on holiday, I am a handful for my partner. I get bored very easily and cannot cope or focus. Even if I try and create another routine when we are away, I struggle. In the beginning I could not read and I did not watch any movies. At the moment I can read chapters, put the book down and when I read it again I can follow the story. I also recently started watching some series and movies on my tablet.

Don’t ever give up hope. Every day might seem like a struggle but in the end it is worth all the hardships. As I said before, this is the best thing that could have happened to me. Stay positive, always see the silver lining in the storm clouds and you will be happy

.

Lost
For
Words

By Beth Browning

My name is Beth. After suffering an unexpected stroke at the age of 19 I was even more determined to complete my Nursing studies. I have recently graduated and achieved my goal of attaining a position in a busy paediatric hospital. I have a passion for helping others and am pleased to share my story.

My name is Beth. I was born in the UK in 1999 and moved to Australia at the age of 4 when Mum and Dad decided to pack up and go on an adventure with just 2 suitcases and 2 children.

It didn't take long for them to fall in love with Australia and choose to stay permanently. Growing up, we spent time exploring rural and remote WA, and the beautiful beaches, with many great surfing and camping trips. These holidays with our close family friends, is where I believe my love of travel and exploring has come from.

After high school I decided to take some time off to work out what I wanted to do. Eventually I realised that I was born to be a Nurse, and I began my Nursing degree at Notre Dame University in 2018.

My first year went well. I knew I had made the right decision. It felt right and I was happily having fun with old friends and new. My social life was great in between work and studies - all the things I had looked forward too once school was over.

At 19 things seemed to be going my way when all of this changed in an instant. The 27th of August 2019 is a day I will never forget. It was the day that I realised that life could throw stuff at you from nowhere - things you never imagined - just when you think life is good and that everything is pretty 'normal'.

It was a regular weekday for me. I had been to uni, come home, revised for my exam the next day and had dinner with my family before a little relaxing and watching tv. I went up to bed and sent a couple of messages to friends before sleep. It was while I was texting that suddenly, mid-sentence I started typing letters that weren't forming words. It was complete gibberish. No matter how hard I tried I could not type a single word, not even my own name. This is when the panic set in and I knew something was really wrong. At that moment I thought if I can’t type can I even talk? So, I tried to say a sentence out loud to myself and I couldn't form words that made any sense. I tried to say something like “I need to go downstairs” but instead I said something along the lines of “I need to catch the bus” and then “I need to pet the cat”. I was so frightened and extremely freaked out, panicking I ran downstairs to my parents, crying, tears rolling down my face, I had no words to make myself understood or communicate with my family.

All that was going through my head was “what was happening to me” and with only random disjointed words coming out of my mouth it was truly terrifying. I could see the fear, shock and worry written on my parents faces but they remained calm, reassured me, and did the FAST assessment. Mum being a Nurse, and Dad always being calm in a crisis, was what I needed right there and then. They told me they were calling an ambulance and explained why; I remember that it arrived extremely quickly. My Sister was 15 and my brother 12 at the time and luckily in bed so they weren’t aware of what was happening to me.

The paramedics asked me questions and asked about my face, arms and speech as a part of the FAST assessment but only my speech was being affected. I had a heavy head and a bit of dizziness but no problems moving, no tingling sensations and no paralysis.

I was taken to the hospital in an ambulance as my speech came and went intermittently and I was still finding it extremely hard to form normal sentences. I was seen briefly, assessed, then handed over to staff in ED, and then asked to go to the waiting room. The time we spent waiting seemed such a long time when

I still had no idea what was causing me to be unable to talk properly. I kept trying to speak and text, but nothing had changed. It was the scariest thing I have ever experienced and gone through.

My mum stepped in and became my voice and advocated for me and thankfully knew that I needed to be seen as soon as possible. She explained my story once more and pushed for me to be taken through for urgent assessment. The next few hours and even days are still a bit of a blur for me as I had investigations, assessments, MRI scans, Ultrasounds, blood tests and so many questions to answer from so many health professionals. Hours felt like days. I was exhausted, emotional, and still really frightened in case something really serious or even life threatening was happening to me. Looking back on that time now, I can hardly recall or remember big chunks of time during my entire hospital stay. My memory of that time is so disjointed and sometimes blank. I often wonder if this was the stroke and bleed affecting my memory or the fact I was in shock and not fully processing what was happening at the time.

They eventually told me (by accident) the next day "now you know the scan has shown you have had a stroke" and Mum jumped in quickly and said that no one had seen us yet to break that news. So they then went on to show me my scans and explain that I'd had a bleed in the parietal lobe which had affected my speech. More tests would be needed to find out why. This was an extremely confronting and daunting moment, having someone hold up a scan of my brain pointing out exactly where the bleed was, being surrounded by a room full of doctors, nurses, specialists and students all standing over me in my bed. Everyone was amazed that someone so young could have suffered a stroke. This was something I was going to hear often from those who cared for me and that I met in the years to follow.

Over the next day or two I had several tests on my heart and it was found that I had an Atrial Septal Defect (ASD) which is a hole in my heart that had been there since birth but was never picked up before. This hole had allowed a very small clot to form, pass through the hole and travel to my brain and cause the stroke. In a way I do consider myself very lucky that this hole was found in the way it was. I always wonder what could have happened if I didn’t have my stroke when I did. Could it have been worse later down the track? Maybe effected a different part of my brain and left severe damage?

Mum and I talked so much as she sat at my bedside each day about what I was feeling, thinking, experiencing and observing as a young person in hospital. There was plenty of time to consider what went well, not so well, what could have been better or different. I was learning so much about what it was really like to be a patient; the journey from emergency, admission, the many departments I visited, the different health professionals I met who cared for me, and how it was all impacting me both physically, mentally, and emotionally on the journey from diagnosis to discharge. Looking through another lens as a student nurse was one of the biggest learnings of my life and nursing journey so far, and something that will make me a better nurse in the future.

After 10 days I was discharged following more reviews and assessments by medical staff, an Occupational Therapist, a Speech Therapist, a Physiotherapist. I was also given a Stroke Foundation "My stroke journey" booklet by the Clinical Nurse Specialist, who gave us as much information as she could, and answered some questions for us.

At first glance the booklet didn't seem to be relevant to a young person like me or have answers to my questions and worries in a way I thought it might. There were lots of medications, Dr's letters and instructions about what was next for appointments and heart surgery to close the hole in my heart. I was so anxious and scared about what was next. What if every time I opened my mouth the wrong words would come out, or what if I had another stroke? The surgery to close the hole in my heart was a month or two away, but least I was going home with my family and would have their love and support throughout my recovery. All I could think about was getting back to normal, seeing my friends and continuing my studies. None of this was mentioned at the hospital. I felt alone, isolated and lost, having to navigate my way back to uni and slot back into my normal life with my newfound diagnosis, health challenges and a fatigue that I couldn't explain or understand alongside an altered sense of who I was.

In September 2019 my recovery journey began. I was so lucky that one of my first outpatient appointments was with a wonderful, kind, compassionate and extremely supportive Occupational Therapist. I was reassured every step of the way through multiple cognitive assessments to see if I had any deficits that would prevent me returning to my studies, work or cause any barriers to my life and future learning. We did tests that seemed trivial and basic, and they monitored my speech, but I felt the tests were so simple that if I had a more complex or deeper-rooted problem with my communication that it may not be found. Everything was happening so quickly, and everyone discharged me from their care including OT, Speech and Neurology. I still wondered if they had just rushed me through as quick as they could because on the surface, I looked fit and well with no real obvious problems. I now know the Neuro-fatigue, anxiety, depression, sleep problems, emotional and physical exhaustion would come later down the track, but no-one shared that information with me.

Over the next few weeks, I tried to rest, have time with friends, and learn more about stroke and that's when I came across the Stroke Foundation and found out how they helped people like me and my family. It was Stride 4 Stroke month, so I kept busy by organising a fundraising event in our community to raise awareness of young stroke, give back to others and turn a negative into a positive. It was great to meet other younger stroke survivors and their families and share my story and lived experience. It made me feel less alone.

After my heart surgery on my 20th Birthday and my quick recovery, I returned to university, got my driving license back - it was suspended after my stroke (that was a shock!) - and I started to enjoy life a little more again. Over the next 6 months I learnt to manage my chronic fatigue, rest when I needed to and listen to my body more and more as the time went on. I felt 'normal' but there were days where I physically couldn't get out of bed or function without sleeping 12+ hours at night and then having a long nap during the day.

My family were supportive and helped me when I needed a break. They would ask me what I needed but would respect my privacy, independence, choices and decisions so I could carry on with living my life on my terms.

I would question whether I was being dramatic or whether I was just tired from a big day like anyone else would be. It became really hard to explain to people that the tiredness I felt wasn't just the feeling you have when you've had a bad night's sleep, but an exhaustion where you feel like your body won’t continue to function if you don’t lay down.

I do still struggle with comparing my journey to others and wonder why I should get to complain with no physical impacts of stroke. I get frustrated with myself being 21 and feeling exhausted after doing next to nothing, even though the support I have received over the years has been honestly insane, and I know I wouldn’t be where I am today without the family and friends I have around me.

Learning to live life after stroke is not easy. I had not really spoken to anyone my age about their experiences and looking back, peer support would have really helped me. It wasn't easy to explain to friends, people that knew me or new people I met after my stroke, how I was doing because they only saw me as ‘well’ and ‘back to normal’. They couldn't see my hidden challenges which was extremely hard. I felt like a toddler who couldn’t function without having a sleep or getting grumpy when they were tired, and there didn't seem to be a fix or ‘cure’ for this unbearable tiredness.

Since my stroke I have connected with young stroke survivors online and through the Stroke Foundation Young Stroke Project where I now volunteer on the lived experience working group. Giving back in a way that can bring about positive change has really helped me stay positive and move forwards with my life.

Storytelling and sharing my lived experience has helped me find my confidence again and I have had some amazing opportunities to grow as a person. I got to record a podcast on self-care with “The Happy Nurse”, talk about life after stroke on a Young Stroke Project podcast, be a guest on the radio to raise awareness of stroke and how to recognise the signs with FAST, participate in co-design roundtable discussions, projects to educate health professionals, and contribute to this book as a co-author. I never imagined I would have been invited to do some of these things before my stroke and they have been some of the most amazing learnings and experiences, especially meeting so many people all around Australia and the world.

I have learnt that everyone’s story and recovery journey looks very different but we all overcome many challenges to be where we are today. Not all challenges can be seen, and many are hidden. I believe we should always reach out for help when we need it and try to break the stigma around mental health and disability to create a better future and an inclusive society where we can all come together and feel safe, respected, supported and welcomed within our communities.

This journey and life-changing experience has given me so much to think about and things to be grateful for both in the past, now, and in the future. Others taking this journey with me have taught me much. Having a positive mindset, being a little kinder to myself and grasping every opportunity that comes my way to make the world a better place has helped me to cope with the hard days and the down days and live life to the full no matter what.

Mid 2020 my university studies and prac placements were going really well and I was managing to cope with shift work. I had a break coming and was looking forward to travelling to Europe and overseas, but then COVID19 changed everything, and the pandemic took hold.

Although this time has been unpredictable, uncertain, and challenging and although I didn’t manage to travel overseas, I did things a little differently and explored WA, taking time out both by myself and with friends to explore Darwin and Exmouth. A highlight of my nursing studies was getting offered a rural and remote placement in Broome on the paediatric wards and living away from home in a shared house for 5 weeks and exploring the beautiful WA outback, beaches, and communities.

I am looking forward to taking more time off after I graduate and when the borders open again to travel interstate, chase new experiences and explore some places I have never been. The long-term goal is to go back to England and visit my family and I am considering working in other countries during this time to develop my skills and knowledge even more.

I will graduate in December with a Bachelor of Nursing degree which is hard to believe as this time has gone so quickly. Just last week I received the best news I could have hoped to hear; I was offered a Post Graduate Nursing position at Perth Children's Hospital starting early 2022.

I am looking forward to embracing this new beginning as a qualified nurse and I am sure my own personal experiences will be something I will continue to reflect on throughout my nursing career and help me be the best nurse I can be. Because of my stroke I would love to work in the speciality areas of cardiology and neurology along with critical care.

I have met so many amazing and inspirational people while volunteering and working with the Australian Stroke Foundation. I have come to realise that having a purpose, chasing your dreams, and not having limiting beliefs are just some of the things that help you turn negatives into positives after having a stroke, and in helping others I hope to make their life a little easier so that they know they are not alone on this journey.

Love
Blessings
Miracles
And Art

By Bob Borth

In memory of Dr. Karen Malone who over recent years worked with me via Zoom.

God rest her soul.

My name is Bob Borth. I am a youthful 64-year-old who had a massive stroke 10 years ago on the 31st August, 2011, and as strange as it may sound, it was the best thing to happen to me since the day I married my wife, Sharon.

Before my stroke I weighed 340lbs, had high blood pressure, high cholesterol, sleep apnea, a very stressful career in logistics and supply chain management and I didn't exercise.

Now, at 6'1", I weigh 195 lbs., workout daily, no longer have a sleep mask, have normal blood pressure, normal cholesterol levels and I have so much more life remaining!

At 6.15am on August 31, 2011, I was getting ready for work when I realized I couldn’t move my right arm and all my weight (340lbs at the time) was on my left leg because my right leg was numb and wouldn’t move.

My wife helped me lower down slowly to the floor, then called 911.

I’d had a Haemorrhagic stroke.

While being rushed to ICU and after a CT Scan of my brain, with a look of sorrow the nurse told me I’d had a bad stroke. I was 54 years old, very much overweight, had high blood pressure, high cholesterol, sleep apnoea, a high-stress job, and was heavy smoker, so when asked what caused my stroke, the answer was…*all of the above*.

I was completely paralysed on my right side. Right-handed of course and nobody was able to provide success stories despite our pleas.

For the next week I was constantly monitored in ICU and then transferred to Garden City Hospital in Michigan.

Upon arrival, the nurse had heard I was a Detroit Tiger fan, so she had the game on for me when I was introduced to my new home for the next 6 weeks. We became immediate buddies.

My wife was by my side all day, every day. At my bedside and glossy-eyed, she handed me a rock and said “You have been my rock since we first met. Now I am going to be your rock. That rock remains proudly displayed in my ‘Man-Cave’.

My family played an inspiring role throughout. Our attitude was gracious, and our sense of humour made us the staff's favourites.

Mary was my Occupational therapist. Marchin, a very muscular man, was my PT. We worked for a week trying to get any kind of movement in anything!

My wife and I knew all the staff on all the shifts, and we all became ‘family'. One night just after my wife had gone home for the night. I was alone watching the ballgame when an Angel knocked on my door. She came in wearing a nurse’s uniform, but I had never seen her before.

Without looking at my chart, she called me by my name. My right hand was clenched in a fist and would only move when I would stretch my fingers. She told me to grab my fist with my left hand and hold it up to my eyes, then visualize that index finger moving while at the same time using all my strength and will to get it to move. She told me to keep practicing and that finger will move. Then she wished me blessings and left the room.

She was right. After two days of practicing this (which we now know as Neuroplasticity), my index finger moved! I tried it again and it moved again! I threw down my right hand, grabbed the phone with my left hand and called my wife.

“Hello?” she said.

“It moved! My finger moved!” We both started crying and praising God! I was up all night getting my fingers, then my wrist to move. Then worked on developing a grip with my right hand. I wore out the call button getting all the nurses and aides to come in and see.

Such a great way to get hugs!

I started asking about that nurse that came to my room that night. Nobody knew who I was talking about. I described her blond wavy hair and what she had told me but still nobody knew. She never signed in or punched in. Thus, an Angel.

The staff threw a pizza party for my wife and I the following Monday morning. After the celebration it was time to go to work. Marchin loaded me into my wheelchair and began the ride down to the rehab room, but the regular elevator was broken so he had to take me around the lobby across from the main entrance to the other set of elevators. My foot suddenly slipped off the foot rest and as he bent down to fix my foot, the Angel walked out the front door, and looked my way with a smile and a wave.

“There she is Marchin” I said, but when he looked up, she was gone, never to be seen again.

The 6-week stay turned in to only a 3-week stay then I was transferred to a sub-acute rehab center. As they wheeled me out on the gurney, the nurses, aides, doctors, therapists, and patients all high-fived me and gave hugs and best wishes to my wife. It was a bittersweet gauntlet as we headed to another new journey.

We arrived at the nursing home/rehab center where I weighed in at 300 lbs. I had lost 40 lbs. in 4 weeks.

My OT's name was Bob. Bob was also a weightlifter and I remember wishing he was my PT. He took me to the rehab room and did his work on me, then introduced me to my Physical therapist. She was 4’8”, 90lbs soaking wet. She was from the Philippines which created a severe language barrier. Meanwhile I’m looking around at all the other PTs and they are all large, strong looking individuals.

I spoke to Bob later in the day and said I wanted one of those big guys. The next morning, he came to get me and told me he got me a new PT. He introduced me to Steve.

Steve had muscles on his muscles! He was 6’3”, lean and mean-looking as he warned me in his Nigerian accent that he wasn’t going to go easy on me, and, in fact, told me I’d end up hating him, but he also told me it would be for my own good!

I’m like…*bring it on bro*.

Within two minutes he had me twisted up like a pretzel as I screamed into the towel he’d thrown at me. Sharon ran out the rehab room crying.

Sharon returned a few minutes later and Steve told me to take a break. Sharon brought me a cup of water and I whispered in her ear. ”Me and my big mouth!” I said, then laughed out loud.

Bob and Steve tortured me for about 6 weeks. After my therapy I would go back to the therapy room and workout on my own. Bob taught me how to get out of bed and into my wheelchair on my own. Steve, while working with other stroke patients, would keep a close eye on me and provide advice and help when needed.

When the day came to be released, 11/11/2011, they had Sharon park the car out the back, at the end of a long hallway.

I loaded myself into the wheelchair and Steve came and got me. We stopped at the rehab room to say goodbye, then we got to the hallway where he applied the brakes and put my walker in front of me.

“There’s your wife at the end of the hall” he said. “Now walk to her.” So, I did.

My rehab never stopped. From there it was Outpatient rehab 3 times per week. Sharon was my driver.

I called my boss the Monday after the first time I moved my finger. He promised I could keep my same job if I could get enough movement back and I went back to work on 02/04/2012. Again, Sharon would drive me and pick me up.

There was a vacant grocery store parking lot where Sharon took me to teach me how to drive again. The second week of September was when I drove solo to work for the first time. Sharon blew up my phone even though it was only a 10 minute.

Because the hospital staff was like family, I returned to the rehab wing of Garden City Hospital to volunteer. I would visit new stroke patients and tell them what happened to me and give them something Sharon and I never got…hope.

The look in their eyes when they would see me was such a blessing to me.

To this day I strive to bring awareness to potential stroke victims and provide hope and inspiration to stroke warriors through Facebook groups, particularly, “Don’t Count Me Out”.

I subject myself to ‘self-induced rehab’ at Planet Fitness on a daily basis. Two weeks ago, I was walking in as a bearded, well-built man was walking out. We both met eyes and said hi.

“Steve”? I said. He turned and looked at me again. Then he recognized me, and I gave the man that had kept me out a wheelchair the biggest bear hug. People must have thought I was assaulting him!

“How did you recognize me"? he asked.

“Shoot” I said, pointing to his arms. “You need to feed some mice to those Pythons”.

We see each other often now, and he’s going to be a guest on the “Don’t Count Me Out” Podcast soon.

I became a regular of a local stroke support group that brought in two professional artists and gave us a 2-hour class on painting with acrylics.

I now paint. with my once-paralysed right hand. It's a great life!

Growing Forward

By Brenda Booth

Brenda Booth is a stroke survivor who enjoys life. In 2019 she received a Medal of the Order of Australia for her contributions to stroke policy development and research. In 2021 Brenda was recognised for her achievements by the World Stroke Organisation and World Stroke Academy "Women in Stroke Initiative".

Finding yourself after a stroke is a challenge. Like everyone who has had a stroke, I had to adjust to being blindsided by the fact that I'd actually had a stroke, and so did my family and my friends.

I was 41, healthy but needed to get fitter and lose a bit of weight. I was a Registered Nurse working full-time as a State Government Disability Case Manager and was team leader of a multidisciplinary team, supervising staff. I had frequently been stepping into the Disability Manager role. My work was important to me; I wasn't married and did not have children, so my focus was on my career.

My stroke occurred on Easter Saturday 2001. I had been doing some house renovation with my mum's help. Initially, I had a strange fuzzy feeling in my head. I wasn't sure what was happening but knew something was very wrong. I told mum that I needed to go to the hospital. I was planning to drive myself!

Very quickly my condition changed. I lost the ability to speak other than saying "yes" or "no", and then I lost the vision in my right eye and was unable to move my right arm. I remember thinking, "I'm too young to have a stroke".

Fortunately for me, mum recognised that I was having a stroke and immediately called the ambulance. My vision and arm movement began to return whilst I was in the Emergency Department. Although my speech had improved, it was still affected. I was sent for a CT scan and this confirmed that I had suffered a Middle Cerebral Artery stroke.

Twenty years ago, clot-busting treatment called thrombolysis wasn't being used to treat stroke. Stroke Units did not exist in hospitals. Fortunately for me, my Neurologist was ahead of the game and had been instrumental in creating a high dependency observation area within the neurology ward. The ward staff were vigilant and very competent.

On about the second day in hospital, while I was having a follow-up Cardiac Echo, I had my first Transient Ischaemic Attack (known as a TIA or mini-stroke). I lost the use of my hand and my speech radically deteriorated. It was very scary however these symptoms then resolved.

On several occasions, I woke up in the middle of the night with no speech and no movement in my hand, and I would frantically buzz for the nurse. It was incredibly frightening. Because of my nursing background, I knew that every time I had a TIA, I could have another stroke. After each TIA, my hand movement came back, but my speech was progressively getting worse. Expressing words was becoming increasingly more difficult. I had the attention span of a gnat, and I was not able to concentrate. I truly believe that the level of medical and nursing care that I received prevented me from having another stroke. Initially, I was on an intravenous blood-thinning drug (Heparin) and later commenced on Warfarin.

I am so thankful for my family's support and assistance. My sister Carol who is a doctor, was the only reason I was able to navigate what was happening to me.

I was in hospital for about three weeks and about a week and a half after I was discharged, I had another TIA, so back to hospital in an ambulance! I was scared senseless. The neurology ward was full, so I ended up in a surgical ward. The poor registered nurses were used to intravenous drips and surgical drains but not an emotional stroke patient who couldn't talk very well. Fortunately for me, after readjusting my Warfarin, I was able to come home.

After leaving hospital, I had community-based speech therapy. One of my main goals was to stay as mentally well as possible. Working as a nurse had taught me that depression after a stroke was a real risk. That was a path that I did not want to go down. Many years previously, I'd dealt with a severe, post-viral depression after contracting Dengue Fever. Having a stroke was enough. I hoped to avoid post-stroke depression and for me being physically active was my best defence.

My stroke risk was still unstable, so my GP said that I could go out walking by myself, but only if I made sure that I had my mobile phone (in case I needed to call an ambulance). So off I would go around the neighbourhood phone in hand. I was incredibly fortunate that my ability to mobilise had not been affected by my stroke. Just being able walk and literally getting out and smelling the roses was the best mental therapy for me.

After my stroke, I went from being an independent woman to suddenly being unsure what would happen or what my future would hold.

In hospital, they discovered that I had dissected my Right Internal Carotid Artery (one of the main arteries to my brain). A dissection is a tear in the artery wall, it took ten years before it was established what had caused the tear and major changes and irregularities in my Carotid Artery. This condition is called Fibromuscular Dysplasia (FMD).

I have had to come to terms with the fact that the blood flow to my brain is impaired. I rely on Warfarin which is a blood-thinning medication. I still have TIA's and reasonably regular neurological "whooshy" moments when I can feel the turbulent blood flow up into my brain. I just hold my breath and hope all is okay.

After the stroke I didn’t have an obvious disability, I looked the same. Consequently, people including health professionals, assumed that I was okay. I struggled with the “hidden” issues from my stroke; my speech and word finding, my memory and ability to concentrate, and the thing that made all of these worse was the mind-numbing post-stroke fatigue.

I did my own investigation into stroke fatigue. Twenty years ago there was very little information available. I spoke with my GP about the impact post-stroke fatigue was having on me. He said that I was the first person who had ever mentioned post-stroke fatigue to him. I became passionately committed to finding out more about it.

I was off work for seven months, and then returned part-time. I was no longer able to juggle the requirements of my team leader role, and my ambitions in the managerial arena ceased to be important. I have never been able to resume working full-time.

Having a stroke made me stop and realise “who” and “what” were important in my life.

Shortly after my stroke, I had the opportunity to become involved with the creation of a Working Age Stroke Support Group. The group was formed by the Stroke Recovery Association NSW and local health professionals who realised younger stroke survivors needed support. This group is called WAGS (Working Age Group - Stroke). The stroke survivors, carers and family members became a vital part of my recovery. I was not alone!

All stroke groups are different however, in WAGS the people in the group are a “family”. We may have different stories, but we all have one thing in common, we all have the lived experience of stroke affecting our lives. The WAGS stroke survivors, carers and their families have become a large part of my life. I will be eternally grateful for their support, love and friendship.

Mantras I have used since my stroke that have been important for me in the way I approach life are “Use it or lose it!” and “How do you eat an elephant? One bite at a time”**.** They help me when I feel overwhelmed and when things seem out of control, helping me refocus on what is important.

A powerful light bulb moment in my life occurred in 2014 when I was critically ill in hospital following surgery that was hugely complicated by my stroke risk. I was back in ICU for the third time, and I had absolutely no control of what was happening to me. I realised that the ONLY thing I had control over were my thoughts. I knew that I had to focus on my thoughts being positive. I started to mentally say “thank you” for everything, including waking up each day!

People who know me well know that I am passionate about productive change. When the chance came up to become involved as a stroke consumer representative with the NSW State Stroke Network in 2004, to work alongside clinicians and advocate from a stroke survivors perspective, I seized the opportunity. As a result, I was invited to be involved in my local area, speaking about my experiences to Health Professionals for the Local Health District Stroke Course. I was also invited to provide stroke consumer feedback at a state and local level.

Twenty years ago, the recognition of stroke as a medical emergency was only just beginning. Treatment and care were starting to change, but there was a lot that needed to be done.

I have had numerous opportunities to provide a stroke survivor voice in many different stroke working groups, events, and forums, at a local, state, national and international level. In 2006

I was thrilled to be asked to be the consumer on a Working Party to review the Stroke Foundation Clinical Guidelines. I have always wanted to use my stroke experience and voice and tap into the knowledge of other stroke survivors to highlight the issues they have faced. I was a bit surprised that the Stroke Clinical Guidelines didn't address stroke fatigue, so during the review process, I took the opportunity to highlight the importance of the impact of post-stroke fatigue on stroke survivors. In 2009 when I was approached again to be the consumer on the Working Party for the Stroke Foundation Guideline review, I was extremely happy to see that "Stroke Fatigue" was included for the first time.

I was a member of the first Stroke Foundation Consumer Council and worked on the Council with outstanding people who had a lived experience of stroke. I also became a member of a Working Party that developed the National "Clinical Care Standard for Stroke" for the Australian Commission on Safety & Quality in Health Care. I was incredibly grateful that I was able to contribute at this level. I have been very privileged to be involved with stroke improvement, best practice recommendations and stroke research development.

In 2016 I was part of a group of stroke representatives who went to Parliament House, Canberra, with the Stroke Foundation, to advocate for the importance of stroke being recognised and funded as a national health priority. TV presenter Chris Bath, Rod, another stroke survivor and I, spoke on Canberra ABC Radio. We talked about how crucial it was to raise awareness of stroke and secure dedicated national funding for stroke prevention, treatment, rehabilitation, and research.

2019 was a big year for me. My coordination and balance had been changing for several years, and in the January of 2019, I had a massive fall, sustaining another brain injury on top of the stroke. I was off work for nearly nine months. Many people did not think that I would manage to return to work, and I won't lie, it was tough. With a lot of readjustment of my expectations of myself, I have been able to continue working.

In June 2019, I was honoured to be awarded an OAM Order of Australia Medal for my contributions to stroke policy development and research. Through my lived experience of having a stroke, I am grateful that over the years, I have been able to use my stroke survivor voice to contribute, to help influence change, and hopefully, to make a difference for other stroke survivors and their families.

I would not be here today had it not been for the medical and nursing care that I have received, and especially my sister who sat by my hospital bed navigating my health care when I couldn't. I am extremely grateful for the love and support from my mum, my family and my friends.

I am continually amazed at the inspirational stroke survivors I meet, either in person or via social media. Sometimes stroke survivors have strong support networks and families around them, but some are toughing it out with limited or no support. Our stroke disability and journeys may be different, but we all have our lived experience of stroke in common, and that links us together.

Thank you for the opportunity to tell my story. Any proceeds that I make from the sale of this book will be donated to the Stroke Recovery Association NSW.

Recovery
Is
Possible

Aphasia won't stop me

By Brooke Allen

Hi, my name is Brooke Allen and I am a stroke survivor. I had my stroke in 2018 it affected my right side, and I was diagnosed with aphasia. I am a wife and a mother, and my goal is to share my story with as many as I can.

I had my stroke on September 4, 2018; I was only 38 years old. I had an ischemic stroke, which affected my right side and I have aphasia. “They” cannot tell me why I had the stroke, but I was overweight and did not have a healthy lifestyle. I was also stressed out with work, I was a smoker, and I was on birth control which can affect it more.

Before...

I’m a mom. I have a son named Koehn who was 12 when I had my stroke, and a daughter named Jessica who was 8. They were busy with sports and band.

I’m a wife. My husband Dan and I like to go fishing, go to car races, concerts, and movies.

I was a Sales Manager for a department store for 18 years, in charge of 9.1 million dollars of merchandise. I worked long hours and was always stressed out about my work and getting the kids to their activities.

The day of my stroke…

On September 4, 2018, I was going to take my husband Dan to the doctor to get a cortisone shot in his back. On the way there I had pains in my stomach. It was horrible! I dropped Dan at the doctor, and I went across the street to the hospital.

They told me that I had kidney stones and I will say *I never want those again!*

They gave me some painkillers, told me it would pass and sent me home.

Just as a side note: I’m not good with medication.

When Dan and I got home I went to bed while he cared for the kids, getting them dinner and then putting them in bed. I think I got up around 8:00pm and my body felt weird. I thought it was the medication.

I was lying on the bed, and I wanted to talk to Dan who was in the living room, but when I tried to get off the bed I fell on the floor. I managed to get myself up and stumbled into the living room, but my speech was slurred and it sounded like I was drunk. I still thought it was the medicine and I went back to bed.

I believe that was the moment when I was having the stroke.

When I returned to bed I went to sleep. I got up again at 11:00pm to go to the bathroom but this time when I fell, I couldn't get up. I tried yelling at Dan, but I couldn’t. I felt like I was in a dream where you want to yell at the monsters but you can’t.

Luckily Dan heard me fall; he ran into the bathroom and he knew I was having a stroke. The right side of my mouth was crooked and I was speechless. He got me up and put me on the bed then called 911.

The ambulance came and Dan asked them to take me to Boise hospital at Saint Alphonsus. They had a stroke team that would be able to take care of my needs. It was 25 miles away but he knew I would be ok. He had to take care of the kids and he called my sister and asked her to meet us there.

When I was in the back of the ambulance, I felt so scared, worried, and panicky!! Was I going to die?? The EMT’s were asking me some questions. I knew what they were saying but I just couldn't give the answers. It was so frustrating!!!

Directly after the Stroke...

When I got to the hospital my sister Kayla, my brother-in-law Rob, and friends, Cory and Dan were there. I remember they were crying. The doctors were running around me taking

CAT/CTI. I don’t remember a lot of the first few days. I do know that I was not able to get a TPA shot, which is an IV injection of recombinant tissue plasminogen activator, because more than 3 hours had passed. The doctor said my stroke was high risk and I would be in ICU before I could go to the recovery unit. Also, my kidney stones were giving me so much pain! My mom Judy said the first couple days I was just screaming in pain because I couldn't have the medicine for the stones. I'm so glad I don’t remember that.

I was in the ICU for 5 days with my mom Judy, my dad Thom and Dan by my side. I had family and friends visit and all I could do was cry. I felt hopeless; I didn’t understand. Why me? Also, the only word I could say was NO! For example, Dan would ask me if I was thirsty and I would say “no”, but I really wanted a drink! It made me so angry!! Would I be able to talk again? Would I be able to walk again or write again? What about the kids? Can I work again? So many questions in my head I did not know where to start! My mom Judy was an amazing advocate for me. She would write down everything! From the doctors to the nurses to the PT to OT and then she would do her research. If she doesn't like something she will tell you! She was my mamma bear!

After 5 days in ICU they moved me to another floor for a week. In that week I started to try to get out of bed. I had a physical therapy team that would transfer me from the bed to a wheelchair and then help me on my feet to walk down the halls. It was hard! I can’t describe it but it's like your right leg and right arm are no longer functional anymore and you had this for your whole life, and it's gone. I still couldn’t get over why this happened to me? Then the kids came and saw me! I love my children, they are smart, funny, beautiful, and so hopeful! I knew when I saw them that I would get off my ass and I would get better every day going forward because my kids and Dan needed me.

After that week I was going to the recovery unit to set goals with the speech team, physical therapy team and occupational therapy team. My days started with physical therapy early in the morning at 6:30am. My physical therapist was Scott. He was determined to get me to walk and get the use of my hand back! He was like a sergeant; if I didn't do something right, we would do it over and over. He was a good man, and I learned a lot from him.

After 1.5 hours with Scott, I would go to breakfast and then I would meet Paul, my occupational therapist. Paul was a traveling therapist and he always made me laugh. We would work on getting dressed, showering, applying makeup, cooking and chores. Having the use of only one arm was so different!

At lunch my speech therapist Tanya would put an Intelect NMES on my face. It would help me with my eating and talking through lunch. After my lunch I would take a nap until Tanya would get me up for speech therapy. Tanya was so patient with me! It was so frustrating! I would tell myself ‘My brain is going to work, and I don’t have to do this’! But that is not how it works. You have to practice, practice, practice every day. I was able to get some words besides no out, but I think speech is more strenuous than physical or occupational therapy

After I was done with Tanya. I was back with Scott again for an hour and then I would have a nap until dinner. After dinner Dan and the kids would stop by and we would play board games or just hang out. After that my mom and I would go for a ride in my wheelchair upstairs to the roof and look out the balcony. Then sleep and do it all again.

I knew that I was doing the recovery for me, the kids, and Dan. I was still upset that I'd had the stroke and still asking "Why me"? One of my friends came by one day and I was feeling down about this, and she said "Why not you? You have always been determined to be the best! So, I know you will kick this in the ass!" She was right! I left that negative feeling and turned it into a positive feeling from that day forward.

I was in the recovery unit for 4 weeks before I could go home. Dan had to do a few things at our house so I would be able to move around. No rugs in the house, two stair railings, chair inside of the shower, chair on the toilet, and a railing for the bed. I came home on October 10, 2018, 4 days before my birthday. I still had the wheelchair for another 1 ½ months until I could use a walker.

Home and Recovery…

I couldn't drive, so my mom stayed with us for a while before she had to go back to Washington State. Dan, Kayla, my mother-in-law, friends and sometimes Uber would take me to outpatient therapy where I still have speech, physical and occupational therapy. I would go to STARS (Saint Alphonsus Rehabilitation Services) 3 days a week for 3 hours-speech, PT and OT. I stuck with this for almost a year.

It was working! I was able to get out of the wheelchair, be in a walker, then be in an AFO brace, knee brace, and for longer walks, hiking poles. My hand is a work in progress. I will be able to write again, it just might take longer. I will be patient with myself. I was able to get my license back with a left foot accelerator and a turning knob so I can drive with my left arm. I graduated speech at STARS and continued to do more speech - practice, practice, practice every day!

When I got home, there was a time that I was angry, emotional, and mean to Dan. I did not do anything about it for almost two years. I don’t why Dan put up with me. I did tell my doctor, finally, and I now take a pill for this, and I talked to a therapist about my feelings. I wish I would have done it sooner. It’s ok to ask for help, I think a lot of us don't do that but sometimes you need it

My Life Now…

I am mom. I have teenage kids. I am a wife. I am a survivor. I'm able to be home more with the kids and help them with their school and sports. I also get to help Dan with the dreams that we want for this family. It can be frustrating because my words do not come out the right way sometimes. But we have a rule at my house: they have to let me try the word three times before they can tell me what I'm trying to say.

I do not work, but I volunteer at American Heart Association Idaho as a social ambassador, Heart Luncheon, and Stroke and Heart Walk. In 2021 I was given a Lifestyle Change Award for making positive changes to improve the quality of my life and health, and inspiring others to do the same.

I try to be active in my life. I work out in the gym 5 days a week, walk my dog Maddie, and ride bikes with Dan. I do a lot on social media to inspire more stroke survivors and aphasia warriors, letting them know that they can do anything! Recovery is possible.

I enjoy talking to others who’ve had a stroke. I joined a group in Idaho with aphasia, apraxia, dysarthria, and we meet once a week. I attend stroke meetings once a month at the hospital. Twice a month I join the zoom International Aphasia Movement

(IAM) in New York. IAM offers FREE speech and language therapy to anyone with aphasia.

Facebook has been a real connection for me with having my stroke and talking to other people that have aphasia. It is a wonderful community because they know how I feel and I can always talk, text, or even call survivors.

I go on Virtual Connections and they are free classes on zoom for anyone that has Aphasia as well. I do a choir, do book club, poems, etc. and speak with other warriors that have aphasia. I'm also in a VIP Club that is trying to get more people in our community to understand aphasia. It's about providing communication strategies and the awareness in our community.

I participate in fall, spring, and summer programs in speech therapy at Idaho State University. It helps the students, and it helps me. I'm like the “guinea pig”. I have a program at my house that helps me with my timing and rhythm in speech and my foot and my arm. It is called an interactive metronome. I am also doing Toastmasters in my community to help me with speaking in larger groups.

Future Goals…

I want to be better than I was yesterday and that's to bring hope, determination, and recovery for me and as well as other survivors. One day I want to run like the wind, write with my right hand and speak in a conference about stroke tools and what aphasia is.

My recovery is not done yet, but recovery is possible, and aphasia will not stop me. I want to share my story with others and let them know it is not the end of the road. It's only the start of a new beginning. It doesn't matter how slow you go as long as you don't stop.

We fight, we will not give up, we will stumble. We will fall but we will stand back up. It might take us longer at times, but we will stand back up and keep fighting.

A
Head
Full
Of
Smarties

By Caitlin Kelly

Caitlin is 25 years old from Brisbane, Australia. She worked in early childhood education for five years. She loves going to the gym and pet and house sitting. Since her stroke she has developed a passion for one-handed cooking and gardening in her veggie garden. However, her biggest love in life is to travel.

Her family would describe her as an old soul. You can reach out to her on Facebook and Instagram.

My name is Caitlin Kelly...My story starts on Sunday the 28th of October 2018.

At just 22 years old I was your average young woman. I was busy travelling, renting my own place, working with children, I had my own pet and house-sitting business and a great relationship with my partner Callum. I'd also just bought myself a better car.

I had seen 20 countries by the time I was 21. A few months prior I had been gallivanting around Fiji, England and Croatia, taking my country count to 21 countries visited by the age of22.

Then, on that Sunday morning, I was planning to go out to breakfast at the local café with my housemate, but I never made it downstairs. I collapsed in my bathroom after stepping out of the shower. I wasn't sure what happened. I was still conscious and thought to myself, 'if I could just get to my knees I can stand up'.

I had seen my Dad do this many times after falls due to weakness when he was going through cancer treatments. Unfortunately he lost his battle with cancer two years prior to this.

For some reason, I just couldn't stand up. My legs were weak. I tried crawling to the doorframe of my ensuite and bedroom and tried to pull myself up while holding the doorframe. I then tried the sink, toilet and crawling to the bed. Nothing worked! My housemate found me on the floor. She wouldn't help me up because she was worried I had broken something. I protested when she wanted to call the ambulance and insisted I was fine. She called the ambulance anyway.

When I arrived at the hospital, I was still talking, and my vital signs were perfect, so they didn't suspect that there could be anything wrong other than fainting, even though, I was on the oral contraceptive for acne. I'd also had a history with migraines with blurred vision.

Hours later a scan of my brain revealed a blood clot on the right side, and I was diagnosed with a middle cerebral artery stroke with mid-line shift, but it was too late for TPA (clot dissolving medication).

I don't quite remember being told I'd had a stroke. It was all a blur and at that point it was quickly paralysing me. I remember being scared to go into surgery, but I felt confident that clot retrieval was a standard procedure and that I'd be okay. Young people didn't have strokes (or so I thought).

There were nine unsuccessful attempts at clot retrieval. I had an emergency craniectomy – this means the doctors removed part of my skull to relieve brain swelling. I was put in an induced coma and then had to have another operation to remove part of my temporal lobe due to concerns of seizures.

I remember waking up from the ten-day coma and asking mum to get my Taylor Swift tickets off my fridge because her concert was that night (November 6). I was firmly told, 'no' by the medical team. Out of all the people that I could have asked for when I regained consciousness, I asked for her!

Because I couldn't go to the concert, the nurses offered me a 'pamper night'. This consisted of listening to Taylor Swift songs on the balcony outside of ICU and then getting hoisted into a shower wheelchair and getting what was left of my hair washed by my mum. The next day I wished mum a happy birthday and apologised to her for having a stroke and ruining her day.

The doctors were impressed by my ability to recall the date despite my brain injury. This gave everyone hope, but my ICU stay was complicated by hospital-acquired pneumonia. I had a nasogastric tube and couldn’t swallow much except thickened fluids.

I remember some things from the coma like giving my sister the middle finger; dreaming of Fiji and squeezing the hands tightly of the people around me when they told me my best friend Jamie (who worked in the hospital on another floor) would be coming to visit me.

Jamie is one of those friends that always make you feel safe and pampered. For most of my hospital stay she gave me massages and rubbed lotions into my skin. The nurses had to come and stretch my limbs for me because I was in pain and needed to maintain the muscle length. Really uncomfortable splinting also did this.

On the acute ward I met my first lot of therapists: physios, occupational therapists, and speech pathologists. The physiotherapist asked me what song I wanted for my first gym session and I requested the song ‘Insane in the Membrane’. The physiotherapist said she liked my style. I just thought I was being funny - it had been stuck in my head a few days prior to my stroke.

I was transferred to the Brain Injury Rehabilitation Unit in November 2018. I still had my nasogastric tube, and I wasn’t able to eat solid food until I’d had a videofluroscopy, which is a type of X-ray where I had food and drinks mixed with barium so the speech pathologist could make sure I wasn’t aspirating. It was cool to watch myself swallow on an X-ray. After this, I could start eating soft food and have normal drinks and I was cleared to eat normal foods by Christmas eve.

It was the greatest gift I ever received especially since I got to have a few hours at home over Christmas It was nice not to have to eat massacred hospital pavlova with no fruit on top. Although my friends decorated my hospital bed with tinsel I still couldn’t get on board with Christmas in hospital. The carollers were special though.

For my first meal after I’d learnt how to do a wheelchair to car transfer, Callum’s older brother Brandon came with us to get KFC. I ordered popcorn chicken, chips and potato mash and gravy. It tasted so good, and it was great eating in my car away from the hospital.

I loved having visits from Brandon because he is a registered nurse himself. I always found him really cool and comforting. I also felt so calm when I’d wake up from rests and see their younger sister Rhianna sitting on the floor waiting for me to wake up. Liam, their youngest brother bought their dog Sammy to the hospital to visit me, and it made me feel really good. Their parents were so supportive which I really appreciated since I only have a small family myself. I was also grateful that my sister truly believed in me. She was sure I would walk again even when doctors said I wouldn’t.

While in BIRU I had a cranioplasty (bone plate put back in my skull). I was relieved to no longer have to wear a helmet to protect my brain! I remember the day the surgeon asked me to sign the consent form for my surgery and I panicked because I was left-handed. I had never written with my right hand before. I apologised for my sloppy signature and asked the surgeon to make sure he ‘put my smarties back in before putting my bone-plate back on. I compared my head to my favourite egg at Easter time - the Humpty Dumpty. The surgeon told me he didn’t think I’d lost any of my smarties.

I took my first steps in BIRU after I’d recovered from my surgery. My approach to learning to walk again was to each session double the number of steps I’d done the previous session. For example, one of the first days I took six steps so the next day I wanted to achieve twelve steps. I continued to do this to work towards less blood thinning injections.

I hid from mirrors in physio for ages because I hated seeing my reflection – particularly my shaved head with 54 stitches in it, and my nasogastric tube. I was concerned that Callum wouldn’t be able to love me when I looked so sick. I certainly didn’t love myself. All I wanted to do was make him proud because I had such intense love for him.

I met lots of other people with brain injuries in rehabilitation. Only one of them was my age and I cried my eyes out when he had to move hospitals.

I have kept in touch with lots of people I met during my stay in BIRU including many of my nurses. I met a lovely volunteer named Kylie who told me she used to be sitting in my position herself. I didn’t believe her for a second. Kylie was beautiful and I couldn’t obviously tell that she’d had a brain injury. Nevertheless, she told me and my mum her story, and we felt both inspired and comforted. I was fired up to work hard and get myself to the point of ‘invisible disability’ too.

I spent a total of nine months in inpatient rehab. After this, I was eventually discharged and allowed to go home to my family home, but not to my own unit. Since then, I have been having weekly outpatient rehabilitation.

I can’t yet use my left arm purposefully. I can’t drive because I have a hemianopia, which means my spatial awareness is not good and my peripheral vision on the left side of both of my eyes is damaged.

I also can’t wear high heels, which makes me very sad, as I have to wear an ankle brace called an AFO (ankle foot orthotic). This makes footwear choices very limited; not to mention how unsightly it is. I really miss dressing like someone in her early 20s.

However, I love to cook one handed and I love animals. I regularly go to the zoo with Callum, and I volunteer at RSPCA. I go out with my friends, and I eat and drink normally. I’ve discovered that I love gardening in my raised vegetable garden and found a new hobby in reformer Pilates and gym. It took me one year after being discharged from rehab to learn to walk without using a cane.

My advice to anyone with an acquired brain injury is:

1) Where you can, do things that make *you* feel like *you.* For me this was wearing mascara and perfume and having my nails painted even when I was in hospital. Feeling good on the outside can improve how you feel on the inside.

2) Be brave and reach out to people who know what you’re going through. They make you feel like you’re not alone and can help you see what recovery, and the future, might look like.

3) It’s important to remember there’s no ‘new you’ or ‘old you’. There’s just ‘YOU’.

4) When going through your rehab journey try to be patient and open-minded. You are stronger than you think.

5) It’s important to remember that your relationships will change after trauma, but you have got to continue working on them and nurturing them and not give up.

I think one of the hardest parts of my experience is seeing your friends moving on with their lives without you and feeling like you’re falling behind when you were once ahead.

As for finding myself after stroke?

The truth is that I’m still searching. I think every day will be a constant and evolving journey of recreating myself and of self-discovery, but I’m excited for my future.

Relationship Rehab

By Caleb Rixon

Caleb is a young stroke survivor, working to mobilise peer-led communities through his social enterprise **genyus network**.

He works with Deakin, La Trobe & Monash Universities, Stroke Foundation & Australasian Society for the Study of Brain Impairment.

His story is featured on Huffington Post, ABC Radio National, Impact Boom, SBS Insight and ABC News.

Surprise! It’s my 24th birthday, and my partner of the past 4 years has unexpectedly whisked me away to spend a night in a fancy-pants hotel on Sydney’s Darling Harbour. I'm sitting on a fancy bed, in a fancy room, wearing a fancy robe and sipping fancy champagne.

I’m revelling in the feeling that I've got it all. After recently travelling to New York City to perform in a new Australian musical, I graduated from the prestigious Western Australian Academy of Performing Arts and secured a performing arts agent. I’ve just finished performing as an understudy in the musical *Altar Boyz* and landed a role in the Australian tour of *Chicago: The Musical*.

I love my career and my partner, an incredible guy with a huge heart who is a significant part of my life. He is also an upcoming performer who shares my lofty goals of performing on the global stage; singing, dancing, and moving the masses. So, we train hard and nurture our bodies to do the tricks we need to perform.

Three days after my birthday, I’m working out at the gym, and five minutes into a Pump class, I feel a smash behind my left eye, and my eye pops out. It’s as if someone with a baseball bat has taken a swing to the back of my head.

I spring up to catch my eye as it falls out of its socket, but I catch nothing. I feel around my eye socket, and it’s still in place. “Okay, something’s wrong. You've overdone it”.

I need to see what’s wrong, so I make my way through the bench-pressing bodies to find a mirror, expecting to see my shattered eye, but nothing. It looks normal. “You need water!”

Turning the corner toward the drinking fountain, I slightly lose my balance. It’s the same kind of feeling as when you get up too quickly and feel dizzy, so I think nothing of it. I’m laser focussed on getting to the water.

When I arrive at the taps, I fill my mouth and lift my head back, but I can't figure out how to swallow. I think “What do you do, again?”. I spit it out. “Okay, Cal. You’re dehydrated. Calm down. Drink some water”. I lean over and start refilling my mouth, but now I can’t close my lips. The water jets into the back of my mouth and ricochet’s straight out. “What the hell is going on?”

I spin around to find my partner peering at me with confusion. I move to a wall to hold myself up and quickly start to explain, “I thought my eye had fallen out, but it hadn’t”. He pushes me his water bottle “Have a drink”. I push it away and collapse to the gym hallway floor. A parade of Nike’s, Asics and Reeboks begin nervously shuffling and surrounding me. “Oh my god” I think. “How embarrassing, Cal. You are the epitome of a drama queen!”.

“4 Minutes” by Madonna and Justin Timberlake continues to pump through the gym, and the voices fussing around me are starting to sound distant. My left side spasms out of control. I’m going to throw up. My heart is in my throat. Something is seriously wrong.

Luckily, a nurse who was working out at the time, identifies the situation, calls 000 and the paramedics arrive quickly. I retell the story of my eye-popping out and not being able to swallow to the paramedic. He looks at my partner and asks, “Does he normally speak like this?” On playback, I hear my slurred speech and eventually, the footlights of my life go dim and the curtain closes.

Whilst the curtain is down and my theatre is dark, my incredible community of stagehands, support crew, and health professionals work together to save my life.

When I open my eyes, I peer through a kaleidoscope and see mum sitting at the foot of my bed. The room is quiet with only a faint echo of Darth Vader sounds coming from machinery surrounding me. She looks comfortable - as if she's been sitting there a long time (five weeks in fact). I call out to her, but nothing comes out. I'm moving my lips, but I can't make any sound.

There were two ruptures in the lining of my brain due to a congenital abnormality called a Dural Arteriovenous Malformation (DAVM) leading to bleeding into my brain stem and impact to my cerebellum, causing a grade 5 subarachnoid haemorrhage. Extraventricular drains were placed into my skull to relieve the pressure on my brain and life-saving surgery was performed involving a partial craniotomy and resection of the DAVM.

My family and friends would simply tell you that a tangle of arteries and veins exploded in the back of my head, and I've had a massive stroke.

The stroke has paralysed my vocal cord and my ability to swallow. I can't sit or stand up and can only see a twisted double image due to damage to my optic nerve.

I've gone from being a budding actor, singer and dancer to a baby unable to walk, talk or swallow - with permanent double vision and vertigo.

My relationship with my partner eventually breaks down due to the pressures brought on by my recovery process, rehab, and efforts towards rebuilding my life. We went from being two ambitious, perfectly matched people to patient and caregiver, eventually leading to the dissolution of the relationship.

Over time, I want to feel young and desirable again. But how do I meet someone? I can't see in nightclubs, I’m permanently dizzy, strobe lights are a nightmare, and I can’t drink because I can’t balance.

The last thing I’m going to do is wear my eyepatch and take my walking stick into a club. I’ve lost my identity, agency and all my confidence with intimacy.

My clinical psych advises I create an online dating profile so I can be in control of how much I disclose and when. But when writing my profile, I stall. Rehab consumes my life, I don’t feel I have much else to share right now and a little tip - writing on a gay dating profile that your interests and hobbies include “learning to swallow” can be misconstrued, and so, I chose not to disclose any of my condition.

Eventually, I get a match with a cute Kiwi dude, and I suggest we meet in a cafe in Prahran. The minute I meet him I internally panic, and judging him on his good looks and preppy charm, I assume I’m not good enough for him and he’ll end the date before it’s even begun.

Unexpectedly, he buys my “I’m cool, calm and capable” elevator pitch, which strategically leaves out any mention of my stroke. But the problem is, he buys it so much he doesn’t want the date to end.

He wants to walk back to his place in St Kilda, from South Yarra, which is about 4 kms away. Another side note, I haven’t walked more than 400 metres since my stroke.

He wants to walk, talk, and make eye contact - things that all “cool, calm and capable” men can do, but I have to concentrate on the pavement and stop every 100m pretending to “window browse” just to steady myself.

He spots his friends and dashes across Dandenong Rd to say hello, so I awkwardly follow him, doing my best “Dandenong Dash”, trying to stay involved in the conversation. I try to appear as ‘normal’ as possible.

We get back to his place and everything I do to hide my situation only makes things worse.

After our walk, my feet are covered in blisters because I’m wearing tight shoes (purchased one-size-too-small to help me balance), so I ask to take them off.

He hears “I wanna get comfortable”.

My mouth has insidiously been pooling with saliva and I can no longer swallow nor coordinate ‘regular-looking-human-breathing’, so I casually ask for a drink. I clock him assessing the scenario: 1) I’ve agreed to go on a date. 2) I’ve gone back to his place. 3) I’m taking off my shoes and getting comfortable. 4) I’m asking for a drink. He raises his eyebrows. I'm thinking “Fuck”.

I discreetly do a controlled landing onto the couch and he jumps in beside me holding 2 glasses of water. “Here” handing me a glass, he goes in for a pash. I freeze. He pulls back and we hold each other’s gaze for an uncomfortably long time. I take a breath and tell him “I had a stroke”.

Immediately, he gives me some space and keeps a hand on my knee to assure me of feeling safe. He discloses a relatable story about trauma in his life. “I would never have known you’d had a stroke. How has it affected you?” he asks. I’m so afraid of being vulnerable, I deflect, as if the stroke hasn’t impacted me as significantly as it has.

After assessing the situation, he tries to lighten the mood.

“How about we grab a quick bite for dinner, get a DVD, and come back here and open up a bottle of wine?” he asks.

At this stage, another walk sounds like my worst nightmare.

“Sounds great”, I reply.

I put my tight shoes back on and we head to the local vegetarian restaurant. With my blistered feet, I’m barely keeping up with him, when suddenly he makes a dash to catch the lights at the pedestrian crossing. I attempt to keep up, but he’s so fast that I stumble, hesitate, and stop. As he gets to the other side of the road, he looks back at me and his face falls.

“Ah, you can’t…”

“Run. No, I can’t run very well. I can’t run.”

We blankly stare at each other, searching for something to say.

Quickly, I move us on to grab our “quick bite” to try and avoid the awkwardness. For anyone with dysphagia (difficulty swallowing) there’s no such thing as a “quick bite”. I use large mouthfuls of water to wash down small mouthfuls of food and maintain the conversation to keep up appearances. After 15 minutes his plate is empty. He sees mine is barely touched.

“You eat like a bird,” he says. I’m embarrassed and nervous he will judge me on my lack of swallowing know-how. Starving, I tell him I’m not hungry and offer him the rest of my meal, which he hungrily scoffs down.

We walk to the DVD store, and he suggests I pick the movie. By this late in the day my eyes are fatigued, and focusing is difficult, but I don’t want him to know; so, I pretend to be excited and pick the first cover that pops out at me. I have no idea what it is other than it’s red. He takes it from my hand and raises his eyebrows “Good choice.”.

Turns out, I’ve chosen a homo-erotic reading of Shakespeare’s ‘Othello’.

We get back to his place and settle in for the movie. Gay Othello finally finishes. He says he wants to watch a second movie and asks if I want to watch ‘Beaches’.

“Sure!”, I say enthusiastically.

“Fuck!”, I scream internally.

I’m so fatigued that I can't converge a single image, so for five hours I watch him out of the corner of my eye, taking his lead and laughing when he laughs, to look like I’m following the films.

Finally, the night is coming to an end. I'm exhausted, hungry, my feet are killing me and I’m so self-conscious that I can’t unfreeze or be truthful about the extent of what’s going on for me. He sees nothing is going to happen and decides to turn in for the night.

He gives me a sincere and wholesome hug and I make my way home.

Despite my comedy of errors, I feel the date has been a huge success. I’m so proud of myself for overcoming the obstacles and getting through it that I want to do it again. But this time, on my terms.

Over the next few days, I fantasise about how much better our next date will be, staging it at my house, in the safe surroundings of familiar walls. Kind of like a giddy 16-year-old schoolboy, I experienced some sort of second adolescence. However, this wasn't the same place where he was at, and he gently informed me he’d decided to not pursue the relationship.

It hurt, and it was hard, but it was right. The truth was, we were at different places in our lives.

Since then, I can’t help but wonder how it might have been if I’d let myself be vulnerable and honest.

Vulnerable in front of him and honest with both of us about what I had been through.

Maybe it would have been different If I’d pressed pause on our dishonest date, taken a courageous, deep breath, looked him in the eye - double vision and all - and simply chose to disclose more of my truth.

Expect
The
Unexpected

By Camille Storms

Camille is a freelance ghost blog and web content writer. She's also a musician and an "Autoimmunee". She loves learning and sharing about how to live life with positive energy and meaning. See www.autoimmunee.com.au.
She's married to the love of her life and hopes to start a family next year

“Now, you’re going to have to dig deep and relive some of your most painful memories,” the psychiatrist said, handing me a sheet of paper. She had given me ‘homework’ a few times throughout my compulsory meetings with her; this was my latest assignment. “You’ll need to be brave, but that doesn’t mean you can’t be afraid; just that you’re doing something despite being afraid,” she continued. Her hands sat lightly in her lap, everything about her pose denoting grace, which was fitting, given her name was Grace. She had a calm and unaffected presence, which was reflected in her gentle eyes as she looked to me. “This is a safe space, Camille,” she reminded me.

I swallowed a lump I hadn’t noticed was caught in my throat. “Okay, I’ll do it,” I replied.

So, there I was a few hours later, sitting down at my laptop to do my ‘homework’, typing away at my keyboard, trying to piece together the story that is my life. Over time, the assignment evolved into this book.

However, to understand *my* story, you need to know *his* story and assimilate *our* story. After all, there is always more than one side to a story. Sharing my story just doesn’t make sense without telling you about him…

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The first time I met Tom in person was on a cool November night in November eleven years ago. We were sitting on a bench in a garden at the mall, and I was sipping a slush puppy, which was basically a glorified frozen Coke - a very trendy drink at the time. The slush puppy probably wasn’t the best idea. I hadn’t yet acclimated to the Australian weather, and I was cold. The frozen Coke dribbling down my chin made me even colder and that probably wasn’t the best first-date impression, either.

While this was officially our first date, I already knew him quite well, as we had been penpals for over a year. In fact, I knew things about him that no one else did. Tom and I shared everything, from the most inconsequential and mundane things about our everyday lives to more intimate details. I knew that he hated the confrontation of answering the phone, but answers texts immediately; that breakfast is his favourite meal of the day; that he sneezes whenever someone touches his nose; and how he felt when his father passed away. I had seen a few pictures of him before we met, so I knew what he looked like going into this. He was handsome, and I got the impression he was tall.

For our first meeting, I wore a nice flowery golden top, jeans, and high heels with very fluffy pink socks. How it was that he was able to think, “Yep, I’m gonna put a ring on that one day,” still astounds me to this day. And fortunately for both of us, he eventually did. Of course, he didn’t propose that day, but he may as well have. He already knew.

Tom has a rare genetic condition called Parry-Romberg Syndrome. It causes epilepsy and hemi-facial atrophy, where part of the face grows slower than the rest. However, he doesn’t bear any resemblance to the many affected individuals you’ll see if you google it. In fact, it’s barely noticeable in him.

So, there we were, sitting on a bench in the mall, under the stars on a clear night. I was sitting like a normal person, facing outwards. Out of the corner of my eye, I could tell that he was sitting sideways, facing me. He was staring at me so intently that it was almost like he was glaring at me. It was a little unnerving.

“What is it?” I asked.

“Can’t you see this?” he asked, gesturing to himself.

I looked at him, puzzled.

“How can you love this?” his hand swept down over his body, then returning to point at his face.

I turned my body sideways and looked at him, *really* looked at him. “How could I not?”

He silently searched my eyes—for what, I don’t know—but he seemed satisfied. He relaxed and turned his body to face forward. Whatever that was, it was over. I felt like I had passed some sort of test.

And so began what turned out to be an unbreakable love. We’ve been through so much together— health scares, travel, moving— but never once losing sight of each other. Not even during the darkest of times, and trust me, stuff got pretty dark.

*****

10 years later…

As I disembarked the plane, alone for the first time having left my husband behind, I was feeling nervous. I already felt tired but now I was also walking kind of funky. I put it down to my migraines. I’ve been having them since 2011, so I thought it was that. My parents were waiting for me in the waiting area in the Bali airport. I couldn’t stop thinking how tired I was, but I could still walk so that was good. As soon as I got to bed everything would be okay, I told myself.

It had been nearly 6 months since I saw my family, they were living in the Philippines while I lived in Australia with my husband. I was so excited to see them, but I was feeling even more tired. Arriving at the hotel, I found my single room was next to my sister and her little family. First things first, I told myself. Bath time! I was going to have a nice, long bath. My legs still felt groggy, but I managed to put myself in. Before heading to the bath, I left a voice message with my husband. I thought I’d said, "I'm fine, you don't need to worry, I'm setting up a bath now, but I've arrived, love you, Bye". But I ended up sending something entirely different. I didn't know my sister was also communicating with him, but he told her he was coming over and he'd booked the first flight available.

Oh yeah, I haven't started to tell you *my* "story". Frankly, it doesn't really matter. Well not to me. And certainly not to my parents. We are family in every sense of the word but I was adopted as a baby and moved to Australia at 10months old. So, as you can imagine, here is where it did sort of matter because I didn't have any medical history to help me understand this thing that was happening to me.

It was 11 o'clock at night when I first started admitting something was wrong with me. I couldn't breathe properly. I couldn't swallow water properly either. As the minutes passed into hours, it was around 3 am when I finally gave in and went to the door that connected me to my sister's room and called out. I tried walking to her room, but it was getting harder to stand up straight, let alone walk.

The next few days passed in a blur, but I found myself in hospital with my husband who'd come all the way from Australia. They ran a CT scan and then an MRI. I recall the doctor telling me that I'd had a stroke and at first, I didn't believe him. How could I, at 27, have had a stroke?

But alas, little did I know that I'd soon be meeting a neurologist.

"You've had a bilateral pontine ischemia - meaning you've had a stroke which affected your pontine region. It's part of your brain stem and it affected you on both sides," the Neurologist told me. I tried to answer her back, but my voice felt as if it had gone. "W-what?" I hesitantly asked. "It's ok we know now that it's probably because you’ve had an autoimmune condition.” the Neurologist calmly said.

“Have you had a stroke before?”, she continued to ask, looking at me expectantly.

"No, she hasn't," Tom answered.

The next several days I learned just how much the stroke had affected me. I couldn’t walk and felt very weak. I couldn’t even go to the bathroom by myself. My husband helped me. He had to hoist me onto the toilet, and it was humiliating. I also couldn’t talk. I just made sounds that – unsurprisingly *not*! - no one could understand except for Tom. After all, over the years, he’d learned how to read me without my having to say anything. Thank God for Tom. It was great to have my own personal translator. He stayed beside me almost the entire time I was in the hospital. The staff was very accommodating, even bringing in a trolley bed for him to sleep on, instead of the uncomfortable chair beside my bed.

The first few days in the hospital in Bali weren’t too scary. Tom stayed with me in my room and he slept by my side and for once, I didn’t mind his snoring. They meant that he was there, breathing the same air, in the same space as me. I couldn’t help but think *I never wanted to be without him again*. He kept me strong.

On the final day of my stay in Bali, after seeing my neurologist, I was given the all clear and was ready to go. Getting to the airport was surprisingly easy. As soon as we got there, Tom made me sit down while he found a wheelchair for me. We wheeled through the small, but rather modern, Bali airport.

We boarded our flight back to Australia. We were flying in business class, and luckily, no one else was occupying the cabin, so I didn't have to worry about feeling self-conscious. After a six-hour flight, we were back home in Australia, but instead of feeling excited, anxiety and doubt filled me.

*****

What happened again?!

As I mentioned before, I have an autoimmune condition in which my own body attacks itself. I was diagnosed with the cutaneous version of Polyarteritis Nodosa (PAN), which means that it manifests in my skin. The blood vessels of my skin are constantly inflamed, and get nodules, or "lumps," as I often call them. They feel like hard, sharp rocks under my skin. A "flare" comes in the form of a barrage of lumps anywhere and everywhere on my body, though they mostly tend to attack my legs. These nodules are also accompanied by arthritis in my knees, hips, ankles, and my least favourite place, my hands. The only good thing about my condition is that it's temporary and migratory, with symptoms lasting weeks or months at a time. Afterwards, I'm left with scars or bruises that show where the last flare occurred.

This was a particularly difficult condition to deal with when I was a teenager, but I've always pushed myself through it and tried to enjoy myself and my life. Still, sometimes, it can be difficult to mask my pain and for others to understand what I'm going through since it is a largely "invisible illness" and not always obvious to outsiders. Still, by this point in my life, I have lived with my polyarteritis nodosa for so long that I don't even think about it; it's just a way of life for me. Well, it's certainly changed since I first knew what it is, I don't experience most of the 'nuisances' of PAN. Instead, I now have the more neurological 'nuisances' that come from stroke such as memory loss. The outer symptoms, I guess could be my walking and the way I hold my gait, but I'm still currently working on improving this. Another outer symptom could be my voice. While I can speak almost as clearly as before, I can no longer sing. It comes out of my mouth sounding weird and disjointed and not at all like I could sing before. However, I think I will repair it in a few years. In the meantime, I play the piano which greatly helps my feelings and lets me feel I still have the music world in me. If I could pass anything on to someone who is sitting in a chair in rehab thinking of all the ‘I used to be...do…’ you know the usual thoughts one might have, I would say, “Yes, you had a stroke; t’s time for acceptance and it’s your chance to prove your body and your worth in your own way. It’s not going to be easy, but is anything worth it ever easy to get?” I now go to Pilates every day with my husband by my side and cheering me on.

Take 2, take 3?!

2 years and a bit later, while I was in the Philippines, I had a second stroke. I feel it was similar to a TIA (Transient Ischemic Attack) because I didn’t really notice but now, looking back, I was really tired around the time. Returning to Australia, I was ordered by the Neurologist to get an MRI which confirmed I’d had a second stroke in the same area of the pontine.

3 years later, I had my final (hopefully) stroke, which was once again very similar to the first stroke. This hit me hard. Not only because it severely affected the way I walk, but I could also feel the difference that stroke can give you. I had to relearn to walk and now I’m going to physio.

Where to next?

To anyone else who has had a stroke, I’m sure you’re very grateful for this second chance. We’re survivors so embrace your second chance (or maybe third?) and make it yours.

Independence Back

By Clive Kempson

My name is Clive and I live in Melbourne, Australia. In November 2015, at the age of 52, I suffered a life-changing stroke.

My life has changed forever and while the differences are hard to explain I have tried to do so in this chapter.

If you would like to connect with me, I am on Instagram - @clive_k1 or you can reach out to me via email at cdkempson1@gmail.com. I'm always happy to chat and help where I can.

My name is Clive Kempson, and on 5th November 2015 I had a “life changing” ischemic (blood clot) stroke.

I was unfamiliar with signs and symptoms of stroke. Being unaware of the effects of stroke, looking back, I had no idea what to look for. Thankfully my (now ex) wife picked up that I might have had a stroke, due to my speech being slurred and my arm not cooperating.

Making people aware of stroke and teaching them about FAST - Face Arms Speech and Time - is now my aim.

An ambulance was called, and I was taken to emergency. I stayed overnight and was moved to a neuro ward, but my symptoms were not that severe, so I was discharged and sent home.

Overnight I got worse and during the day I became unstable and unable to use my arm. The paramedics took me back to emergency late in the evening where I was monitored then moved to the neuro ward in the morning. This was the start of my new life.

It's a Sunday and I missed seeing the doctor. I’m feeling very alone and scared - I’m getting no information on what is going on and what has happened to me.

Monday brought the doctor and two therapists (OT and Physio) it was time to get out of bed with their help. WOW what a weird and scary feeling not being able to stand on my own. I have never felt so helpless in my life, and I’m wondering what happens next.

The OT explained a little bit to me about getting up on my feet to start the recovery process and about creating new neural pathway connections.

The Dr indicated that I’d had a stroke and that they would organise scans to see where and how my brain had been affected.

Time seemed to be standing still but I was being moved today from a single room to a ward of 4 and now I’m feeling embarrassed to have other people seeing me like this.

It was Wednesday before they came to take me for a scan - 6 days after my initial visit to emergency. I had to have an MRI as well. What a claustrophobic experience having my head strapped down for over 20 minutes.

The OT I’d nicknamed *Bossy Boots* came to see how I was feeling and got me up from the chair trying to stand and balance. Now I realise how she was helping me to start my recovery journey.

Its Friday now and they’ve told me that I will be moving to a rehabilitation ward closer to home on Monday which sounded good.

The weekend seemed to last forever, but here we are moving to start my rehabilitation. Who knows what lies ahead for me from here?

The worst feeling for me was the “Loss of my Independence”; having to have help to go to the toilet, shower, get dressed and get up.

Day 11 after my stroke journey started and I settle into my rehab ward for the next few weeks. I meet some therapists and AHAs on the ward, all asking me lots of questions and giving me an idea of what tomorrow will bring.

My diabetes has been up and down, with lots of finger prick testing to check my numbers. I was being woken up at 11pm for another test and being told I needed to eat and drink to stop it dropping to low overnight.

On my first day of rehab in the ward gym, the AHA came to collect me in a wheelchair, as I can’t walk. Standing between the rails was a weird feeling. Doing this was so natural last week.

It is amazing how many things in life that we take for granted!

OT was next, and it was so hard to move my arm, wrist and fingers. My arm was in a collar and cuff to protect my shoulder from a sub luxation. The OT then introduced me to Estim (electrical stimulation) for my arm and shoulder to start the recovery process and help in creating new neural pathways for my arm and hand.

They estimate I will be in here till at least mid-January, which is disappointing when I think about what needs to happen about my business, with work currently being completed, and a planned holiday to Queensland. You might think these are the least of my problems, but I am also thinking about others besides myself.

During my stay in the rehabilitation ward, it became apparent it was about getting me up on my feet and walking. The OT was really about preparing me for life at home, preparing breakfast, lunch and cups of tea safely, as well as showering independently and dressing myself.

I spent just over 5 weeks in the rehab ward, learning to walk, use my arm, see a speech therapist and the ward social worker. There was so much to take in about what had happened, but there was no real discharge plan put in place.

Time came to leave hospital, and I am very apprehensive about going home and seeing people while I am like this. I saw a lady from RITH (rehab in the home) today to tell me I would see a physio and OT during the Christmas holiday period.

Christmas was a little different from normal and being unable to help prepare things made me sad. Feeling helpless and like I was a burden on my family made me emotional. I felt like I was being watched by everyone as I was still not 100% stable.

Home therapy was different, but it was good to have continued support and help getting prepared to go to the rehabilitation centre. I really didn't know how I was going to cope going out in public the way I was.

It's now January 2016 and time to head out in the real world - heading to the rehab centre for the first time. I was fortunate the OT I'd had at home would continue to be my OT at the rehab centre.

Heading there was really emotional for me, and not knowing what to expect. There were so many people around that now I'm scared.

I checked in at reception, feeling awkward as I was really conscious of my speech issues. Here comes my OT, a familiar face which made me feel a bit more comfortable. I was introduced to my new physio who seemed to be very nice and we discussed the plan for the first few visits.

My therapy sessions meant attending the rehab centre 2-4 times a week for the time being, to give me the best opportunity for recovery. Seeing a Physio and an OT plus the social worker gave me plenty to think about and so many questions.

During therapy sessions there was a lack of discussion about what I was being told to try and do. There needs to be a change in language between therapists and patients or clients.

Over the time I have been involved with some personal development of therapists, where we tried to explain the concept of talking about what we are asked to do and the reasoning behind it. It will take a long time to change the dynamic of how we are seen and included in the conversations.

Having spoken with some influential people in the stroke field, it was agreed there may be better outcomes dependent on how the patient or client is involved in the conversation.

Over a period of 12-18 months, I had many different physiotherapists which caused me anxiety as they wouldn’t really know how far I had come, and each would have different ideas. Looking back on this I can now see there are some benefits of having different physios, and different ideas for recovery, and all with the survivor’s best recovery being the goal.

As time went on, I realized setting goals was really important – short-term goals that are achievable and give you that sense of accomplishment and success, and longer-term goals for striving towards for the future – but always being realistic.

There was a lack of information forthcoming about the range of services, help and emotional support that was available.

I had many issues that caused me anxiety and I was suffering depression about my stroke and life. I asked about getting help from my health care provider, to be told they don’t offer that sort of help and to speak to my GP for assistance. I was very surprised they couldn’t help me!

I did a lot of searching online and found the Stroke Association of Victoria and the National Stroke Foundation who were very helpful. I found out that I was eligible for a Taxi Card giving me half price taxis, a Companion Card to help to have someone with me at Sport and lots of other activities. I also found a local free counselling service and a local Stroke support group. While doing this I found many Stroke groups on social media, but not all were a positive influence.

With therapy coming to an end, I was keen to continue so I did some research into medical research and trials in the stroke area. I came across an Upper Limb Intense trial being run by Professor Natasha Lannin at the Caulfield Acquired Brain Injury Unit. It was a trial for evidence-based progress from Botox injections, serial casting and Intense 12-week therapy. Taking measurements at the start and at completion to document any improvement.

From this trial I have worked with Professor Lannin on several occasions and am involved on a stakeholder committee through a local university. Being involved with the direction of research that will help other brain injury survivors has helped me so much.

I also found a Facebook page “StrokeEd Collaboration” where I met Dr Annie McCluskey (OT) and Karl Schurr (Physiotherapist). They run training courses for therapists and have an Upper Limb Retraining course for Occupational Therapists, which I became a participant in for the therapists to work with me over the course of 3 days. This has been a really good experience for me - and hopefully for them as well - learning different strategies for improving upper limb function.

I joined several Stroke groups, both in Australia and overseas, to read other people’s stories and understand what they are going through. I connected with many people around the world with many and varied types of stroke and different levels of recovery. It was so helpful to understand that while we were all were going through different recoveries, we were all connected by our brain injury.

I’ve connected with so many amazing people through social media and been involved in online zoom catch ups, speaking openly without any judgement, finding people who understand the difficulties you can go through, offering support and advice.

I have become involved with the Stroke Foundation, raising much needed funds for them, speaking with State and Federal Government MPs about stroke funding and I’ve been involved with their Stride4Stroke annual fundraiser.

I help raise awareness by speaking about my journey to health professionals in different settings, helping them understand the recovery journey from a person with lived experience and being honest about how I felt - both good and bad. The only way for them to understand how a survivor feels is to speak to them in a group setting, so they can understand and discuss with each other about inclusion of the survivor in the conversation.

I am still in recovery, and having therapy to improve my walking and my hand function. I’m always looking at new ways to help myself along this journey. Don’t give up. It is a marathon not a sprint. You are in charge of your recovery progress.

I have learned so many things about myself and stroke through my journey, some of them I have highlighted below:

- Life has changed so much for me, but I have learnt that there is so much still to achieve.
- To always try your hardest every day, even on your bad days have a go. Get up, get dressed and work at recovery.
- There are good therapists and there are some exceptional therapists who go above and beyond to help you improve for a better outcome.

- Stand up for yourself, no one will fight for you better than you will yourself.
- Mental Health is just as important as your physical health, so reach out to get the help you need. If you don’t connect with the psychologist or counsellor you find, find another one. It took me till my 5th one until I felt a good connection.
- You will meet many new people through your journey; some will be amazing for you and others will be a negative influence. Don’t let the negative people get in your head and drag you down. You are better than that.
- Always ask questions. There’s no such thing as a stupid question when it’s about your health.
- Having a good support network around you will help you be more positive.

Life continues for us all, so make the most of everyday. You will have good and bad days which is normal. Make the most of the good days but remember It is ok to have a bad day and always take the opportunity to move forward rather than stand still.

NEVER give up. There is a great community of people who understand. Reach out and connect.

Strength
In
You

By Cynthia Joi

Cynthia Joi, born September 23, 1982, is a wife, mother of two boys, writer, stroke survivor, F/T student, resilient, employed, and a motivational volunteer.

She is also a *handicapable* comedian that believes in the power of positivity (P.O.P), reminding you that “Strength lives in you to keep pushing through”, and to have “strength through recovery over kneading emotions (S.T.R.O.K.E)”.

Strength in you comes through with a story of resilience and the ability to strive, which means to be strong and live. This chapter, although serious, will consist of a bit of humor as we all need a laugh. The survivor writing this chapter is overjoyed to still have life. I am here to remind you that there is a purpose for your pain, and there is absolutely nothing in this world that you cannot do with a positive attitude. This does not mean that you become a robot and pretend you have no feelings. It just means that you understand things will not always be rainbows and unicorns and you can handle whatever comes your way, so do not sit in sadness. Allow it to strengthen you for you to get through.

My name is Cynthia Joi. I am originally from Chicago, Illinois in the United States of America. I now reside in Colorado Springs, Colorado. I had a ~~H~~emorrhagic ~~S~~troke when I was 31 years old while at home cleaning. My hubby was at work. The only people who were there inside the house were my sons who were then aged three and five. Luckily, my neighbor at the time was in my garage working on my truck.

The date was August 6, 2014. It was sunny and warm outside as Colorado summers last until late September. But wait, before I get into that day itself, let me tell you about a couple of leading things that I feel played their part in this blessing in disguise. My sister told me more than once, after my son and I almost died at the time of his birth; “Sister start taking yo medicine, baby girl”. I was young and thinking nothing would happen to me. You would have thought I would have known better seeing my mom die~~d~~ from a stroke when I was ten years old, but I was stupid. Yes, I am not afraid to admit that I was stupid and naïve about my health. Not fully understanding medicine is trial and error, my stupidity had me taking nothing. Saying stupid shit like "If they don't know what I'm supposed to take, I won't take anything", "I'm tired of being the fucking guinea pig". Silly me, tricks are for kids; I was playing a grown-up game though. All I was taking was exercise, cigarettes, and liquor; still not listening to my body.

Then, there was another situation when I was “stupid”, it is the day to go get the keys for our first house and that is my only task this particular day. So, I get up excited, singing “we got a house”, get me and my boys ready, and ask a friend to ride with me to get the keys. My husband agreed because he did not want me to be alone and we were both excited to show our friend our (new) house. Our friend was elated that we thought so highly of him to bring him to our new home before anyone else.

Anyway, we stopped at Wendy’s because no one had eaten from the excitement, and I had to feed my babies. I ordered a chicken nuggets kid’s meal for my boys, and a Baconator combo for the rest of us, including my husband, because I knew he was meeting us there. Now, what does everyone usually order if available?... A Pepsi. Well, so did I that day. I sipped that thang and a few seconds later passed out behind the wheel. I know you are probably thinking how were you stupid when that was just scary? Let me tell you, hell yea, that was scary, but not enough to make me go to the hospital. I think I had a (Traumatic Brain Injury) T.B.I. before I ever heard of T.B.I. or knew what that meant. My husband asked if I wanted to go to the hospital and I said no, and of course in hindsight, I wish I had. But hey, everything has a purpose, and this was part of mine.

The night before was not the best and there were some things brought to the surface that I needed to work on. So, I woke up with a plan in mind to clean my house from top to bottom, go restock my house and enjoy my kids on the trampoline that use to be in the backyard before the storm took it away. But that is a whole other story. I woke up in a new mood, feeling like a change was coming but unknowing to what extent that change would impact.

I am doing my normal routine of a morning dump while smoking a square (cigarette), showering, brushing my teeth, and putting on my clothes. I go into the kitchen and make my babies some oatmeal because it was easy, fast, and I wanted to get to work so when the hubby gets home, it will feel like a new place. Oatmeal is made, check. Now let me sit with them while they eat, because if I would have left two toddlers at the table with oatmeal, I would have come back to a tragedy. After making sure my young ones were fed and entertained the deep cleaning began in our four-level house.

Starting in the basement and working my way upstairs, walls were wiped down as old school, represented, soul music played in the background. It reminded me of my mama and Chicago sounds like “Love and Happiness” by Al Green. Singing, vibing and cleaning was the name of the game, and I was great at it. I got the walls done and now it’s time for the carpets, and that shit was everywhere except the kitchen and bathroom. Well, no need to complain. Just get it done, and so, I began. The sub-basement was first, as I started shampooing the carpet and singing more soulful music, this time I can remember singing "Man in the Mirror” by Michael Jackson. I can recall bits and pieces before the shit hit the fan and one of the things I remember about this song was saying to kids as they watched me from a distance looking at me like this lady crazy as hell but, I told them, we have to “Be the change we want”. Yay! Sub-basement is complete, so on to the family room where the pool table is. This should be a fun room.

In the family room, not only is there a pool table, but this is where my Zero, an Alaskan Malamute would live. Needless to say, there was hair everywhere and it clung to anything and everything. It was hell shampooing this room, and it had stairs. I don’t know if you are familiar with the Kirby system, but that machine is heavy and inconvenient; this is what I have been using the whole time. Boom! I made it to the living room; I am feeling accomplished! Halfway through the struggle before I can fully enjoy what I have done, I thought about it and decided to do the living room last because my kids were chilling there. So I went to the top floor, toward my boy’s bedroom. While cleaning this room, the chemistry in my mind did something that in my opinion, was meant just for me. I am cleaning their carpet and I start feeling “different”, my left leg fell asleep, you know those tingles you get through whatever part of your body that has fell asleep, and for me, that was my left leg and foot. So, I did what everybody does and stomp on it and then, I did the best thing I could do and that was to call my husband. The phone rings and he answered, "Bae, I don't know what it is but something just doesn't feel right with me". He said, "you ok"? I continue with "I don't know but I don't feel right". He said, "okay, I'm on my way". Now, I am still not thinking of anything. I'm just like maybe I'm just tired from all the cleaning and I have not eaten yet. So, I stopped with the carpet and thought it would be best to go take care of myself because I'm a bit dizzy. I made it downstairs to the couch, sipped water, and immediately had to pee. I stood up and I hit the floor within a three-second period. In front of my kids who were too young to have to experience this. I remember peeing and throwing up on myself. Luckily, I had the sense to call my hubby beforehand because he had my neighbors in my garage working on my truck at the time and his wife was familiar with the signs of a stroke. I can recall her voice and hearing “Joi, stick your tongue out, you are having a stroke” That sentence did not register in my brain or my heart because I was fighting in that hospital, wailing my affected arm saying, "I want to go home". I remember beating the hell out of a certain nurse. A couple of weeks later, I had to find her and apologize. But that next day, I was beyond pissed off at everything and everybody, including God. Thinking why the fuck did I ask for help to be a better me and have a damn stroke. My speech was very unclear, I was unable to swallow, or even sit up on my own, let alone walk. I was beyond overwhelmed with mental and emotional pain, constantly thinking why me! Then something happened; I took a nap and woke up anew. The first thing I thought was "well, why not me?" Everything I have ever been through in life, from being molested at an early age by a relative, losing my mom at ten, being pimped out, and the separation from my sisters were just a few of the tragedies that happened in my life that strengthened me to use that fire to burn up the thought of stroke.

All I kept saying was "I'm still here", andEd "my mama did not make it, but my kids still have me!” That led me to start speaking life into myself and my situation, saying "There's a purpose for my pain", "My kids saw me fall and they will watch me rise", "I am not what happened to me". I began early excited for therapy knowing that is what I needed to be successful and redefine what the word stroke meant. The therapist would fight for who would work with me because I was driven and never said “NO!”, only “Yeah” to the point they put me on punishment in the hospital for overworking even after therapy! I was determined to have strength through recovery over kneading emotions or S.T.R.O.K.E.

Every day was a new obstacle to face and what I thought was the third day was more like the third week and it finally occurred to me, my left hand does not work so I cannot style anyone’s hair anymore. I had been braiding hair since I was 7, so I started crying, saying over and over again, "what am I going to do now"? My husband said you are going to work on getting healthy and home, and everything will fall in line.

On September 11, 2014, I went home scared out of my mind for my new life. For a couple of weeks, my neighbor was a great help to us, taking my oldest to school, as he had just started kindergarten. That depressed me because I was very active in my kid’s life in school. Not long after that, I got mad and said, "You know what? I'm taking my son to school.” And I did. I got in a tiny accident in the parking lot after I dropped him off, thanks to my left side neglect, but I did it! That was part of the beginning of "I am not a handicap, I'm handicapable! I can do everything everybody else does, it just looks different and slower, but it gets done". I say that to say “life will be life and you will have setbacks in it because you are human. Embrace every moment because they are all growth opportunities. Never forget anything worth having will be hard and you are worth it. Try to focus less on why me and more on why not me because there is nobody who can do what you can do, like you, including going through a storm like this. You can't have flowers without rain, and you can't know good without the experience of bad. Keep pushing through with the strength in you!

Emma 2.0

By Emma Beesley

Emma Beesley was a lawyer working at the Family Court of Australia when she had a stroke at the age of 33. She is passionate about aphasia awareness and stroke in young people.

On Friday the 9th of September 2016, I woke with a bad headache and sensed something was wrong. I didn’t go to work and spent the day in bed trying to ease the pain. I loved my job. I am a Lawyer and was working as a Judicial Associate in the Family Court of Australia in Sydney.

I had experienced headaches and migraines before, but this one was different. I was crying to my fiancé, saying something is not right. He said if it was still bad on Saturday, we could go and see a doctor.

That evening I became unsteady while in the toilet and I tried to call for help but no words came out. My fiancé and his parents found me about 15 minutes later. I’d managed to open the door but then collapsed. They dragged me into the spare bedroom and placed me on a blow-up mattress and they believed I would wake up after a few hours and be ok.

I realised that I was suffering a stroke because I had no feeling on my right side and I knew I was in big trouble. I thought I was telling them to “call an ambulance, call an ambulance”.

I didn’t know how to get their attention because my words made no sense. After at least an hour I was thinking to myself “What am I going to do? What am I going to do? Maybe I’ll vomit to get attention.”

Eventually an ambulance was called, and it took me to Wollongong Hospital where I was rushed through casualty to have an MRI. I had suffered a left middle cerebral artery stroke due to a clot in the carotid artery. It was too late for me to be transferred to a Sydney hospital to have clot retrieval surgery. Instead, drugs were administered to dissolve the clot, but that caused bleeding in my brain.

My stroke was **completely** unexpected. I was healthy and had no underlying medical conditions.

I was in the neurological ward Intensive care unit and I was in a lot of pain that first night, but when I woke the next day, I felt better, however I was unable to talk. I recognised my family who'd visited but I struggled to say their names. My sister Katrina became the honorary parent, keeping my Mum and Dad informed of my condition as they were in Portugal on holidays.

After 2 days I was moved into a single room in the Neurological ward and began physiotherapy and occupational therapy. I remember feeling very emotional. I was trying to put on a brave face, but I felt all alone and scared.

My parents arrived back from Portugal after 3 very long flights and came straight to the hospital on the 6th day after my stroke. I was so happy to see them, crying when they came to hug me. I couldn't say their names. I called Mum "Wednesday" because everyone had told me that they would be home on Wednesday!

From then on, they came to the hospital every day. They were there to see the Doctors on their rounds and stayed until I'd had my dinner. They became my advocates as well as carers, speaking with the Registrars, nurses, my therapists, and the social worker, to find out as much as possible about my prognosis and care.

In the absence of speech therapy, they did what they could to try and help me relearn words. I remember Dad would not let me eat my food until I could name the utensil to eat it with!

Every day was the same. It was demoralising having to rely on nurses for showering and toileting. I wondered if I would wake up one day and my words would be back.

One day Dad decided to try playing music on his phone for me to listen to and the song that first appeared was “I Will Survive” by Gloria Gaynor. I started to sing along to the song. I could not speak more than a few words, but I could sing along to a whole song. The part of my brain that recognises music was not affected!

The physiotherapists saw me Monday to Friday and pushed me to do just one more ‘bridge’ exercise to increase my core strength. I was smiling on the outside but internally I was worried that I might never be able to walk again.

All this therapy was very tiring. So was the daily visitors who came to see me. It was lovely to see my family and friends but being unable to say more than a few words meant I found it hard to concentrate on their conversations. I was often exhausted by their visits.

Two and a half weeks after my stroke, a bed became available in Port Kembla public rehabilitation hospital. We had been told that here I would receive daily therapy from physiotherapists, occupational therapists, and speech pathology.

Unfortunately, this was not the case. I was moved there a day before a long weekend, and with many staff extending the break it meant I spent four days in bed not seeing anyone.

To say I was unhappy was an understatement. I was frustrated by not being able to walk and talk and wanted to begin the journey to recovery as soon as possible. I felt alone and upset about what had happened to me, and Irritation at not being able to do simple things for myself was commonplace. Being a young person in a rehab hospital that does not just treat stroke patients was depressing and lonely.

Eventually I saw the physios Monday to Friday, and I was pushed and pulled and spurred into action to stand again, and then walk. Mum and Dad attended the hospital every afternoon and were taught some extra exercises they could do to help me gain strength. I longed for their visits as a means of distraction from my thoughts and the chance to work on getting better.

Speech therapy at Port Kembla was almost non-existent. I had a whiteboard with my schedule written down and I was frustrated and annoyed when no one turned up.

The Occupational Therapist I saw did not encourage me. Being told “You had a stroke. You’re not going to get better than you are” was not the news I wanted to hear. Nor was the news I received from the Doctor at the rehab hospital who told me my recovery would plateau 9 months after my stroke.

I was finally able to walk out of the Rehab hospital with a stick and an AFO on my right leg. It was just before Christmas. I was excited to go back to my house that my fiancé and I had moved into just 6 weeks before my stroke. My fiancé had visited me daily after work, and at first, he was there for me. Gradually, though, I felt him become distant as time went on. Unfortunately, our relationship failed.

Without being able to communicate my thoughts and feelings I felt depressed and alone. He gave up on me and I had to move back to Maitland with my parents. This was another devastating blow to my self-esteem. It was 15 years since I had left home, and I knew no one in the area.

I became an outpatient at Rankin Park in Newcastle and then at the Hunter Brain Injury Service (HBIS). The Doctor and therapists I encountered there believed in my ability to achieve a good recovery with hard work and determination and I was placed on a Botox trial to assist my right ankle and arm.

I went to live in at HBIS for 9 weeks at Bar Beach, Newcastle. There I attended from Monday to Friday, living in, learning to cook with one hand, going shopping and out in the community. I had physio and speech therapy every day, OT every second day and weekly clinical psychology consults. This place was great for me. I knew I needed to do more, and they encouraged me in every way.

The biggest turning point for me was finding out that there was a name for my communication problems. Speech therapist Georgi told me that I had aphasia and it was a light bulb moment! Yes, I had a stroke, but I also have aphasia. I could understand what was wrong with me and that gave me hope that I could improve!

I have Broca’s aphasia, which means I struggle to get words out, often speak in short sentences, and omit words. It’s extremely frustrating as you know what you want to say but can’t get the words out the way you wish. I also have trouble spelling words and can only work on one task at a time.

As part of developing an NDIS plan it is necessary to set goals for living independently. My priority was regaining my licence, then trying to find some type of meaningful work leading to an eventual goal of living on my own.

In 2018 I began relearning to drive a modified car. Unfortunately, the NDIS would not pay for modifications to my own car until I gained my licence. It took a while, but one of my proudest moments post stroke was regaining my licence. No longer did I have to rely on others to take me somewhere.

My life was slowly getting back on track, but I missed connecting with other people. Luckily, a speech therapist put me in contact with the Maitland Aphasia Communication Group. Connecting with other aphasia sufferers was vital to making me feel whole again.

They get me! They care and understand, we celebrate the little achievements and encourage everyone in the group to participate. They know what I am trying to say, even if I struggle to find the right words. Together we share our thoughts and feelings, laugh, and go out into the community for coffee and meals. Mutual support is invaluable for improving social and mental health.

By 2019 I felt ready to begin some type of meaningful work.

Fortunately, the Newcastle branch of my previous employer were willing to welcome me back - in gradual steps - to a job that I felt I could manage with my aphasia.

I will be forever grateful to them and the Rehab consultant who liaised with me and listened to my needs. It took time, but I am now proud to be working permanent part-time in a job that uses my skills and knowledge. I feel great to be earning a living again!

From the time when I discovered I had aphasia I felt the need to help spread the word about the challenges of living with this invisible disability. Many people in the greater community including the health profession do not understand aphasia. My family and friends did not know about it either.

Without the ability to communicate you lose the human connection we all need to thrive. Aphasia is not a loss of **intelligence**; it is the loss of **language,** and every sufferer is affected differently.

With the support of my parents, I began to speak at groups like Rotary and Lions. My aphasia friends and I have addressed fourth year speech therapy students at Newcastle University. I have used social media to post messages on Instagram, Facebook, videos on YouTube and appeared in a documentary that aired on SBS The Feed.

I am involved with the Centre for Research Excellence in Aphasia and the Young Stroke Project with the Stroke Foundation. This year I was thrilled to be nominated and receive the Stroke Foundation’s Courage Award for 2021.

I have accepted the “new me” and am thrilled to be living and surviving post stroke. I still have regular Speech Therapy, and see an exercise physiologist fortnightly to help me move better. I try and walk as often as possible, but I know when to stop if I am fatigued. I plan to continue to advocate for aphasia and Young Stroke awareness.

Never
Give
Up
As Long as
There's a
Dream

By Eunbyul Cho

Eunbyul Cho is an ordinary woman in her 30’s, living in Korea. She is not afraid of challenges and wants to give hope to people.

At the age of 30 she went through a stage of wanting to give up on life due to a stroke but through “getting to know herself”, she became hopeful about life and is now dreaming of becoming a global motivator.

I was 29 years old when I had a stroke. I tried to get up in the morning to breastfeed my six-month-old baby, but I couldn't get up. I lied down to sleep some more, thinking I wasn't fully awake, but suddenly I had a severe headache. It was as if someone had hit my head with Thor's hammer. "My head hurts so much!" I shouted to my husband who was sleeping, and as hard as I could, I grabbed my head because of severe headache, and collapsed.

My husband didn't know what to do. He realised I was paralyzed, so he called a company colleague who was a paramedic and explained the situation. The colleague told him to take me to the emergency room immediately because he thought I was having a stroke, so my husband hugged me and took me to the hospital. That’s all I remember until I arrived at the emergency room. I was worried about the baby, but as soon as I arrived at the hospital, I lost consciousness.

When I found out I’d had a stroke, I realised I didn't know anything about it. I was paralysed and couldn't move. I don’t recall having any particular thoughts or feelings; I was just sad that I couldn't go home. I was sorry and distressed that I could not take care of my child, and that my family had to give up their lives to replace that part of my life. I didn’t have any idea about what a stroke was. In the past, I thought that if someone had a stroke, they would die.

The remaining deficits for me after a stroke are not being able to move the left side of my body freely and not being able to feel it. There are more than one or two negative consequences to list from that including physical paralysis, sensory defects, balance problems, double vision, strabismus, menstruation issues, hormone disruption and fatigue. Among them, the most inconvenient thing is movement. Now, three years later after stroke, it is still a daily routine to fall and sprain my ankle.

Before stroke, I was an ordinary housewife on maternity leave. To ensure a healthy childbirth, I went to yoga, and I walked regularly. From childhood, I have lived a healthy life without much hardship and after graduating from university I got a job, got married, and gave birth. Even after giving birth, I have been raising my baby at home without any major problems.

Every day is a challenge for me. Even three years after the stroke, it is still confusing to sit and stand up from a chair. It's new every time and I don't know how to do it. All the movements are like that. Even if I practice and repeat the same movement every day, it's always new and I don't remember how to do it.

In the process of recovery, the challenge for me was to raise a young son with only half the use of my body. It was impossible to keep up with my child because my child's development was faster than the speed of my recovery. I was also unable to take responsibility for my child's safety. The leave of absence period given by the company I worked for had ended, so I had to return to work. The new challenge was whether I could return after having been separated for more three years and adapt well as a functioning member of society.

What I learned at a young age, after going through the great hardship of having had a stroke, is that it is really important to focus on getting to know your body and mind. This helped me to keep working. Learning to close my eyes and move my body and continue to focus on my body during rehabilitation was a great help. Physical and emotional problems that are common in stroke patients have been better managed by focusing on my body.

For example, when controlling the subdued emotions of anger or any other emotions, I would go to a quiet place and try to grasp them rationally. For some reason, it was much easier for me to control emotions just by acknowledging them. The more I practiced this, the more I felt that my body and mind had improved a lot, and I think this would not have happened if I had taken the time to listen to my body and mind a little more before the event.

One benefit for those who, like me, are on the journey of stroke recover, is that we have one more chance to create a better life. I believe it happened because we did not take good enough care of our bodies and minds ourselves, and because of that, we have had to learn the lesson of listening to the needs of our bodies and minds.

When it first happened, I didn't think I could return to work. However, the day of reinstatement came, and on that day, I had a dream. The dream was about my son and in the dream, he was an elementary school student playing in the playground with his friends. I was working as a teacher, dressed up nicely and I drove to his school. I got out of the car looking good, and my son's friends teased him. "Your mom is disabled!" At that moment, I woke up crying, and even though I knew it was a dream, I made up my mind that I would be a great mother. Even now, I cry when I write this story, and the dream was shocking and unforgettable for me. After dreaming of that, I vowed to live a wonderful life, and I decided to return to the world starting with what I was doing.

I still feel that there is a lot I cannot do, and I thought I was far from ready to face the world, so I needed to find courage to return to work. So, I challenged myself to buckle down before returning to work and go mountain hiking. No one would imagine hiking with hemiparalysis.

I did it and it was thrilling. I was able to get rid of the fear of reinstatement after a four-year break by taking a bigger challenge first, and it was a huge success for me. I climbed a small mountain 210m above sea level in an hour, breaking my expectation that it would take more than three hours, and that I might not be able to reach the end. It was easier than I thought. There was a tense moment when I fell, and it might have been a mistake that I exercised the healthier side more than the paralysed side, but what I thought would be difficult was not as big a deal as I thought it would be.

When I said I would go hiking with hemiparalysis, all my family said, "Are you crazy? Don't do it because it's dangerous.” I’d planned to climb a week earlier, but I couldn’t due to three consecutive days of rain, and I was concerned that I would not be able to climb. In addition, I was not happy with the lack of encouragement from my family. In order not to get hurt though, I calmed myself down and climbed. I fell once, and sometimes my hands became feet and I walked on four feet. On the way down the mountain, I received encouragement from another hiker saying, "Cheer up.” I cried but I completed the race. It was touching to hear the support from others that even my family did not give me, and I wanted to share with everyone that there are people in the world who see my challenge as a challenge. We are living in a good world.

When I finished hiking safely, I told my family and friends the news. My family was proud and encouraged me, and I received great support from many people who saw my challenge through SNS. Above all, the biggest change was the reaction of the family. My family, who had been afraid for me and tried to stop me, have been cheering for since I completed the hiking challenge.

After successfully hiking the mountain, I promised to continue to hike sometimes, but I didn't keep my promise. There was also the promise of exercising the paralyzed side of my body, but when I tried it, it didn't seem to help. However, I think that if I choose to hike up a new mountain, I will be able to do it safely without falling, so while I'm thinking about it, I'll plan my next hike.

Stars were falling into my head in the sky
Very tiny and tiny friends are hit and fall down turned red
and become stars again
The star tried to go to its original place, but it got lost
and went to a new place.
The red stars that went to a new place has become a big universe.
I call that universe a dream.
That dream changes the world.

I have worked at a bank for the last eight months. However, due to the nature of Korean companies and banks, overtime work is repeated every day and there is a limit to working with one hand, so I quit. I wanted to prove that I could do anything with hemiplegia, but it ended in failure, and I decided to call it a new opportunity. "A new opportunity to change the world".

It has become a valuable experience to learn what is needed for a systematic work system tailored to an individual's condition and environment, and what parts strikers like us, who are more important to deal with themselves, should train to adapt to society and overcome irrationality. And I think it's finally time to realize my wish little by little that the aftereffects of stroke will be conquered.

While in the hospital for two years, I met numerous strokers. Everyone’s challenges have been unique, but we have all worried about being judged by others. We, as strokers, are a little noticeable in appearance, but have only changed a little due to an unexpected accident and we have challenges in overcoming our limitations.

Focusing on yourself makes a change in the body and I think that changes in the body create changes in the mind. I think it is possible to overcome all difficulties when you can control the body and mind for yourself.

You can connect and follow me at
https://www.instagram.com/zo.eunbyul/

George After Stroke

By George Triantafillidis

Hi, my name is George Triantafillidis, I am a stroke survivor! I live at home with my wife and daughter. I am blessed with a married son, daughter-in-law and 2 wonderful grandchildren.

While enjoying a Greek holiday with my wife and daughter, I had a severe stroke and was lucky to survive.

I would like to acknowledge that the LOVE of my family and MY Faith have played a HUGE part in my Road to Recovery, as has my DETERMINATION and being POSITIVE.

Through God and my faith, God has plans for me and allowed me to live!!

A Will to Survive

Before the stroke, life was stressful at times. Things like the TV breaking, the home phone not working and being overweight, all really set off my stress levels. I was self-employed and running my wife’s business “Connie’s Schnitzels and More” on Wednesdays and Saturdays at the Markets at Fox Studios Sydney. I found that although it was an early start each of those mornings, I enjoyed the selling of the chicken schnitzels, having fun with my regular customers and fellow market holders. The business was doing quite well, and I sold out every day.

We were able to take several overseas holidays because of the success of the business. In 2017, we decided to take a holiday to Greece and visit a lot of places including villages where we would catch up with family on both our sides. My wife Connie and Mary (my daughter) went on the trip with me.

Before leaving on the Holiday, I had a full check up with my doctor. An MRI was done, and my blood pressure was checked. I took Blood pressure tablets with me, and my doctor gave me a clean bill of health and told me to enjoy my holiday.

During the boat trip to the Island of Milos, we all got sick on the boat and that lead to being very dehydrated. We arrived on the island, and we had planned a cruise on a yacht around the Island on the next day. For some reason I decided not to rest in my room as my wife suggested but instead walk around the Island while my wife and daughter enjoyed going to the beach and doing some shopping. I was drinking a lot of water, walking up hills and generally pushing myself too much. After the boat ride, I was not feeling that well and had a headache.

Catching up with my wife and daughter, we went back to the Hotel room. My face was droopy, and my wife noticed this as well. This was the last thing I remember before my Stroke. The following is an account of events and actions that were taken by my wife.

Connie Triantafillidis account during Stroke

After Mary and I had spent time on the beautiful beach in Mynos, we caught up with George in the Café near the beach. George was still not feeling well, so we all went back to our hotel room.

George went to the bathroom, and when he came out, I could see that his face and mouth had dropped!! I asked Mary to look for the owners of the hotel as I knew that he was having a Stroke. Upon Mary's return I had George sit in a chair and went down to the shops to find someone who could help us.

I walked into the pharmacy, explained to the girl what had happened, and she immediately rang the ambulance. The ambulance arrived 10 minutes after George had the stroke. They took us down to the medical clinic and we were greeted by the Doctor and Nurse. They took George's blood pressure which was 230/110 and they proceeded to do everything that they could to bring down his blood

pressure. I rang our family doctor at home, and he talked to the Greek doctor and told him about George's history. After the doctors had talked to each other, my doctor confirmed that George had had a Major Stroke.

The Head Doctor then came over to see us, and he advised that we were better off to go to the major hospital in Athens, Greece. The ship off the island waited for us, and the Ambulance also went on the boat with us.

I was amazed that we had not found any obstacles on the way to Athens Greece!

As it was a Friday night, not all hospitals were open. When we arrived at the hospital, I could see that they were very busy and had a shortage of staff. I waited 30 minutes, and no one had come to see George (they were already advised by the Doctor in Mynos that we were coming and George had had a major stroke). I am a patient person, but I knew that some of the people they were seeing were for only minor things.

I went to the nurses' station and told them that my husband had had a major stroke and needed to be seen straight away. The nurse got the doctor who came and saw me. I told him that George needed to be seen straight away. The Head Doctor then came and saw me and told me that we had to wait our turn. I told him that if my husband died, I would be coming back from Australia with my barristers and I would be suing the hospital.

They now saw George straight away. I was the only one allowed to go in and my daughter and my cousin had to wait outside.

The CT scan confirmed that George had had a massive bleed on the left side of his brain and that he'd had a major stroke. I prayed to God and said that he wanted to take George then I knew that it was his will but if George was to live then I put it in God's hands.

George opened his eyes and said he was ok and smiled. I knew my husband was a fighter and he would be a Stroke Survivor.

As this hospital was very busy and short staffed and very dirty, I realized that George needed to go to one of the top Hospitals in Greece in a cleaner environment and this would help in his recovery. They arranged for George to be transferred.

George does not remember much of the next 3 weeks after his stroke. The doctor looking after him, explained to us that it may be 3 months or more before George would be well enough to return to Australia.

George Continues his story after his stroke….

During the first 3 weeks, there is very little that I remember. As I passed in and out of consciousness, I realised that I was paralysed down the right side of my body but I knew how thankful I felt for my family and for my faith in God. The doctors told me that until I was well enough to travel home to Australia I would have to stay in the hospital in Greece. The first day that I was able to get out of bed and begin to walk was such a blessing!

After 3 months, I was finally able to return home. The Greek doctor had to come on the plane with me and he brought my hospital records with him. Upon getting off the plane, am ambulance was waiting for me and took me to Bankstown Hospital. I was given my own room and stayed in the hospital for several weeks where my recovery began. I had to do physiotherapy and was surprised to see so many young people also recovering from a stroke. I asked what had happened to them, and I was told that they'd gone to a music concert and became dehydrated from not drinking water and this led to them having a stroke.

Eventually I was well enough to return home and a physio therapist came on certain days each week to help me with my recovery. My family doctor also visited me each week at home to check my blood pressure and how I was going generally. I had previously been told by the doctors in Greece that I was lucky to be alive. I was determined to work hard on my road to recovery.

In 2018, my granddaughter Penelope was born and although I had lost my ability to be able to show my emotions due to the stroke, I was so happy to be able to meet her, as my daughter-in-law was pregnant when I'd had the stroke.

Eventually the need for physio sessions reduced and I was able to go for walks and to a local gym in Punchbowl. The owners where advised I'd had a stroke and adjusted the gym sessions accordingly. During my walks, as I walked slowly, people used to think I was drunk and showed no patience waiting for me to cross the road at lights and crossings.

I could not drive anymore, so my wife Connie did a refresher course through NRMA, and we were able to buy a small car. My wife was now the driver, and I was the passenger. I guess it was a strange feeling after driving since I was old enough to drive but it was good to see things and not have to concentrate on the road!

My prayer life became more important to me and of course the time I spent with my family and friends. The stroke did not affect my memory which was another bonus for me. My relationship with God was important in my life before the stroke, but I appreciate the opportunity that God has given me to achieve more purpose in my life and improve my prayer life.

Unfortunately, through social media, I became a victim of trolls. They said nasty things to me such as "the next stroke will kill you". They sent me pictures of coffins with my name on it and called me a retard and a space. While I have met some beautiful people on my journey, I have definitely met some lowlifes with no respect or common courtesy.

I also found that the American Stroke Association was very helpful as I could tell my story and listen to other stroke survivors tell their story. I met a broadcaster named Mark who had his own podcast called "Determined". I have gotten to know Mark very well and have had 3 interviews with him which have been posted on You tube. I have listened to some inspirational people, and In Australia, I have also met some inspirational people as well.

Prior to COVID_19, my week was organised, going for walks, meeting friends in the local café at Bankstown, going to my gym sessions, praying and spending time with my family and friends. One of my friends had a treadmill that he was not using, and he was able to give this to me and help install it. This has been helpful during COVID-19.

As people cannot see a physical disability such as a wheelchair, walker and walking stick, they judge me differently, thinking that I am drunk as I am slow to walk anywhere. While there have been some very kind people in my post stroke life, I have seen how rude people can be.

I am Determined and remain Positive. I will survive and I am proud to be called a Stroke Survivor!! I now have two beautiful grandchildren and I know how lucky I am. Prayer and the love of my family have helped in my journey.

I would like to finish with a poem.

Will to Survive

You have a licence to survive, speculate positivity don't turn around

There is so much to achieve, do you have all that you need?

With Energy, Determination and love do you believe you can succeed?

Everyone has a right to survive, set yourself goals and take little steps at a time!

Has your own philosophy and faith in yourself which can help you along your journey!

Determination will make your dreams and goals come true.

Time is a true mystery, Time has a way of changing things, there is no guarantees of what the future

May bring??

Take what you need and use those special things such as Love and prayer.

Being Positive and Determined will help you become a Stroke Survivor

President B. Positive

Vice President D. Termination

Injoymeant

By Jodi O'C

(O'Connell)

I am a stroke survivor who woke up at the other end of my experience with the burning question, 'why am I still here?' and I have made an adventure out of discovering why!

I now support others, helping them reconnect with their inner joy and purpose via my business, ***Injoymeant***.

www.injoymeant.com.au

"If I could do it all over again, I wouldn't change a thing. My stroke has taught me so much about myself. I wouldn't give that up for anything." – by Jodi O'Connell

June 27, 2012 - I had a Doctor's appointment with my family GP, at which he asked, "So, how are you going at giving up smoking?" I jokingly replied, "Really shit, actually, I think I need a scare. Tell me I have emphysema or something." Then off I went to my osteopath for a neck adjustment, as I had been experiencing neck pain for a couple of weeks. Little did I know…

June 30, 2012, at approximately 3:30 am - I had returned from our End of Financial Year Party and was lying in bed trying to get to sleep. I started to feel a warm sensation run down the right side of my neck, felt dizzy and the left side of my body felt numb. I had been drinking that night, so my initial thought was that my drink had been spiked. I got out of bed to go to the toilet but could not walk properly and my vision was blurry. I kept crashing into the righthand wall as I moved down the hallway. Something was not right. My face felt lopsided. After bashing my way back to my bedroom, I looked in the mirror. Closing one eye I could focus on my face and it looked ok so I crawled back into bed and thought I would sleep it off, grateful that at least I was home in bed instead of being raped somewhere by whomever had spiked my drink!

I then began to examine my symptoms more closely. Blurry vision, numbness on the left side of my body, droopy feeling face. Holy Shit…a stroke? I tried calling my Best Friend (who lives next door), but no one answered. I called my sister to collect me & take me to the hospital. After listening to my symptoms, she rang the ambulance and met them at my house. The ambos kept asking me what drugs I had taken that night. I continually answered with "none." It got me angry that they kept insisting that I had taken something! To the emergency ward we went. By then I had double vision and could not see anything clearly. That day is still a bit of a blur, in more ways than one!

I was seen by at least one doctor, that I recall. Each time someone came in to see me, I was told to smile at them. At one point a doctor diagnosed a migraine and dosed me up with migraine medication. This made me violently ill. In and out of sleep I went. A CT scan was done, but this showed nothing, so the doctor gave my sister discharge forms, ready for me to go home and sleep off my migraine. Luckily, the nurses argued with him, and I ended up being transferred to the medical ward. By then I could not walk or see clearly at all. And to my shame and dismay, I needed to be wheeled to and from the toilet on a commode chair.

More Doctors came to see me. As it was the weekend, an MRI scan was booked for Monday. In the meantime, it was Sunday, and the doctors were still not sure what was wrong with me, as migraine, which they had initially diagnosed, does not usually last over 24 hours. This was the most frightening time during the whole experience. I needed to know what was wrong, so I knew what to do to fight it!!

Monday arrived and an ambulance took me to the medical imaging centre for my MRI. Light had begun to really hurt my eyes, so I developed strong headaches during that day. One of the ambos (thank goodness) organised for me to lay in a dark room whilst I waited for the MRI to take place. I was incredibly fatigued so slept whilst I waited. After the MRI I was returned to the hospital to await the results.

Tuesday Morning arrived, and, surrounded by my Mum (who had travelled down from Darwin), my sister, and my best friend, I was told by the doctors that I’d suffered a stroke.

A stroke! A "Brainstem CVA Secondary to vertebral artery Dissection" to be precise. The doctors then asked if I had suffered any trauma or had any neck manipulations in the past week. When I explained that I had been to my osteo for a neck adjustment three days earlier due to neck pain, they noted this and got my Osteopath's details.

Once the doctors left, I burst into tears. We all cried and consoled each other. What would this mean? Would I still be able to look after my children? Work? Walk? Live? I don't recall much more of that day, but I know I grieved heavily during my wakeful periods. As I was now diagnosed, I was moved to the Rehabilitation Ward that evening, and rehab was to begin the next day. I must admit, I was shocked at this, as I was so very tired and just wanted to sleep.

Now I knew what I was dealing with, the next day I did some research on my condition. I needed to find out what my chances were of full recovery. Upon doing a search of the type of stroke I was shocked to discover that many people who experience this kind of trauma either end up in a vegetative state or do not survive. I experienced such an overwhelming sense of gratitude (that I still hold strong to this day). I made the knowledge of what ‘could have been’ a constant motivation to embrace what abilities I did have left and work my ass off at getting back on my feet!

Rehab began with physio - simple balance tests & exercises. Oh, how difficult these were to start with. I was not allowed to walk, so was still relying on staff to take me to and from the toilet and shower. For someone who was fiercely independent, this was really challenging. I had speech pathology to ensure my breathing and swallowing were up to scratch and had some pretty weird exercises to do that involved humming into a straw, among other things. Occupational Therapy involved testing my sensitivity and use of my left side. This included activities like placing my left hand in a container of birdseed and feeling for and identifying objects by touch, and screwing nuts onto bolts of various sizes with my left hand.

I had a very intense rehabilitation program and rested when I could, as fatigue was an ongoing issue (and still is if I push myself too hard). My progress in hospital was quite speedy in the whole scheme of things, and I truly believe my positive outlook and 'can-do' attitude helped me achieve all I did. So, 27 days after experiencing my stroke, I was allowed to go home. Being a single mum of two sons (then 11 and 15) presented its own set of challenges. Here we were, carer roles reversed, with me feeling like a failure as a mother because I couldn’t even take my kids to school. Thank goodness we had family and friends rally around and assist with food preparation, transport & other requirements. I witnessed both my boys grow up quite quickly during this time, and I acknowledge it was tough on them at times. Super proud mum here!

Pre-stroke I was also a Practice Manager of an Accounting firm and boy did they come through for me! As you can imagine, as a single mum and homeowner, the idea of a long period of time with no income to cover my mortgage and other living expense, things felt pretty grim. I did, luckily, have income protection insurance, but that was going to take some time to come through and was only a percentage of my income, so I was not even sure it would be enough. My amazing bosses offered to continue paying me my full wage, until my insurance payments came through, with the understanding that I could pay them back once I returned to work, and over a period of time. I am forever grateful for these generous people. Not needing to worry about money certainly assisted in my rehab progress and sense of security.

Despite my positive attitude, I still experienced bouts of depression. I struggled to get out of bed at times and felt shame and frustration at myself for my low energy, limitations and lack of independence. My grief was raw and very real – my world often felt like one of anger, frustration, and hopelessness. Gratitude for my gift of life was really what kept me going during those tough times, and the belief that 'everything happens for a reason.' The turnaround for me was when I chose to make it my mission to find out that reason!

In my experience, there are two types of stroke survivors. Those that ask, 'Why me?' and those that ask, 'Why am I still here?' I tried my hand at being both types. The 'Why me' version felt right for short periods, while I progressed through my grieving process, but ultimately, I would get sick of myself and felt a strong resistance to living my whole life there. As my journey progressed, I began to feel powerfully drawn towards discovering the reason why I was still here - the reason the Universe thought I needed 'waking up'. Step one in this self-discovery journey was reconnecting with who I actually was – my truth. I didn't realise, that pre-stroke I had fallen into living a life of mere existence, hiding behind a mask, denying my own needs, and feeling numb. What a wake-up call!

As a result of this new thirst for WHY, I began to source personal development and self-discovery tools that would help me in my journey back to ME (which is a whole other book!). But in summary, I got clear on my values, I identified my beliefs (both enabling and limiting) and how they impacted my perception, I studied the Enneagram (a personality model) and identified how my personality impacted both myself and others, I learnt the importance of expressing emotions (particularly those related to grief), I created daily self-honouring rituals to increase my sense of self-love and worth, I recognised there is choice in EVERYTHING, including how we perceive things and how we react, and I even spent 5 years working in a personal development company!

Not always smooth sailing, I have done the hard yards of defining my truth and identifying and releasing the things that no longer serve me (or others). I have created a new normal of living a fulfilling life with the abilities I have and loving myself in the process! As a true believer that we all have a unique spark within us, that, through our life-long conditioning many of us have forgotten how to tap into (and based on all of my learnings!), I have created my business, Injoymeant (www.injoymeant.com.au). This is where I live my dream of providing services and resources that assist others (not just stroke survivors) navigate life with joy and purpose.

It is my experience that sometimes our biggest challenges in life become our biggest unique points of inspiration. As someone who has survived a stroke, who has released my 'I am a burden' story, worked through my powerful grieving process and now embraces my new version of normal, I truly believe that my reason for still being here is to guide and support others in their journey to reconnect with their own inner joy, live their truth and embrace the unique difference they are here to make in the world. After all, everyone is gifted. Some people just forget to open their package.

Bad Genes
Bad Habits
Stroke

By Joey Sydney

My name is Joey Sydney. At 58, I had an unexcepted stroke. My stroke was the latest in a list of health problems since turning 46.

Following is how I felt about my stroke and the problems I faced.

My name is Joey Sydney, and at 58 years old of age I had a stroke. I never imagined that I would ever have a stroke. There were some things I thought that could happen to me, but never a stroke, despite the fact that my parents had problems within their genes - as do I - and my lifestyle choices or bad habits. Yes! I smoked cigarettes and drank alcohol for a long time.

One of my grandmothers had rheumatoid arthritis, and so did my mother, and I was 46 years old when I found out that I had rheumatoid arthritis as well. My grandfather on my father's side died at 48 years old from heart problems and my father at the age of 54 had a heart attack. On 13th December 2014, at the age of 53, I suffered a heart attack and ended up in Concord Hospital. The doctors asked me if I'd had a heart attack before and to my surprise they'd found evidence that I had. So, this was in fact, my second heart attack, and it left me with a damaged heart. Then I had a quadruple bypass on 20th January 2015, and a defibrillator implanted on 13th of May 2015. So, I am indeed my parents' child.

On the 8th of January 2020 I woke up at 4:45 am with my wife Judy, and we started the day. She left for work 5:15 am that morning, and I had breakfast. At about 7:30 am I took my car to get a service, I dropped the car off and decided to walk home, because it was a nice day. The walk was 6.4 km, so I took my time. I arrived home and do not remember much from then. The last thing I remember, I was going to change the TV channel, but as I reached for the remote I fell to the floor.

So, I asked my son Jimmy, what he remembered. It was about 12:30 pm, he came down the stairs and found me on the floor. I was incoherent and covered in sweat. Jimmy rang his mother to check if he should ring for the ambulance, which he did. The ambulance came and we headed to Westmead Hospital, where they gave me a scan and took some tests. The doctors discovered that I'd had a stroke. They decided that I needed surgery, but the surgeon had gone to the Royal North Shore Hospital (RNSH), where my wife Judy works.

By that time Judy had left work at RNSH and travelled to Westmead Hospital, Jimmy had rung to tell her that she had to return to the RNSH. Judy stopped to ring my daughters Caddie and Lulu and told them to come to the RNSH. Lulu and her partner Liam arrived at the hospital to visit me post-surgery and Caddie and her husband Simon visited the next day.

Judy arrived back to the RNSH at about 2:00 pm. She found Jimmy with my doctors who needed forms signed for my surgery and then I went into surgery for clot retrieval. At about 6:00 pm I woke up with my wife and family around me. I was not sure why I was in hospital, and I still cannot remember much of that day. I was able to determine my family and who they were, but I could not speak in full sentences, for some time.

With my defibrillator, I am unable to have an MRI, so there is no way to determine how bad my stroke was. The best the doctors could work out is that my heart caused a blood clot travel up to my brain which resulted in my stroke.

I was later told that I'd had an ischemic stroke on the left side of my brain. The stroke has left me with loss of strength of my right side and now I have aphasia.

I still remember thinking how lucky I was that my son Jimmy was at home at the time I had my stroke. I realise how bad it could have it been if I had been on my own because Judy usual got home between 4:00 pm and 5:00 pm, meaning I could have been laying there for something like five to six hours before she found me.

I don’t remember having had any thoughts about how unlucky I was after I’d had my stroke. This may have been because I’d had a heart attack previously, and realised that as long as you are alive, there is always a way forward.

My main thought was how long it would be before I could go back to work. It was not whether I would reach that goal or reach another. It was something that had to be reached and I remained focused on it as a positive part of the goal.

I do not remember a lot about my time at the Royal North Shore Hospital, other than my wife and children and some friends coming to see me. There was not a lot of physical therapy, although there was speech therapy to help define the severity of my aphasia.

I had a headache for first three to four days. I spent a lot of time asleep or dosing. After a week in hospital, I was ready for three weeks at the Royal Ryde Rehabilitation Centre.

I remember that before I was transferred from the hospital to the rehabilitation centre, I needed to have a shower with an occupation therapist with me. I thought, ‘why?’. I’d had a heart attack and then a major operation and thought no one would want to see me having a shower. The reason was to check my balance and see how I dried myself and got dressed. It’s important to observe these things after stroke and before you move to the rehabilitation centre.

While I was in the Royal Ryde Rehabilitation Centre, I started physical therapy and continued with my speech therapy. The physical therapy was fine and almost enjoyable. My speech therapy was difficult as I was trying to remember what synonyms and antonyms were, and what the hell is an anagram?

Now is the time to talk about my aphasia.

What have I found about my aphasia? Firstly, I realised that after my stroke I have not become dumb or stupid. I was just having difficulty finding words when I required them. I found that I was very isolated initially because these problems did not exist before my stroke.

The isolation was the most difficult part of my aphasia from my stroke – I did not want to have people around me or to interact with them. I have found that it takes time to learn how to use your new skills and the way I now need to process language.

After three weeks I was able to leave the Royal Ryde Rehabilitation Centre. It was the 30th of January 2020, and about the time Covid 19 pandemic started. I was told that I could go to Concord Hospital for my physical rehabilitation and my speech therapy. Unfortunately, when I rang, I was told there could be a six- to eight-week wait before they could start my rehabilitation. This left us with a problem that needed a quicker response.

Firstly, I spoke to our local physiotherapist who was willing to help with my physical wellbeing - especially my balance and the loss of strength on my right side.

Then I needed to look after my other problem, my aphasia, which needed me to ring and talk to some of the speech therapists that were on the list from the rehabilitation centre, and I found one, who was very good.

I was able to get five weeks at a reduced rate, but both my wife and I realised that I would need a lot more help, which was fine. After that I believe the reason why I hired a speech therapist was to help me to improve my ability to find words more quickly. This helped me to be able to hold a conversation with more than two people at a time. Although I disliked the subject of English at school, I now needed it more than ever before. I’m sure that desperation can be inspiration.

As I stated before, I hoped to return to work one day. My wife Judy and my daughter Lulu had another idea, which was that I should retire. Guess who won the debate!!

Lulu started by ringing my financial advisor, who had a look and told me that I could retire. There was one major problem though, I’d forgotten to sign the latest form to keep him as my advisor. He sent the form to me with a sticker on to show me where to sign it but I needed to practice my signature a few times before I could sign it. He then arranged funding to help with our short-term finances.

Before he took me back on again and before he started the work for my retirement, he asked me to give him a call, because he wanted me to tell him that I wanted to retire. This was a little difficult because my aphasia was still very new at the time, but I got it done. Yes, I lost the debate and now I’m retired.

There were many forms to be filled in by my medical advisors, myself and/or Judy, for superannuation and for an income protection claim. Lulu also told us to see our solicitor to renew our wills, get Power of Attorney and Enduring Guardianship with her as our guardian. It is always good to have a social worker in the family, hey Lulu!

In April 2020, we had to go and see a neurologist at the RNSH, which was an interesting day. I was able to pass the test to get my driving licence again, which was great.

Afterward, we spoke to the neurologist about how I was going after my stroke and found out I’m doing fine. Then we spoke about the drugs I was on, including warfarin, and there was a discussion as to whether I should be using it or not. The neurologist said I should not be on it at all.

There is a story about me being on warfarin. It started when I was in RNSH and the neurologist who I saw while I was there said the warfarin was the best way forward. While I was in the Royal Ryde Rehab Centre the debate was still going on. They have a cardiologist who come in every week, and he said he would talk to my cardiologist, and they agreed about the warfarin. Being on warfarin and methotrexate for my arthritis both have effects on my liver, so my alcohol drinking days are gone.

Before I end this, I want to thank Judy, Caddie, Lulu, Jimmy, Simon, and Liam, as well as my friends Ken, Wendy, Tamara, John, and Sandy for their love and support though this tough time. Also, I would like to thank staff at the Hospitals (RNSH and Westmead) and Ryde Rehabilitation Centre, all my personal medical advisors, my physiotherapy, and my speech therapists for all their help.

What I have learned from my stroke is that patience is very important to us and from others, especially if you have aphasia. The condition from a stroke can’t be cured but we must learn to live with dignity afterwards. I always thought that fatigue after my rheumatoid arthritis was bad, it got worse after my heart attack, now it can be impossible sometimes to cope with it. Managing to get dressed especially when standing up now can be difficult. Hopefully we are all stroke survivors and not victims of a stroke. Still the best piece of advice is to never give up.

The Miracle Migraine

By Kara Ockendon

Kara is a professional, intuitive healer and writer. Having experienced a life-threatening health crisis at 32, Kara has found purpose and strength in sharing her healing journey with others. Being a qualified lawyer with a degree in law and behavioural science as well as being a certified Akashic Record reader, Kara has learnt to balance life as a working professional and spiritualist. Kara enjoys inspiring others to discover their own healing and balance and is providing support for others to create nurturing and healing within themselves with ritual bath packs sold via her recently established business *Salts, Sage and Selenite*.

You can find her on Instagram @little_wisdom_notes and @saltssageandselenite or by her email littlewisdomnotes@outlook.com.au.

“An atypical migraine” and “Here’s a referral for an MRI” is what I was told upon discharge from the emergency department on 17 September 2017, after suffering a range of neurological symptoms on my way to work. I felt relieved to have been “cleared” of stroke, but I didn’t get migraines. I knew in my gut that the facial numbness, slurred speech, and inability to walk straight, although brief, was something more.

Fear set in as my symptoms rapidly deteriorated. My brain fogged over, my speech slowed, and my written type was gibberish. I recall trying to call for pizza and realizing my speech was so slow that I handed the phone my husband. Something was seriously wrong! I spent the night on Dr Google. If it wasn’t a stroke, surely, I had MS or a brain tumour!

When I woke the next day, I was unable to even type the message to tell my boss I would not be in. I needed hubby to do up my bra and clip up and necklace as we got ready to go to the GP. At this point, I started to really feel scared. Would I ever be able to type again? How could I work? Was I going to get worse? It had to be MS, or a tumour!
But at the GP I passed all the same neurological exams as the day before and was told to await the MRI.

Come the following morning, a Saturday, I was not improving. My taste had gone funny (coffee tasted like pepper). I also felt heat creeping up my neck, but it was not hot to touch, my typing was still gibberish and my thinking and speech remained slow.

I presented at the emergency department, and I recall as I spoke I explained “I don’t normally speak like this; I am a lawyer; I normally speak fast”. I was desperately trying to convey how bad things were. I was terrified the doctor would not understand how significant the change in me was. He reassured that he believed me, before I again passed all the neurological exams; except perhaps my right side was somewhat weaker.

Back and forth as I was examined by yet another two more senior doctors.

I was told they had to weigh up the benefit of “bringing in” a person to conduct an MRI “on the weekend” vs the risk that I had something “serious” that required “immediate attention”. This was incredibly disheartening to me, as for me it was clear something “serious” was going on. But my husband was my champion, insisting I ought to be admitted, and I was.

It was another harrowing 24 hours on the orthopaedics ward before my MRI. It was an awful night of regular observations and me feeling like my symptoms were worsening.

I remember being questioned as to my drug and alcohol use around my symptoms, suggesting to me, that somehow it was related to drug use by the doctor. This made me feel so angry and helpless as it felt like they weren’t listening to me and didn’t believe something was seriously wrong!

My MRI results came back late on the Sunday afternoon, and I was sympathetically told that, indeed, I had suffered a stroke.

Even though Stroke was my first instinct at my symptoms, I was in shock because I was cleared of that. How did they miss the brain damage? It wasn’t until much later I learnt that CTs don’t pick up fresh brain damage so easy and are primarily used to identify clots with respect to suspected stroke.

In my shock, I was in a bit of a daze. But it wasn’t long before my anxiety and fears set in around how permanent my symptoms would be. I was terrified I would never be able to speak and type normally again; terrified I would be unable to return to work as a lawyer; terrified of living with a brain that still running 10,000 faster than my capacity to convey the thoughts I was thinking.

I was quickly moved to the stroke ward where I was then under constant observation. The worst thing for me at this time, was the aftershocks. That being the random firings of your brain as it tries to work around the damage and figure out what has happened to it. The random firings that translate to your body reacting in ways exactly as it would if you were suffering another stroke!!!!

I had never been so afraid in my life. My stroke symptoms were mild to begin with in the scheme of things, so every little neurological firing raised my anxiety and blood pressure way high. I could see it on the monitor.

Yet I started to calm somewhat as my symptoms started to improve; they often do after the brain stops swelling from the stroke damage. I was incredibly lucky that I didn’t suffer any noticeable physical impediments and that my cognitive impediments were limited.

But there was still one big question??? I was just 32 - too young and too healthy. All my initial tests and examinations showed this. So why did I have a stroke? It was a weeks’ worth of testing during which some imaging of my brain showed narrowing of the internal carotid artery system on my right. It wasn’t plaque build-up; it was stenosis (inflammation and narrowing). But why inflammation?

Initially the immunology team considered I had a rare autoimmune disease called cerebral vasculitis. The type where your brain attacks itself all over and you are at constant imminent risk of further stroke. Hello Anxiety!

It would take 9 months, plenty of nights breathing through neurological symptoms, holding hubby's hand, wondering if we go to the ED, multiple hospital admissions with transient ischemic attacks, many more tests (mostly repeated), a brain biopsy and an opinion from the United States before I was eventually diagnosed with Moyamoya, an even rarer condition, BUT one that is far more easily treatable and contained to the internal carotid systems of the brain, rather than the entire brain.

Come late July 2018, I underwent what is most simply described as a brain bypass to re-route the blood flow in my brain to compensate restricted blood flow, resulting from the stenosis. It was a great success!

But the success goes well beyond the functioning inside my brain.

This experience has given me so much wisdom and growth, not to mention spiritual connection.

I'm much less afraid of uncertainty. I learned to trust, allow, and surrender to what was in that space between stroke and diagnosis.

I became acutely aware of how fantastical the human body and brain is. Neuroplasticity, where the brain creates new synapses to relearn things that were lost in the damage, is remarkable, but in my case, I experienced something that was baffling for my initial treating team. My stroke and brain damage were both on the right side of my brain and yet all my symptoms were also on the right side of my body.

Given that the right side of the brain controls the left side of the body and vice versa, it was abnormal for my left side to have been unaffected.

It turns out my brain stole blood from the left side during the stroke (and in the months following my condition) to compensate for the blockage, and in doing so, it not only resulted in right sided symptoms but also prevented more significant damage on the right side of my brain. I have since learned that this is called "steal syndrome".

Why they call it a syndrome, I don't know. I rather like to call it a miracle!

This miracle has taught me not just to be in touch with my body through awareness, but also to trust in her magnificence. I am far more conscious of her whispers, even if still often ignored. I slow down far more often; I know the importance of balance and I consciously work to refrain from pushing my body to extremes in the way I did before.

Mediation was big part of my healing practice, and I am so grateful for that as I had always tried to do it but had never been able to make it part of life before my stroke. I am incredibly gratefully for this shift, as mediation has helped me to tune into myself, my purpose, my soul and my gifts; it has seen me start sharing them with the world in a more meaningful way through writing and intuitive, soul-remembering guidance. Not just in this book, but another I have contributed to - *Mother's Making a Difference* - and via my social media platforms.

And whilst I am still very much at risk of further stroke, I don't give that knowing any space in my life.

No, it wasn't a migraine. Nor was it just a stroke, or just Moyamoya. It was an unfolding miracle for which I am very grateful!

Living With Locked-In Syndrome

By Kati van der Hoeven

My name is Kati van der Hoeven (Lepistö) and I am a professional model, Writer, Blogger, and Speaker.

I suffered a haemorrhagic stroke in 1995 (at 20 years old) and have LIS Locked-In Syndrome.

Career: Modeling, Huffington Post blogger, VIP Ambassador of Special/Effect England, Miss Wheelchair World Ambassador, and Face of Sisu (Finland).

Published: Silmän-Räpäys (2006) and Living Underwater (2019).

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Fall 1994, Los Angeles, California.

I was having the best time of my life, living my childhood dream of being a professional model. Only God knows from where I got the crazy idea to become a model. There I was on the other side of the world, in the city of angels, meeting celebrities like they were ordinary people. I was working for extensive international campaigns, doing music videos, fashion shows, you name it. It was a crazy, hectic time but still so wonderful that I would not change it for anything else.

For Christmas 1994, I booked a job for a distinguished Finnish company. It was perfect timing because I could use this opportunity to spend Christmas and New Year in Finland with my family and friends.

It was about 8 pm on January the 10th, 1995. My mother and I were watching TV, and suddenly I started feeling weird, much like I was drunk. Mom took me immediately to the nearest health center, and from there to the emergency room.

The doctors were running all kinds of tests to figure out what was happening to me. However, they disregarded the chance of it being a stroke because I was just twenty years old at the time. And the belief back then was that only people over forty could get strokes.

As we were sitting there waiting for some treatment, hours passed. And after 6 hours, I was completely paralyzed. It seemed that when I was watching TV, I had a Hemorrhagic stroke and life as I knew it ended abruptly.

I was entirely paralyzed. I could not move any part of my body except for my eyes. I could not even speak.

Even hope was swooped away as the doctors told me that the stroke severely damaged my brainstem. Messages from my brain do not go through to my muscles to make them move. Their diagnosis was Locked-In Syndrome (LIS), a condition of which there is no medicine or treatment. In other words, no cure.

At rehab, I learned to speak with my eyes by using a transparent board with all the alphabet letters.

The therapist noticed that I did have some jaw movement. It was very little. However, she thought that even though I could not move my tongue, I could chew, so I could learn how to eat in a slightly different way.

At first, I had to practice eating by chewing candy and fruits wrapped up in a cotton cloth attached to a string (this was to prevent the food from sliding down my windpipe). Part of the cloth would stay out of my mouth and then be removed from my mouth when I was done chewing. We practiced for about a month. After that, an X-ray had to be made to see if the food went down the right pipe, and not into my lungs by accident. Luckily, it did not, and I could start eating by myself again.

They also noticed that I had some movements in my legs. I can move them just a little, like making short kicks, which makes it possible for me to swim with the help of the therapist during hydrotherapy.

After six months of rehabilitation, I was given the bad news that they could not do anything else for me. The doctors recommended my parents to put me into an institute, but they refused. They took me home.

At twenty-one years old, I wound up living with my parents much like a baby, completely paralyzed, utterly dependent on them. It’s not what I had had in mind for my future. Depression sunk in. Every morning when I woke up and realized that it was not a bad dream, I would start crying, even howling. Why couldn't I have just died on that awful evening? I kept begging my mother to help me end my life because living life like that was not worth living.

To say that those were the darkest days of my life would be putting it lightly.

My parents tried to put on a brave face. Nevertheless, the depression got to them too. They should have been living the best time of their lives, enjoying the fruits of their labors. But instead, they were living the most challenging part of their lives, taking care of their all-grown-up daughter.

I would spend my days dwelling on what that stroke took from me. I had lost my mobility, my future, my life, all of it. I was numb, and I thought, "What sense is there in continuing living in such a state." A life like this is not a life worth living.

Well, that was over twenty years ago. My arms are still paralyzed, and I still cannot speak. The doctors were right; there was no treatment or cure, and no chance of recovery. I was wrong, though; life was still worth living.

In the beginning, I had no dreams, no plans, not even a will to live. The only reason I was living was because I was alive. My only pleasure was the company of friends that, from time to time, would drop by to say hi.

Through the years, I came to terms with what has happened and my situation. It took three years to get out of the state of depression. And to understand that even though physical recovery was not possible, mental and emotional recovery was plausible.

I have reached a total acceptance along the way. I cannot pinpoint the exact moment when it happened or what was the actual turning point. I probably just grew into it. I managed to understand that these were the cards that have been dealt, and there was nothing else left for me to do than to make the best of it.

Even though the turning point of my life came with the acceptance of the situation, I have learned that to reach that point is a process.

First, you must grieve for all that you have lost. The mourning process is part of the healing.

Second, you must try anything which is your power to regain what you have lost and not just throw in the towel.

Third, you must look within for the answers. Then you can truly heal.

I have learned that appreciation is the key. Instead of lamenting what you have lost, appreciate what you have. Instead of focusing on what you cannot do, be appreciative of all that you can do.

Something else that I learned through the years was that laughter is the best medicine, especially when you learn to laugh at yourself. Having black humor and laughing at myself and my situation made it all more bearable. Humor was a small tool that helped to lift a considerable weight.

Another fact that I learned through the years and through this experience is that anything is possible no matter what the circumstances.

My belief in 1995 was that I would have a short life in which I would not do anything else other than to see my life go to waste. Oh, how wrong I was.

I have lived a whole life filled with beautiful experiences. I have traveled the world, published two books, I participated in the first Miss Wheelchair World. I did a TED Talk and so much more. I even did what seemed to be the most impossible thing for someone in a situation like me. I found love and got married. I lived a wonderful and meaningful life filled with blessings

The stroke could have killed me on that awful evening; it did not. I was blessed with a second chance and with the power to achieve a higher purpose in life.

The meaning of life is to turn negatives into positives, and I have been presented with the opportunity to show others by example. For this, I thank God, every day.

My name is Kati van der Hoeven (Lepistö), and paralyzed is what I am, not *who* I am.

Redirected From Head to Heart

By Letisha Living

Letisha is the founder of Kindness Empowers, an online space dedicated to Young Stroke awareness, connection, and empowerment.

Visit www.kindnessempowers.com

Or follow her on Social Media::

www.facebook.com/kindnessEmpowers

www.instagram.com/young_stroke_empowerment

www.linkedin.com/in/LetishaLiving

I had put the kids to sleep, and I was sitting down at the table doing some work that I had brought home. It was dark and cold, and I was stressed, trying to cram in as much as I could into every 24 hours.

I'd convinced myself that because I was so busy all the time that I was successful in life. I was in the job that I'd spent my whole working-life striving for. I was a single mum, and the kids were in private schools, and doing well in their academics and competitive sports.

After coming out the other side of a traumatic relationship, I had recently started seeing someone.

It was about 10pm now and I could no longer concentrate as my headache was overwhelming me. I called Home Doctors to visit me, and I was given an injection of pain relief.

I decided I'd get some sleep then continue working early the next the morning before the kids woke up. I set my alarm, laid down, cuddled up to my 4-year-old and drifted off to sleep.

I was awoken in the middle of the night by my headache, which had returned with a vengeance. The pain in my head was unbearable. I attempted to get up and just knew that I couldn't walk. The entire right side of my body was tingling with pins and needles - from my face all the way down to my toes. There seemed to be something wrong with my vision.

Having had hormonal migraines since my teens, I told myself that this must be a "really bad" migraine. I called out to the others in the house to help me. I didn't know if I was speaking any legible words or if I was loud enough, but no one heard me. In typical Mum mode, I began to feel more concerned for my little boy who was sleeping next to me, and I didn't want to wake him up.

The sun rose and everyone woke up. I still had pins and needles on the right side of my body. It had also become more obvious in the daylight that there was something wrong with my vision. It wasn't like the usual aura from my migraines. My visual perception was impaired, and I couldn't see at all on my right side. I was struggling to walk, and I was bumping into walls and doorways. I used my hands to navigate through my environment and I felt like a stranger in a strange body.

I organised with the person I had recently entered a relationship with to take me to a Medical Centre to see a doctor.

The doctor formed the view that I'd had a reaction to my contraceptive implant. It was then removed; I was given some more pain relief and told to rest.

A couple of days passed, and I was still no better. My vision was not improving, and things didn't seem to make any sense. I would look at words, but they didn't look right. I couldn't remember simple things like my pin number or my phone number. Things I would normally just know became a challenge and it affected my confidence.

I went to a different medical centre for another opinion.

This doctor told me to go straight to the emergency department at the hospital.

Upon arrival, they took me straight in, assessed me and put me into an ER bed. I have never felt such anxiety. By now I really thought that something bad was happening to me and that I might die.

I had a brain scan and blood work done. A doctor came to speak with me and told me he suspected I'd had a stroke and that they were transferring me to a different hospital with a stroke ward.

I was transferred by ambulance and admitted into the stroke ward at the Gold Coast Hospital. I felt immediately out of place as a young person on a ward full of older people who had suffered strokes, many of whom appeared to be in a far worse condition than I was. The nurses put a cannula in, put the sticky bits on my chest to monitor my heart and I was neuro-observed every hour.

I kept thinking that they must have had it wrong, I couldn’t have had a stroke; I am a young person and young people don’t have strokes.

The following day I was seen by the neurologist. He confirmed that I’d had a stroke and wanted to do some more tests. He did his neuro-observations on me and organised for a social worker to come and talk to me. I was then informed that my driver’s license would be suspended. The tests showed that I had a Patent Foramen Ovale (PFO), which is a hole in between the upper chambers of the heart. With a PFO, blood doesn’t always flow freely or forwards as it should, and this can cause blood clots. On this instance, a clot escaped through the hole in my heart, travelled up an artery into my brain and I had a stroke.

I went to the medical centre 24hrs ago thinking it would be just another check-up, and that I would be returning home where everything would go back to normal. I never expected to be admitted to hospital and I did not think for one minute that I had had suffered and survived a massive stroke.

Even though I was told why my stroke occurred, it still didn’t make sense to me. I was a young person; how could this happen? Why didn’t I know about the hole in my heart earlier? Was the contraceptive implant the catalyst for this to occur? Did all the stress in my life cause this? Would I be able to return home? Would I have another stroke? Would I survive another stroke? Am I going to die here? Will my body return to normal? What if I didn't see my kids again?

I spent the next three weeks recovering in hospital. Because it had been days before I got to the hospital and was diagnosed, the damage to my brain was permanent and irreversible. They were not able to retrieve the clot and the entire occipital lobe had died. The pins and needles finally stopped and the feeling on my right side returned to normal. I also learned to navigate myself around with my limited vision, but I still felt very strange and disconnected to my outer environment. I found it difficult to use my right hand as it wasn't functioning as it used to, I couldn't stretch my fingers out straight or grip and hold onto things without dropping them, and my confidence was at an all-time low.

I returned home. I had a few meetings with my directors at work and it was decided that due to my disabilities I was not able to return to my position of employment.

I found the transition back home very unsettling. I was not used to being at home during the day, not being super busy all the time, nor was I used to depending on others for assistance.

My new partner and I decided to move in together and we soon discovered that I was almost 3 months pregnant.

Even though the pregnancy was high risk, had a few complications and involved direction from my neurologist, cardiologist, and endocrinologist, I gave birth to a beautiful, healthy baby boy by c-section.

After the birth, I was still adjusting to my post-stroke life. My partner worked long hours, six days per week about an hour's drive from where we lived. The people who were in my life prior to my stroke were not in my life anymore. Some relationships came to an end by my choice, and others were a complete surprise which left me feeling rejected and worthless. Not having any support around me while caring for the children I already had, plus having a newborn baby and these new disabilities was a battle. My neuro-fatigue was beyond overwhelming. I was not coping with the demands of the household, and I felt like I was having an identity crisis. I didn’t know who I was anymore, and I kept thinking things were going to go back to normal. I cried most days and prayed that someone would help me. I had become physically inactive after my stroke and pregnancy and was also diagnosed with hypothyroidism (Hashimoto’s). I had put on 40 kilos of weight which lowered my confidence even more. I felt like I was failing as a parent as I could no longer drive my older kids to and from school to their sporting commitments, appointments, nor be the mother I wanted to be for them. I struggled to get through most days. I knew I was giving so much love to my baby, but I still felt like I was failing as a parent and as a person. I was so hurt by the people who I expected to be there for me but weren’t. I had already experienced so much trauma prior to my stroke, I couldn’t believe that my life had turned out like this.

I decided one day that I needed to pull myself out of this inner turmoil. I was in so much emotional pain. I was focusing on all the things I had lost and blamed it all on my stroke.

I had to let go of my old life ‘before my stroke’. That life wasn’t coming back, and neither were the people who were in it.

I created a template for myself so I could discover where I had gaps in my needs being met. I went to work on filling those gaps, which were:

SOCIAL & EMOTIONAL: I joined Facebook groups with other stroke survivors. I was amazed at how many young people had strokes and all the different reasons why they had them. I was no longer alone.

FINANCIAL: I started an online work from home business. I earned some money which took away the burden of financial stress due to losing my income.

PURPOSE: I studied Personal Development, Integrative Nutrition & Hormone Health Coaching, Reiki Level 3, NLP, Timeline Therapy, Hypnotherapy, Business Development, and Social Media Marketing.

MINDSET: I paid a coach to help me with my mindset and limiting beliefs.

When I worked on my internal world, my external world changed.

I no longer felt guilty for not being “employed” and embraced my role as a stay-at-home parent. I no longer felt the need to be identified by my career, money, material possessions, or body size. I felt genuine appreciation for all the little things. I love being able to walk the kids to and from school, stopping to admire things like rainbows, flowers, and feathers along our way. I love being available for them when they need or want something. I love the time that we have now. Most of all I love how I have let go of the dependence I had on the opinions of others. I hid my stroke for such a long time because I felt ashamed of being a stroke survivor and a young person with disabilities. I didn’t talk about it openly for fear of judgement. I learned (the hard way) that my true value and sense of self-worth comes from within me and not from anyone else.

I created a new life after my stroke. I met new people - strangers that turned into genuine friendships. I finally felt connected, accepted, and not limited by my post-stroke deficits.

The kindness of people reignited the spark in me that disappeared when I was in a dark place after my stroke.

My partner and I separated but we co-parented our child.

Fast forward a few years and I am now paying it forward and helping others. I have created and trademarked a business called Kindness Empowers. My mission is to raise awareness and empower the lives of young stroke survivors all over the globe.

I do this in a few ways.

Firstly, by raising awareness. It is important to me to raise awareness because until I had my stroke, I had no idea that people of all ages can have strokes, and for several reasons. I raise awareness through the sale of Kindness Empowers merchandise and through social media platforms. Proceeds from profit are kindly donated to the National Stroke Foundation for prevention, treatment and care of stroke survivors and their families.

I am also an Independent Support Coordinator through the National Disability Insurance Scheme (NDIS) in Australia; I assist with Capacity Building in a young survivor's plan by connecting them with supports to maximize their independence and access the community once they leave hospital.

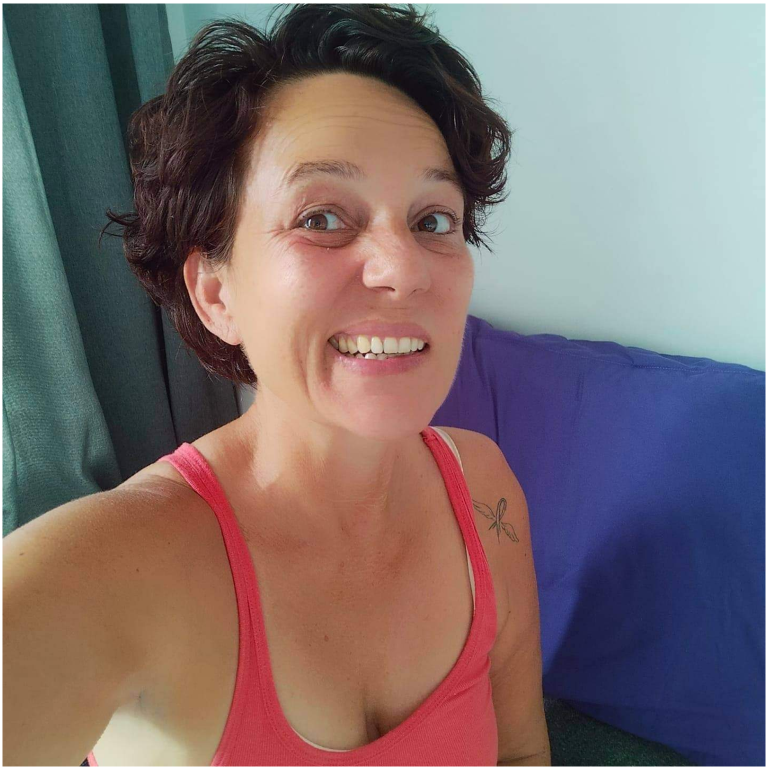
I also volunteer my time on the Consumer Advisory Group at the Gold Coast University Hospital and the National Stroke Foundation's Young Stroke Project Admin team.

I know how life-altering a stroke can be and that is why I care about raising awareness, improving outcomes, and empowering others.

Stroke certainly changes your life, but it doesn’t mean you can’t continue to have a meaningful one.

Embracing
My
New
Normal

By Lisa Astermann



My name is Lisa. I am a proud Australian Stroke Survivor and TEFL teacher living in Siem Reap Cambodia.

My story is one of survival, hope and strength. This is my personal experience of recovery following a massive stroke. I hope to show you how the power of positive thinking turned my life around. When you believe in yourself, anything is possible!

I was 44 on February 4, 2018, a day that will be forever etched in my memory.

This is my story…

I have always been full of life and have a passion for travel and discovering new people and cultures. I am an independent woman and enjoy my own company. During one of my solo trips throughout Southeast Asia, I fell in love with Cambodia and knew in my heart, I needed to stay there. Arriving home from the incredible trip, I made the big decision to give up my life in Australia, and after 12 years of working in the Home Entertainment industry, move to Cambodia to teach English. Which I did!

I loved my new life in Cambodia. I had a lovely apartment, beautiful new friends, and a job teaching English. My landlord and her family lived downstairs. They treated me like part of the family. Life was great!

In September of 2017, I woke up feeling really strange. I had a high temperature of 39 Degrees Celsius, and I was very dizzy and weak. I sent a text to a friend and couldn't type or use my words. He couldn't understand me, so he quickly came over and took me to the hospital. I had a few tests and was told I had a virus. I felt ok after a few days but ended up taking antibiotics and going back and forth to the doctor. After about 8 weeks, I finally felt strong again. I would learn to know sometime later, that I'd actually had a TIA (transient ischemic attack), a warning as to what would come!

A few months later, it was like any other morning. I got up, had a coffee sitting on the balcony, then I went for a shower before going to school. While standing in the shower, I was suddenly overwhelmed with nausea and dizziness. I collapsed on the floor and became unconscious. I didn’t know how long I was out for but I came to when I heard my phone ringing in the other room. I tried to get up, but I couldn’t move. I tried to pull myself up using the pipe under the basin, but I wasn’t strong enough. I collapsed again on the floor and didn’t wake up again for two days. I eventually woke up to my neighbour holding my hand and telling me that it was ok and that an ambulance was coming. He told me that the landlord had asked him to check on me because she hadn’t seen me in a while. I am now grateful for my daily coffee routine on the balcony, as I had left the door open, and that allowed my neighbour to get into my apartment.

I only remember lying there unable to move with a lot of people trying to help me. I was once asked, “Weren’t you scared?” I surprisingly felt pretty calm.

The next few hours was a blur. I only remember small parts of the time at the hospital in Siem Reap. I was told, I was being sent to Phnom Penh (Capital City of Cambodia) for a brain operation.

I don’t have any memory of the 5-hour drive to Phnom Penh. I only recall waking up to a nurse shaving my head ready for surgery. Fast forward several hours later to waking up in ICU after a craniectomy.

It was now more than 3 days since I’d collapsed in the shower, and I was lying on a bed in ICU when I finally understood the enormity of the situation. The doctors explained I’d had a massive Right MCA (Middle Cerebral Artery) Stroke and I was paralysed on my left side. I couldn’t speak properly or move. Thoughts were running through my head like” Why?” “How?” and “I’m too young to have a stroke!” I soon discovered that a stroke can happen to anyone, anywhere and at any age.

Myth: A stroke only happens to elderly people. That is completely false!

At some point, something triggered in me to accept that ICU was my home for the foreseeable future. I decided not to let this situation beat me, so I fought! I started physiotherapy for 2 hours every day. I pushed myself and had the most incredible therapists and nurses supporting me along the way. About 10 days later, I took my first steps. This was my first positive milestone. An extremely emotional moment, that made me push even harder. My family and a great friend flew over from Australia to be by my side. Their support was encouragement enough to keep me going.

As the days turned into weeks, I was talking much better and my walking improved tremendously. By this stage, I had been informed that I'd had Endocarditis (a bacterial infection of the heart), which caused the stroke, so I was on a daily drip with strong antibiotics for the infection.

After 6 weeks in ICU, I was ready to fly, so it was time to be evacuated back to Australia for ongoing recovery. I was devastated to leave my second home in Cambodia. I am forever grateful for the incredible staff at the hospital, who made me laugh daily, and made this trauma such a positive experience overall. I never thought of this as "goodbye to Cambodia". So, I set myself a long-term goal and was determined to work hard enough to come back. My mantra…Never Give Up!

Back on home soil and in an Australian hospital, my home for 6 weeks. I was subjected to numerous tests daily, including CT scans, MRI, x-rays, a TOE (Transesophageal Echocardiography) and many more. Sadly, it was an unfortunate experience compared to the hospital in Cambodia. I was left in a bed alone with no exercises. Therefore, I took it upon myself to do my own exercise routine. I walked the corridor and did other exercises in a chair next to my bed.

Eventually, I was moved to a rehabilitation hospital for intense therapy, and it was here that I met my “stroke warrior sisters”. We were a daily support for each other, as we all had a personal understanding of what each was going through, even though we all had completely different side effects from the stroke. Meeting these women made me realise how blessed I was to be alive. In my mind, I thought my after effects could’ve been a lot worse, and this made me push even harder.

The daily routine consisted of physiotherapy, occupational therapy and speech therapy, and eventually, aqua therapy.

Day one was an exciting milestone as after having had a subluxation shoulder, my arm finally started moving!

I also started walking outside daily and I learned how to run up and down stairs. Yes, run! I would never have thought that was possible a few months prior. My next goal was in the daily group physiotherapy session where we did a sit to stand exercise. I wanted to beat the record, and I did! A massive 1,280 reps!!! I learned to set small goals along the way and embrace it.

My time in rehab was such a positive experience, mainly due to the constant support of my family and friends and my therapists. I learned a lot and I knew I could move forward positively with the life ahead of me.

After six weeks, I was ready to be discharged and I moved in with my mum. The hard work didn’t end there, and there were numerous doctors and specialist appointments and therapy sessions as an outpatient.

I was blessed to have had a wonderful medical team. They were all extremely supportive of my goals. I believe it is very important to have a great team behind you and one of the most important lessons I’ve learned is that asking for help is OK because you are not alone.

I was thrilled to confirm after seeing an optometry specialist, that my eyesight was not affected. In fact, it was better than before the stroke. Also, I was cleared by my cardiologist, advising that the endocarditis was a random, unlucky occurrence.

Yes, it was challenging and frustrating at the time. I had lost my independence and lost a few so-called friends who abandoned me. So, I’ve learned to focus on myself and avoid negative people. My advice to others is ‘be kind to yourself and embrace what will be; you are stronger than you think’.

My first taste of gaining my independence was when I passed my driving test. I was so happy to be able to drive again and not rely on others all the time.

It’s an exhausting time, so it is very important to sleep, cause the brain needs the rest to recover. Do not feel guilty about that. Let’s talk about the emotional impact of a stroke too. It is very strange, not having control over your emotions. Crying, laughter and anger is a regular occurrence. I compare it to be in constant mourning.

Other than therapy, I decided to educate myself. I kept busy by teaching myself how to paint, which I loved. Also, I completed and passed a few online courses, did a work placement working with kids with disabilities, and my OT invited me to present to university students about living with a stroke. With the support of my speech therapist, we organised a walking group for people with brain injury. Eight months post, I entered and completed a 5km colour fun run. Huge progress indeed!

I hope other survivors can find something they love as a distraction from of the doctors’ appointments. A great tool is to join stroke groups. I have met many amazing survivors through the groups and it’s great to hear from others experiencing the same thing as me.

Every day there is a form of therapy. Even little things that I took for granted, like tying my shoelaces or putting on a bra. Now I can do it, no problem! The key is patience, practice, practice, and practice!

In the beginning, I hated my smile because the left side of face dropped. I would stand in front of a mirror and do face exercises and pronounce the alphabet repeatedly. Over time, it got better. I was so excited the day my therapist told me he could see dimples. I know it sounds a bit vain, but for me, my smile was important. Now, I smile all the time!

Do you remember my long-term goal to go back to Cambodia? Well, guess what?! 18 months post, I jumped on a plane and went back. It was an incredible moment to see all the beautiful people again that supported me from afar. I was completely embraced by everyone I saw. I did not feel like I was disabled or belittled, and I wanted to show that stroke was not a death sentence. Yes, my life changed, but that’s OK.

Shortly after my arrival, I went back to an NGO teaching English, found an apartment to live in on my own, and started my newly-found independence. A few months later, I got a full-time job teaching English Phonics at an International School, where I am still today. My students and colleagues know about my stroke, and they encourage me all the time.

I am completely open when talking about my stroke. So, I can’t use my left hand properly, so what! That doesn’t stop me from doing things. There are always other ways.

I think it’s important that the stroke doesn’t define me. I want to educate and inspire others instead.

It is also important to note that every stroke is unique as well as the progress. Life does get better – I promise! The reason I’m alive today is because of the overwhelming support of my family and friends – they pushed me to get better!

Have You Ever Had Two Cars for Dinner?

By Marcela Brotto

Marcela Brotto used to work in the film industry before moving to Australia. She holds a Bachelor of Marketing and has communication in her heart, although she has always had a passion for psychology. Currently, she fully feels her heart working in the disability industry, supporting people to find employment.

It was coming towards the end of January 2011, and I was an overseas student living in Dillon, Colorado, in the USA. I was there because I so wanted to spend wintertime in the US, see the **snow, and** improve my English language.

I was living in front of a frozen lagoon called Dillon Reservoir - a beautiful place with snowy mountains on the horizon. It was Tuesday, - 30C outside, snow everywhere and knee-deep. It was romantic but freezing.

Day one:

It was my day off and I'd overslept. My phone went off; someone was phoning me. It was a phone interview for a second job and the interview was over after three questions. I was so confused. I had blurred vision and thought, 'Oh no, a migraine!' So, I took a tablet for it and went back to sleep.

I woke up minutes later feeling terrible, like I had the worst hangover in my life. I had to get up, as it was time to go to the local College for an English test. The College was about 1 km from my home, a short walk. There were parked cars, snow, and crows on the way, and I was the only person on the streets.

The test was English and Math - the score I achieved was level 2 and the only personal details I got right was my full name: Marcela Caroline Brotto.

After the test, I became quite ill, so I went outside and threw up on the sidewalk. Some people saw me, but no one came to help me. I had to stand in line to enrol back inside, but I didn't have the energy for that, so I decided to walk back home. Looking back, I am so glad that I made it home. If I had fainted, I would have frozen on the path and died.

Back home I decided to order online a pizza for lunch. It was hard! I was so confused. I tried to chat with my flatmate, but he started to laugh at me. Nevertheless, he placed my order, I had another blurred vision, and I took another tablet for migraine. After lunch, I had a nap.

It was my cleaning day, so I asked one of my flatmates for a cleaning product because 'I need it to drink'. She looked at me seriously: 'What?' Then the discussion started! My flatmates were laughing at me. They thought I was high and being weird. I got so angry with them. Eventually, my roommate understood that something was wrong with me, and she rang her mum in Brazil using Skype. It was about 3 AM. She asked about my lunch, and I said: 'Yes, I had two cars.' I even remember her surprised face looking at me: 'Two cars, Marcela'? Me: 'Yes, two cars. I wasn't hungry enough.'

Day two:

Day off again. I woke up feeling better. The blurred vision kept coming back, but there were no migraines.

My roommate, whom I would like to call Angel, had a chat with the manager from our work, and he decided to meet me to see how I was. Angel, my manager, and I went to the supermarket for a short walk. I looked fine that day, not mistaking my words - just in my mind.

Day three:

I was energised, but the blurred vision was still there, so I put some tablets in my pocket. It was pretty tricky remembering some numbers at work - I forgot what number came after 6, and 18. So, I decided to write them down on paper from 01 to 20. My manager saw it and said, 'Marcela, I will take you to the hospital. We need your passport and your insurance.' I didn't want to go, but he convinced me by saying he had spoken with his flatmate, a rafting guide. He said to take me to the hospital because he had seen people having accidents hitting their heads on rocks but had not seen anyone who changed words without realising it.

At the first Hospital in Frisco, the closest and biggest town, I still had blurred vision and was more confused. I was wearing hospital clothes - the ones where your butt sticks out. It was so awkward! I had to do a urine test - Oh no! Weed was illegal for recreational use in Colorado at the time and I was worried. Oh, I was! I was also living in the US holding a student visa. Anyway, I had no choice.

I spent the day on a hospital bed in a little room. The doctors and nurses were running around me, talking with my boss. I tried to explain the blurred vision to him, and he was translating it to the nurses and doctors. I was tired and full of confusion in my head, and I had blurred vision again. They did an MRI of my head and neck: 45 minutes each. Because of my young age, the doctors were suspecting brain cancer. Even so, they realised that I was having TIAs - Transient Ischemic Attacks, otherwise known as minor strokes. I could not believe it, considering I was awake and speaking.

A nurse came in and gave me the most painful needle in my belly. It was a liquid to make my blood thinner which would prevent blood clots.

I saw Angel by the room door looking at me. She was a tiny woman with long dark hair, and a beautiful woman. She looked more terrified than me.

The doctors decided I should travel to Denver, the capital of Colorado, which meant about 2 hours driving from where I was on a snowy road. They referred me to a bigger hospital with a team of specialists. One of the nurses asked if I wanted to travel by ambulance and have my roommate at the hospital with me or fly by helicopter. I clearly said: ‘I can go by ambulance. My friend has her life, and she doesn’t need to come.’ It did not help much because they decided that I should fly.

In a blink of an eye, a paramedic arrived. She asked me my name and DOB. Angel was there with me, crying, poor girl. I told her my full name, and my DOB was 07/04/1883. Angel screamed: “No! That is wrong!” The paramedic looked calmly at her: ‘It’s ok.’ In my mind, I was thinking, ‘what is wrong with it?’ Then I had blurred vision again! And then they proceeded to attach a lot of plugs to my body.

It was dusk outside when the paramedic was taking me to the helicopter. Inside, there was just the pilot and the paramedic. I was alone at the back. I was terrified to fly due to the snow and the numerous hills on the way. I thought that the helicopter would hit a mountain and I would die.

When I landed at the helicopter platform, a male nurse approached to take me to the hospital - I had blurred vision again! I went straight to the ICU, into a single room with highly technical medical equipment and there were also monitors around the bed. Plugs were stuck to my chest and back to check my heart rate and again the annoying painful needle into my belly. I had an intravenous catheter in one hand to deliver medications, a clip-like device in my finger to measure the blood oxygen and an analogue phone translator with two handsets - one for me and the other for the doctors to help the communication go smoothly. Occasionally, I spoke with a Portuguese woman; it was fun!

Another MRI, same answers - painful needle in my belly and a few bruises on my body, although the blurred vision stopped!

I do not know how, but Angel was able to speak with my mum in Brazil, so they were aware of what was happening. Angel was brave!

Day four:

A painful needle in my belly for brekkie, then doctors decided to check my heart with a tiny camera. ‘Voila!’ They found the problem. I had a hole in my heart which was the size of a dollar coin. The doctors explained that this hole is common at birth but often closes as a baby grows. So, the expectation for the unlucky ones is a stroke between the ages of 25 - 30. Me! The doctor asked me if I wanted to have surgery or preferred taking medication for the rest of my life. I had no doubts: surgery!

After that discovery, I was able to eat food. My first main meal was a sandwich with chips - for someone who has heart issues? Well, this was the US after all. I also had the opportunity to be disconnected from the plugs for a short walk along the corridor. I was in a large area with private rooms, with no doors edging the walls. There were a hundred tables, computers, busy nurses, and doctors in the middle of the place. I remember seeing a patient on his bed who had had a car accident. His head was open after the surgery. He was sedated. I felt guilty being there because I could see, talk, and walk. During the afternoon, a lovely old lady came to my room playing a harp. It was so lovely to see someone smiling at me, trying to make me feel comfortable.

Day five:

I was in surgery. Nurses and doctors were getting ready, and a nurse said to me: ‘You can sleep or you can watch the surgery. What do you want to do?’ Me: ‘Sleep, of course!’ In my mind I was thinking: ‘Who would want to watch their own heart surgery?’

The surgery went perfectly! It was done through my right groin, and a little umbrella was inserted into my heart. After that, I went back to a private room where nurses, doctors and psychologists came constantly to check on me and do memory games.

I had a headache for about seven days after surgery. Other than that, I was ok; I just had some trouble remembering some words. I had to close my eyes and draw the word in my mind to recall it. My brother flew from Brazil to see how I was; he brought a book from our mother as a gift. I had to read each paragraph 3 - 4 times to understand them.

My doctor explained that my birth control pills had too much estrogen, which caused the blood clots to appear. Since I had a hole in my heart, clots had been able to travel to my brain.

He also explained that after the surgery that I would be able to have an everyday life again. He stressed: ‘You cannot take the birth pills anymore, nor any ‘ine’s such as caffeine, nicotine, cocaine, amphetamine, or any other stimulants.’ Me: ‘Can I have wine and weed?’ He said: ‘Yes, you can. But I never said that to you.’ Welcome to Colorado! Whatever, I do not smoke anymore. Seriously, I get too high!

After that tumultuous experience, I have realised how how fragile we are. So I decided to take care of myself and my body by eating healthy foods and being active. Nobody could believe I had had TIAs and had no physical disabilities.

I moved to Australia 4 years later. To be honest, it’s still not easy remembering words I’ve learned. I believe my memory was affected. Sometimes I swap words such as cold and hot or borrow and lend. And learning grammar is challenging.

Other than that, I am so grateful for moving to Australia and living close to my brother. I am also glad for the opportunity to meet amazing people down here.

To keep in mind:

There are two simple tests if you suspect someone has had a stroke:

1) sing a simple song such as happy birthday

2) keep both arms straight and in line with their shoulder for 10 seconds

Please send them to the hospital straight away if they cannot do it!

A
Matter
Of
Matt
Journey

By Matthew Weingartner

My name is Matthew Weingartner. I am 34 years old, and I live in Long Island, New York. I have Aphasia after my stroke in April 2018. I have a story to tell about my journey which I hope inspires others. My family and friends have been instrumental in my recovery.

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I'm Matthew Weingartner and I’m from Long Island New York. Growing up, my life was moving along without a hitch. I followed my dad’s footstep and was an avid athlete in High School, and our baseball team won the State Championship! After graduating High School in 2006 I went to a local college, having received a scholarship to play baseball. This is where my life changed.

This was the first year this college required ALL the baseball players to get an EKG. To my surprise, I had a failed my EKG and was required to go to a cardiologist for clearance. An appointment was set up and another echocardiogram was done. It revealed I had a heart condition which caused my aorta to enlarge. I was then diagnosed with an ascending aortic aneurysm. This was so surprising as I’d never had any symptoms in my 18 years of life. The cardiologist said I was lucky it was caught and in time. On December 28, 2006, I had open heart surgery. I was 18 years old. The doctor replaced the malfunctioning valve and placed a surgical graft on my aorta. After recovering from open heart surgery, I finished my 4 years of college at Farmingdale State College, earning a bachelor’s degree. I had been cleared to play after the first season, playing the remaining 3 years. During that time, me and my team went to the 2009 NCAA Division III World Series at Fox Cities Stadium, Grand Chute Wisconsin.

I was called for the New York City Police, but after having a physical, I was denied due to having had open heart surgery. I tried appealing their decision but moved on to become a part-time Public Safety Officer at a local college on weekends, and a full-time heating and air-conditioning contractor for a small company.

After 5 years, I continued as a Public Safety Officer at the local college, but I left the heating and air-conditioning company to pursue another job opportunity.

In November 2017, I was newly employed by Local 3 Electrical Union as a full-time apprentice, which required 5 years of night-time classes. It was a dream come true job for me as my grandfather worked for Local 3 for 40 years and I was proud to carry on the tradition. Then just a few weeks later, I was having trouble breathing and tests revealed that my valve needed replacing, so on December 21, 2017, at 29 years of age, I underwent my second surgery to replace the malfunctioning valve from 2006. Recovery was a little tougher this time around but after 8 weeks, I returned to both jobs, continuing to work 7 days a week.

Everything seemed to be back to normal, and on track, but on April1 16, 2018, I was feeling unwell. I had injured my hand slightly at work a day or two before and went to urgent care, a hand specialist and then my cardiologist. An infection was determined, and an antibiotic was prescribed. I didn't think much of it, but as I was having leg pain, my cardiologist set me up for an appointment for April 20th to have leg doppler done. I didn't think I would never make that appointment.

The morning of April 18, 2018, I drove my truck to the train station and took the train to work as I had done every other weekday. However, today I was really feeling the pain in my leg and I had difficulty walking up and down the stairs at the train station. I did put in a full workday and that evening I headed over to the subway to get to my night class. When I got to class, I started sweating and feeling strange. Then, suddenly, I fell and passed out. The paramedics were called, and as my classmates knew I’d had open heart surgery December 2017, the paramedic quickly determined I’d suffered a stroke and needed to get to the hospital right way. I was rushed to the hospital and my parents, and my brother were there when I arrived. I have a vague memory of them being there and of my mom crying and saying she loved me. Then I was wheeled to the emergency room where they tried to extract the blood clot. They couldn’t get all the clot out but got most of it. We later found out I’d suffered a massive ischemic stroke which, after days of blood testing, was revealed to have had resulted from a blood bacterial infection (Endocarditis).

When I woke, my life had changed forever. I was in shock, and I did not really understand what was going on. I did not know much about strokes, and at 30, who really does. All I knew was that I could not move or speak. I was in the hospital for several weeks with extensive occupational therapy, physical therapy, and speech therapy. Then I was released to go home, and my parents had to do absolutely everything for me. They set up two-week in-home therapy and then after two-weeks, I went to a rehabilitation facility as an outpatient 3 times a week, where I continued with Occupational, physical and speech therapy. It is still on going.

As a result of my stroke, I have been left with aphasia, no movement in my right fingers and hand, and a limp when I walk. I welcome my limp, given where I was after my stroke. I’ve learned to manage somewhat with what I call one and a half arms. However, having aphasia has been difficult. Aphasia is a loss of language, not intellect. I've come to terms that this is something I will always have It's truly an invisible disability that most people don't understand. More than 2.5 million people in the US have aphasia, yet most Americans are unaware of this invisible disability. The only way to describe aphasia is to imagine understanding what people are saying to you, and knowing what you want to say back to them, BUT, not being able to get the words out.

Speech therapy has helped me tremendously with saying a few words at a time, and reading a few words, but I am still not able to speak or read complete sentences. I was told about a Voice to text application to download on my cell phone. It reads what people have texted to me and I then I can speak words back to respond. It’s been a blessing in communicating with family and friends, not making me feel as isolated. It’s been difficult adjusting to the things I took for granted like being able to tie my sneakers, zipping a jacket, cutting my nails, ordering at a restaurant, or calling for a doctor’s appointment to name a few things.

I’ve found online support groups such as Voices of Hope for Aphasia, Dudes with Aphasia and Aphasia Recovery Connection (ARC) which have been instrumental in my recovery. So many people are, or feel, alone, and this brings us together virtually, from different places. As a matter of fact, I’m an Aphasia Ambassador for ARC, raising awareness for my cause. I really enjoy Dudes of Aphasia as only younger members are in this group. Most people I’ve met have been much older than me. It’s nice to interact with my age group and talk about our struggles and fears.

Prior to the pandemic I also went to two local colleges for one-on-one speech classes, and group sessions. Thankfully this Fall, in-person sessions will start up again. I'll go to Post College, which offers a 2- or 4-hour Aphasia Group session. It’s not covered by insurance, but the out-of-pocket cost is minimal. It's held Mondays and broken down into 4 "mini" half hour sessions with a 1/2-hour lunch break. You can pick and choose which session or sessions you want to go to. They have yoga, current events, sports, and music sessions. The sports and music sessions are my favorite. The other college is Hofstra University. Again, it’s not covered by insurance but the out of pock cost is minimal. I'll go for an hour of one-on-one speech therapy then immediately following, go to what they call "Men’s Group" for 1½ hours. This is a small group for men only. We talk about anything and everything. It's a great way to communicate with one another and help improve our speech. I've met so many friends at both these groups and look forward to seeing them in person again this Fall.

Also prior to the pandemic, I went to a conference where a cardiologist spoke about the benefits of a plant-based diet. He advised the importance of eating plant based, especially if you have a heart condition, which I do. Since then, I've changed my diet to 100% plant based. I love to cook and have purchased a few cookbooks that have delicious plant-based recipes which I’ve made. A close family friend has a vegetable garden. As he knows I eat plant based, he set up an entire section in his garden for me to grow vegetables. With his knowledge and help we've grown kale, Brussel sprouts, cauliflower, snap peas and broccoli. All these fresh ingredients have made my recipes taste even better!

Going back into the workforce hasn't been something I've been able to do as I can no longer perform the job at Local 3 Electrical Union, or as Public Safety Officer at our local college. So, to keep busy, besides going to therapy, gardening, and cooking, I’ve done some volunteer work. I'm still in touch with my High School baseball coach, so, during this past baseball school season I helped at baseball practices and local games. It was great fun and brought back my High School memories. I also helped at my next-door neighbor’s gym, cleaning the equipment. It felt good volunteering, being around different people, and feeling like a part of society again.

While my life has changed, I feel it’s a positive change. Positive? Yes, because it taught me how precious life is and to never give up no matter your circumstance. My motto is, "Life goes on. Stay positive. I'm not giving up. That's the bottom line". The greatest lesson I have learned is to never give up. Continue to work hard. My family and friends have stood by me since day one. They have been a constant support and I’m so grateful for them.

My goal for the future is to go back one day to work, drive and do ALL the things I did prior to my stroke. My hope is that one day my speech will be fluid enough for me to be a motivational speaker. My dream is that one day there will be a medical breakthrough with stem cell to allow me and others like me to regain movement in their hand and fingers.

One last piece of information to share with others is my "A Matter of Matt" YouTube channel. My brother and my mother help with my videos. To date, I have done 16 episodes which are about my life, my journey and my hope to inspire others like me. Check it out!

https://www.youtube.com/channel/UCBp7I4M-ecHoaRd6n9wVHDA

My
Stroke
Of
Inspiration

By Priya Sharma

Hey, I'm Priya and I'm from Sydney, Australia. I suffered a life changing stroke in July 2015 at the age of 24. Life has definitely changed a lot and I now do a lot of volunteer work for the Stroke Foundation and share my story as much as I can.

I would love to connect –

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I was diagnosed with a Cerebral venous sinus thrombosis (CVST)/Dural Sinus Thrombosis, a Pulmonary Embolus (PE) and Deep Vein Thrombosis (DVT) in July 2015 when I was just 24 years old. I had also had a stroke and seizures that were caused by blood clots, an intracerebral haemorrhage, and a blocked artery.

It started when I was sick for a week with Gastroenteritis. At that time, I just thought it was food poisoning. I was taking the contraceptive pill for my skin/acne, which is the likely reason for my health issues, and it changed my life forever.

I remember it like it was yesterday. Okay, maybe not yesterday, but very recently. I started getting quite sick, vomiting, diarrhoea, you name it. I could not keep food down for long and was barely drinking any water at all. I thought I had food poisoning and the doctor I went to had the same thought. After 2 days, I was still not getting any better, so I went back to the doctor and was advised to rest as much as possible and to make sure that I was staying hydrated. The next day, there was still no change, and my symptoms were getting worse, so I went to see a different doctor. He ended up diagnosing me with Gastroenteritis. I remember feeling really gross the next day and got up to have a shower. Afterwards, when I was stepping out of the shower, it was as if my body was jelly and I suddenly collapsed. I was really confused and a bit scared because nothing like this had ever happened to me before and I was home alone at the time. I did manage to get back up, get dressed and go back to bed. My parents came home later that evening and saw that I looked quite weak, and Mum asked me if I wanted them to take me to the hospital. Luckily, I said yes, otherwise my story would have had a very different outcome.

I was taken to Sydney Adventist Hospital. When we got to the Emergency Department, we were told by a triage nurse that it would be a two and a half hour wait and she asked us if we wanted to wait. Of course, we waited. We went and sat down, and, in the meantime, they decided to take me to get some blood tests done. Apparently, it took two men to lift me out of the chair and put me in to a wheelchair because the whole left side of my body was paralysed, and I was dead weight at that stage. As they were taking me to get the blood tests, I started having a seizure. It was then that they realised that there must be something serious going on and they took me to get a CT scan and an MRI. The Scans showed lots of blood clots in my brain, so they transferred me straight to an ICU room. I was put under the care of Dr O, and he and his team later decided to have me transferred to Royal North Shore Hospital, under the care of Dr A & Dr F. I was booked in to have my first procedure, a thrombectomy, first thing on Monday morning. Two days after the procedure, I had an MRI which the doctors said still showed a lot of clotting in the brain, so I was scheduled for another thrombectomy to be done the day after and this time, I was able to give my consent and sign the papers myself. I remained in ICU for 9 days where I started physio and learning to walk again. After this, I was taken up to the step down ward, where I spent another 2 weeks. During this time, I had a vasovagal episode in the shower and another fall in the bathroom, which resulted in a nurse being by my side from here on out, including showering and going to the toilet. I also had tachycardia whilst in the step down ward, which resulted my Neuroradiologist sending me to get a lung scan, just to check if everything was okay. It was there that they found blood clots in my lungs and the doctors were quite surprised as I'd had no trouble breathing this whole time. This also prompted them to have a leg ultrasound on me as it can be common to have blood clots in your legs and lungs at the same time and unfortunately, they also found clots in my legs. After all this, my neutrophils started dropping below average which was a result to an allergy to the anti-seizure medication, and they decided to put me in isolation, which meant my own room, and visitors would have to wear a mask and gown and sanitise before they came in (a glimpse of covid, perhaps?)

We had the cutest therapy dog come to cheer up the patients in the step down ward. Georgie loved curling up on my bed! After a few days, I was ready to be discharged and sent to Inpatient rehab (Royal Ryde Rehab) and spent the time there doing physio, gaining some strength back, learning to walk and climb up and down stairs unaided, speech therapy and occupational therapy. My speech was slower than it was before the stroke which was the reason for speech therapy, and I even had to learn basic things such as using a fork and knife to eat. I was due to stay in rehab for three weeks, but I ended up spending two weeks in inpatient rehab as my recovery was going well and then started outpatient rehab for four weeks, twice a week.

One of my first walks in rehab! I was very lucky that I was in a supportive and understanding workplace who kept my job while I was in hospital, and I went back to work in November, 2015. I started off gradually and built up my hours and days (per doctor's orders) and was able to be back to working full time by June 2016.

Prior to my stroke, I was a healthy person. I was eating healthily and going to the gym 4-5 times a week. My doctors say that this definitely helped in my recovery and is one of the reasons I was able to recover so well and fast (aside from being young). I was lucky enough to be given the ‘all clear’ to go back to the gym about 10 months after the stroke.

Unfortunately, there was not much information given to me about stroke or the stroke community and after I got home, I went on Facebook and found some support groups myself. Over the years, I have been able to connect with so many stroke survivors and families through social media and am so grateful for the different stories I hear and the community we have. In 2016, I found the Stroke Foundation and started volunteering with them and in 2018, I became a Stroke Safe Speaker. I also fundraise for the foundation as much as I can and have spoken with State and Federal Government MPs about stroke funding. I've had so many amazing opportunities with the Stroke Foundation, and I’ve met so many awesome and inspiring people! I've been on so many amazing adventures, including the Sydney Harbour Bridge Climb and City2Surf, since my stroke, that I didn't think were possible. After my stroke, I also came across an app called Perx which has been a major lifesaver for me. You can schedule your medication and vitamins within the app and then receive daily reminders when the task is due. You can also add in daily tasks (that you might otherwise forget) such as drinking water, meditation, brushing your teeth etc. You can also add in doctor’s or specialist appointments which is definitely very handy and schedule a reminder for them. It’s also really handy for prescription reminders, you can add in when you last filled your script and set how often you fill it and be reminded when it’s due to be filled again. It’s been super handy and definitely kept me on track with my health after stroke.

Unfortunately, they haven’t figured out the cause of everything. The stroke was caused by the clots and the haemorrhage, but they are still stumped for the cause of the clots. They just know that a factor was the contraceptive pill. I learned more about blood clots and the blood thinners that treat clots and the risks for blood clots, including birth control pills. It’s very important to spread the word about the signs and symptoms of blood clots and its associated risk. I was fortunate enough to be left with no physical deficits apart from the odd muscle weakness in my affected leg and migraines, and since my stroke, I have suffered from Anxiety and Depression.

My Haematologist says he has never seen someone with blood clots in all three places at once, so I'm incredibly lucky that I walked out of this. I was told that if I hadn't had the procedures when I did, I would have been dead by now!

I look at life differently now, and I am thankful every day when I wake up. I now appreciate everything life offers, both good and bad. I've learned that life has lessons, and that life can be so short so make the most of it. I'm so blessed and fortunate that my blood clots were caught before it was too late, and I am grateful to my family and friends who have supported me the whole way. I'm also glad that this was caught early and that I could recover so quickly from it. My advice to others is to stay healthy, move, and keep in shape to keep your blood flowing. It is also important to be aware that birth control pills carry risk for blood clots.

My advice for those going through something similar would be to try and stay positive in this situation. I know it's hard sometimes, but a positive mindset can help your recovery in a good way. It did for me. Six years later and I'm still seeing both of my specialists every year and I'm still on blood thinning medication, as my haematologist says, 'you're so good at clotting that we don't want to take you off them too soon'. Recovery after stroke can be a long process but I'm very grateful to have amazing doctors and specialists who take the time to answer any questions I have and really look into any new problems that arise for me.

Between
Two
Lives

By Rob Gast

Rob Gast was born in Dayton, Ohio but grew up in Pleasanton, California. He returned to Ohio to attend college at The Ohio State University where he earned a Bachelor of Science in Business Administration: Double Major - Transportation & Logistics and Marketing. He worked as a senior manager at Abercrombie & Fitch and The Limited for 10 years. He now volunteers at Riverside hospital and Columbus Humane. Rob is married to his loving husband, Matt Hall.

My Old Life

It was Friday, May 10th, 2013, and I was working in the Abercrombie home office. I was working and figuring out our comps for denim retail reports and I could feel a migraine coming on. I could feel my pulse throbbing and felt a sharp pain. The team assembled for a meeting with my CEO, sourcing, merchants, and planners. We spoke about our strategy. It was a big deal for denim back to school. We were very excited to see the product. I was a planner and forecast strategist. For denim, our lead time usually takes 6 months to cut, sew, make the product, ship (boat), distribute, to transportation to retail stores and online. In July, our Floor set would be back in time for school. We're very nervous, excited, and had a lot of anxiety. The job was stressful. I was a person who tended to turn inward rather than outward. In my life I always pushed inward. That means, I was very well restrained in meetings. I was a person who figured things out with logic, reason, and strategy. It was natural for me. After the meeting, I told my manager that I was feeling ill, and I used my Half-day Friday because something was wrong.

As I drove the 30 minutes to my home, I was thinking to myself, "what has caused me to feel aggravation"? I was a workaholic and had worked long hours for years. I worked 10-12 hours per day, sometimes weekends too. I was very focused and driven. I loved the people and the culture. I was usually working on a computer at least 8-9 hours per day and sitting the whole time. I remember my shoulders, many times felt sore. Then, I was thinking maybe it was because of my headaches? I needed rest.

Saturday, I slept, and I still had a huge headache. I did not do anything that day. Watching TV or light agitated me, and I felt pain. Sunday was Mother's Day. I still had that small headache, but I went to buy flowers for my aunt. I sent flowers for my mom, too. After visiting my aunt, I felt that I should probably check it out at a clinic. I went to an Urgent Care and the doctor listened to my symptoms. The doctor said that because I was a young man, very healthy, and active, that I should just take it easy. They gave me a Ketorolac shot. It’s a nonsteroidal anti-inflammatory drug. I drove home. I took my doctor's advice and I rested.

Monday, I got up and felt dizzy. I was thinking about that shot from yesterday. Did it work? I felt weird. I drove to my job. My job was very demanding, and Monday was always the worst. I did not want to eat much, and I still felt a little ill. But I kept pushing through it. It was a long day, 10 hours, which was pretty typical for me. That day I felt burnt out. I was never good at life balance. I was so exhausted! I drove home and went right to sleep. I needed more sleep.

Tuesday, I woke up feeling groggy. I was still worn out; I felt beat up. I made my coffee and drove to work. I looked at the parking lot. The temperature felt cool, and it looked like a beautiful day. I love the campus at Abercrombie and Fitch. There were beautiful trees, ponds, and birds chirping. At my desk, I checked my schedule and it looked packed. First off, I had a meeting at 8:30. As I was climbing three flights of stairs to the boardroom, I felt heavy; winded. I was presenting for HR with planners and my colleagues. We were working on a strategy to create a quarter development touch base. I was making a tool to guide development plans. My passion was to create tools and templates for Excel. It was my analytic craft. We did not even start that meeting. I had my papers, and I was ready to start but something snapped. From my chair, I leaned on the conference table. I was unsteady. My colleagues saw me, and they said ‘’are you OK’’. I was really trying to stand up and then I couldn't speak! I felt flimsy. My colleagues helped me down to the floor. My HR colleagues called 911. It was very strange, my blood was rushing, and my pulse quickened, but I couldn't speak. Everyone was talking to me, but I couldn't hear what they were saying. Like Charlie Brown’s teacher speaking “wauwawa”. It was not too long, and the paramedics were there. A paramedic said, “what’s your name?” I responded gibberish. I felt drained, like I was running on empty. The paramedics carried me to the ambulance on the stretcher.

I was rushed to a hospital in 20 min and they found a room for me in the ER. I hated all the attention. I didn’t know that I had an IV, but I did. Nurses took a blood sample. I was so tired. My manager, Dan, was there in my room. He was talking to me, “Do you want TV?” I nod. First channel was “The Big Bang Theory”. I loved that show. My friends always called me ‘Sheldon’ because I was a little bit nerd-ish. It was my nickname. But now, I did not laugh. I could not understand the jokes. Dan was talking to my nurse but all I heard was “wauwawa”. Like people were talking Greek. Why did I feel like I had been run over by a truck? I felt acute fatigue.

That day, I sank into the abyss. My cognitive skills were shot. I was thinking to myself “breathe, breathe, breathe”. I felt helpless. Someone needed to help me, and I was confused. I slept in a bed in the ER which felt cold and sterile. Then suddenly the nurses and doctors woke me up. They said, “we are ready to help you”. I thought they had a test that would be like an MRI, but no, it was much worse. They used a long needle in my groin to explore and find a route to my brain, and I yelled, ”ouch” and “f&!k”. It was extraordinarily painful - like torture. They were trying to repair my carotid artery dissection. I felt detached in my body and my mind. After 10 minutes they couldn't push me because my external arteries were blocked so they used TPA. Ischemic Stroke Treatment was an endovascular procedure called mechanical thrombectomy, in which doctors try to remove a large blood clot by sending a wired-caged device called a stent retriever to the site of the blockage. They were trying to remove the brain clot by threading a catheter through an artery in the groin up to the blocked artery in the brain. It was to no avail. I wanted to mitigate the pain and I cried.

That day I had a lot of tests, a CAT scan, and an MRI and that evening, I was in bad shape. My VP, who was my friend, visited me at the hospital and I wished that I could speak. Her name is Stacie, and her daughter was there, too. They were talking to me and asking, "Do you need anything?". I could not speak but I motioned and pointed to my eyes - I had contacts but the hospital personnel did not know that, so Stacie helped me to remove my contacts. Relieved! She said, "I will find your glasses tomorrow". I was trying to thank her but could only give a crooked smile. That night I was checked every two hours and I was thinking to myself, "I'm going to die; something is wrong". "Severe stroke" was written by my name on the white board. Yes, I'd had a stroke! I was not comprehending.

Life Reborn

Two days in the hospital, looking out my door to the hallway, I felt enervated. I was aware that I was dizzy, and I felt hungry. Then the nurse said, "you have a guest", and as I turned in the bed, a man peered at me. The man was talking to me, saying, "Rob, you had a stroke". I do not understand, but I know that voice and I will know him forever. Who is it? I can't speak but I realize it was my dad! I was thinking to myself, "why is dad here?" My Dad lives in California, and I live in Ohio. In my head, I felt punished or shamed, and confused, but I also felt grateful. Thank God, I had my dad here. I needed help! My dad was with me in the hospital every day for five weeks. My family visited often, and my sister and my brother flew to Columbus. One day, I'd had my therapy and they were saying "do you try singing?" So my sister said, "sing happy birthday". I felt childish but she sang it a few times. Then, I said to Beth directly, "stop singing!". I spoke for the first time 10 days after my stroke. She said "whoa", "he speaks". My sister was helping. My sister is a teacher like my mom. We were working on my ABCs and my speaking was jabberwocky and nonsensical but we laughed!

Another time, my best friends (Bill, Tommy, Collin, and Andy) were visiting me, and Andy was saying to me "my name is Andy", "Could you say ANDY, Rob?". Long pause, I was trying to speak to Andy, but it was very muffled that I said "wwwh….wwwhh…..whore". We were dying laughing. It was hilarious. It was a chuckle for years. Damn Aphasia!

Dark years!

I had to start over again! My therapy had been ongoing for years. My task was to draw ABCs over and over again. One time, my dad needed to find my medical family doctor's office and I thought I was losing my mind! I have known my doctor for years. I knew about that office a long time ago. I am not crazy; I cannot speak but we had an iPad which is the best visual for me.

So, I felt stressful; overwhelmed. But I took a moment to center myself, pause and breathe! For me, I'm pretty good at navigating areas. I looked at the iPad and I found it. I gestured "up", which means two floors up to my doctor's office. My dad drove to the site, walked up 2 flights of stairs, and saw my doctor's office and they printed out my medical forms. It was my first time to figure out directions and I realised I could do something. It was a win for me.

My Aphasia was trapped in my head but always thinking. My doctor, Dr. Hicks II, MD, is a neurologist specializing in vascular neurology. Dr. Hicks says, “keep working at it” and he believes in my recovery. After OT, I was discharged from the hospital. He is a great doctor! Then, my mom or dad was here for my therapy and appointments. My therapy was very slow; it was grueling. I had speech therapy three times a week for my aphasia. It was two years. I was almost nonverbal, so my insurance assumed I had plateaued, and they cut off my therapy. They told me to work alone with my mom or my dad.

We worked weekdays, 4 hours a day: reading, writing, math, and conversation. I wish they had a template, but they don’t. Everyone is different. We had worksheets in the therapy and looked at time (numbers), but I needed more visuals. So, we created a visual digital clock of hours and minutes. For example, my dad would say the time was 3:30pm so I would look at the flip cards and find the time. I practice 3 things to help me: listening, looking at the visual, and speaking. Sometimes I was correct; sometimes I wasn’t. I have auditory processing disorder.

We worked on my ABCs, and we practiced. My mom or dad were helping me to work on my prepositions and practiced speaking small words. I was so frustrated. I wanted to speak but I’m finding it very hard. We made a lot of cards to practice with and we use syllable words like two words with two syllables - outcome, three syllables - perspective, four syllables – motivated, and five syllables - determination.

We build and grow my vocabulary. We work on my nouns first and then adjectives; then I work on my verbs for years. It was confusing to me, past, past participle, present, present participle, and future (e.g., swam, swum, swim, swimming, will swim).

It was so foreign to me, and my brain was overloaded! In my college, I had dual majors in marketing and logistics; but now I felt stupid, and I was not speaking. It was a struggle, and the years were tough. I was also depressed, and I was going through the grief process. I grew a full beard. I felt lonely.

My family is very musical; we play guitar, drums, trumpet, baritone, singing, and piano. I felt lost without music. The therapy was helping me to start over again and I needed to learn to play the piano and baritone, but I was very resistant. I couldn’t read the music and my right arm was numb. It was really challenging but I stuck with it. I was the high school drum major and in my college years I played & marched, and I played my baritone in the Ohio State University Marching Band which earned its name as The Best Damn Band in the Land (TBDBITL). Practice, practice, practice! In 2018, I played for the first time after my stroke and marched Script Ohio for the 50th anniversary reunion band. I have passion and grit. I always loved music. If I couldn't speak after my stroke, I tried music. I believe music helps the brain to heal.

Often in my free time, I looked at Facebook and watched YouTube. I love technology. I watched many videos on YouTube. I saw people make videos about their stroke anniversaries and I thought it would be a great idea to reinforce my speech! It helped my confidence, courage, and my speech every year. The first video for my stroke anniversary was 1 year after my stroke and my speech was arduous, but in 8 years you can hear my speech progress as I improved. I am a member of the Aphasia Recovery Connection “ARC” on Facebook. They connect patients, families, and friends who are dealing with aphasia. It is a wonderful group. I went to the retreat (twice) with ARC friends in Ohio - it was very inclusive - and I saw young aphasia groups who were trying to live their life.

Never give up!

I loved exercising. I could not speak but I could run! I would always go to the gym to help with anxiety and I started a 10k race - that felt really good. It helps to have a focus and goals. I ran in a dozen 5k and 10k races. I shaved my beard! Then, I ran my first half marathon in May 2015 which was a big deal for me. Ohio Health made large posters of me and one of the posters was placed in the reception room at Riverside Hospital.

I was interviewed on TV and articles were written about my stroke. I was so scared in the interview, but they were good at editing.

My colleagues and other people donated $25,000 for my therapy. I was so appreciative for all the generous donations, and then in October 2015, I raced a full marathon! On my back was a sign that said “APHASIA”. Helps awareness!

I attended The University of Michigan in Ann Arbor for intensive aphasia therapy. I was there for 3 weeks. In the therapy I built my confidence. Afterwards, my mom drove me home and I was talking! I was speaking. It is a blessing. My mom was there, and we were working on my sentence structure and speaking. My mom and dad helped me for 3 years after my stroke. I was very lucky to have such a helpful family. I was very lucky to be alive!

It was very hard being single. Dating and socializing was rough. People don’t really know what aphasia means, but I was very courageous. In June 2016, I met a friend whom I dated prior to my stroke, and we went to a restaurant. I was nervous and I could not speak very well but we talked! Two years after that first date, Matt & I were married in October 2018. For our wedding, friends gave gifts of money for more therapy. Determination!

I am still working on my therapy. Patience and practice are the key! I had to go to Florida (St Petersburg) for intensive therapy and I attended an Aphasia Center three times – online as well. It keeps getting better and better.

Life goes on

I took a step back in my life and analyzed. What does it mean in life? I think people need compassion, decency, love, and understanding. Every stroke is different. I've learned that brain injuries are so individualized. I'm trying my best to navigate life. I have a purpose but it’s a struggle. If you’re lonely or depressed, you’re not alone. The little things are hard and I still cannot multitask so I am focused on one thing only. It is so hard to concentrate with other distractions. In an instant, my life and career were gone and I had a new beginning journey with aphasia.

I am a Survivor. I had a massive ischemic stroke 8 years ago. I had aphasia and was only 33 years old. I had severe receptive and expressive aphasia, and cognitive deficits. My life stress caused my stroke. I was overworked; it was a hard lesson. My life needed to reboot. It was taking a very long time to wire my brain. Pivots in life don't mean failure. It means opportunity. Tomorrow is not promised for any of us. My truth, for my recovery is ongoing. The road to recovery is not measured in miles but inches. It's a very slow pace. It’s very hard to express yourself without words. I get that! You are valid. Life is too short! Life is precious. Keep working at it, it will get better. Always be present and engaged. Always have a good attitude. Above all else, everyone needs love!

Hope Is The Last Thing Ever Lost

By Sarah Gapp

I'm Sarah I'm 34, and in 2008 I suffered from a severe brain stem stroke resulting in locked in syndrome. Locked-in syndrome affects around 1% of people who have a stroke. It is a condition for which there is no treatment or cure, and it is extremely rare for patients to recover any significant motor functions. About 90% die within four months of its onset.

Hi there, reader, I hope you're enjoying your day. I'm Sarah-Jane, I'm 34, and I'm probably one of the younger authors in this incredible group of stroke warriors. I suffered a severe brain stem stroke a less than a month after my 21st birthday in '08' – it's not a present I would recommend. I wish I was somewhere exciting when it occurred like at a comedy show or shopping centre but that was not the case. I was at work, on my lunch break. After eating reheated leftovers from the night before the headache I'd had for a week got really bad. I'd had a massage which moved a blood clot into my brain. I often think about the poor person who gave me that massage and how it's impacted their life - I want you to know at NO point should you feel bad because it was just a crappy moment in time, and I'm honoured to be bound to you by it.

I started vomiting at work and felt dizzy, so I went home and fell asleep. I never suspected a stroke because I was young, and they don't happen until you're old. It wasn't until I couldn't sit or swallow that I knew something was really wrong. I've always had a high pain threshold, which in most cases is bad - strokes included – and it has been my downfall. I thought I'd just had the flu that was going around. I was forgotten about for some time at the hospital and there's nothing in my hospital notes for hours. A CT scan was done, and I was rushed into theatre as there was a lot of damage evident.

Lucky for me, one of the best radiographers was close by and was helicoptered in so he went up through the femoral artery in my leg and removed the blood clot in my neck. I had an arterial dissection. Two thirds of my cerebellum was dead so it was removed during brain surgery and a metal coil was inserted into my basilar artery to restore blood flow to my brain.

I was in intensive care for five months and in a coma for three weeks so my brain swelling could go down. I remained in a ward for 22 months. Every day was so boring. During this time my poor mother had breast cancer, but she was by my bed during her surgery, chemotherapy, and radiation therapy. I saw how the surgery drained her hairless body. This was a scary time for us both. I've blocked much of it out, alongside other bad memories, because there's so many. If I sat and thought about them all I wouldn't be here. I definitely get my resilience from my mother.

I must stress how important it is to stop the hands from shutting – it's very common with stroke and I'm not sure why. Mum would often straighten my hands out flat. A rolled-up towel under my palm would be sufficient. I still get hand rubs while gently stretching the fingers - the importance of moving what you can. My legs were cycled for hours a day. There are now machines that go over the bed and cycle your arms and legs. Final advice would be to go to a rehabilitation hospital and get help to rehabilitate. I didn't. I was too ill to go, and I never received any rehabilitation, but looking at the gains other people have made, it's probably because they received proper rehabilitation.

Being locked in was very scary. That is when you are cognitive and can hear everything, but you can't move anything accept your eyes, so your only form of communication becomes a blink.

Locked-in syndrome is defined as a rare neurological disorder characterized by complete paralysis of voluntary muscles, except for those that control the eyes. People with locked-in syndrome are conscious and can think and reason but are unable to speak or move. Vertical eye movements and blinking can be used to communicate.

After months of mum's dedication and vigilance, breathing support was gradually turned down. Years went by but slowly I began to make gains. I remember the first time I sat - it was agony and felt like my back was going to break

I was very fortunate to have a General Practitioner grandmother and a really strong mum who helped me go on when I thought I couldn't. Growing up with a disabled Aunty showed me there is no limit. She got married, had a baby, and completed several degrees. Sadly, she lost a battle to cancer a few years ago, and I miss her so much, every day. Having had many breakthroughs when my favourite musicians would play by my bedside. Amongst all the machines and leads keeping my alive I've won several awards for determination and resilience and one for courage. I had the best opportunity to have my story told by channel seven's current affairs show, *Sunday*, which aired here on television. During the filming, Norman Doige flew over from Canada to meet me, as no one else has come out locked in syndrome. He's written several books including "The Brain That Changes Itself" and my mum used a chapter from this book to rehabilitate me. Here's the link to my *Sunday* story:

https://youtu.be/PYpcYUCXswM

These days I still have locked in moments where I find myself staring at nothing. I have a tracheotomy because I can't swallow, and it keeps my airway open. I'm in a wheelchair permanently but I can walk with assistance, and I want to do this by myself one day. Something many take for granted is something I strive for. I can't swallow, so I'm not allowed food or drinks via my mouth. Everything goes through a tube in my stomach. I have with me at all times a portable suction machine that I use every ten minutes to clear out the saliva that most people are able to swallow. I am also ventilated at night as the stroke effected my automatic impulses to swallow and breathe and as I stop breathing sometimes.

I aim to write and share my story in book form. I've started, but it's been very emotional remembering and reliving things I've chosen to forget about, but one day I'll complete it.

Before my stroke I had great self-esteem and was often the conversation starter. I was fit and healthy, I knew what I wanted, and I was very driven. I'd give anything a go. I worked full-time as a legal secretary in the city and was studying law part-time. I enjoyed being busy and being intellectually stimulated. I'd moved out of home young, and I've always been fairly independent. People would often comment on my appearance, but I wanted to be more than good looking. I thoroughly enjoyed riding my dirt bike and taking long drives - both activities gave me times of freedom and clarity.

The musician Michael Franti and his wife Sara changed my life. His generosity and kindness created a rippling effect that steered me in great directions. I couldn't be more thankful to him. They've started a foundation which I'll link below. They're such a wonderful couple.

https://www.doitforthelove.org

I've also worked with a clinical Pilates instructor for 7 years and I highly recommend that. He's a trained physiotherapist and has, over the years, helped me improve heaps.

Now I have a soft, generous caring partner. He's a musician and he's a very creative soul We have 2 dogs and a cat. I'm lucky to live in a country with good health care. I've had several relationships since my stroke. Each has ended in heartbreak, but each has also made me grow and taught me something. It's very tricky for guys to play the role of my partner and care giver. I require a lot more assistance than most girlfriends and I have no doubt being with someone high needs is hard. I’ve been engaged for years now. I’m not really a big wedding girl. I’m an introvert now I know I’m different. I suffer from social anxiety and get depressed often. My brain has changed, and I have trouble getting used to that. It can be very frustrating always relying on others.

The biggest gift this stroke has brought to my life is awareness of my resilience and my stubbornness. I will do something 100 times if I have to, just to complete it. I can fall down, but I’ll always get back up. I’m very quick witted, funny, and I try to look for positives. I’ve lost a lot from my stroke. It’s been a massive learning experience for me. I’ve lost myself many times in this mess, but I’m here, hopefully giving hope to those broken by stroke. There is hope, and even though my life will never be the same, it’s far from over, and it’s good.

It’s important to always have hope and gratitude - it’s definitely kept me going through tough times. Hope for a good day, hope to improve, and hope to give and receive love. I want to create awareness about stroke in young people.

Life
After
Stroke

By Shannon Nelson

Shannon was 45 when stroke struck out of the blue. She is a mum, wife, nurse, daughter and sister.

Throughout her stroke journey Shannon has made documentaries with her son, Sean. These documentaries can be found on Sean’s YouTube channel:

https://m.youtube.com/channel/UCJ1lPBtAdMeMz0z8x8hC37A

Shannon has also become an advocate for stroke.

Before my stroke I was a busy mum of two teenage children, and a wife working full-time as a nurse in a nursing administration role. I volunteered at my daughter’s netball club as the registration officer, and I enjoyed going to the movies and spending time friends and family. I wasn’t overweight, walking almost every day, but I did smoke two cigarettes a day. I was stressed about a few things in my life.

I went to bed as normal one Sunday night - it was Mother’s Day 2018 – and I got up to go to the toilet at 3am. Stewart, my husband, heard me but I don't remember.

When I woke up again it was about 5.30am and I was thrashing around in the bed until I fell out. Stewart tried to pick me up; I was paralysed down my right side; I couldn’t speak, and I had a facial droop.

Stewart recognised my stroke symptoms immediately. I remember him calling 000 and saying, “I think my wife is having a stroke”. He saved my life. He is my FAST hero.

And so, it dawned on me, I was having a stroke! I was petrified. The next thing I remember was the ambulance officers arriving. They couldn’t get me out because I was between the bed and the window. They strapped me to a HoverMatt and dragged me down the hallway of our house. I remember seeing Gemma, our daughter, holding our dog in the doorway of her room as I was being dragged out and I began to cry. I thought to myself that I might not get through this. Our 17-year-old, Sean, slept through the whole ordeal!

I remember arriving at Box Hill Emergency and being assessed by the stroke team; it was approximately 6am. I was then diagnosed with a Left Middle Cerebral Artery (MCA) ischemic

Stroke, and I had the clot busting medication, Alteplase, at 6.20am.

I'm lucky that Stewart heard me get up for the toilet as Alteplase must be given within 4 ½ hours, so my stroke onset could be timed from 3am. Then I was transferred by ambulance to the Royal Melbourne Hospital for clot retrieval. The clot was retrieved at 7.35am.

That day was my father's 70th birthday. Stewart called my parents at 7.20am; they answered the phone thinking we'd be calling to wish Dad a happy birthday. Instead, it was the devastating news that their only daughter had just suffered a stroke. My parents live in rural New South Wales; they were in the car and on their way by 8am.

Those first few days I cried a lot, such as each time I saw Stewart sitting by my bed. The next hurdle was seeing our children and my brothers. I couldn't talk and I couldn't walk; I was paralysed down my right side; I was scared. I wanted to tell them it was all going to be alright, but I couldn't communicate this to them. We all cried!

The physio got me out of bed the next day. I still couldn't talk, but I was able to walk. I was seen by the speech therapist, to see if my swallow was affected - it wasn't, thank goodness. I was transferred back to Box Hill on Wednesday afternoon. I saw another doctor with whom I couldn't communicate. My non-verbal communication was really getting a workout! I decided on day 3, I wasn't going to be a stroke victim, but instead a stroke survivor.

The next morning, they took 11 vials of blood from me. They didn't find anything abnormal; I didn't even have high cholesterol. A handy thing they gave me was a white board, so I could finally communicate with the doctors, nurses and most of all, my family. I was bit rusty with my left hand - of course I am right-handed! I had no usable function in my right hand; I could only raise that arm. I had an echocardiogram at Royal Melbourne and Box Hill as they were looking for what could have caused the stroke. In the process they found a hole in my heart, a PFO which is a hole between my left and right atria. The doctors aren't sure what caused my stroke but I say now that there was the perfect storm – I had the trifecta - a PFO, I was stressed, and I was smoking.

One week after my stroke I finally spoke! The first word I said was "one". The speech therapist spoke the word "one" and I repeated it. I had apraxia and still have. Apraxia is defined as having difficulty planning and co-ordinating the movement of muscles used during speech. I knew what to say but I couldn't get the words out. I did slip out the "F" word in frustration at my husband the previous day, but that's another story! The first phone call I made was to my friend, Jacki. Gemma was sitting opposite me; she spoke the words and I repeated them.

I was in Box Hill for 8 days then I transferred to the Peter James Centre (PJC). It was time to start my rehab. I had speech therapy mostly twice a day and Occupational Therapy (OT) on my hand once a day. I exercised my hand three times a day with the TENS machine, and they gave me exercises to do. I had no real hand function in my right hand, and I had apraxia which meant I was repeating words endlessly, and then eventually, functional sentences. My favourite was, "Put your crap away", but of course I also used functional phrases like "Good Morning" and "How are you?".

This is when I discovered I had Aphasia. I'm a nurse, and I thought Aphasia was an absence of speech. Aphasia is a language disorder caused by damage in areas of the brain that control language expression and comprehension; it’s not a loss of intelligence. I had difficulty with word finding and spelling, and these are still issues for me now. Since my stroke I say ‘thingo’ a lot. Sean often reminds me that he doesn't speak stroke.

Thankfully, I was able to go home for day leave on the weekends from PJC. I spent 15 days in inpatient rehab, and I chose to stay a week longer because I needed the intensive speech therapy.

I went home 3 weeks and five days after my stroke. I resumed walking every day, starting with slowly walking three kilometres, then four, and then five, until I reached my pre-stroke routine of five to six kilometres a day. I also started ESD (early supported discharge program) on 12th of June. It's a four-week intensive program for stroke patients. I had an hour of speech therapy and OT daily during the week, both home and centre based. I also worked on my own speech therapy and OT throughout the day.

About six weeks after my stroke, I received a call from the Stroke Foundation to see how I was doing. The call lasted about twenty minutes, and I felt they really understood what I was going through. That call changed my life. I was invited to tell my story at the Stroke Foundation Annual Staff Meeting in February 2019, and there wasn’t a dry eye in the house, including mine.

Seven weeks later, I attended the stroke clinic at Box Hill Hospital. The doctor was surprised when I walked in and was talking so well; he had just been looking at my scans. He described mine as “a massive stroke”. I viewed the scans; my left brain had been completely cut from oxygen; it was dying. He said I was the poster girl for when things work out right. The “FAST” acronym definitely worked for me. He said, “are you driving yet?” I said “No, no one has told me I can drive.” He replied, “You can drive.” I was gaining my independence back!

I also went to see my GP to get a mental health plan. I felt I wasn't coping because I couldn't say the word monotony, and that was the straw that broke the camel’s back. I went to see a clinical psychologist. It was a severely stressful time for everyone, and it helped me deal with the loss I’d felt, because I was grieving the loss of the person that I was beforehand. I had sessions alone, one with Stewart, and then we had one as family. The thing that struck me was that Stewart and I had raised two resilient, compassionate humans in Sean and Gemma, and how lucky I was to find a life partner in Stewart.

My parents gave up 3 months of their lives to take care of me and my family. Stewart had to return to work; we had a mortgage. My mother, Denise, drove me to my appointments. Sean then passed his driving test and drove during school holidays.

I was then transferred to community rehab at Wantirna where I had two speech sessions per week. One was centre-based and one tele-health. I also had one OT session per week and upper limb group. Throughout ESD and Community Rehab I attended a Communication Group at PJC. This really helped me because it was with people who had Aphasia, just like me. It was comforting to know that I wasn’t the only one. About 3 months after my stroke, I shot a video with my speech pathologists, about Aphasia: https://youtu.be/7yLYq7bNMiQ. It had a positive impact on my family and friends and it was a way for me to share my story, keep me connected with my family and friends, and raise awareness of Aphasia.

My ultimate rehab goal was to return to work, and this I did on the 8th of October, (following surgery to fix my PFO). I worked for a large public hospital in the city, in nursing administration and I had a graded re-entry to work starting on five hours a day, three days a week. After 10 months, I was back full-time. A great deal of my work is communication, so I did all my talking in morning, and the emails and spreadsheets in afternoon. My speech has improved immensely but some days, even now, fatigue at end of day sees me slurring my words.

In April 2019, I got my first tattoo. It's on the inside of my right wrist, and it says: "Hope 14.5.18", which is the date I had my stroke. It was really important to me to mark my survival. My Mum and Gemma have also got the same tattoo, but without the date.

In June 2019, I completed the StrokeSafe ambassador program. I wanted to do something to raise awareness of stroke and I felt it would help with my Aphasia. The Stroke Foundation has supported me and my family every step of the way through our stroke journey, and five months post stroke, my family and I walked the 5 km in the Melbourne Marathon raising over $1500 for the Stroke Foundation. In 2019, I decided I wanted to participate in 10 km Melbourne Marathon and just a couple of months beforehand, I decided I wanted to run it instead of walk. So, I downloaded the couch to 10k app, and I started to train. Seventeen months post stroke I ran 9.5 out the 10 kms and I was really proud of myself for what I had achieved. I try to run three times a week now and I never thought I would enjoy running, but I do. It makes me feel that I can achieve anything as long I set goals.

In September 2019, I was asked by the Stroke Foundation to be on Channel Seven's House of Wellness, with my neurologist from Royal Melbourne for National Stroke Week. I was also the face of the March 2020 donor appeal for the Stroke Foundation; it was about Aphasia. My husband Stewart was one of the faces on last year's Stroke Week campaign - FAST Heroes. Stewart and I were on channel 9 news on the Sunday night of stroke week. It’s such privilege to work closely with the Stroke Foundation to prevent stroke, save lives and enhance recovery.

I was also encouraged by my OT to apply for NDIS, National Disability Insurance Scheme, funding. At first, I was denied because “my impairments were not likely to be permanent”, but I persevered and after twelve months I was finally successful. I do speech therapy once per fortnight, see a neuropsychologist once a month via zoom, and I attend OT once per week in person, all funded by NDIS. My goals for speech are to improve my fluency and naturalness for my work and public speaking. For OT my goal is to improve handwriting and get function back in my right hand. I was planning to walk and run the world’s toughest half marathon in 2020, the point to pinnacle in Tasmania, but due to COVID I was unable. Fingers crossed I will be able to do it sometime in the future.

I’ve started a new job, doing admin work for my OT three days a week. I’ve also returned to clinical nursing, one shift a week.

I haven’t had cigarette since my stroke; I don’t sweat the small stuff anymore; I don’t take anything for granted; but most of all I appreciate family and friends.

I wouldn't say our family is back to normal, rather that we have a new kind of normal. I don't know whether I could have gotten through our stroke journey without the love and support of my family and friends. Stroke affects the whole family, not just the individual.

A
Stroke
Of
Poetry

By Shelagh Brennand

Shelagh Brennand is a retired UK Detective, Private Investigator, wife and mum. Following her stroke, Shelagh wrote ‘A Stroke of Poetry – Poems of Healing and Hope after Stroke’ and became a Stroke Safe Ambassador and Motivational Speaker. Shelagh now spends her time travelling around Australia with her husband in their caravan.

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‘Not me – I’m only 49!’

“T’was a sunny day in Queensland, the day that changed my life.
How was I to know a little gardening would cause us all such strife?
The day before, I’d been with friends, and really feeling great.
49 and fit as can be, and I’d even lost some weight.

The last day of the holidays, I cherished with my son.
We weeded, seeded, trimmed, and chopped, until it was all done.
“Please can I now go inside?” he said with a frown.
So, that left me in the garden, lawn mowing on my own.

The day was hot, I’d done a lot, and I should have taken a break.
So, I went inside to have a rest, perhaps a meal to make.
I suddenly came over all dizzy and hot and felt a little squiffy.
My head into the toilet, I thought would sort it in a jiffy.

That’s the last thing I remember, before I clearly fell.
When I awoke, I saw my son and I didn’t feel too well.
His name that I first shouted; I could say no more.
I could not move a muscle, from that cold, tiled bathroom floor.

My mouth it moved, but no words came, I thought I had gone dumb.
My right leg couldn't move at all, my right side had gone numb.
Oh, his little face, I still see it every day.
Such calm, then panic looking at me, slumped there in disarray.

A friend, thank goodness, she came around and knew just what to do.
The next thing I remember were the marvellous Ambulance crew.
"A stroke," they muttered to themselves, I thought it could not be.
In three months' time, I would be only half a century.

"I'm far too young, you've got it wrong," I thought and tried to say.
I couldn't be a stroke victim, on that lovely sunny day.
The words, the tubes, the tests, and lots of things they had to do.
Scared, confused and helpless, but that crew, they got me through.

The flashing lights at every stop, the sirens, and the rush.
Could this be really happening to me, a 49-year-old lush?
The hospital, now that was fun, the chaos and the mayhem.
Those doctors they worked tirelessly; I could never be one of them.

The days that followed had good news; the stroke team did their bit.
A clot had caused this sorry mess and soon I would be fit.
My voice came back quite easily, and soon my walking too.
I knew I was a lucky girl, despite the hullabaloo.

So now this brings me three months on and wow have I improved.
Though fatigue still racks my head and my body too.
"Don't rush back to your old life," advice it came in droves.
Since I've been well, I seem to have my brain so full of odes.

These poems are the strangest thing; they swirl around in my head.
Quite often, I just cannot sleep and must get out of my bed.
My social worker, what a lady, Judy was so great.
She said the brain does wondrous things; don't fight them, celebrate.

I'm 50 now, I got there quick, with friends to roust me on.
A husband, sister close at hand and of course my loving son.
The recovery months are still to come, so rest is still a key.
Who knows what lies ahead for us, life is a mystery?

So please take note of my young age, for this tale it is so true.
Just be aware of your own limits, or it can happen to you.

Hi, I’m Shelagh and on 15 April 2013, my life changed forever. As you read my story, you will find my life subsequently changed for the better and no matter how bad things seem to be in your life; always believe you WILL get better, and you CAN turn your life around once again.

As a retired UK Detective Inspector of 25 years, and a Queensland Private Investigator of 4 years, I was only 49, fit, healthy and living life to the full, so my stroke rocked my world and that of my family and friends. Some of the many questions asked were:

“How did it happen?”

“Why did it happen to you; of all people?”

“When will you fully recover?”

I simply had no answer but my wonderful Stroke Physician, Dr Rohan Grimley, was the only one that could put this sorry mess into perspective.

I became overheated, dehydrated, and nauseous whilst gardening, and the movement of lowering my head into the toilet bowl to vomit (not pleasant I know!), caused a basilary artery dissection (arterial tear in the back of my neck). The blood then flowed, clotted, and dispersed. The only evidence on the CT scan was a small black dot where the blood tore the artery. I was told I was incredibly lucky but at the time, I did not feel lucky and felt my world had collapsed.

My son Patrick, 11 years old at the time, found me on the bathroom floor. I had no right-side movement and although my mouth moved, I was unable to utter one word.

I spent only two days in hospital. My right-side movement slowly returned, and I was able to walk. My voice returned (perhaps a little too soon for my husband David, as I am such a chatterbox!) My words were slurred, and I was unable to string full sentences together. I was diagnosed with Aphasia (**Aphasia** is an inability to comprehend or formulate language because of damage to specific brain regions). Despite being told once again I was "lucky", this was the scariest thing that had ever happened to me, and I never thought I would function normally again.

Two weeks post stroke, despite the terrible fatigue I experienced because of my stroke, we received our Australian Citizenship at a local ceremony. Two months

later, Patrick and I flew to the UK to attend my nephew's wedding; and in the July, David and I visited Melbourne to celebrate my 50th birthday.

These events happened in the first three months of my recovery, which I am told is the critical time, but despite the ongoing fatigue and some cognitive issues, I honestly thought I had recovered well.

Having returned from Melbourne, David returned to working away and I suddenly realised that I had nothing to look forward to. Due to my inadequate cognitive function to perform my investigation work, I was unable to work, and my fatigue was debilitating. That was not everything. I became overwhelmed with grief. Not simply 'feeling sorry for myself' type of grief, but I felt that I had lost my identity (*Recommend reading: Identity theft by Debra Myerson*). I was no longer the person I used to be, and I desperately wanted that person back. I could walk, talk, and function physically, but I no longer felt I had the mental ability to cope and move forward with my life. I wanted the 'old Shelagh' back, but she was nowhere to be found. I was heartbroken and retreated to my bed, constantly crying and being unable to move.

Dr. Grimley had warned me that post stroke depression was common in two out of three young stroke survivors but having dismissed this statistic, the reality was that I was simply depressed. Thankfully, my younger sister Patricia who had recently moved to Australia with her husband, sought medical intervention for me and medication was prescribed.

I wrote this poem during the onset of depression, and it helped me cope with my feelings of grief, loss, and utter despair. I know many have gained strength from *'Feeling low'*, so I hope you do too.

Feeling Low

Today I'm feeling low.
There's just no place to go.
Please let me go and hide,
as I feel so sad inside.

Stop telling me I'll soon be well.
Not one of you can really tell,
how much I hurt today.
Please will you all go away.

This feeling that I have.
It's not good, it feels so bad.
The desperation in my voice,
somehow, I know it is my choice.

I hope it doesn't last.
I thought this feeling would be past,

but each day it gets much worse.
Will I end up in a hearse?

I don’t really want to die.
I just want to shut my eyes and fly.
So, the pain can go away,
and I won’t feel as bad today.

But that feeling never comes,
and my head, it sort of hums,
with feelings of despair,
and what’s happening out there.

I know you love me so.
I hope you understand and go.
My rest it is the key.
Even if I wallow in self-pity.

So today I choose to rest,
and hope tomorrow is my best.
But if tomorrow isn’t grand,
then leave me be, please understand.

The medication reduced the tears but not the sadness, and the months that followed were a blur until February 2014, ten months post stroke. I had gained 10 kgs, felt flat and de-motivated, so began fitness training with my friend Melinda at her local studio. Melinda was one of the keys that turned that lock into making me more self-aware of my feelings. I entered an 8 week ‘Mind and Body’ challenge where we underwent intensive physical fitness and mindfulness training.

This was my ‘light bulb’ moment, as halfway through the challenge, I realised that I could turn my thoughts around, if I focused on what I COULD do instead of things I could not. This is a mindfulness tool, amongst many others, that I still use today and share with every stroke survivor I know.

I became physically fit, with legs that worked. I walked, ran, climbed, cycled and I had arms that lifted weights. I became mentally fit too, as I wrote and shared more poetry, about the ‘ups and downs’ of my stroke recovery.

This would be a good time to explain my poetry. In the days that followed my stroke, my brain began to work in rhyme. I was unable to think or say a sentence without it having to rhyme at the end. Bizarre but true. The brain is amazing, and I could not stop the poems from coming through. I had not been particularly poetic (some may say I am still not!), but once my social worker advised me to embrace the poetry, the odes then flowed.

The introductory poem to this chapter was one of the first I wrote, at 3am one morning when I could not sleep, and having sent it to the Stroke Foundation, it was published in their 2013 Spring newsletter.

My continued poetry helped me release the negative emotions, the frustrations, the sadness, the forgetfulness and even some of the amusing times that were all part of my stroke recovery. Once I shared these poems on the Facebook Stroke groups and in local media, I felt I was not alone in my feelings. That mattered. A lot. It was important for me to know that my poetry not only helped ME cope with the emotional aspects of my stroke recovery, but the poems helped others understand and explain their own feelings, which proved to be a huge motivation for my continued writing.

I felt more positive about my life and slowly released the need for the ‘old Shelagh’, and my poetry changed. I wrote poetry which had less sadness and included more positivity. Many say this was an ‘acceptance’ of my condition. I felt that I could move on once again and make something of my life. Many friends encouraged me to share these poems in a publication of my own.

In August 2015, after two book workshops with the amazing Alex Fullerton *(Author Support Services),* plus many weeks of being sat at the computer in my pyjamas, and days of tears through overwhelming fatigue, *‘A Stroke of Poetry – Poems of healing and hope after stroke’* was born.

In January 2016, due to the continued support of the Stroke Foundation, I found purpose once again in my life, and became a Stroke Safe Ambassador (SSA), delivering stroke safe presentations to health and corporate organisations around the state. I am still a passionate stroke advocate, especially for young stroke survivors and childhood stroke. I share stroke awareness online, through the local media and anyone who wants to listen. I have gained many close friends through my association with stroke and to this day, we have continued to support each other in our quests to become better individuals.

My book and my fitness training were purposeful goals that were reached with determination, arduous work and as always, a positive mindset. I honestly believe that with the love and support of your family and friends, and organisations such as the Stroke Foundation, you can do and be whatever you want to be in life.

You must reach out for help at every stage of your life where you feel lack lustre, sad, de-motivated, and whether those feelings are due to stroke, other illness, or a negative experience you may encounter. There are people out there who can help. Just let them in.

My positive attitude is steadfast (yes, I have my off days like many do) but being engaged in such worthwhile, educational work which resulted from the worst experience of my life, has given me such joy.

Being focused on what you CAN do is especially important if you want to move forward and change your life. I will leave you with my poem, *'Be Positive'* which is one not in my book.

Be Positive

Do you ever feel lost and helpless,
and feel like a person you don't know,
and all around you're looking,
but you don't know where to go?
Outwardly, you seem OK.
Your friends don't have a clue,
but deep inside you're hurting,
and you don't know what to do.
You retreat inside yourself each day,
and never let the sadness out.
Even though your head is hurting,
and you want to scream and shout.
There are so many people,
who often cannot cope.
They feel their life is over,

and no longer have that hope.

Please now let me tell you,

I have been there, just like you.

I've tried to cry each day away,

believing I would pull through.

It is ok to feel like that,

be positive and have some hope.

Listen to what your heart is saying,

and deep down you know you'll cope.

We know it isn't easy,

to move on with your life,

when you've had such a setback,

lots of worry, stress and strife.

What's the key to getting better?

So many people will tell you how,

they turned their lives around somehow,

and keep celebrating the 'now'

A life full of positivity,

moving forward with hope and grace.

Is really what it's all about,

and it doesn't need to be a race.

Please tell us how you're going.

Reach out and don't do it alone.

Nobody is judging you,

but if you need help; pick up the phone.

Stay healthy and happy always.

Much love,

Shelagh