

Anote from Michelle

A collection of Poems and Stories from the Stroke Community

It has been my joy and privilege to work with survivors of Stroke, their families and carers for 28 years.

During that time, I have met many remarkable people who have bestowed on me the gift of sharing their deeply personal and moving stories of surviving a Stroke against all odds and often when given little to no hope by medical professionals.

A "Stroke of the Pen" is a literary collection of Short Stories and Poems which reflects the often-difficult journey travelled by survivors of Stroke and their families.

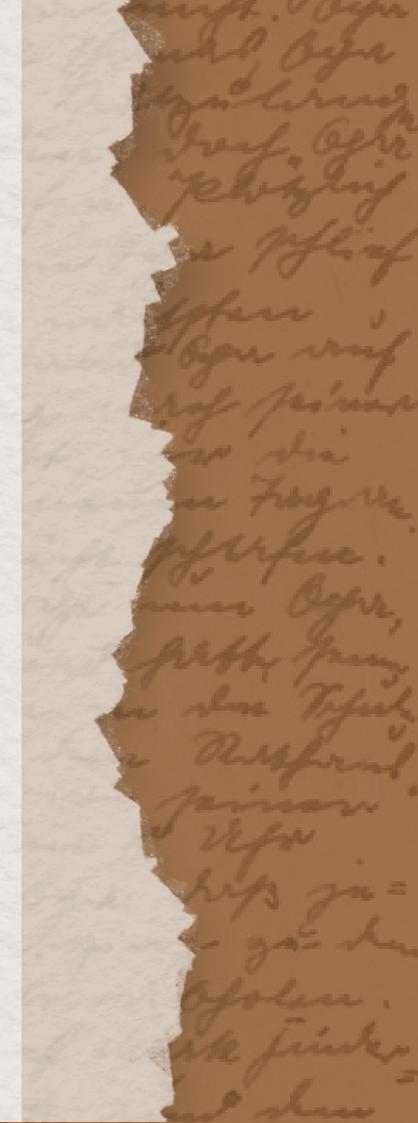
They showcase the innumerable experiences that individuals and their loved ones who survive a Stroke have encountered. Through the acute Stroke hospital, to rehabilitation, then back to their families and community to reclaim their lives where they ultimately thrive when they connect with a Stroke Recovery Club, linking with others who share a similar life challenge.

You will be astounded when reading them at the talent of our members, who have created genuinely warm, and heartfelt stories which reflect their lives to "Survive; Recover and Thrive" from the catastrophic life event, that is Stroke.

These stories and poems reflect their strengths, their perseverance, their appreciation for the support they have received along the way while also celebrating the commitment, dedication and resilience of their carers and families

This book is dedicated to all the inspirational survivors and carers of Stroke that I have had the honour to work with and for at the Stroke Recovery Association.

You are amazing and together we did amazing things.



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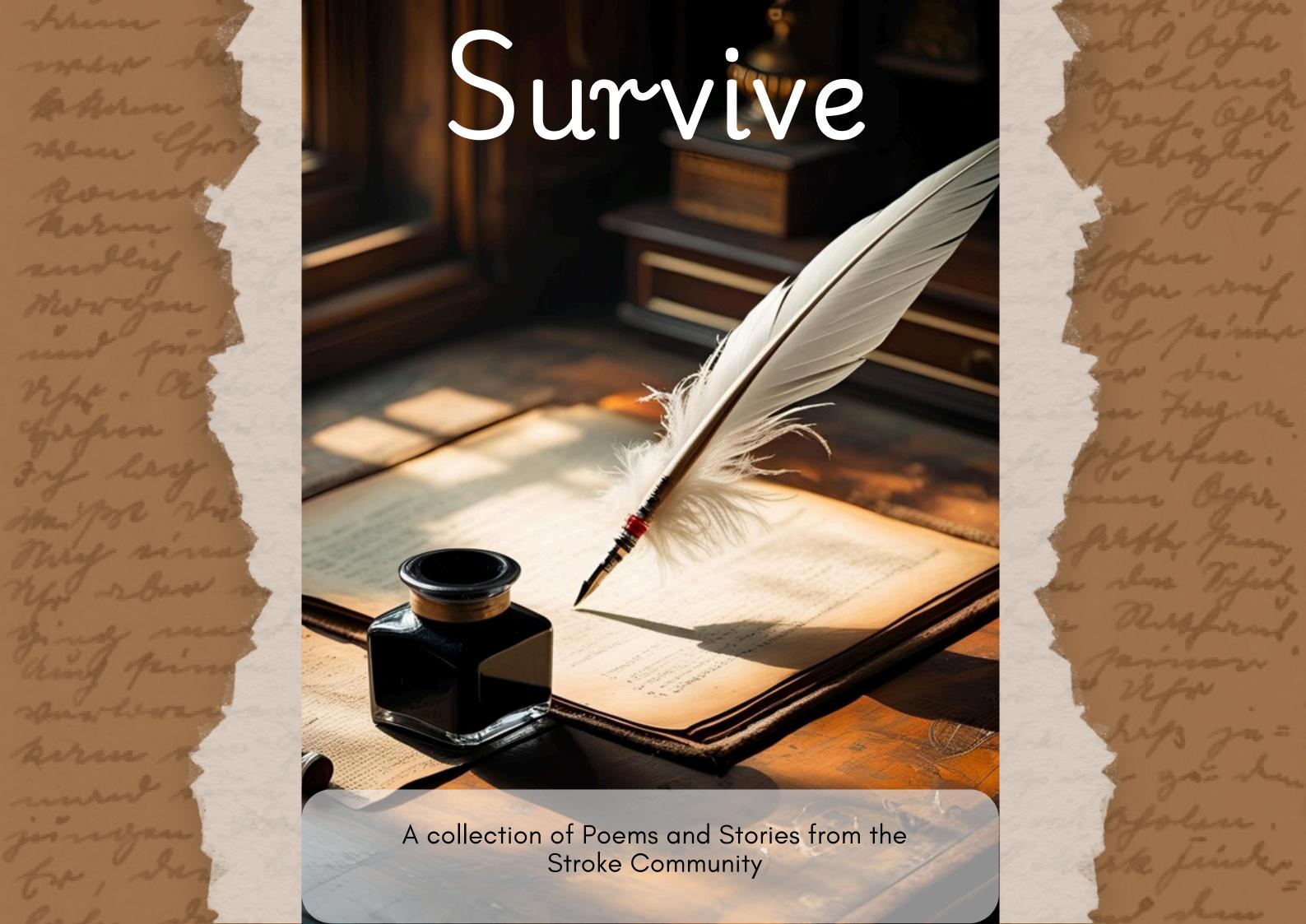
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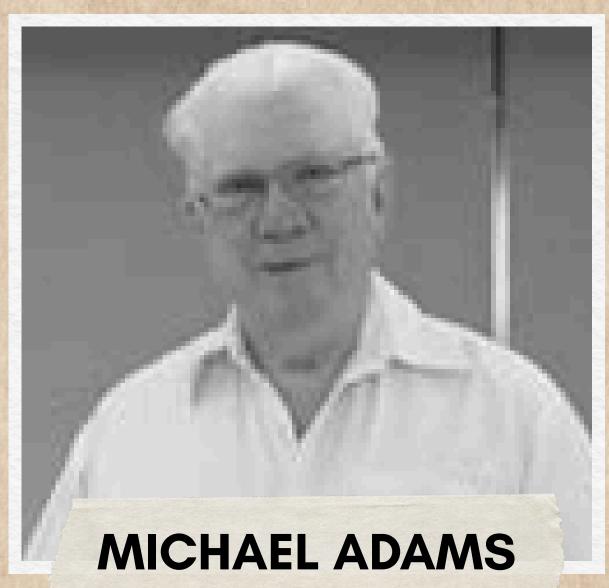
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Stroke Survivor, 2015

My stroke(s) came suddenly about 10 years ago.

Watching TV one minute, passing out in the next.

Near perfect health one minute, Stroke following Stroke the next.

Luckily my wife was here; on the phone as I was passing out.

Luckily there was an ambulance on the road, diverted to my assistance.

In hospital I was given some magic injection which meant I still had most of my faculties on awakening.

My eyesight was badly affected, one eye next to useless.

So my driving days were over, by far the biggest negative effect.

And so were my reading and writing days, cruel after publishing several books, mainly historical.

It had been a clot, killing off small part of the brain, and totally blocking the right artery to the brain.

Then followed atrial tribulation where my heart beat in all speeds randomly.

The combined effect was several phaseouts and faintings since.

The best remedy is a rest during the day.

Memory is a problem, as much from old age as from the Stroke I suppose.

And the remembering of personal and street names, more difficult as time goes by.

The lifelines for management of the side effects are: my computer, my diary and a white board my wife writes each day to remind me of daily activities.

But I consider myself lucky to be able to do this report, albeit slowly. Most of all, my good wife and positive attitude keep me sane.

And knowing the stroke could have done far more damage.



Carer for Elaine, 2014

10th of November 2014

I was busy in the kitchen, preparing a farewell dinner for Elaine, Cassandra and Winter who were flying to Honolulu two days later.

Elaine had been busy at the computer and phone, organizing her travel insurance which took most of the day. Finally, she came downstairs triumphant for completing the task and as usual getting a good deal. She said, "I'll set the table" and proceeded to do so.

A little while later the phone rang and Elaine answered it and talked to her sister Marjorie for a while, then came to put the phone back on the holder on the kitchen wall. I heard the crash of the phone hitting the floor, but thought nothing of it as I heard Elaine picking it up to put it on the holder, so I continued cooking with my eyes on the stove, then I heard a second crash and then a third so I raised my eyes to look at Elaine whose left hand had taken a curled appearance, and I realised she was having a Stroke. Elaine looked puzzled by what was happening with the phone, I called the ambulance and got her to sit, and I said: "Elaine you are having a Stroke", to which she rebutted "No I am not!" with a slightly slurred tone. It took some effort convincing her. I rushed next door and told Cassandra who was cooking a storm of her own, that her mum was having a Stroke.

That day marked the beginning of a very different, as most people affected by Stroke know too well, remainder of our lives.

While aspects of Elaine's personality had changed instantly, others were totally unaffected and in fact a little exacerbated. One of the first things Elaine said upon arriving at the Stroke ward, after several hours in casualty was: "This is not 5 stars, this is not even three stars!" One must make allowance for her as she was after all, expecting to spend a couple of weeks at the Sheraton Moana on Waikiki Beach! The other thing was, that Elaine refused wholeheartedly to use a bed pan, which caused considerable frustration to all concerned, so out came the commode and holding belt and numerous trips to the toilet. Next day Elaine, was a little more talkative, while she had always been a chatter box, her talking had literally double overnight. She also kept saying: "if I get better tomorrow can we still go to Hawaii?" and "Why can't I have a toasted sandwich?"

A few days later they moved Elaine to a single room. We could never be sure that her talking had nothing to do with her been moved!



Carer for Elaine, 2014

When I am alone, I cry

Please take my hand it's strong It will guide you through the unknown this path is dark and long

Please hold my arm real tight It will guard you through the night the dawn brings a new fight

Pictures in my mind force tears through my eyes so I look away and hide but when I am alone I cry

Then I dream of you at night like an eagle you soar high and free as a bird you fly

Please hold my hand it's there Gently waiting to take care It all seems so unfair

Pictures in my mind
Force tears through my eyes
so I look away and hide
but when I am alone I cry

Then I dream of you at night like an eagle you soar high and free as a bird you fly

Please take my hand it's strong As you step through the unknown You know it won't be long

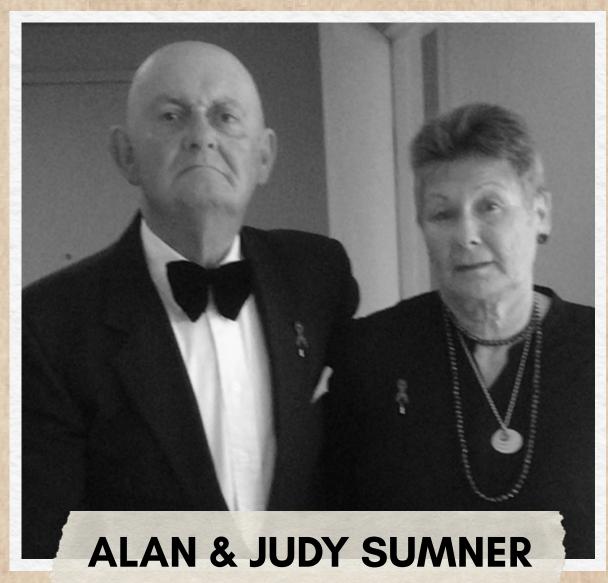
Please hold my arm real tight I will hug you till it's bright All through the night

Pictures in my mind Force tears through my eyes so I look away and hide but when I am alone I cry

Then I dream of you at night like an eagle you soar high and free as a bird you fly

Then I dream of you at night like an eagle you soar high and free as a bird you fly

and free as a bird you fly



Stroke Survivor, 2004 & Carer

Sleep Shock Upside down Understanding R Rest Routine Victory Vacation Intelligent **Impatient** Valuable Vocal E **Exercises** Encourage



Stroke Survivor, 2006

I was visiting family in England for Christmas in 2006 and one morning on December 14 we were preparing to visit relatives when I simply rolled off the toilet in the bathroom. My sister in law heard the thump in the kitchen below, and called up the stairs "Are you ok and I replied yes but when I tried to get up I had no strength and kept rolling to my left. Having knocked over an ornament, she checked again and called an ambulance.

The paramedic asked me to squeeze his ankle, which I could with my right hand. I don't remember how they got me out of the bathroom, down the stairs and into the vehicle but I do remember the driver getting angry with the traffic not getting out of the way, saying "Can't they hear the siren?!" I was obviously in and out of consciousness as the next I remember was waking up in the Stroke ward.

My sister in law visited daily and what I couldn't say, made me write down. This helped in the recovery of my speech and handwriting (luckily, I was right handed!)

I must have been in a coma for a few days because I was later told that my brother had my phone ready to tell everyone that I wouldn't be coming home.

Doctors were anxious to discover what caused the Stroke and found I had been a 'blue baby' with a hole in the heart through which a clot had passed to the brain. This was closed with an Amplatzer device - a little umbrella inserted in the vein at my groin.

Physiotherapy focussed on preparing me for the flight in February. An SOS nurse accompanied me on the journey. I was delivered to Blacktown hospital where I started to progress well with physiotherapy, but the neurologist shocked the physios and ward manager by terminating my treatment, telling my family that I would not progress further and never live independently and that they should consider taking me back to Queensland to stay with them.

With the help of the ward manager and friends, I discharged myself and transferred to Minchinbury to continue my rehab. They arranged modifications to my house and a brother organised appliances that were easy for me to operate.

I was discharged from Minchinbury in March 2007 and I joined Blacktown Stroke Recovery Club. I've lived independently, alone ever since. I passed my disability driving test in 2013.

A year before my Stroke, I was off work for a couple of months with chronic fatigue, but my heart wasn't checked! A point for physiotherapists is to tell Stroke survivors why they are doing certain exercises because in hindsight I think I might have progressed further had I been made aware of the ultimate benefit of some ritual routines.



Carer for David, 1999

One day, November 14th 1999 my husband (61) and I (54) were on holiday with our semi-retirement plans intact, the next day we were at Gold Coast Hospital.

David had suffered a brain stem stroke and was on Life Support, conferring with his daughter, Barbara, in the UK the decision was made to take David off Life Support. There I was with the support of a social worker and a nursing sister in the ICU waiting for David to take his last breath. Suffice to say it didn't happen, after a while of listening to David's stochastic breathing I enquired "how long" my knee was patted and reassured with "it won't be long dear". Eventually I asked if they were worried about his breathing and added that he had sleep apnoea and always breathes like that. Next thing David is whisked up to a medical ward with me in hot pursuit. Unbeknown to me it was the start of the RECOVERY progress.



Stroke Survivor, 2020

My Stroke Journey

It was a rare week in the middle of COVID in 2020 when my husband Don, two friends and I decided to have a holiday at Tuncurry on the NSW Mid North Coast. While we were there, only one day into the break we went to meet my friends. I went to get the cart to take to the cabin as cars were not allowed there. On the way back my legs started to go one way and body the other. They found me slumped over a car. The ambulance was called. I was rushed to Manning Base hospital, an hour away. They called my sons in Sydney and told my husband and friends they didn't know what was wrong, I was either having a Stroke or seizure. But there was no way I would make it through the night, my heart was down to 20 beats a minute.

If they gave me the Stroke medication and it was a seizure they would kill me. They had no idea what was going on. I didn't have symptoms of Stroke. Well, I made it through the night. Nobody understood my words. I knew what I was saying. Why, couldn't my husband understand me when I knew what I was saying. The doctors and nurses thought I was speaking a different language. So, I had to communicate with pictures. My son had to tell Don what I pointed at as he could not see because he is blind.

At the end of the week, they flew me by air ambulance to Blacktown Hospital where I started some therapy. I was on tube feeding with a tube down my throat. Lifted by hoist to get in and out of bed, unable to sit or stand or feed myself, and on oxygen. I remained there for 3 weeks before I went to rehab at Mt Druitt Hospital.

There my transformation began. They came from the gym and asked if I wanted to go to the gym. My answer was no. Wrong question – it should be, do I have to go to the gym? Yes. Once a day was all that was expected. But I knew if I was going to get anywhere, I needed to exercise more. This was a foreign concept to me. But I must do it. Exercise is an important part of recovery. The main motivation was the doctor telling me that my husband and I would have to go to a nursing home. I cried and cried but this gave me more determination to prove the doctors wrong. I worked hard and improvement was slow, but I did improve!!!

So, Don and I came home. That was five years ago. Yes, I need help with some things, but I also frustrate my carers because I am stubborn to keep my independence. That's important! Yes, there is life after Stroke. It may not be life as you knew it but you adjust.

There are great people in Stroke recovery clubs as I have met at Blacktown Stroke Recovery Club. I have improved my speech through attending Maitland Aphasia Communication Group online and I go to the Stroke choir online with "a little bit of help from my friends". I have so many new friends now who understand and encourage me. So much so that people from Maitland travelled 2 hours to meet me in person.

My photo is Don and I celebrating our 50th wedding anniversary and Don's 80th birthday. Guests included people from the Maitland Aphasia group whom I had only had met online, but now in person. How wonderful to have people from the Blacktown Stroke Recovery Club attend as well. People from both Stroke Recovery Clubs are fun and have good senses of humour.

Finally, each step that you gain, celebrate. Some days we move pebbles, some days we move mountains, and mostly we move nothing. But if you don't try you lose everything. Be positive and it is important to learn to laugh at yourself.



Soft sings, silence

Unrelenting signs. FATIGUE! CONFUSION!

Recall, return, regain

Ventilation - talk to others in SRA

I will, I will, I will keep going forward! I will NOT GIVE UP

Vital - to not lose HOPE!!!

Every part of my world impacted. Embrace Mel 2.0. Exercise - body + brain



Stroke Survivor, 2020

I have written my story to emphasise the stages that make up the well known FAST acronym. But to properly reflect on it, I find I need to expand the acronym to 'FASTER', adding 'E' for expertise of medical personnel and 'R' for resources available.

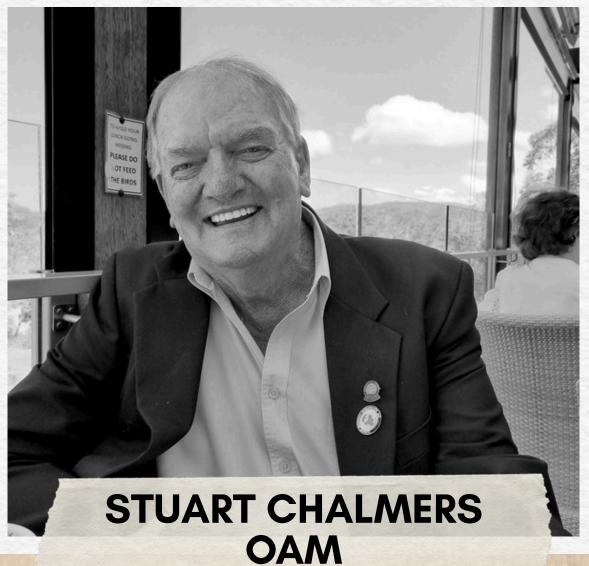
The day of my Stroke, 28 March 2020, is a date remembered as the start of the first mass COVID lockdown across NSW. Looking back, I know that I was very fortunate - the sequence of events combined favourably for me, and I was able to survive as 'all the ducks lined up for me'. If not, I may not be here today, or if I was I probably would not be able to relate my story to you.

That morning, my wife Karen, although unfamiliar with the FAST principle was concerned because my face "didn't look right". Ignoring my protests that I was perfectly fine, she called an ambulance. When it arrived the paramedics gave me some physical and verbal tests. Despite passing the tests, and me insisting that I was alright, the paramedics relied on their training and combined experience to be persuaded by Karen's passionate assertion that I "did not look like my usual self" and that she would have "difficulty recognising me". They decided it was best to take me to hospital and to save time at the hospital's emergency department, the paramedics used a dedicated radio frequency to contact nearby hospitals and arranged for a specialist neurological emergency team at the Royal North Shore Hospital to prepare for me. I benefited from the lockdown as the traffic was very light and we made good time to Royal North Shore Hospital. Once there, the neurological team was waiting for us. We experienced a slight delay as we weren't allowed to enter until we passed a COVID test.

Once inside, the Registrar was faced with an emotional Karen insisting that I did not look right, and me protesting that I was perfectly okay. Although I again passed some tests the Registrar, calling on all his experience, decided that Karen's concerns were more pertinent than my protestations, so he sent me to the hospital's MRI scanner for a brain scan. Returning to emergency I saw the Registrar and Karen looking over a bright image on a computer screen which I realised was my brain scan. Pointing to the screen, the registrar said to Karen "here is a thrombosis..." No! I cried out desperately", there can't be a blood clot, I'm not having a Stroke."

After consulting with Karen the Registrar sent me for a procedure to retrieve the clot. I was taken into an operating theatre where a surgeon and anaesthetist were waiting for me. Unfortunately there were complications and I suffered a bleed on my brain, which caused pressure to build up between my brain and skull. This had to be relieved to avoid permanent brain damage or even death. Fortunately there was a neurosurgeon on call and they were available to perform a craniectomy – he cut away some of my skull to relieve the pressure on my brain. All this was explained to me by Karen after I awoke from a deep sleep. I gingerly brought my hand up to my head and I found what felt like a mound of spongy tissue at my right temple. "Careful!" urged Karen, "you have no bone there and it's only a flap of skin covering your brain."

Assuming it was the morning after my Stroke, I was keen to go home. But no! Karen told me I had been in a coma for six weeks and it was now the middle of May. Thus began my stay of nearly nine months in hospital but that's another part of my story....



Stroke Survivor, 1989 1946 - 2022 My name is Stuart Chalmers and I had a Stroke in 1989 when I was 43 years old. At that particular time I was probably fitter than I had been for years because we had been training for the Masters Division of the Australian Surf Life Saving Championships.

We had just finished rowing in the finals of a boat race at Freshwater, had put the boat away, changed our gear and were waiting for the BBQ to cook. I collapsed like a sackful of spuds and couldn't do anything for a fair while. Luckily for me the Patrol Captain saw me collapse and within a short time had the oxyviva on me and the ambulance and helicopter on its way. I can remember hearing the helicopter and thinking to myself "God I hope the ambulance gets here first!"

After a brief stay at Manly Hospital, I was transferred to Royal North Shore Hospital. After 6 days I was transferred to Newcastle Hospital but after 2 weeks there my wife Sandra claimed that I was not being treated properly and that the best place for me was Coorabel – the Neurological Rehabilitation Centre at Royal Ryde Hospital.

The treatment at Coorabel was the most productive treatment I have ever witnessed. They made me work hard from 8am to 4pm every day for months. They were on to me all day every day – watched me like a hawk and didn't let me get away with a thing! I recall that if something ever went wrong there was always someone with me in an instant.

It was after several weeks in Coorabel that I made a conscious decision to quit smoking. I was sitting on the veranda with cigarettes and lighter beside me. Every time I put the cigarette between my lips, the damn thing would fall out! When I eventually worked out I had to put it in the other side of my mouth I didn't have the strength to work the lighter! I threw the whole lot over the railing in disgust. You should have heard the giggles from the peeping Toms behind me!

You know, I really didn't recognise that I'd had a Stroke until I saw a video of someone else with the same right-sided disability. The thing is that we Strokees are all so different in the way we are affected and the way we behave.

I was in Coorabel for 6 months and then came home. At home I had no wheelchair so I threw myself into learning to walk again. I also had rehab twice a week at Rankin Park Hospital. It was difficult re-learning to do things that people take for granted – like doing your pants up, doing up shirt buttons and stuff like that. When you've got the use of only one arm it's really hard to do the buttons up on the sleeve of the working arm.





Stroke Survivor, 2013



8th February 2013: Flown to John Hunter Hospital from Taree after aneurysm erupted in Brain while at work. While in ICU at JHH my stroke happened.



2014 I walked my daughter down the aisle with no walking stick (which was a goal during my physio sessions)



In 2018 I had my 1st overseas travel post stroke with my daughter & girlfriend for my 50th birthday



I had to learn how to walk again and was able to with the aid of a walking stick



I was able to help my 2 sons through their HSC exams, and then both gaining apprenticeships.



As a member of my local Stroke recovery club (GLAMS), myself & a couple of other members won the Clubs Trivia quiz



Carer for Elaine, 2014

At Balmain Hospital

We were impressed with the kindness and care shown to us at Balmain Hospital. The resident doctors and nursing staff were excellent. The physios, occupational therapists, speech pathologists etc. were all special people with a very special job. There was only one problem, Elaine hated exercise! I would arrive at Balmain hospital about 10 am and leave about 10 pm with a short break in the middle of the day. Often, she would call me as soon as I got home to tell me she needed to go to the bathroom, and I was the only one who could take her!

I often would cook for the Hospital staff as a thank you, spaghetti aglio olio, cannelloni, pizza and crostata.

Once home, Elaine continued her rehabilitation thanks to the outreach service who did their best, but still did not like exercising, however She was most cooperative with O.T. students that came from time to time.

Elaine had a wonderful attitude to life and a positive outlook. She kept saying "I am not going to let a stupid Stroke stop me" and "every day in every way I am getting better and better"

We tried to keep our lives as unchanged as possible and have everything as close to pre-Stroke as possible. We enjoyed overseas trips, parties with friends, wonderful food, movies, musical theatre etc. Up until July 2024, Elaine would read the morning paper, her weekly magazines, watch and tape her favourite shows (including Two and a Half Men) and play with the shares. Eventually she lost interest in her favourite things but still loved listening to the downstairs piano. She even received a video message from Jon Cryer, from the show Two and a Half Men, and a message of encouragement from Sharon Stone.

One of the best things that really helped Elaine a lot when she returned home was receiving copious handwritten cards from the Golden Letters Club. Wonderful people sending wonderful messages of support!

Elaine having the Stroke, was a terrible thing, but in some ways, it brought us closer together, and we made many new friends along the way. We could not have made the journey without the love and support from our loving daughters Cassandra and Lisa, granddaughters Amber and Winter, the rest of our family and the help from the Stroke Recovery Association along the way.

There is life after a Stroke, and with the right attitude, love and support, it can still be a very good life and that it certainly was.



Stroke Survivor, 2012

We moved to the Bega Valley area in April 2014. I was looking for some kind of support group for Stroke survivors.

I started volunteering for Parkrun (walk/run), I made a great friend who works at the hospital and she rang Michelle Sharkey, and the rest is history. I started the Bega Stroke Recovery Club in August 2017.

I have several sayings,

Why not.

Never say Never.

Never give up.

A friend that I have had another friend. We met up and that was Judith.

The first meeting we had was on the hospital grounds Renata and Judith and I was the only ones there.



Stroke Survivor, 2014 & Carer

What Tomorrow Brings

One day I was fit and strong.

Next day everything went horribly wrong.

My legs gave way beneath me

How could this possibly be?

Christine rose quick with the sound of the fall Lift your arm she said, can you speak at all? She knew in an instant, she was on the ball, that a Stroke had got me, it was best not to stall.

A swift trip in the ambo, panic hung in the air. Thank God for the good folk with sirens to blare. When I got to the hospital, they were all thee; the medics, the nurses, giving all their best care.

A life changing moment, not one to desire.

A bleed in the brain, I'm now stuck in its mire.

A man of action, handy and useful,
thinking I'd be forever active and youthful.

How life can alter in the blink of an eye.

Now I limp and struggle but I will get by.

No good to complain and make yourself sad

Life's just too good, even though there's some bad.

Each day brings beauty in one way or other In the faces who love me, just like my dear mother. How lucky to be with friends who do care, even though some strangers may give me a stare.

You just never know what tomorrow might bring.
Stay close to the people who make your heart sing.
Counting your blessings, no truer word said,
Being grateful will hold me in very good stead.



Stroke Survivor, 2022

So you've had a Stroke. You've gone from being fit and active one day to being confined to a bed in hospital the next. Depending on the degree of disability you basically have to say goodbye to your old life and come to terms with the new. For some it is a total shock just being in hospital for the first time and then there is the reality that you are reliant on others for help, even to just get out of bed. Adapting to the hospital routine comes surprisingly quickly and you stop questioning things such as dinner time at 5.30. What?! Don' get me started on hospital food – I use that term loosely as it was neither nutritional nor appetising. We were required to take our meals to the dining room which was a large room with tables lining the 4 sides. A favourite game amongst the patients was "What meal is that?" in an attempt to identify what had been served up.

The morning routine began at change-over of the night shift staff at 7.00 a.m. The day staff would cluster around your doorway while the night staff yelled out your details so the rest of the ward could hear all about you. An important factor was if you "had your bowels open". This question seemed to take precedence over all others with hardly a reference to your physical progress. There is no dignity in hospital. Wardsmen can take you to the toilet. Nurses can help you in the shower and perhaps help you dress, but you are only allocated a shower every second day. I should mention the subject of bed pans, and as a woman I can't believe that in the 21st century there hasn't been a radical modification of the gravity-defying model. I vowed that if I ever had a big win in Lotto I would donate money to bed pan research. If they can put a man on the moon, why not a workable design for a feminine bed pan?

The day was taken up with physio in the gym and O.T. sessions. To their credit the physios were fantastic, very encouraging and supportive while at the same time being hard task masters.

Once you are back in the outside world and coming to terms with your new reality it is important to focus on what you can do and not lament the things you can do no longer. It is also a period of adjusting to how you are perceived by outsiders. This is especially so if you are in a wheelchair or use a walker to get around.

There are three basic reactions you will encounter:

- 1. The benign or sympathetic smile;
- 2. The approach from the kindly couple at the next table at the café who smile sweetly and ask "how are you dear?";
- 3. The person who wants to engage in conversation by asking "what happened to you?" and then launch into the story of a family member or friend who had a Stroke.

Remember you are not your disability. Try to maintain an optimistic outlook with patience and acceptance and not forgetting there is always hope.



Stroke Survivor, 2005

Aphasia

Aphasia was not a word I had heard of...

Even when admitted to hospital several times -

No-one mentioned the word, 'Aphasia'.

Is it a term to be discussed behind doors?

Is it a scary affliction? Should I be afraid?

Why is it not known throughout the wider community?

It is a 'silent' condition....

BUT it does not affect intelligence.

We are not drunk or dumb, we have a communication disorder.

People cannot communicate their thoughts in tangible terms.

It is so frustrating to be unable to express our thoughts and opinions fluently.

Bring on the publicity – tell the world there are people overcoming obstacles every day!

People are coping with Aphasia and its challenges each day.

My Aphasia is mild (Broca's and anomic)

My words come out jumbled occasionally

It can be quite funny at times -

Wrong words spoken improperly...

I can amuse myself, too!

I have created 'NEW' words....

Fiona's creative word dictionary!

Tiredness steals my word.

Spelling is a problem,

Thanks for the spell-checker on my computer!

Confidence has evaporated.

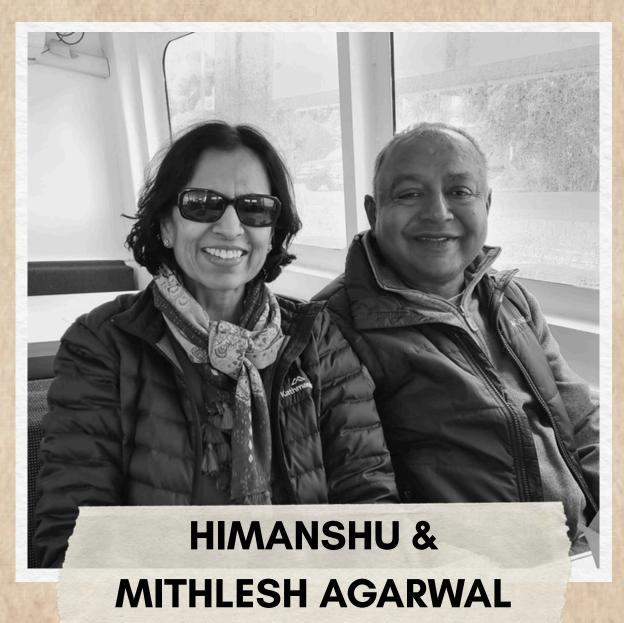
I am lucky – I can read.

I am so grateful for that blessing!

Please say loudly and repeat that aphasia does NOT affect intelligence!!

Keep striving to overcome each little frustration,

Stay positive – congratulate myself when I kick goals!



Stroke Survivor, 2020 & Carer

Sitting Under a Tree

Tall tree, that touching the sky

Touch my heart in low and high,

Living in nature, standing alone

This strength, where you find it all.

In fierce weather in hail and rain,

Who holds you tight when you're alone?

Nature that has brought us here on this journey of life, that we all go. Give us chance to learn and grow.

Teach us lessons in rise and fall,

It depends on us how we take it all.

Under the tree shade, I thought again.

It's the nature of trees to give us all

What they grow and whatever they have,

Caring and sharing with love with all.

We need to learn it while walking along.

Tall tree that touching the sky

Touch my heart in low and high!

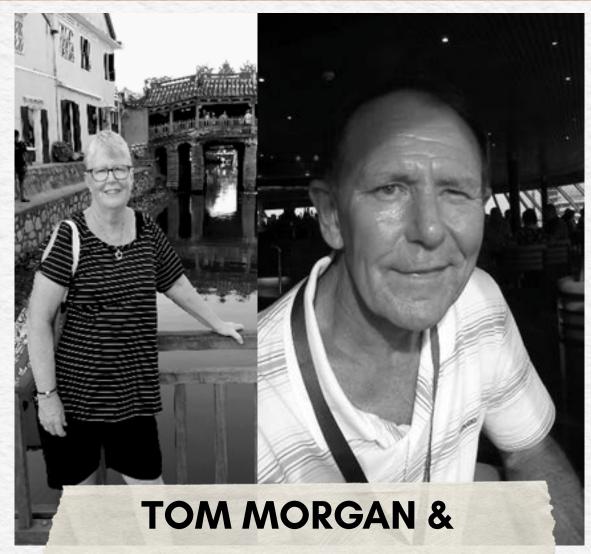


Stroke Survivor, 2022

When you have a Stroke, its no joke, it can even make you choke

But we've got Michelle, who will always fight like hell

And we've got the SRA, Hooray, Hooray!



LEE DEVINE

Stroke Survivor, 2010 & Carer

SURVIVE

So, my story started in May 2010 – I became a Carer to my partner Tom, who had had a Cryptogenic Stroke the day after an Inguinal Hernia repair. To say that this was a shock was an understatement and Tom took it particularly bad as he believed that the Doctor was at fault as he displayed no factors that would cause a stroke – hence being Cryptogenic. Tom had some Aphasia and had lost the use of his right side. After 3 months Tom came out of hospital in a wheelchair. Our once active world was turned upside down, but he was home.

RECOVER

Reality set in, and Tom was determined to beat it as best he could. He had been a fit and active person and he began exercising, exercising and more exercising. This has made a very substantial difference in his recovery journey. However, emotionally he was not in a good place. Then we found WAGS, initially he did not like going to the meetings – it was too confronting. However, I loved it. MY world had changed also but no one really paid attention to my situation and by attending WAGS I found that other Carers were there for ME. WAGS probably made me a better carer as I did not have to feel guilty when I had feelings of 'what about me' that others also experienced that and that it was ok.

THRIVE

To be honest, I wouldn't say that we are thriving, but we are doing quite well. We both have had/are going thru major health issues which doesn't help. When Tom had his Stroke, I knew nothing about it nor had I met someone who had had one. Mostly, I would say that joining a Stroke group - WAGS - has been a major contribution in our journey going forward. Tom enjoys it now, he/we have made lovely friends which is very important as many of our original friends are no longer; it became too difficult for them because of our restrictions.

We have managed to have a reasonably fulfilling life considering our restrictions. Would I wish it on anyone NO, but I know that you can still move forward with the right support.



Carer for David, 1999

The bed side vigil for three days, with me constantly nattering to David, ended with telling him "you cant die David I'll have a house full of unfinished crosswords". With that I noticed rapid eye movement behind his eyelids, I said "hello, darling, are you there" his eyes opened and I got to see his beautiful blue eyes, heaven! He could only move his left hand, so for communication we had one squeeze for yes, two squeezes for no and three squeezes for I love you. The latter remained David's form of communication, whilst at Gold Coast Hospital, which was handy when his daughter arrived from England. Barbara and I camped in a nearby motel until her return to England and a friend flew up to drive me and our car back to our home in Hunters Hill, Sydney.

David was transferred to Royal North Shore Hospital early December, where he stayed for 20 days, and he had a PEG tube and a suprapubic catheter inserted. Communication progressed to an alphanumeric board I made up on a PC and got laminated, plus arranging with our solicitor that David putting an X on official documents was accepted as his signature. The board remained his main form of communication, good thing he was a good speller.

On the 23 December 1999 (my birthday) he was transferred to Coorabel Rehabilitation Centre at Putney, where we had a quite Christmas. I was working at Macquarie Hospital, where I was able to rent a house on the grounds, as I was under the false belief that David would be in rehab for the next 6 months at least. After the Christmas break the staff had the first 'family meeting' where they informed us that David could only be in Rehabilitation for 43 days and that we should make arrangements for David to be admitted to a nursing home. Shattered, I met David's neurologist in the corridor and enquired what David's prognosis was. His answer was "Mrs. Watkin in all my years, I've never known a patient that has survived this long after such a severe brainstem stroke". David's final diagnosis was incomplete quadriplegia. Though David was physically shot, his cognitive function was okay. David did not want to go to a nursing home and I didn't want him to either. David had given me the best 18 years of my life, and if I couldn't care for him something was radically wrong with me, that was my attitude. Back to the drawing board. In consultation with David, he wanted to go to Forster, as this was part of our retirement plan for 2010. I telephoned Great Lakes Council, where I got my first 'light at the end of tunnel' moment. "Yes Mrs. Watkin, we have a very good rehabilitation service here, I'll send you the directory of services." So that weekend I, with a friend, went to Forster. My request to real estate agents was "I want a flat house with good neighbours". Suffice to say that is what we purchased, and with help of friends I was able to move our furniture up to the house. On the 1st March 2000, I wheeled David into our new home, presented him with the keys of the house and wish him a happy 62nd birthday to start our journey to THRIVE.



Caroline survived a significant Stroke on 12 September 2013 resulting from a clot entering an undetected leak in the chambers of her heart. She was in hospital for over a month before entering rehab to begin her recovery phase. At the time she was 42.

However, Caroline did not enjoy her 2 months in rehab mainly as I was to discover later, she was not ready. In 2013 I was told if she did not begin her recovery in the first 3 months then she would not recover any movement or speech. She would, as the chief nurse in the first days in the Stroke ward at the Mater Hospital in Newcastle stated - not walk or talk and be in a nursing home for the rest of her life. She gave us no hope and at that stage I knew no better.

Well, she did end up in a nursing home for 7 months. But in that time, she was able to rest and when we obtained NDIS funding, she was ready for rehab. She took off going from needing 2 nurses to transfer her to doing laps walking around the nurse's station in a walker. She returned home in July 2014 and has been there ever since, back with her family including our daughter who had just started high school and our son who was in his last year of primary school.

And talk!!! She has improved every year and now thrives thanks to the support she gets from her professionals, carers and her family. I think I have played a role here!! Being her chief advocate and relaying her wishes despite her continuing battle with aphasia and the effects of her Stroke including loss of movement in her right arm, she now enjoys swimming every day except Fridays when she is an active member of the Maitland Aphasia Group.

This group has been an inspiration to me and many others especially Caroline, supporting Stroke Survivors who seek to improve their communication difficulties during recovery. The confidence I have seen instilled in members who join our group has been tremendous along with the positivity and friendship.

This group and Caroline's journey through surviving, recovering and then thriving has taught me many lessons. The main one is to never listen blindly to experts giving you no hope or thrusting generalities at you like you must do rehab as soon as possible after a Stroke. Everyone is different and deserves to have their wishes considered.

I have seen Stroke Survivors, months and years after their Stroke improve with the right support and their own determination. It is never too late if you are willing to give it a go!!

Caroline and I now enjoy our life after her Stroke - we are indeed thriving!!



Stroke Survivor, 2020

Reasons you are alive!! My hive!! Go find new ones

Every Stroke is different

Considerate to self, be kind, it's ok to cry. Confide in trusted others. Change helpers, cry.

Others - you can help share your knowledge

Visit new Stroke Recovery Association friends

Exercise body and brain

Retain, humour, kindness. Regain, strength

Yes - to new beginnings, to new lifeblood in every step forward, to support help offered and deserved





Carer for Paul, 2009

Life is a Gift

Shock, numbness, and despair.

Why did this happen? How can it be fair?

Unlucky perhaps? We'd never know why.

But as numbness faded, a new normal we'd try.

Slowly at first, baby steps they advised.

Keep looking forward, no past to despise.

One day at a time, tiny changes we'd see.

Emotions were high, yet hope set us free.

We're here beside you, through every stride.
Working on speech, pushing you with pride.
Crying and laughing and swearing too,
But always together, we'd see this through.

As days turned to years, a new life we made.

So very thankful for the time that you stayed.

We made many memories with family and friends,

And the most of each day right to the end.

Life is uncertain; what comes next, we don't know.

Just make the best of it, let your spirit grow.

Thrive in the moments, cherish each day,

For life is a gift, in every way.



After 6 months at home I went back to work for a while although there wasn't much I could do around the place. I was able to use the ride-on mower but had to be careful because my balance was not the best. The other miners were a bit worried that one day for crib they'd be having Chopped Stuey!

My wife encouraged me to take special driving lessons. After 9 of these and some renovations on my utility I was like Willie Nelson "On the Road Again". I was once more mobile. My wife was deliriously happy as I left for the Surf Club each morning. In 1992, three years after my Stroke, my brother and I drove across to Perth with the surf boat on the trailer.

Soon after coming home I contacted the Hunter Outreach Centre and joined the Belmont Stroke Recovery Club and the Stroke and Disability Information (Hunter) Inc. The people in these groups helped me in many ways. I have been on the management committee for S.A.D.I for many years and also sit on the Board of Directors of the Stroke Recovery Association.

I have assisted in the commencement of Y.E.S.S – our Young Enthusiastic Stroke Survivors group and am the organiser of their bi-monthly outings that include bus trips of substantial distance. My wife and I have taken on the pleasant task of rearing our granddaughter Keira, who is now five. It's pretty hard for a bloke to hold down a little one when she gets her needles.

A message that we Strokees try and get across is that: Stroke is a Brain Injury. Stroke is an emergency. Dial 000 immediately!

It's a fact that if a scan is performed within a few hours to determine the kind of Stroke and treatment is started immediately, the damage and resulting injuries will be much less severe than if treatment is delayed. This gives the patient a much higher quality of life and it also saves the health system a considerable amount in later rehabilitation costs.

I'm back at Caves Beach Surf Club holding the position of Chief Volunteer - mowing the lawns and supervising other volunteers. I currently have some limitations but I was lucky. Let me tell you though that I've sure tidied up my eating and smoking habits since I was given the ultimate warning.



Stroke Survivor, 2011

Some people said I was the fittest person they had known. I had finished the New Zealand Ironman triathlon back in 1987. Even in my 50s I was still swimming, biking and running most days.

On 14 April 2011, aged 55, I had a Stroke. The ambulance took me to the RPA Stroke Unit, where my positive recovery began. While in Intensive Care I thought about my grandfather having a Stroke about the same age as me. He survived and recovered through grit and determination. That inspired me to "NEVER GIVE UP". While in Intensive Care, I was trying to move the fingers on my right hand. A doctor gave me a ball of latex gloves and told me to squeeze them. That was my first physiotherapy.

In the general ward, the Stroke rehabilitation team became involved. I had lost feeling and movement in part of my tongue. My speech therapist encouraged me by giving tongue twisters. The occupational therapists walked me up and down the hallway until my leg started to improve. I was moved to Balmain Hospital for two more weeks of rehab. Staff let my wife take me for walks locally.

Back home, I set up a gym in the backyard. I used household items and tools to practise movement, like pressing the trigger of a drill, shifting objects from one cup to another, and placing coins in a money box. We set up my bike on a stand and I would ride it stationary. I would go over my speech exercises to try and help me not muddle words. After about four hours I would have to sleep. I remember thinking, 'this is as hard as Ironman training.'

After a few weeks I started going to the swimming pool regularly to help movement in my right arm. After I had been home a couple of months, I walked/ran for 20 minutes. Four months to the day after my Stroke I walked the City2Surf fun run.

A couple of months after leaving hospital, the specialist signed off that I could do triathlons again. I found a GP who was very supportive. Having the right doctor was brilliant. It took me until September to do my first open water swim. By January I was running 5km. One year later, I finished my first post-Stroke sprint triathlon (750m swim, 20km bike, 5km run).

The first few years after my Stroke was a difficult time. Triathlons helped co-workers to see me not as a Stroke victim but as an athlete. In 2017 I did the triathlon at the World Masters Games in Auckland. Someone there said to me that I should try to get into the Australian age group team.

Well, this Stroke survivor became an age group athlete. In 2017 I did a number of duathlons (run, bike, run) and made it into the Triathlon Australian age group team for the sprint duathlon at the World Multisport Championships in Denmark. The next year I qualified for the Standard Duathlon in Spain.

At this point there was no holding back this old Stroke survivor. I wanted to finish an Ironman Event. In 2020, after 18 months of lifting up my mileage, I finished the Geelong Ironman 70.3 (1.9km open water swim, 90km bike, 21km run).

Since then, I have finished the Western Sydney Ironman 70.3 twice, Husky Ultimate, the Half at Challenge Wanaka in NZ, and a lot of shorter triathlons and trail runs. I have also finished the City2Surf every year since my Stroke.

I am proud of what I have achieved since my Stroke, but the biggest thing that makes me happy is my family and my three wonderful grandchildren.



Stroke Survivor, 2001

My Stroke Club

It is my community.

It is connection with people who understand.

It is a place where I don't feel alone.

It is my safe place.

It is my dear and treasured friendships.

It is a place where we can talk about our Stroke journeys, our losses, experiences and our achievements.

It provides an opportunity to ask questions, share useful tips and information.

It is a place where we can laugh or cry together.

It is something that I am grateful for.

It is my Stroke Club!



Stroke Survivor, 1968 1938 - 2025 At age twenty nine, Robyn was healthy and strong, had made plans for her future and set a new direction for herself and her young children. Then her game plan was permanently interrupted.

Through determination, courage and tenacity she learned to set a new course and manage her disability rather than allow it to manage her. She was overtaken by hopelessness and fought her way back. She has not allowed herself to be defined by her illness.

"I am not a victim. I had a broken arm and had to go to hospital and I was really down. I said to myself: 'How dare you. Pick yourself up.' And I did. I do not think negatively, I really don't, not at all. I think positive, positive, positive."

The NSW Stroke Association and Stroke social club president has travelled overseas and refuses to allow disability to govern her life.

Robyn lets out her trademark raucous laugh, loud and free with her head thrown back and lips beaming wide and a mischievous glint in her eye. "People come up to me and say: 'What happened to you' and if I'm in a good mood I'll say: 'CVA' and just walk on. Other people will stare, and I'll just smile. It's their problem, not mine."

"My son, when he had the Stroke said: 'I've got to get further than you', and he did. It was the same when I had by Stroke, I said: 'I have to get further than my mother', and I did. I could never have just said: 'I'm sick, I can't do anything'. I knew my husband wouldn't have taken care of the children. I thought I'd get better, which I did, but I only had one hand (you only need one hand) and I walked funny. I was stubborn, really stubborn, and I didn't want anyone to help me."

Reprinted from the beautiful publication "People Like You" (2010) with the kind permission of Ellen and David Hill - Deep Hill Media ww.deephill.com.au



Carer for Elaine, 2014

You Look Perfect to Me

When I look at your face in the morning light Your eyes still closed and tight You look perfect To me

When the first ray of sun through the window rips I gently kiss your lips You look perfect

to me

Days that have passed and days that we face
Will not change the way we embrace
I never married
your body
But I did marry your soul

So you always look perfect
To me

So you always look perfect To me

When your eyes shine in the candle light I hold you gently and tight You look perfect To me

When the night is dark and the winter cold
And the flames throw shadows of old
You look perfect
To me

Days that have passed and days that we face
Will not change the way we embrace
I never married
your body
But I did marry your soul

So you always look perfect
To me

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So you always look perfect To me

So you always look perfect To me

I never married
your body
But I did marry your soul

So you always look perfect

To me

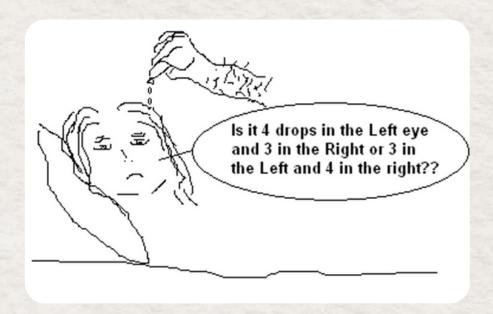


Carer for Elaine, 2014

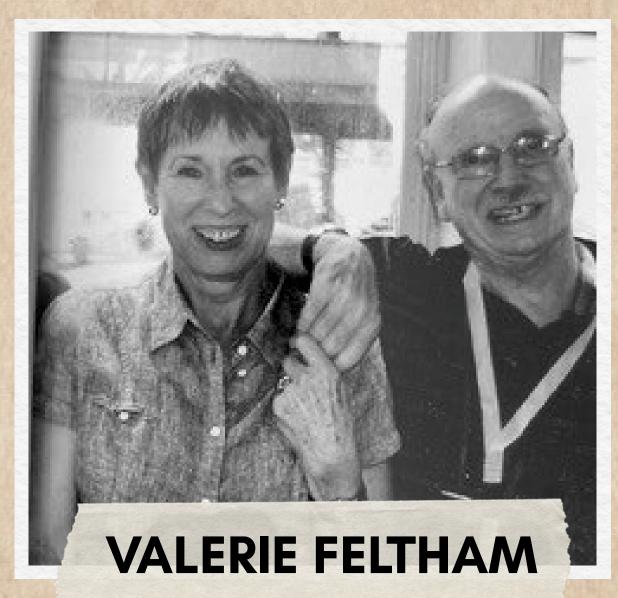


This is terrible! I can't find my glasses...Have you seen my glasses?? Vincenzo??









Carer for Chris, 2005

My husband Chris had major stroke resulting in a dense hemiplegia and frontal lobe damage in April 2005. Chris was working at the United Dental Hospital as a dentist. He had the Stroke just as a patient seated himself in the chair. A trip to St Vincent's hospital followed where the clot busting drug was administered. Unfortunately that broke the clot up but did not disperse it resulting in many many little Strokes. This is a known side affect and we were warned that it could happen.

After 10 days at St Vincent's Chris was discharged to Mt Wilga Rehabilitation hospital for rehab. I was working there as a neurological rehab Registered Nurse, ironically my speciality. Chris spent 10 weeks there learning to walk again albeit it with a walking stick. His left upper body did not respond to treatment therefore he was left mobile but severely handicapped physically and complicated by the frontal lobe damage. Chris's ability to keep himself occupied was limited, his concentration was poor – reading became difficult, driving impossible, walking tiring. Chris was dependent on others to help him in all activities of daily living.

Then - our daughter saw a flyer on a notice board at the community centre in Crows Nest. It announced that there was a choir formed for Stroke Survivors with aphasia in the local church hall and that they were looking for people to swell their numbers.

Well suddenly there was something Chris could do. Chris did not have aphasia in fact he had the opposite, waylaying complete strangers in the local shopping centre and treating them to various opinions and thoughts as they came into his head. But he could sing. He had a beautiful deep bass voice.

Keystrokes choir is conducted by a registered music therapist. It has been established through research that singing is an effective method of improving speech following Stroke, and is viewed by participants as much more enjoyable than the traditional forms of speech therapy.

They say if you can talk you can sing. Well let me tell you than even if you can't talk you can sing. Music therapy is the answer to any aphasic person's prayers. Music unlocks a part of the brain, and once this is unlocked there is no end to how aphasia can be improved. It is magical to see those so afflicted suddenly find a voice. Not only can they sing which on its own is a joyful thing, but they can be part of a group, part of a bunch of friends who understand them, who support them, who encourage them and applaud them.

Social life improves, community engagement improves, one's sense of self worth improves. Imagine the pride you would have in yourself when having been struck down by a Stroke and then struggling to speak and be understood - you then get up and perform to an audience, how would it make you feel?

Thursday mornings became the highlight of Chris's week, he so looked forward to it, especially the performances. He felt he had friends, he felt he was part of a community. He was with people that understood his problems, he felt needed and an integral part of the group. He loved it.



Stroke Survivor, 2004 & Carer

If Alan Could Speak

I have been here a while I am withered and old "He is weak, he can't speak, he is of no use" they say "They don't understand the resources are

tight"

It's for the best, we know
We won't tell them and then there's no fight

I hear and I see I know it is me
My Stroke has done this
But I will get better you'll see
I am willing to die but is it my time?

I wait and you come
You always do
You have been with me all along
In you I can trust
"No", you say this is not the way
He's a husband, a dad, a grandpa too

You stay you watch you refuse to leave
I wake and you're there
I sleep and you go
I know you will return
I am important to you

We have a good life
I am here; you are beside me
We go fishing and camping
With family and friends
I love Stroke Club and Men's shed,
the choir and aphasia clan
We laugh and we share
Tigers forever - Well maybe next year

It's not what we signed up for
But it is where we are
Forever together
That was our vow

Life will not defeat us
Not with you by my side.
Your love is my saviour
I am important I am loved
You do not see
The man who is weak, can't speak and battered by Stroke

You're with me
You see me
You hear me
Your strident, your valiant
In you I can trust
Your voice is my voice
You know what I'd say
If Alan could speak



Carer for David, 1999

On reflection, the first 3 years were the hardest, though we made a lot of gains. We were able to get rid of the PEG tube and suprapubic catheter and we finally found a physician who diagnosed the trouble with his breathing, his lungs were full of air, the Speech Therapist gave us an exercise which was for David to blow a ping pong ball up a stable table through a straw, the Maccas straws were ideal and we soon said goodbye to the breathing problem. We joined the Council's Access Committee, I joined a Carers Group run by the Council and in 2004 we started the Forster Stroke Recovery Club - David the Treasurer, as he could use Excel, and myself the coordinator. The Stroke Club continued with the name changed to Great Lakes and Manning Stroke Recovery Club (GLAMS) as result of the first Stroke conference we had in Forster (2006). I realized that as the Wingham Stroke Recovery Club had folded we needed to have a name that covered the shire. As a matter of interest, David's neurologist was invited as guest speaker to the Conference and David had the opportunity to show him his progress.

We continued to carve out as good a quality of life as we could. We went on holiday every year, celebrated our milestones, made good friends and generally became part of the Community.

Unfortunately, in January 2014 David had another Stroke. I knew when the ambulance drove out that my David would not be home again as he would not be able to help with transfers. His next stop was full-time nursing home care, where he was cared for very well. He died 10th August 2014 and I had the privilege to be with him. Bless him.

I trust my sharing this experience will show that post-Stroke life has it challenges and that with those there are a lot of wins.



Carer for Len, 2013

My name is Lynette Elario and I am the Secretary of Woy Woy Stroke Recovery Club. I joined the club in 2008 with my husband, Len. We started by doing hydrotherapy twice a week.

When Len passed away in 2013, I wasn't sure if I should keep coming. My boss at the time, Helen Anderson, encouraged me to stay. Helen had joined not long after her husband Adrian experienced a Stroke more than 20 years ago, and she knew how important it was to have people involved. The club needed volunteers, so I stayed on. Over time I found myself helping with the meetings, organising activities, and joining the bus trips.

In those years I've made some good friends. We've also lost a lot of good people along the way. But what keeps me here is seeing how much the group helps people keep going, even through hard times.

The hydrotherapy pool has been especially valuable. It gives members the chance to do exercises to improve balance and coordination that they couldn't always manage on land. Many members swear by it, and they enjoy coming for the company as much as the exercise.

We also run games and activities that encourage members to use whichever side or part of their body was most affected by stroke. A physiotherapist from Woy Woy Hospital visits quarterly to check on progress and give advice. That professional input gives people confidence that they're doing the right thing.

I haven't had a Stroke myself, but over the years I've stood beside many people who have. I've seen that every Stroke, and every recovery, is different. What I've also seen is that with encouragement and the right support, people can go beyond just surviving. They can thrive.

Our group offers more than survival. It gives people a chance to get out of the house, to socialise, and to feel they're not alone. Stroke can happen to anyone, young or old, and it has a lasting impact on survivors and their families. Being part of the club helps people rebuild confidence and enjoy life again.

None of this happens in isolation. Behind every person who joins our club is the care and expertise of doctors, nurses and physiotherapists — including many at Royal Rehab Putney. You give survivors the foundation they need to begin their recovery, and without that, thriving would not be possible. For that, we are deeply grateful.

Stroke Recovery Week is from September 7 to 13. During that week we'll be out in the community, raising awareness and funds to keep programs like ours going. When someone buys a pen or ribbon, they're not just supporting our club. They're helping people who've experienced a stroke to survive, recover, and, most importantly, to thrive.



Stroke Survivor, 2020

- Take time, all learning is good learning. Take care of self and own hive
- Help, hive, hold your standards
- Review where you were, to where you are now. Rid of unkind, unhelpful, unused
- Involve local, state and beyond in Stroke world.
 Invest time.
- Volumes of chapters in this book of me. Only part of the story.
- **E** Evolve into new. Every step is important in right direction.



OSCAR

Stroke Survivor, 2010 & Carer

Henry's Stroke Journey

It happened in Macau in the year 2010
I felt pain in my chest, I could sense something comin'
To emergency by taxi I was quickly driven
My heart's giving up, and my life started crumblin'

I woke up to speak but somehow no words came Only a yes and a no, couldn't say my wife's name I returned to Australia to start doing rehab And hoped to regain God's gift of the gab.

Singing "Danny Boy" often was my magic song My speech did come back, and my words were long Karaoke was fun, so was watching TV It improved my speech greatly as now you will see.

I joined a few Stroke groups to help and socialise
To share my Stroke journey and to get some advice
Not to mention how Zoom makes music such fun
Overwhelmingly glad when the session is done.

Though my speech was affected, my body is whole I can drive, I can run, I can swim, I can bowl Cooking curry I love, it's a skill I have learnt Perfection's the aim, making sure it's not burnt.

So here I am now, full of hope and good cheer I am making the most of each passing year I travel to places that I've never been Because, as we all know, wasting time is a sin.



Words and music by R.W. Kilpatrick

Aphasia

We hear what you say as you turn away, you don't understand what we're sayin'.

Just give us time, and things will be fine, as we get around to explainin'.

It drives us insane, again and again, as people don't seem to listen;

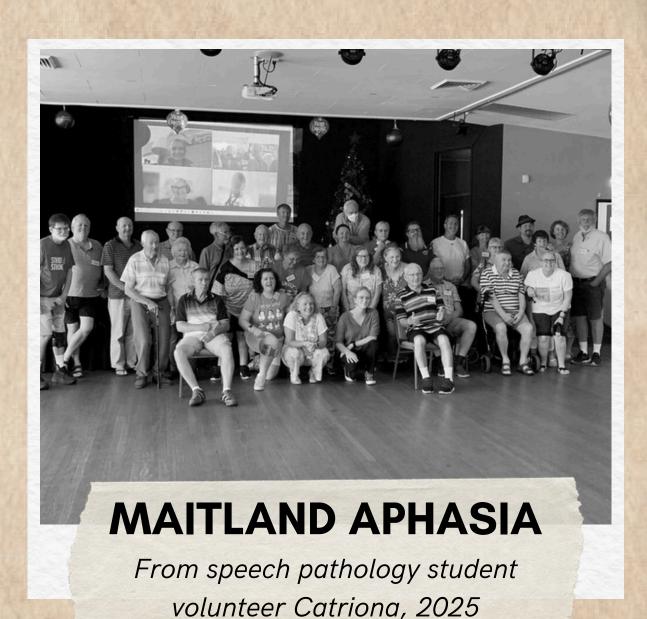
Don't walk away, we've got something to say, although some words may be missin'.

Aphasia, aphasia
Just think it through,
you'll realise it's true,
We're just people like you.

A brain injury, has done this you see, but don't think us useless or lazy; and don't make a fuss, when talking to us, for we're not stupid or crazy.



Aphasia, aphasia
Just think it through,
you'll realise it's true,
We're just people like you.



A Chorus of Courage

In whispers soft, in glimmers bright,
A symphony of strength and light.
Each voice a note, unique and true—
Together forming something new.

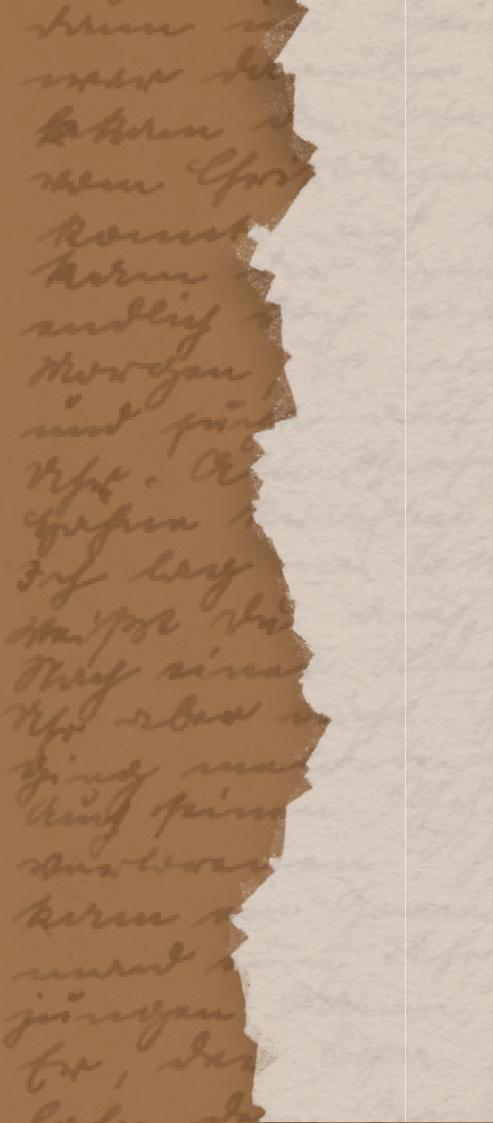
Though words may wander, shift, or stray,
You journey on in your own way.
From Broca's brave to Wernicke's bright,
You lift us up with wit and light.

You face the blocks, the days that sting,
When words won't land or meanings cling.
But still you rise, you find your way—
A quiet strength, day after day.

You share your laughter, stories deep,
The kind of treasures we all keep.
With every smile and moment kind,
You speak in ways that free the mind.

So keep on going, hearts aglow,
There's more to say, more ways to grow.
Each step you take, each word you find,
Shows courage, humour, heart, and mind.

You all inspire me—more than you know— With every courage that you all show. Your vibrant spirits, shining free— Each amazing, wonderful you, I see.





STROKE RECOVERY ASSOCIATION NSW

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