



**Losing his sight after a brain injury.**  
We meet Doug and Helen Merrick, page 4

# Shine

Sharing stories, ideas and news across  
Lifetime Care and Workers Care.

Summer 2021

# Brigitte Bullen: making the most of her “second” life

Brigitte is a Lifetime Care participant



Brigitte was a busy corporate psychologist and mum of three when she nearly lost her life in a car accident. She now channels the same strength that got her through months of rehab into her new passions.

The home that 46-year-old Brigitte shares with her family in Avalon on Sydney’s northern beaches, is filled with the signs of a household happily entangled in the demands of children’s music, surfing, soccer and tennis.

With the children back at school after months of lockdown home schooling, Brigitte leads *Shine* across the garden, past the raised garden where she is growing vegetables, to the long table in her airy studio. Here she spends her days massaging clay into organic shapes, while listening to music or podcasts on meditation and climate change.

“ I don’t miss my former life. Yes, I miss having a dance, surfing, tennis, swimming in the ocean. But I actually like my second life — it’s simpler, slowed down. ”

## Nothing to say

Driving to work in December 2014, Brigitte swerved to avoid a car and hit a pole at high speed. She was in hospital in a coma for three weeks and had post-traumatic amnesia for another six. She thought she’d walk out in a week but was in rehab until the following April. In spite of physical and brain injuries, she discharged herself early to return to then six-year-old son, Rocket, and three-year-old twins, Cassius and Lucette.

At first, Brigitte was only home for weekends. She had to use a walking frame and her speech was still badly affected. Old recordings show Brigitte being a fast and articulate talker in the days she volunteered at FBI Radio. But after the accident she felt she had nothing to say. Even Rocket couldn’t understand his mum. She relied on a speech therapy program called Interact-ABI-lity to help with her articulation. (For more on this program see page 19.) Now, although her speech is slower her articulation is much improved. “And you can’t stop me from screaming from the sidelines at Lucette’s football games,” she laughs.

Since the accident, Brigitte has faced mood and confidence challenges and her husband Nigel has been the parenting hero: “He’s a wonderful human and I couldn’t live without him,” she says. But in the past year, Brigitte has been able to step up to be the protector: “I can now be the person who puts the bandaids on. Before, I was too slow, the cupboard was too high. I love being mum and every day it feels like a new role for me.”

## Two lives

Walking independently is still tiring and Brigitte relies on physiotherapy to build her stability. A big challenge in the seven years since the accident has been fatigue.

“By 3pm, I’m dilapidated so a great support worker helps when the children get back from school. It’s lovely to return to the house and spend time with them in the afternoon.”

Brigitte feels she has had two lives. In the first, her work as a corporate psychologist took her to Kuala Lumpur, New York, Chicago to interview senior executives. She once flew business class to LA for a two-hour interview and then straight back to Sydney.

In her second life, Brigitte rides her slightly unstable electric trike a couple of kilometres to her local shopping village, with the children cycling alongside to protect her in the event of occasional spills.



“ I can now be the person who puts the bandaids on. Before, I was too slow, the cupboard was too high. I love being mum and every day it feels like a new role for me. ”

*Brigitte working in her studio.*

“I don’t miss my former life. Yes, I miss having a dance, surfing, tennis, swimming in the ocean. But I actually like my second life — it’s simpler, slowed down. Everyone is in such a hurry. For what?”

### **Moulding clay**

The family has gone from two incomes to one and can no longer go out for dinner, “but we have such a good life and do so many lovely things”.

One of Brigitte’s dreams for the future is to be acknowledged as a ceramicist. “My equation for success is not money,” she says. “It’s to be recognised.”

She’d first studied ceramics as part of an Arts degree. “But now I can no longer work as a psychologist. I have limited choices, but I do love that I have clay to work with.”

A week after the interview, an elated Brigitte tells us she has just received an order from a local home-interiors shop – “my first proper client!”

Brigitte has limited movement in her previously dominant right hand but using it to press a roller into the wet clay and to support the moulding action in her left hand builds its strength. “Ceramics is a way of passing my life, while listening to podcasts and music. That’s as good as it gets.”

Apart from the family, laughter has been Brigitte’s survival kit. “Part of my brain injury

has made me laugh a lot and see the stupid side of life. The children laugh a lot, both with me and at me. It’s also a force with the friends who’ve come through and stuck by me.”

Throughout the interview, Brigitte calmly works with her clay — almost without pause, the room lit by light from the wide-open door and windows onto the garden on all sides. The setting belies the passion she feels for issues close to her heart.

### **A lot of listening**

Fired by a thirst to protect our planet, Brigitte has joined other locals in “Our blue dot”— a community group dedicated to making Avalon carbon neutral. “I’m an Australian who is so grateful for our health system but so ashamed of our environmental policy. I believe we have to make some radical changes if we are to leave the planet in reasonable condition for our children.”

And there’s listening to be done too. “People see you walking with a cane, see you vulnerable, so they open up about their issues. That allows decent conversations that are real. They allow me to listen to their story. The children, though, often find it a bit too much. Lucette says, ‘Mum, is there anyone you’re not going to make friends with as we walk down the road?’”

On her cheeky Insta account, Crackedintheconoconutclay, Brigitte quotes the famous US judge Ruth Bader Ginsberg, “If you want to be a true professional, you will do something to make life a little better for people less fortunate than you.”

Brigitte cares deeply about all those with brain injuries around the world who don’t have money, support and care.

“If I did anything noble in life, I’d want to raise awareness for all the world’s hidden victims.”

Brigitte anticipates she will always be on antidepressants.

“They give my brain the extra support it needs,” she says.

“It took four years to get from ‘Wish I was dead’ to choosing this life. But no education could give me all I’ve got from the accident, from having this second go at life.

“If you asked me which life I’d choose – I would say the second one.”



# Doug Merrick: still in fine voice

Doug is a Lifetime Care participant



Doug and his wife Helen were looking forward to a quiet retirement. Then Doug was hit by a car while out walking. The resulting brain injury has meant big changes for both of them.

We meet Doug and his wife Helen in their neat villa in Booker Bay, near Woy Woy on the Central Coast. A dignified couple, Doug and Helen have been married 55 years and moved to the Coast from their long-term family home at Mt Colah just over a year ago. “Helen always wanted to live near the water,” says Doug.

They had been in their new home only three weeks and were still getting to know their neighbourhood when they left their house for a walk. Doug, who had a long history of poor peripheral vision, was using a cane.

“We had only walked about 100 metres,” says Helen, “and I was just ahead of Doug when I heard him scream. I turned and saw that a car had backed out of a driveway and hit him.”

Doug fell heavily to the ground, hit his head and lost consciousness. In hospital he was diagnosed with a traumatic brain injury, a broken collar bone and broken ribs. The bones healed but the extent of Doug’s brain injury wasn’t known for some time.

“When he could express himself after a couple of weeks, he kept saying ‘Why have they got these black curtains around me’,” says Helen. “That’s the first time we realised something had gone very wrong with his eyesight.”

“I’d had poor peripheral vision since my 30s,” explains Doug. “It was due to some misguided treatments I’d had back then for my diabetes. And after that, some laser surgery to supposedly save my central vision. I call myself a medical misadventure!”

“But until the accident my sight was functionally okay. I could watch TV and go to the movies. I could walk by myself and I could navigate a computer screen and read emails. I only gave up driving in 2009 because I thought the poor peripheral vision made it unsafe.”

Further scans revealed damage in three of Doug’s brain lobes. He’s had two operations since, to relieve continued bleeding.

## On the railways

Doug had grown up in Hornsby. “My dad was a taxi-truck driver and I’d go out working with him helping load parcels, or kegs going to the local RSL. Dad died at 51 – he was a diabetic, and we now know he had a rare form of early-onset diabetes which I inherited.”

Doug left school when he was 15, did an apprenticeship in fitting and machining with the NSW Railways and studied for a certificate in engineering. He then worked with a company that imported maintenance equipment for the railways.

“My job was to demonstrate and operate the equipment for lifting and maintaining rail lines. We went all over the place with the machines – often to remote areas where we lived in rail vans. Even to Western Australia where I had to rebuild one of the machines.”

Doug and Helen met through their church when they were teenagers and married in 1966.

“ At one stage I was entering talent quests almost every day. And I won a few too. ”



“ When he could express himself after a couple of weeks, he kept saying ‘Why have they got these black curtains around me’. That’s the first time we realised something had gone very wrong with his eyesight. ”

Doug with his CD – “The Other Three Tenors”.

“After our marriage I got away from the tools,” says Doug. “We ran a service station, then I worked as a marketing engineer and in 1983 we bought a cleaning business.”

Doug and Helen have two sons and a daughter, now in their 40s and 50s, as well as ten grandchildren and two great grandchildren.

### Getting out to sing

Music has been a big part of Doug’s life.

“I was keen to learn to sing well, and in my 20s I did voice training with Joan Allen, a wonderful teacher and musician. Eventually she said to me ‘Darling you’re wasting your time here. Get out and sing!’.

“So I started competing in talent quests – singing classic ballads as a light baritone. At one stage I was entering these quests almost every day. And I won a few too. This was in the 60s and clubs were using talent quests as a form of entertainment. And I did a lot of amateur shows like ‘Jesus Christ Superstar’, ‘Showboat’, ‘Brigadoon’. I did these up until the late 80s when I got into professional cabarets.

“In 1990 I was asked to become part of a trio – ‘The Other Three Tenors’. For 16 years we did over 20 shows a year – operatic arias, ballads, songs from musicals – mainly in NSW and Queensland, in all the big clubs.”

### A different life

Doug and Helen are still coming to terms with their changed circumstances. Since the accident, Doug is effectively blind and relies a lot more on Helen. For someone who valued his independence he is finding that hard. “I can see shapes and movement, but really that’s it. I can’t go out by myself anymore.”

Doug is seeing a psychologist for depression and he also has regular visits with a speech pathologist and physiotherapist. “They encourage a lot of physical activity,” says Doug. “It’s good for the brain as well as the body.”

“We still do nice walks, maybe a couple of kilometres. But he needs to hang on to me,” says Helen. “But I did a walk with Darius from Vision Australia the other day,” responds Doug. “I walked without him having to touch me. That was a great inspiration.”

Doug is looking forward to returning to performing with another singer, Sue. They’ve worked together over the past five years, doing duets in retirement villages, clubs and churches.

“COVID has stopped things this year, but we’re looking forward to getting back to it soon. We get paid for doing them, but it’s also part of my therapy!”

“I’ve also got two lovely support workers who come twice a week. They take me to aquatherapy, sit with me when I do my exercises and we do trivia and crosswords together.”

icare and Vision Australia have provided Doug with a new voice-activated computer.

“I’m learning to use it, and learning to touch type too,” says Doug proudly reciting the layout of the keyboard.

“I try and be helpful as well. I get up earlier than Helen and I empty the dishwasher and take her a cup of Earl Grey tea. Then later I’ll collect her phone and iPad from the charger and carefully take them to her with another cup of tea.”

As Helen and Doug show us out, Doug bursts into a rousing farewell chorus from Puccini’s aria “Nessun Dorma” – and a passerby looks up from the street and smiles ...



# Bill Yu: I want my life to be fulfilling

Bill is a Lifetime Care participant



Bill was in his final year of school when an accident on his motorbike left him with a severe brain injury. But the accident and its impacts haven't dented Bill's buoyant spirit and enthusiasm for new opportunities.

Like most 21-year-olds, Bill Yu is indecisive about some things and decisive about others.

He's not sure whether his immediate future is about working or about studying. But he is sure about what he enjoys doing — he enjoys eating. His enjoyment isn't just about the food. It's part of a commitment to connecting with people and an interest in health and exercise.

Bill describes himself as chubby but lovable at school — hence his nickname, Panda. Now he's a striking young man with shoulder-length hair, a warm disposition and a ready laugh.

On Mother's Day 2018 while in year 12 at his school in northern Sydney, then 18-year-old Bill was on his way to his part-time job at Hungry Jack's when a driver knocked him off his motorbike. He sustained a severe brain injury and multiple fractures and was in intensive care at Westmead Hospital for three weeks followed by six months at Royal Rehab in Ryde.

Bill remembers nothing of the accident but distinguishes his time by food memories. At Westmead, he'd been put on a protein diet to put on weight, but his mum brought in enough food for several people.

"So I ate to feed a small family. The protein diet wasn't necessary for long. At Royal Rehab there was a choice, a menu — the food was great."

## Memory and confusion

Ongoing impacts of the accident have been memory problems and some confusion as well as concentration, mood and fatigue issues.

Bill lives with his parents, Delan and Li Fan, in leafy Cherrybrook in Sydney's northwest. His two older sisters have left home and he's now the sole focus of his mother's committed Chinese cooking. And parenting. "I was a good child. I ate by myself at age six. Now, I'd like to be more independent but Mum is Mum. She feels good about doing

things for me. I washed my sheets yesterday and she did them again today."

Bill reckons his parents don't want to accept that he has a brain injury, only that he's moody. They expect him to set his own goals and honour them. "Now I have a whiteboard in my room and I set my goals on it to motivate myself."

In 2020 Bill completed a TAFE course in Allied Health Assistance and is now doing a course in personal training. "I chose those courses because they're both beneficial for others. I'm now selling gym equipment in a local store. There are all sorts of ways to help others. You just need to be a good person."

"My boss sometimes gets frustrated if I can't do something, but then he writes the instructions on a whiteboard and it's fine."

## Volunteer work

Bill's commitment to helping others started with his school mates. In Vanuatu they built a classroom and painted the roof of a church. While there, Bill's contribution to a talent show was eating six bananas in two minutes. Back home, he and his mates also did volunteer work at

“I've shifted. Maybe it's growing up, maturing, maybe it's even because of having a brain injury— I no longer worry so much about what everyone is thinking.”



“ I see volunteering as a stepping stone that’s really great for social interaction, meeting other people and getting work experience. Those things can be tough after a brain injury. ”

*Bill with his dad Delan.*

the Buddhist Tzu Chi Temple and prepared meals for Vinnies’ vans. “In those days, volunteering was something fun. Now I see it as a stepping stone that’s really great for social interaction, meeting other people and getting work experience. Those things can be tough after a brain injury.”

At school Bill was keen on sport, particularly rugby and volleyball. He is still committed to working out and found not being able to go to the gym regularly one of the biggest challenges of the COVID lockdown.

But there were also lockdown pluses. At school, Bill had found public speaking terrifying but recently he presented online as part of a webinar on brain injury through Liverpool Hospital (see more on page 11). He’d like to do more public speaking to motivate others. “I’ve shifted. Maybe it’s growing up, maturing, maybe it’s even because of having a brain injury— I no longer worry so much about what everyone is thinking. I just focus on my presentation and its impact.”

Bill participated in the Cerebral Palsy Alliance’s Challenger program for young adults with a disability. The course is designed to empower participants in developing skills they need to live their best life. Bill says that on the course he found “his” people — friends his own age who understand.

“My old schoolfriends – not all of them get me and that’s frustrating. They feel sympathetic but they don’t really see me. Friends from the program do. People on the Challenger course give you a sense of community and even though everyone’s accident or issue is different, there’s a semblance of similarity. We just understand each other on a different level. We get it. We understand if someone says something weird.”

### Being there for each other

Since the program, Bill and some of his new friends have formed a Facebook group currently called ABIG or Australian Brain Injury Group. Bill’s very keen to establish a forum in which those who know what it’s like to live with a brain injury can share ideas, socialise, be there for one another.

Bill and his co-founder, Ben, would like ABIG to have a bigger footprint than just Facebook, with funding to allow them to arrange entertainment and gatherings, as well as to encourage and support one another. He’s giving one of the members guidance in job interview techniques. “After all, I did a Certificate in Mental Health and I might as well use it.”

Bill’s parents speak Mandarin to him and he mostly speaks English in reply. He recently made an Italian lasagne and a Latin American dulce de leche cake, which he describes enthusiastically as “a three-milk cake, perfect for summer, not too sweet, cold. It worked amazingly.” Experimenting with Italian cuisine in contrast to his mum’s Chinese cooking may be Bill’s statement of independence.

He’s still tossing up between studying further and finding a job that’s about working with people, “but also with downtime as I don’t like too much interaction. I like time to myself.”

Bill also wants to get his driver licence so he can be more independent.

“I don’t want an easy future. I want it to be fulfilling. It doesn’t really matter what I do but who I do it with.”



# Kim Grunsell: WTF! – my evolving chaos

Kim is in the Workers Care Program



Kim has written her own story detailing her insights into the many layers of her brain injury.

All of us with brain injury have a horror story about the incidents that got us there in the first place. Our stories – the impact on our loved ones, our struggles, our courage, our defiance to walk, talk, think, and do – are the stuff of inspirational movies and novels. However, living and experiencing it is a long way from understanding it.

It's nearly four years now since my accident and it's only now that I am able to reflect on my journey, and not because of its traumatic nature. In rehab, I had been warned my life was going to be different. I thought I had a few broken bones, I had trouble finding my words and my focus was all over the place. I really thought this was the “different” they were talking about. I was OK with my defects, as I called them, and thought they were reasonable considering what I had gone through.

I knew from the beginning that something was “off”, I just had no clue what it was. From there it was a slow, drawn-out progression downhill into a world void of all logic. A vacant, distant, disconnected, uncoordinated, messy, chaotic place I had no control over. One day I was in a world I used to function in and be a part of. The next, I am an alien in a world I have absolutely no connection with.

## **A bespoke brand of weird**

When I talk with my brain-injured fraternity, we discuss our bespoke brand of weird in order to understand or comprehend what is happening to us. “Do you do this?”, “Does this happen to you?” I suppose we do that because we are trying to get a grip on some sort of normality, even if it's only normal in our world.

The labels and words used to describe the cognitive effects of my brain injury include speed of thought, memory, understanding, concentration, solving problems and using language. Although accurate, these labels lack the perspective, context and depth needed to get a true indication of the absolute manic, bizarre, weird, illogical place my head, my world had become.

## **What lies beneath**

The acceptable definition of my situation in your world would be a “silent disability”. In my world, my chaos, it's my pile of “WTF”. It's when I know there is something wrong and can't put my finger on it. I can't ask for help, as I have no clue what the problem is. It could take days, weeks, months and years to figure out exactly what the issue is, and only then am I able to deal with it.

How is it that I don't know, until I know I don't know? I didn't know I couldn't find my words until I couldn't find them. I didn't know I couldn't type until I couldn't. I didn't know I couldn't “imagine” when I'm trying to learn or comprehend. I didn't know I had to learn how to separate the noises in a room. I didn't know I had to learn how to have a

“ People's perceptions of me are tainted, uneducated, confusing and flat-out wrong. I am still figuring out the best way to deal with that. ”





“ It was a slow, drawn-out progression downhill into a world void of all logic. A vacant, distant, disconnected, uncoordinated, messy, chaotic place I had no control over. ”

conversation and interact. I didn't know I had to learn how to focus. Only a month ago I realised I didn't know I had to re-learn the process of thinking. How do I explain, comprehend and process that? I can't hold a normal conversation because nothing in my life is normal.

In your world the measurement of success is measured at the finish line. In my world, it's all about the incremental steps in just getting there.

### **Where's the line drawn?**

Ignorance and apathy shatter confidence and retard independence. My lack of confidence leads others to not have confidence in me. It hinders progress, creating a barrier for others to understand, empathise, evaluate, be patient, and interact with me.

The flow-on effects cascade into more drama. My learning path is complex, unconventional, time consuming, and evolving. It has become easier and more cost effective to place me in menial positions rather than put the extra time and effort into me in order to be the best I can be.

At what point do I concede to my limitations and not try and learn to adapt to them? At what point do I accept others' ignorance or apathy limiting me, belittling me, suggesting

I'll never be good enough or this is the best I can do? Is it acceptable to get paid off and discarded because I'm too hard? Exactly how hard is too hard? Or am I simply inconvenient? In my other world I was someone's solution, in this world I'm someone's problem. I'm not comfortable not being the very best I can be. I'm even less comfortable when other people decide this is the best I can do. This isn't something I can do alone. It really is going to take a village.

### **How hard can it be?**

Every day I try and get better. I do my exercises, I do puzzles and learn new words and try to articulate. I try and engage in conversation. I evaluate all aspects of my life in order to regain structure, purpose, confidence and acceptance. But people's perceptions of me are tainted, uneducated, confusing and flat-out wrong. I am still figuring out the best way to deal with that.

Who works this hard on trying to get better with no results? Nothing is resolved. Rather than a work in progress, it's more like a work in turmoil. I have to laugh when I read information stating, "Traumatic Brain Injury patients often suffer depression, anxiety, and can be aggressive and frustrated". ... Dude! Seriously?

### **Navigating darkness**

How can you navigate anything unless you can see or understand what's in front of you? My brain has been navigating in darkness unable to communicate, comprehend or process until now. Though its light is dim my brain has switched on. The mere fact that I have recognised, articulated, described and conversed says volumes - and I know it!

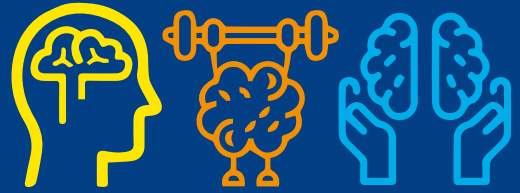
It's the beginning of some form of normal, although exactly what sort of normal I still don't know. All I know is it's taken me nearly four years to get here and I have just realised I'm only getting started.

Whoa ... WTF!

“ I knew from the beginning that something was off. I just had no clue what it was. ”



# Brain Injury Awareness Week



Brain Injury Awareness Week is a national event that raises awareness of brain injury. Often a journey of challenges and triumphs. To recognise and celebrate the people we support with brain injury we hosted a panel event. Meet the team here.



## Tristan

30, from Blacktown  
Collided with a truck while riding his trail bike in 2007

### Biggest challenges

It can be hard to meet people. I try to accept how I am and move on. I've got to live my life the way I am. Sometimes people stare at me and that annoys me. I'm taking on the challenges. I'm not happy the accident happened but I'm happy with the outcome and how my life is turning out, it could have been a lot different.

### Proudest moments

I'm proud I'm still here. I'm back playing footy. I'm growing a garden and I have a son. I love the talks we do to the public; I like helping people. I've accepted that I'm me as me and I'm happy.

### Advice for people

Don't stare at me if you see me down the street. I'm me, come have a chat. I like meeting people, but it can be hard meeting new people.

### Mates

I love these other three blokes - brain injuries stick together!

### What's in the future

Just living life, the one I was supposed to live. I want to do more of the speaking events and share my story and help others. I love them, I get really inspired doing them.



## Hemu

20, from Shalvey  
Pedestrian hit by a bus in 2019

### Biggest challenges

I don't look like I have an injury. Not many people around me know about brain injuries. I need to stick up for myself. Sometimes the way I react to things is hard and my old and new life often don't mix well. I'm a lot angrier than I was before. Understanding my reactions is hard, not knowing if I'm reacting a certain way because of my brain injury. I'm still young, and immaturity and brain injury can get in the way of each other. Sleep is much harder now.

### Proudest moments

I'm a proud person. I'm proud of the bounce back I've made and how far I've made it, from not being able to talk, to learning to drive again, to go to the gym and to work. That I can wake up every morning, make my own bed, drive to work - I'm proud I can do these things and the work I've done to get back.

### Advice for people

Don't feel sorry for me, don't dwell on my injury, or treat me like a little kid. Not everyone knows how to act, just be considerate. Be a nice person - it's not hard to be a nice person.

### Mates

It's been so good meeting Bill, Tristan and Jon. Jon and Tristan were the first people I met with a brain injury - it had such a strong impact on me. Listening to their talks made me realise I needed help and needed my therapists.

### What's in the future

I want to get my licence and take myself to work. I want to drive by myself. I'm keen to study and try out nursing as a career.

### People with a brain injury

**59%** Workers Care

**75%** Lifetime Care

## The “Fab Four”

Brain injuries are as individual as people, their impact varies. To highlight the uniqueness of brain injuries we held a presentation with four speakers with lived experience from Lifetime Care and Workers Care. The “Fab Four” as they were coined, shared their stories of life since brain injury. They entertained and captivated the crowd and we’re told it was better than watching anything on Netflix.

Watch them [here](#).



## The facilitator, Melanie Moses

We’d like to thank Melanie for bringing this event to life.

As a speech pathologist Melanie’s been working with our Fab Four on communication issues. Melanie describes the talking events the group do as “the best real life therapy”.



## Jon

41, from Griffith  
Car accident while driving to work in 1999

### Biggest challenges

Friendships, family, relationships, and work colleagues have come and gone. I’ve had to leave old friends behind to remove bad influences. I can’t remember my childhood. Living with a brain injury has been hard, it’s a challenge in my everyday life – even the small things like making my bed in the morning.

### Proudest moments

Giving back to the community. I just love it. The Griffith community has given me everything I have ever wanted, except for the surf coming in! After doing the brain injury presentations to young people, I go home and think I could have saved a life – it makes me feel proud.

### Advice for people

Everyone can tell I’ve had a brain injury because of my delayed speech. I often make a joke about my injury and that I forget things. People’s reactions sometimes hurt but I’ve learnt to not take it personally. I like meeting new people and having a chat. Just treat me like anyone else and understand I may forget things.

### Mates

I’ve thrived meeting these three. I love talking to people who’ve been in my situation. My injury was years ago, and I like to help people with what they’re going through. We help each other not to give up, I’m never giving up.

### What’s in the future

I’ll keep fighting. I want to keep doing my volunteer work. Just keep going along the road I’m travelling on now.



## Bill

21, from Cherrybrook  
Motorbike collision in 2018

### Biggest challenges

Coming to terms with my injury, recognising I have these issues. In the beginning I drove away all my therapy team, I didn’t want or need help. I didn’t understand what I needed and why it was important. Allowing time to recover and understand wasn’t easy but it’s made a big difference.

### Proudest moments

I’m proud that I’ve been able to study and finish a course. I’ve always hated study and had issues with it, but after a year of challenges I found study very rewarding. I’ve made some great new habits, I go to the gym a lot and getting work has been great. Doing the CPA Challenger program and starting my own Facebook group to connect with people with brain injuries across Australia.

### Advice for people

Accept people with brain injuries, accept me and get to understand me. I might say random things, I might say weird stuff, that’s who I am now, that’s me. I’m not going to change to fit someone else’s needs. This is me and that’s cool.

### Mates

My spark came back from meeting Tristan, Jon and Hemu. We have a laugh with each other and “get” each other.

### What’s in the future

I want to study something I really enjoy and appreciate. I’m interested in food and nutrition and I just want to do things I genuinely enjoy.

# Tom Hawthorne: moving onwards and upwards

Tom is a Lifetime Care participant



Four years ago Tom survived a head-on car accident. He is still living with the ongoing effects of his brain injury but is determined to make his life a good one.

When *Shine* meets Tom in his share flat in the Newcastle suburb of Merewether, the books for his wine course are open on the kitchen table and he's just finishing a call with his mum who's been giving him some tips for our interview. Not that the polite, confident 24-year-old is nervous.

Tom grew up in Armidale, the second of six kids in a close-knit family. He went to O'Connor Catholic College where his dad Jon was a senior teacher. "I always felt I was part of a big, interconnected parish community," he says. "A big supportive network."

When he was 16, Tom's dad took him and two of his siblings for a holiday to Calgary in Canada to see family friends.

“There's a missing 11 months in my memory. I don't remember anything in the three months before the accident or eight months after.”

"I fell in love with the area, particularly nearby Banff with all its natural beauty and outdoor activities. I decided I wanted to come back after school and work at the famous Fairmont Banff Springs Hotel. When we got back to Armidale, I got a job in a luxury hotel to get experience."

## Gap years

On finishing his HSC, Tom took off to Canada to follow his dream. He did get the job he'd wanted at the Banff hotel and stayed there 18 months before driving across Canada and then backpacking through South America.

"My mum was upset with me - a typical 20-year-old who wouldn't come home for a second Christmas - but I had already decided to make a surprise return. I arrived back on Christmas Eve 2017."

On Christmas Day the whole family had a picnic at a nearby swimming hole. Afterwards Tom decided to drive back into town on his own.

"I must have turned onto the wrong side of the road, driven for a couple of kilometres, then turned a blind corner and straight into a Landcruiser.

"My car folded in half like a tin can, my face broke the steering wheel, and I had to be cut out. There's a missing 11 months in my memory. I don't remember anything in the three months before the accident or eight months after. So, in a way, I missed all the trauma. My family, of course, had to go through it."

Tom was in a coma for a week in Newcastle's John Hunter Hospital and doctors told his family he might not survive and, if he did, he would be living with the effects of a serious brain injury.

"It was particularly hard on my elder sister who was an intern in the hospital when I arrived."

Tom admits he can be a bit brutal and insensitive in telling the story of his accident and its aftermath. "Partly it's my way of coping, but also they aren't actually my memories - they're synthetic memories, those of the people around me.

"I was four months all-up in the hospital and brain injury clinic. I had my 21st in there. From my experience, you don't get better unless you want to. You need the drive to do the physio and all the allied health stuff. Luckily I'm young and had the tools to do that. And I think my fitness and my travelling gave me some of those tools. All the '... ists' - speechies, psychologists etc - are inspirational mentors but I reckon 50 percent of recovery is yourself, 50 percent your supports."



*Tom in hospital with his family.*

“When I left John Hunter in April 2018, I had only a small scar over one eye and a scar on my knee, but still had lots of issues resulting from the brain injury – a right side weakness and limp, double vision, a lot of fatigue and short-term memory issues.

### **Into hospitality**

Two friends, including a Canadian roommate, asked Tom to join them in a trip to New Zealand that October. “So I used that as a goal and kept up the physio and the exercise.” Tom went to New Zealand. And although doctors had told him that he was a seizure risk, he did more than 100 km of alpine hiking. And sky-diving. And hang-gliding.

“I only told my parents afterwards.”

Instead of taking up a deferred place studying psychology at the University of Newcastle, Tom started a TAFE Certificate III in hospitality.

He completed the Cert III and then a diploma in hospitality management. He also got a job at the Newcastle Club, a high-end club where he does bar and barista work, a la carte service and big functions.

“I didn’t tell them at first about my brain injury, although my managers know about it now. Although there’s nothing obvious that gives my injury away, I’ve got routines to deal with my memory problems,



*Working in the Fairmont Banff Springs Hotel.*

like always using a notepad, and I’m also always working on my communication behaviour. Sometimes I can speak for too long on one topic and I know it’s a fine line between being too attentive or not enough.

“But I love it. I’ve been there 18 months now. It’s a wonderful place to work.”

Tom is studying to be a sommelier through the globally recognised WSET qualification system. He’s had to do some of the classes online, which he finds hard given there is no human interaction and he can’t ask questions.

### **Goals for recovery**

“Hospitality is my passion. But to go further, to go into high-end hospitality I need to have more resources, more tools. Becoming a sommelier – doing formal study in wine and wine service – is part of that.”

Late this year Tom was awarded a scholarship by TAFE to use in further study or training. He wants to use this for additional wine study, possibly in New Zealand.

Tom sets himself lots of goals. He sees them as important checkpoints for recovery. His family is involved in the South West Rocks Running Festival and in 2018 he ran the 5 km race. The next year he increased it to 10 km, and this year he did the half marathon.

“ From my experience, you don’t get better unless you want to. You need the drive to do the physio and all the allied health stuff. ”

“One of the ongoing physical effects of my injury was double vision which led to really bad fatigue. I had surgery about a year ago which has fixed most of it. Now I only get the double vision when I look down, and I don’t get tired nearly as much.

“I don’t drink alcohol now – except for wine tasting. I got frightened seeing people with dependencies, and with brain injury you are very susceptible to dependency.

“I’ve still got memory issues, and my behaviour has different filters from most people. One symptom is impulsivity – I sometimes say quirky things and don’t always read a situation appropriately.

“But then the impulsivity sometimes works in my favour in meeting people. And also I’m now more aware of the impermanence of things – I believe you’ve just got to go for it.”



# Stuart Jones: finding the silver linings

Stuart is a Lifetime Care participant



Stuart was an active cyclist with a good job and a comfortable life. Since an accident left him with a spinal cord injury, he has come to value the opportunities his changed life have brought.

When Stuart Jones welcomes *Shine* into his unit in the Sydney suburb of Harris Park there is a ruckus of pigeons cooing from his veranda. Stuart has only recently returned home following his dream of competing at the Tokyo Paralympics. With training camps in Queensland before the Games and two weeks quarantine following them, he was away for three months. In that time the pigeons set up a nest on the veranda, laid eggs and started raising their young. So the pigeons are the constant backdrop for our interview. "I've got to let them stay until the chicks are gone", says Stuart apologetically.

"I grew up in Brisbane, one of four kids. My dad was a science teacher and my mum had worked as a primary school teacher.

"I went to a very sporting high school which I loved but I wasn't very interested in the academic side so I never felt school was really for me and I didn't apply myself. Because my marks weren't that good I thought it meant I wasn't particularly bright.

"I joined the army straight after school - it was perfect for me at that time - physical and active. I started off in the infantry and later moved to the military police."

Six years later, however, Stuart was medically discharged due to a bulging disc in his back.

"I was a single dad at that stage and needed a new career. It was the 1990s and computers were taking off." Stuart did a degree in information technology (IT) in Brisbane and moved to Wollongong for a job in IT support with BHP.

"I stayed in that job for 15 years. It was comfortable and I got paid well, but in the last few years I thought there must be more to life than just making computers run."

## On the bike

Stuart met his partner Sandra, a police detective, in 2009. When she got a transfer to Singleton they moved to the nearby town of Greta and he continued in his IT job, transferring to Newcastle to monitor software rollouts for BHP.

Stuart had taken up cycling for fun in Wollongong. "When we moved to the Hunter Valley I still only had a \$900 Malvern Star, but I joined a mate riding into work - 45km door to door. I took the bike home on the train at first, but soon I was cycling home as well. I even extended my ride to make it 100km for the day."



“ If you have a spinal cord injury, life doesn't end. There's still lots you can get out of it - you've just got to look for that silver lining. ”



“ It took me about three years after the accident to accept what had happened to me. I was trying to be who I was before – the pre-accident Stuart. ”

Stuart with his cycling medals.

“In 2013 I took up a challenge to ride the most kilometres in a year – by that stage I had a lightweight titanium bike – and managed to clock more than 13,000 km. I used to joke that work was rest between bike rides!”

Later in 2013 Stuart started racing with a cycle club in Newcastle. “I really enjoyed it and was moving up the grades.” But on 16 January the following year, Stuart’s life was turned upside down.

“That day I was commuting along the highway into work. The last thing I remember was Sandra saying ‘Be safe’ as I left home, and me replying ‘Always’.”

On a slight rise Stuart swerved to miss an unregistered car parked in the cycle lane but caught the rear indicator and was thrown into the path of a Landcruiser travelling at 90kph.

“That’s where the journey started. I was really lucky – the ambos reckoned my helmet saved my life. I was in Royal North Shore for a month and then Royal Rehab at Ryde for another two. At first the doctors told Sandra I would never be able to walk as my right side was totally paralysed due to fractures of my C5/6 vertebrae.

“But I never doubted that I’d learn to walk again. At about three weeks I started getting tingling in two of my right toes.

Each morning I tried to move a bit more. I did a lot with the physios, starting with stand-and-sit, and slowly progressing to the parallel bars. I’d keep upping the numbers. They called me ‘Rain Man’ because of my obsession with the figures.”

The idea of para-cycling came to Stuart while he was in rehab.

“I saw someone ride past on a recumbent tricycle and I thought ‘I can do that’. At that stage I was on walking sticks and in a neck brace but I hassled the rehab sports guys and soon I was on a trike too. They said I was the first client to ride outside the hospital grounds. That’s how I got back into cycling.”

### Accepting the new me

Stuart’s physical condition hasn’t progressed significantly since he left rehab seven years ago.

“I’ve lost the fine motor skills in my right hand and I walk with a limp. And there are other things that people don’t see – the body spasms that cause fatigue, and the constant nerve pain in my left leg. I’ve made a choice not to use drugs for the pain, but to try and live with it.

“It took me about three years after the accident to accept what had happened to me. I was trying to be who I was before – the pre-accident Stuart. That’s where my psychologists

have helped. While I hate what’s happened to me, I know now that it’s not going to change. I’ve got to accept, for instance, that I can’t open a can easily and not get frustrated.

“The hard bit was that it happened to me later in life. Forty-five years of being ‘normal’ and then suddenly my life gets turned on its head. So I’ve come to be grateful for things that have come my way as a result. It’s also taught me different perspectives about what’s important. It’s often the small things in life that count.”

### icare support

Stuart remains very appreciative of icare’s help in his journey.

“I think it’s a brilliant system. It’s given me independence. They helped with modifications for our home in Greta. The biggest thing for me now is psychological support. I’ve really needed that every two or three weeks for six years. I could never have afforded it myself. I haven’t needed it for the last 18 months, but I know it’s there as a safety net if I hit a low.”

Stuart took a redundancy from his employer in 2016 – “I was over IT” – and started a law degree which he finished at the end of last year. He is thinking of working in family or sports law.

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Stuart was classified as a T2 cyclist for official para-cycling events. His vehicle is a trike with two wheels at the back and one in front. He started with long-distance events and charity rides, having lots of falls, building up his strength and confidence, and losing weight. "Every race where I don't crash is a good race for me!" he smiles.

In 2017 he entered the Nationals and won both the time trial and the road race. The following year he competed with the Australian Paralympic cycling team at a World Cup in Belgium coming fifth in the time trial and second in the road race. "It proved to me that I could be competitive on the world stage."

Over the next two years Stuart competed at a number of international meets. In 2019 he won a silver medal in the time trial at the World Champs in the Netherlands. But for Stuart all the events were a leadup to the biggest of them all – the 2020 Paralympics in Tokyo. When COVID forced their cancellation, "I felt everything had been suddenly taken away from me".

“ Every race where I don't crash is a good race for me! ”

*Stuart (left) at the 2019 World Championships.*

2020 was a big year in other ways. His relationship with Sandra broke up and he moved to Sydney to be closer to his two boys, Ashley and Cooper. "The NSW Institute for Sport offered me a scholarship, so moving to Sydney turned out to be the best thing for my cycling as well."

### Unfinished business

When the Tokyo Paralympics were rescheduled for 2021 Stuart was selected in the Australian team.

"It was very competitive. There are only seven slots for all classes in the men's para-cycling team."

But Stuart was disappointed with his results. A slipped chain on the final straight in the time trial cost him a medal, and in the road race in wet conditions he found himself in ninth place and well behind the pace.

Then something happened that made world news.

The women's road race was being run concurrently with the men's. Stuart cycled past South African cyclist Toni Mould, a lap behind the field and doing it tough.

"I knew who Toni was and by that stage I knew that I was only going to get a minor place. I saw she was struggling, so I stayed with her for the last three kilometres encouraging her all the way to the finish line. I thought that's what Paralympics are about – overcoming adversity."

Stuart feels he's got unfinished business. He'd love to get a world title and hopes to get to the Paris Paralympics in 2024.

"I have a limited window for this cycling caper – five to ten years max. So I want to make the most of it. The silver lining from my accident is that I'd never have got to an elite athletics level without it.

"If you have a spinal cord injury, life doesn't end. There's still lots you can get out of it – you've just got to look for that silver lining."



*Twitter fame. Stuart urges on South African Toni Mould at the Paralympics.*



# Synapse launches the BrainBank Podcast

SYNAPSE



*Dr Zara Weedon and Marie Carroll.*

**Synapse, one of Australia's leading brain injury organisations has launched the BrainBank Podcast to explore the key issues for people impacted by brain injury.**

From tough topics to diverse perspectives, the BrainBank Podcast presents an inside view on what it means to have a brain injury. Created for people with a brain injury, as well as their families, carers and community support people, the podcast shares the ups and downs and the lessons learned along the way.

Join host Dr Zara Weedon and her guests as they explore and navigate life after a brain injury.

## Episode 1



### **When brain injury strikes, who cares for the carer?**

Marie Carroll discusses her experiences caring for her son who lives with a brain injury.

## Episode 2



### **Making the impossible "possible" after brain injury**

Katherine Varley discusses pursuing goals and building a new life after brain injury.

## Episode 3



### **Finding friendship after brain injury**

Jayden Alexanderson discusses finding new friendships and hobbies after brain injury.

## Episode 4



### **You only stop improving when you stop trying**


Sandy Denison shares insights from her experience as Nurse Unit Manager of a brain injury rehab facility.

## Episode 5



### **Where there's loss there's grief**

Kathy Walls is a clinical specialist and an expert in supporting families through the emotional upheaval of brain injury.

 Listen [here](#).

## **The BrainBank Panel**

Synapse also recently launched the BrainBank Panel, a new approach to sharing experiences and creating change for people impacted by brain injury.

The BrainBank Panel achieves this by offering practical encouragement and motivation to individuals and families impacted by brain injury as they navigate the brain injury journey - building resilience, confidence and hope.

The panel is made up of people who either have a brain injury or care for someone who does. It's a free, one-on-one service where you can speak to the panellist you relate to the most.

### **How can you connect with a panellist?**

Visit the BrainBank Panel page on the Synapse website to learn more and submit an enquiry or call 1800 673 074 and ask about the BrainBank Panel.

[synapse.org.au/brainbankpanel](https://synapse.org.au/brainbankpanel)

# The notice board

Sharing your news highlights, handy information and upcoming events.



## National Assistance Card – people with brain injury

This is a personalised card to assist people with brain injury to be more independent and feel more confident in the community.

The card supports cardholders to communicate the impacts of their brain injury and any assistance they need.

The card:

- is personalised for each user
- has information that helps communicate the impacts of the brain injury
- includes the cardholder's nominated contact person's details.

### Interested?

Fill in an Expression of Interest Form on the National Assistance Card website [here](#).

## Prosthetics guidance

In October we released a guidance to better support and understand the needs of people with prosthetics, and limb amputation.

The guidance explores the pathway for people who have experienced limb amputation following injury. It provides information on best practice, resources, and recommendations, in an easy-to-use format. It's designed for everyone involved in the pathway following an amputation.

A working party of 23 experts including those with lived experience, met for a total of 28 hours over 10 months to develop the guidance.

To find out more [visit](#).



## Loop+ – an activity tracker for your bum!

We're proud to be working with and supporting loop+ in the development and rollout of their activity tracker for wheelchair users.

Loop+ continuously records your body's seated movement and position to understand your activities and risks. It's designed to give you confidence in your seated position and pressure management, helping you understand your habits and their impact.

To find out more [visit](#).



## Ageing with an injury

Our population is ageing, and it's important we meet everyone's injury needs as they age.

16% of people in Lifetime Care and 23% of people in Workers Care are aged over 65 years.

We are keen to support older people to maintain their independence, health, and wellbeing as they age.

So we've established an ageing working group and a range of activities to better understand the needs of people ageing with severe injuries.

### Your feedback

We asked a research provider to interview a sample of older people, their family and carers. Eighteen people aged 55 to over 75 years, with different injuries and locations, were interviewed by the research team.



In Lifetime Care **16%** are over 65 years

In Workers Care **23%** are over 65 years

Research showed:

- older participants and workers generally felt well-supported by icare
- most felt confident icare will be there for them to meet their longer-term needs
- people value their independence and want to remain in their own home as they age
- more information is needed about the aged care system and processes.

Helpful strategies to support people planning for their future included:

- maintaining health and wellbeing in the present, and
- keeping active, and engaged within local communities and in activities people enjoy.

### A big thank you ...

... to everyone who participated in our interviews. Your feedback is helping us develop resources and supports to improve recovery and outcomes for older people after a severe injury.



## International Day of People with Disability

### Growing a more inclusive Australia

The International Day of People with Disability is held on 3 December each year. It hopes to increase awareness, understanding and acceptance of people with disability.

Here's a handful of activities we've come across this year:

- stories about Australians with lived experience of disability [here](#)
- videos that celebrate Australians with lived experience of disability [here](#)

On the ABC:

- bop away with a Spotify playlist featuring artists with disability
- check-out Re-Frame – short films made by people with disability.

Find them all on the ABC [here](#).

## Interact-ABI-lity

### Learn how to interact with people who have a brain injury

Interact-ABI-lity is an online program for family members, friends, support workers, and professionals working in brain injury. It was developed by the University of Sydney, University of Technology Sydney and Brain Injury Australia, funded by icare.

You get to:

- hear from people with a brain injury and their family members
- learn about communication changes
- learn how to support people with their communication
- gain a certificate of course completion.

Sign up [here](#).



For more information, contact Rachael Rietdijk

[Email](#)

Ph: **02 9351 9685**

# Support for families and carers



Jess and family.

## The Carers Way Ahead

### Managing challenging behaviours in your person with brain injury.

The Carers Way Ahead is a free online program provided by the

University of New South Wales and funded by icare. It offers support for families who are managing challenging behaviours in a person with a brain injury. It's a step-by-step program teaching families how to manage challenging behaviour in the home.

The program offers a series of online modules on common issues, such as understanding triggers and consequences of behaviour, low motivation and apathy, irritation and aggression, and self-care.

Each module provides information and strategies for dealing with the challenging behaviours people may experience following a brain injury.

### Take part

We're inviting families of participants with challenging behaviours to take part in a pilot of the online program. Support is provided to the family member to work through the program.

Contact Kim Wallis:

[Email.](#)

Ph: **02 9385 3310**

[Website.](#)



## Taking care of you - how the wecare program can help

We celebrated and recognised National Carers Week this year with a tribute to Jess Emeny. Jess wrote her own story for *Shine* back in June "Sister, daughter, young carer - her own person". She talked about her journey as a young carer, and how the wecare program helped her find herself again and improve relationships with her family.

Jess's story is now available as a video [here](#).

Caring for a family member can be very rewarding, but it also has its challenges. Carers are more likely than other Australians to experience a range of health and wellbeing issues, and many don't access the support they need.

If you feel like you need some additional help to take care of yourself, why not talk to the wecare team. They'll be able to chat with you about what options might work for you and they'll work with you to develop a plan that fits around your schedule. There are a range of services and supports available.

Contact the wecare team:

[Email.](#)

Ph: **02 9280 4744**

[Website.](#)

icare acknowledges the Gadigal and Wangal Clans of the Eora Nation and the Gayemagal Clan of the Kuring-gai Nation as traditional owners of the land on which *Shine* was created.

## We'd love to hear from you!

Would you like to share your story or news in *Shine*?

Email [shine@icare.nsw.gov.au](mailto:shine@icare.nsw.gov.au) or call **1300 738 586**.

SCAN ME



## Shine online

Scan the QR code to view the online edition or click [here](#).

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Insurance and Care NSW