

Mother and carer Meet Tanya and Karen, each caring for a son living with brain injury, pages 16 & 17

Shine

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

Summer 2022

Gabby Vassallo: still on her bike

Gabby is a Lifetime Care participant



Gabby on Rosie watching the Olympic cycling.

When she was growing up, Gabby's parents taught her to look after herself and to create her own opportunities. Now, more than a decade on from the accident that changed her life, she values those lessons more than ever.

Gabby's dad showed her and her 3 siblings how to change a tyre – even in a tight spot. Her parents wanted to ensure that their children would all grow up with a can-do attitude. It's a maxim that still underpins everything that 48-year-old Gabby tackles.

Fiercely independent, Gabby has always been determined to have the opportunity to achieve things just like everyone else.

Her own team

Her brother played AFL so Gabby did too. But at 9 she had to stop because there was no mixed comp.

When she later took up swimming and joined Cronulla Surf Lifesaving Club there was only a men's row boat team. So Gabby started a women's one. "I've always felt that we shouldn't have barriers, and I now apply that to my attitude as a person with a disability."

"Society sometimes looks at you as though you can't do things but I'm determined not to accept things as they are - to at least have a go at changing things." After an AFL injury, a physio told Gabby that while she couldn't swim until her knee was healed, she could cycle. And there began a love of all things bicycle so that, even now, her sunny apartment features a bicycle clock and bike pedals for hooks in the hallway.

After working in a variety of admin jobs for most of her 20s, Gabby moved to Italy for 8 months and then to England to work with her brother and sister-in-law in a pub in Oxford. She continued cycling wherever she was, even when it was cold and visibility was down to 50m.

In England, a friend suggested Gabby join her on a cycling tour of the Pyrenees. For 8 days they were based in a small French village, riding out each day in a new direction.

"It was a great way to see the countryside, meet people, smell the fragrances. Language never seemed a barrier." In 2008, Gabby returned home and took a job with the NSW Police, cycling the 57km round trip from Loftus to Surry Hills.

"Riding to work is a great way to start each day – you really hit the ground running."

BC and AD

Gabby set her sights on doing a long-distance triathlon, organising a coach to help her train for the 4km swim, 180km cycle and then 42km marathon. But in August 2009, Gabby was riding along Southern Cross Drive when a car drifted onto the shoulder of the road and hit her. Diagnosed with a traumatic brain injury, she spent nearly 2 months at St Vincent's Hospital before transferring to the Liverpool Brain Injury Unit.

Gabby now divides her life into BC/AD, or Before Crash and After Detour – that's how she now sees her accident – a detour in her life. Because she doesn't remember it, she says the accident hasn't affected her enthusiasm for cycling.

"It's still as strong as ever," she says. "It makes me feel free."

I still cycle - not as far, but with the same joy of it. Joy of the camaraderie you share with other riders and people saying hello as they ride by.





I've always felt that we shouldn't have barriers, and I now apply that to my attitude as a person with a disability.

Gabby has taken up painting.

Gabby can walk short distances but uses a wheelchair in busy places or when she needs to stand or walk for long periods.

"But I still cycle – not as far, but with the same joy of it. Joy of the camaraderie you share with other riders and people saying hello as they ride by."

She's also taken up art. Using her left hand, instead of her weaker right, she paints with a skill that belies the fact that she hasn't been doing it all her life. Her paintings of a stone staircase in Italy, a field of flowers in France and many more hang in her apartment.

Feeling valued

She confesses to having been a workaholic but now says she's better paced. Her goal is to do what BC Gabby did even if things have to be modified.

AD Gabby still swims, but now uses fins which once she considered "cheating".

AD Gabby still plays team sport - but now it's wheelchair basketball.

AD Gabby still drives - but is tested every year to renew her licence and won't drive now if she's not feeling great.

AD Gabby still cooks – a passion her mother generated – but she has a pullout kitchen bench at sitting height for days when fatigue sets in.

Her sense of independence means that Gabby asks for help only if she's short of time or something is beyond her. "You need the right support network. People know I'll ask for help if I need it. Clinicians, friends, family — they are Team Gabby and I know they're there."

In 2019, to mark the 10th anniversary of her accident, Gabby rode in the Pyrenees again – this time on her tricycle, Racing Rosie. Radiating out from the same French village she set off from many years ago, she tackled the climbs and challenging twists and turns with only a support rider behind her.

"It was even more wonderful than I'd hoped."

For road riding, she now uses Nemo – named for being mostly orange. When Gabby meets friends for regular catchups in local coffee shops, blokes often stop to check out Nemo's trike conversion. Gabby enjoys asking: "Are you stickybeaking my rear end?"

Her independence

She's now working for a disability support provider – mostly from home.

"How good is it to be paid for work you enjoy! I feel I'm valued and I don't stand out. I understand the people we work for - my people, my tribe."

"Disability is isolating. Those work and sports connections make all the difference. When you're with other disabled riders, you feel normal. It's great not to stand out." Gabby is determined to ensure people with a disability are visible. If there's any discrimination, she speaks out. "I now see how much society comes from a place of ignorance and thoughtlessness, so it's worth speaking up to

make people aware." During her rehab in 2009, mates put up an enlarged photo in Gabby's hospital room of her on her first tour of the Pyrenees. The photo was taken by friends above the road and it looks like she's waving as she hurtles past. But she's not waving. She's giving her friends "the bird". And she's still doing that - asserting her independence, calling out discrimination, ensuring people with a disability are seen - the determined legacy of a dad who taught her to change a tyre in a tight space.



Danette Rowse: sewing as therapy

Danette is a Lifetime Care participant

Danette and Evan in their mountains garden.

Clothesmaking, family and community – they have always been important to Danette. Now, almost a decade on from a traumatic brain injury, these are still the cornerstones of her life.

Danette's home in Hazelbrook in the Blue Mountains has bluebells carpeting the front garden and a back garden full of the family's animals – two dogs, a curious rabbit and a cheerful cluster of contented chooks and ducks.

There's also a large shed divided between partner, Evan's, motorcycle workshop and Danette's extraordinary collection of recycled fabrics and sewing machines. With them, she makes children's clothing which she sells through her business, Sami Bop.

Danette first started to sew when she was 11 after her mother died of a brain haemorrhage. "Sewing is recreational therapy," says Danette. "You get out of your body and think of nothing else."



Danette, her older sister, Donna, and younger brother, Scott, were born in Fremantle, before the family moved to New Zealand. Her parents soon split and when their mum died and their dad remarried, Donna and Danette were sent to boarding school.

Free spirit

After school, Danette studied to be a dental nurse. She moved to Auckland and met Evan when she was 19. They've been together for more than 35 years. Evan does the maths: "That makes us 22 now!" he laughs.

But for free-spirited Danette this was never going to be a settledown-straight-away relationship. She and Donna wanted to explore their roots so they bought an old Holden and drove across the Nullarbor to Perth.

Eventually I learned to stop asking how long recovery would take and just get actively involved in my rehabilitation. It was the beginning of a complicated journey for Danette and Evan as they crisscrossed Australia following their separate passions – Perth where Danette worked as a fashion-industry pattern cutter, then Geelong where she studied fashion design, and finally to Sydney where they settled when Evan moved there to study horticulture.

By day, Danette worked in the fashion business and by night played drums in a 4-girl band, the Del-Emmas. They did 60s garage-band original songs from Brisbane to Melbourne and all over Sydney. Life was busy and full but, wanting to live somewhere leafy, the couple saved to buy a house in Hazelbrook — the one they're still in 21 years later.

Collision

In 2003, son Jasper arrived and in 2004, daughter Samara. It was when the kids were little that Danette started her Sami Bop business.

In 2013 Danette was driving home from a doctor's appointment in Penrith. About 20 minutes from home, she blacked out and, weaving across the road, collided headon with an oncoming car.

She was helicoptered to Westmead Hospital where she was in ICU for 2 weeks with a severe traumatic brain injury, fractures, a snapped tendon in



Danette (centre) in the Del-Emmas.

her neck and paralysed except for some movement in her right big toe. At first Danette wasn't expected to live but after titanium rods were inserted into her neck she moved to Royal Rehab at Ryde for 5 months.

Slow recovery

"When I asked how long recovery would take, I felt really frustrated by the 'how long is a piece of string' answer I always got. The nature of brain injury is there is no real answer, but back then I needed hope that things WOULD get better.

"Eventually I learned to stop asking and just get actively involved in my rehabilitation."

Evan and the kids did the 2-hour round trip to visit her several times a week while Donna arrived from Melbourne with big-sister energy and registered-nurse skills to organise doctors and see to Danette's needs.

"Donna and Evan are rocks to me," says Danette, clearly still moved by their support 9 years after the accident.

Slowly, Danette learned to walk and eat and the house was modified for her return. She still gets tearful remembering her first night back at home.

"Evan and I were lying in bed holding hands. We had carer support but there was still so much to deal with. I felt overwhelmed."



Rag trade entrepreneur.

After the accident, Evan took most responsibility for the kids while support workers helped Danette around the house and with getting to appointments. She feels the kids have missed out on a bit because her shortterm memory often fails her and she couldn't be as involved in their schooling as she had been. The accident was difficult for the children to understand. Their normal teenage bumps have been exacerbated so that when Evan and Danette felt their "coping toolbox was empty", they went to family counsellina.

Reconstruction

After the accident the nerves in one side of Danette's face were severed, while the other side was compressed, leaving her without a smile. In 2019 she had an 11-hour operation to reconstruct her face and reduce her facial palsy.

"I also have problems with balance and fatigue.

"But I go regularly to the gym, working at my physical strength, getting facial physio and expanding my skills."

She remains determined to make the most of every small improvement.

Danette defiantly signed up – against a doctor's advice – for a Certificate in Community Service at TAFE. She has had support from an "entrepreneurs When I asked how long recovery would take, I felt really frustrated by the 'how long is a piece of string' answer I always got. The nature of brain injury is there is no real answer.

with disabilities" program to develop her Sami Bop business and consultations for guidance in improving online sales.

She's also been on the steering committee for Synapse, the national brain injury organisation.

A source of much fulfilment is the work she does at The Nook, a craft cooperative in Leura. Danette has worked there since before her accident, but values it even more now as a way of integrating her creative and organisational skills.

She's also joined a ceramics group and for this year's *Shine* Arts Prize has made a ginghampatterned ceramic vase, as well as two other pieces.

"Evan and I are a real unit. We each do our own thing and then things together. That's why we've lasted so long."

For all her challenges, Danette is able to say she feels lucky the accident happened when it did. "I already had a career, my kids, a business. There was so much established in my life already and I had the gung-ho to keep going."

"Gung-ho" is a word that pops up often in Danette's conversation.

"They say a brain injury can make you gung-ho. But I was already gung-ho. Now I'm double gung-ho."

Steve Hill: back to work at last

Steve is in the Workers Care Program

A work accident left Steve with a traumatic brain injury. Almost 2 years later he has managed to return to most of his previous activities and hobbies and, in particular, get back to the job he loves.

Coming home from hospital after a brain injury, 67-yearold Steve Hill felt he was confronted with a wall of restrictions. It was April 2021 and for more than a year he wasn't allowed to drive, to climb a ladder, use hand tools, use power tools, play golf or drink alcohol. As someone who sees himself as practical and competent, he found the enforced inactivity at home very frustrating.

Support team

He worked with different service providers including a psychologist, occupational therapist, speech pathologist and vocational rehabilitation consultant. He had driving lessons to get his licence back.



Steve's irritations have now passed and he is back at work with his former employer. He says he would've liked to have had a booklet of dos and don'ts to better prepare him for life after brain injury.

Varied work

He now understands why he was restricted from doing certain things. "After the injury I needed to rebuild my stamina and stick to the methodology. I needed to be patient – it pays dividends."

Steve grew up and went to school in Sydney's Liverpool area. He enjoyed designing and making things like bookcases and dreamt of being an architect. But after training as an architectural draftsman, he worked as a state manager for a bank, a quantity surveyor for a housing company, and for a construction company.

In 2011, a friend pointed him to a job at a company installing

toxic-fume exhaust systems. Steve loved the work – being on site, reading drawings, putting fume cupboards together.

The work took him to all sorts of interesting sites like a gold refinery, university labs and the zoo.

At Taronga Park Zoo they installed a ventilation system to capture ozone gases given off when cleaning the ocean water used by the fairy penguins, seals and sea lions. The water was cleaned a number of times a day and needed to be decontaminated before being returned to the harbour.

Steve and his colleagues watched the behind-thescenes activities at the zoo. He tells wonderful stories about the antics of the animals as they needed to be moved to different areas to accommodate the work his team had to do.

Full-time dad

Thirteen years ago, Steve's wife Anne suddenly died of a heart attack aged 48. Their older daughter Renée had already left home but their younger daughter Kayla was only 12.

After the injury I needed to rebuild my stamina and stick to the methodology. I needed to be patient – it pays dividends.



[Returning to work] made me feel wanted. Fulfilled. Not useless like I did when just sitting at home.



Steve with Buddy, the Russian Blue.

Steve and Kayla's worlds changed overnight. Steve rang his boss to tell him what had happened and his boss replied, "Give one of the reps 6 hours to bring him up to date on your job then go and be a daddy to Kayla".

Steve left work and became a full-time dad. Kayla said to him, "This was our home with Mum. Now we need to make our house a home with Mum's memories".

Workshop accident

Once Kayla had finished school, Steve returned to work.

Then in March 2021 when he was building a couple of washdown stations he had the accident. An offcut of heavy 20mm plastic from elsewhere in the workshop landed on his head.

Steve describes the scene in slices. "People were rushing about ... I was being loaded into an ambulance ... I was blacking out."

His skull had been fractured, his brain was injured and he needed an operation to insert mesh over the gash. Titanium screws were inserted to hold a piece of his skull in place.

Steve still suffers from loss of focus. He gets distracted and feels overwhelmed.

"I have too many projects in my head and don't finish them. I always used to complete a project I started." But things are getting better. "As I said, if you stick with the recovery plan, you get there!" All the while that Steve is chatting, his beloved cats are chasing one another around the house and up onto their scratch gymnasium that's almost as high as the ceiling. Buddy is a 7-year-old Russian Blue that his daughters gave him as a 60th birthday present. Then there's the 2 rescue cats, Hunter and Myra.

Bush photographer

Everything Steve does, he does with intensity. He'd been an amateur photographer of wildlife – birds especially. His recreational therapist suggested he take up photography again so out came his collection of cameras and lenses.

Several times a month he heads out to Burragorang Lookout near Warragamba Dam to photograph rainbow lorikeets or eastern rozellas in the bush.

Cats and cameras are not the extent of his passions. He collects knives in an array of shapes, sizes and functions. He has 15 plastic tubs of fixed and folding blades, of blades with interesting handles, blades that are gravity-fed, others that are front-flippers, and blades that are billeted, or folded, steel. With his driver licence restored earlier this year and his golfing rights back, Steve feels he's recovered the independence he craved. And being able to finally return to work has been the icing on the cake.

Message of hope

"It made me feel wanted. Fulfilled. Not useless like I did when just sitting at home."

But Steve's challenges weren't over. Just before he was due to return to work, he was diagnosed with stage 1 prostate cancer. He was operated on and finally back at work in August.

The adage Steve lives by is: "Just take life in your stride, each day as it comes. Tomorrow will be a better day.

"Worry about what you've got control over and the rest will fall into place. Let the other stuff go.

"I want to give a message of hope to others after an injury: you feel that everything is moving too slowly but if you stick to and believe in the system, you get there!

"Things may not come as fast as you want, but they will come. Your support team all want to help you."

Jason Wright helping others avoid the dark times

Jason is in the Workers Care Program

After a spinal cord injury more than 20 years ago that left him in a wheelchair, Jason went through periods of depression and hopelessness. Having turned his life around, he is now working to help others in the same position adjust to their new lives.

The open doors of Jason's lightfilled new home at Buff Point on the Central Coast are verv welcoming. As is Jason's smile as he enthusiastically greets us from his wheelchair.

It's fitting that the home overlooks sparkling Budgewoi Lake since much of Jason's early life was spent on or in the water.

He grew up in Newcastle and had an early job driving the charter boat for a dive shop in Port Stephens. He worked on tall ships in Sydney Harbour and on whale watching boats and trawlers in Hervey Bay. He represented NSW in the Australian Spear Fishing Championships and has spent hours scuba diving.

Jason started work as a motor vehicle wholesaler for an



auction house in Newcastle. The work required a lot of driving out to dealerships all over western NSW to buy trade-ins. It was on one such trip in 2001, near Singleton, that he had a microsleep just where the road fell away into paddocks. He only remembers hitting a tree and then electric pain running through his legs as he faded in and out of consciousness.

False hope

He was taken first to John Hunter Hospital and then the next day to Royal North Shore. He'd suffered a burst T12 vertebra and needed part of his hip bone grafted into his back.

He was in hospital for 3 months and then in Royal Rehab at Ryde for another 3 months.

I was more worried about my daughter than about myself and left rehab a bit early and before learning all I should have.

A surgeon told Jason he had every chance of walking again but, when that didn't happen, he fell into a deep depression. "I'd completely lost the life I knew."

As a single dad to his 10-yearold daughter, Tiahn, Jason was also worried about losing his identity as a father.

"I was more worried about my daughter than about myself and left rehab a bit early and before learning all I should have."

Challenges

Jason wasn't using the prescribed equipment and suffered a pressure wound - a common ailment among wheelchair users - which required flap surgery and 100 days lying on his side to allow the wound to heal.

Finding a home for himself and Tiahn, was a challenge. There was a cycle of battles with private landlords to arrange minor modifications to accommodate his needs.

He did business and admin courses at TAFE and applied unsuccessfully for numerous jobs.





It's so rewarding to help people adjust and to avoid making the same mistakes I made – helping them be as independent as they can be.

Jason and Kate.

He felt he wasn't coping and started using drugs – a way of self-medicating to forget his troubles. They were dark times and he admits that the 16 years after his accident were tough for his parents and daughter too.

Small steps

Eight years ago things slowly started to turn around. Jason was sick of not making progress on any front. "I woke up to myself and started seeing a drug and alcohol counsellor." Step-by-step he was inspired to

make positive changes in his life. In 2017 he met his partner, Kate, who helped him see his

potential. They moved to The Entrance on the Central Coast.

By 2019 Jason hadn't worked for 18 years when he applied for a job at Spinal Cord Injuries Australia (<u>SCIA</u>) as a peer and family support coordinator.

Getting that job was another turning point. He is now one of a team of 11 people all with lived experience of disability. The team – located across Sydney, the Illawarra, Canberra and Perth – share their stories with new spinal injury patients both in hospital and the community.

Working alongside clinicians, the team participates in education sessions on topics ranging from bowel, bladder and pain management; driving after a spinal cord injury; travelling on

With daughter Tiahn and granddaughter Peyton.

public transport; sexuality and intimacy; skin care and pressure wounds; wheelchair skills and how to be safe.

"It's so rewarding to help people adjust and to avoid making the same mistakes I made – helping them be as independent as they can be."

Jason wishes this kind of support had been offered when he was injured. "I wouldn't have gone through the darkness I did if I'd known this stuff."

He loves the work. It takes him 2 hours in the morning to get ready before driving his handcontrolled Honda CRV 4 days a week 90 minutes each way to Sydney.

Proud granddad

In his dark days Jason didn't understand the benefit of playing adaptive sports. He's now been sailing and mountain biking. Through Sargood at Collaroy, which provides specialist accomodation for people with spinal cord injury, he's driven 4WD-powered wheelchairs on the beach and tried para-golf and sit-skiing.

The 52-year-old is now a proud dad and granddad to Tiahn and her young daiughters. Tiahn lives near Lismore and they maintain their close relationship on Facetime. He'll see all the family when he travels north in January – relishing that his parents, siblings and daughter are all proud of how far he's come. Yet another turning point has been the construction of his and Kate's new house. Last year they moved into their beautiful home with icarefunded modifications including roll-in spaces and wider doors.

"It feels fantastic to have our own place and to be working again after so long."

"Life's really taken a turn. I appreciate it and don't take it for granted."

Long hours

As well as his peer-support job with SCIA, Jason works online for 12 hours across the weekend as a call taker or dispatcher organising wheelchair-accessible taxis.

Jason doesn't mind his long working week. "For 18 years I've known what it's like not to work. You've just got to make your own destiny."

That's why, 21 years after his injury, Jason smiles warmly and looks out across the water of Budgewoi Lake with a sense of achievement and joy. Kate's a big part of that joy too.

"Life like this is something I thought would never happen for me. I never thought relationships would work out again. But they do."

"I really just want to age happily and healthily."

Connecting through Creativity

Your story through art



The Shine Arts Prize was developed to showcase the artistic talent within Lifetime Care and Workers Care and to recognise the role of art in maintaining wellbeing.

Overall winner

Huntah Hawkins

Category Visual arts **Title** Drone selfie, Shapes from above, Purple and yellow

Medium Photography

Huntah, 18, became interested in art at Manilla Central School. He finds freedom of expression through modern technologies such as cameras and drones, and draws inspiration from his love of landscape.

"Art is important to me," he says, "because I get a sense of self accomplishment. I always feel happy when I am doing art, especially with the drone.

"My advice to those who might like to give art a go is to just do it. It doesn't matter if you don't think you can as long as you're having fun and enjoying it."

Huntah will put the \$2000 prize money toward a cruise to New Zealand where he plans to take more amazing drone pictures.

Top: "I took this picture of myself as I like the way the drone can capture images from above that you can't normally see. I thought it looked unusually abstract for a selfie."

Centre: "I like the beauty in this drone shot with its different lines, shapes, textures and colours all coming together."

Bottom: "This photo was taken at a property where my school was in a cross-country event. I particularly liked the garden and house positioning from above. I changed the colours to give it a bit of an out-there Bauhaus feel."



Visual arts winner Caroline Graydon

Title My husband

Medium Canvas, acrylic paints, brushes, water

"My daughter took a picture of my husband and turned it into a cartoon on her phone. It captured a side of him that I wanted to capture on canvas. There is nothing to say but this is MY HUSBAND."



Music winner Wayne Williams

Title Blue angles

Medium Voice

"Blue Angels' is a song I have written and performed with assistance from RMT. The title refers to the nurses who wore blue scrubs in the brain unit where I was recovering. The lyrics detail the emotional turmoil and uncertainty that my condition brought about, as well as the hope that the nurses provided for me."



Children under 15 winner Shaylah Sandery

Title Fancy dress Medium Paint and pencil

"Wearing my fancy dress dancing under a rainbow when I can get out of my wheelchair and walk on my own."

Thank you to everyone who submitted entries. The judges had a difficult time selecting the winners.

Scan the QR code to view the full online exhibition or click <u>here</u>.



Daniel Wallekers: achieving his goals

Daniel is a Lifetime Care participant

Daniel was only a few days away from his final electrician's exam when he had the accident that would change his life. Seven years on and still recovering, he retains his sense of humour and optimism about the future.

Daniel is a lively 30-year-old with a cheeky smile. A bit of a jokester. When we arrive at his family home in Barden Ridge he wants to try out the mixed media presentation he is working on – a motivational speech about his accident and recovery to be used in corporate resilience training. He says all the tips he has seen on presentations say to start with an icebreaker. We are sworn to secrecy – particularly on the icebreaker.

Apprentice

Daniel grew up in "the Shire" – as the Sutherland area in Sydney's south is affectionately known to locals – one of 4 children in a close-knit family.

He went to school at the local St Patrick's College. "I enjoyed it I guess. I wanted to study IT at uni, but I was too hard on myself and didn't think my marks were good enough. Then I thought I'd be an electrician – I'd heard it was the bestpaying trade – and got an apprenticeship with a cable and data company in Mascot."

Didn't get to work

In March 2015 Daniel was in the final year of his apprenticeship and less than a week away from sitting his last exam. He was riding his motorbike on a hot afternoon to his night shift on a big retail refurbishment his company was doing in Miranda.

"I never got to work. I don't remember anything of the accident, but at an intersection a driver turned right across me and I was knocked off the bike." Daniel had numerous fractures and 2 severe bleeds on the brain. He was in a coma on life support for 17 days then in the Liverpool Hospital brain injury unit for over 3 months before 8 months of rehab.

"I had to wait and see how bad the injury to my brain and body were."

"My mum was with me every day. It's her support that has helped me the most." Then Daniel goes into his jokester mode: "But hey, I don't want to give her TOO much credit!"

Daniel returned home from rehab a year after the accident. He knew that he'd be living with a traumatic brain injury.

"I had some physical goals and some mental ones," he says.

"Physically I needed to strengthen my right leg so I could walk and also my arm which was still partially paralysed.

"Mentally I needed to improve my attention and improve my memory. And I needed to reduce my swearing!"

Daniel notes all his milestones. At 77 days he could walk with assistance. By 18 months he could walk without assistance.

He shows us a video of his first ungainly attempt at running: "Usain Bolt, mate!"

Another goal was to sit the final electrician's exam that he'd missed due to the accident. Six months after he returned home Daniel did the exam and passed. He was ecstatic.

"I just felt I needed to maintain my strength and positive attitude."

55 I reckon everyone can achieve their big goal, but first they need to break it down to smaller goals. And it might take a long time as it did for me.





My mum was with me every day. It's her support that has helped me the most.

Daniel with his family in hospital.

10,000 steps

Daniel regrets the loss of some of his pre-accident hobbies.

"I can't surf now. I can't skate. I used to kick the ball around with my brother. I can't do any of them now. It's frustrating. But I do like walking. Until last year I was walking 10,000 steps a day. I'd get up early and walk an hour or 2 in the morning."

In September Daniel had corrective surgery on his right foot to straighten his toes.

He hopes to be back walking again soon, doing his 10,000 steps.

"And I can move my right arm pretty well now. It's just my hand I have trouble with."

He wants to be able to play the guitar again and uses an adapted guitar with a foot pedal instead of his right strumming hand.

Daniel still uses a wheelchair occasionally, but doesn't need it as much these days.

"The main thing that stops me being completely independent now is that I suffer from severe anxiety. It's often about things that everyone else takes for granted, like walking.

"I'd get dizzy, I felt I was going to collapse. I'd have problems breathing. I'd start swearing and then I just couldn't walk. It used to be anywhere but now it's mainly only indoors. When it happens I don't know what I'm afraid of. I just can't walk. It's my brain playing tricks with itself. "But it's a lot better now than it used to be."

Daniel was able to get his driver licence back about 2 years after the accident. And he's done some work placements as an electrical estimator.

"I'm not sure where I'm going workwise. I might stick with the electrical estimating or I might get into IT. That might be more feasible for me because I can work around my physical disabilities better."

Letter to driver

And he's interested in continuing with the motivational speaking. He's already done talks for Lendlease, for hospital trauma teams, high schools and, in June, for the Brain Injury Australia conference.

"I love public speaking. I've got a good story to share and I really like motivating and inspiring people."

"Motivational speaking – it's my calling don't you reckon?" he asks mischievously.

A big thing for Daniel was writing a letter to the driver of the car that had hit him. "I knew the accident had also had a big impact on his life. I gave him the letter the last time I saw him in court. I said that I knew both our families had also suffered from the accident. I told him that I forgave him and I hoped that he could forgive himself as well.

"I just didn't want to hold on to anything negative, and writing the letter also gave me some closure around the accident too."

Small goals first

"I reckon everyone can achieve their big goal, but first they need to break it down to smaller goals. And it might take a long time as it did for me, but each accomplishment even if it's very small – they really are the best feelings!"

When we say goodbye, Daniel is still telling jokes.

"Have I made the cut?" he asks. "How are you going to pay cash or card?"



Matt Allen: still enjoying his life

Matt is a Lifetime Care participant

Matt was in a good place – at the start of a career he liked, in a relationship with someone he loved. An accident left him unable to move from the neck down, but 6 years later he is happy and still looking to the future.

Matt is a thoughtful, contemplative 28-year-old with a quiet sense of humour. He speaks about his accident as if he was watching it from afar.

I never saw it

"I was rushing back to work after lunch and was walking across the road down from the traffic lights but didn't see a small black Honda approaching. I was hit and carried some 20 metres on the bonnet.

"I remember the details of the impact and the aftermath very well as I stayed conscious right through it. I was aware of the sensation in my body slowly disappearing. I wasn't in any particular pain, just uncomfortable.

"I can reconcile myself to the injury better by knowing and remembering how it occurred, rather than if I'd lost consciousness and had woken up in a coma and was told that I sustained a spinal cord injury. That's the way it works for me." Matt grew up in Parkes in central west NSW and has one younger brother.

"I grew up in town although I had quite a few friends on nearby farms. It was a loving home. I went to a Catholic college in Forbes. I got decent marks and moved to go to Sydney Uni where I studied physics and maths. I enjoyed the study and I enjoyed university life. I had a great group of friends who are still my best friends today."

Meeting Allison

One of those uni friends was an engineering student called Allison. Their relationship flourished and by his third year at uni, Matt and Allison were a firm couple.

"I did well in the course and finished an honours year in physics before thinking that I'd like to take a break and get some real-life experience before deciding if I wanted to stay in academia and do a PhD."

It was a slow realisation finding out the extent of my injuries and how much movement I might get back in my limbs.

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Hospital and rehab

Matt started his first full-time job in 2016 as a radio chemist at a laboratory in Arncliffe compounding and dispensing nuclear medicines. He enjoyed the work and then, one day, 2 months into the job, he walked down the road to the nearby KFC for lunch.

"Fortunately, I at least made it to the KFC and ate my lunch. I was relaxed, in a good mood but lost track of time. That's why I was rushing back to work. That's why I had the accident."

Matt was taken to Royal North Shore. He had surgery the next day, then was put into an induced coma. His parents came down from Parkes to be with him for some of the time in hospital and rehab. Allison visited him every day and their relationship deepened.

Matt was about 7 weeks in ICU, 3 weeks in the spinal cord unit and 15 months at Royal Rehab in Ryde.

"I was at Ryde for that long because there was no appropriate place I could be discharged to. I couldn't move back to my student house which wasn't accessible and I didn't want to go to



Matt and Allison at Collaroy.

my parents' place in Parkes because that would separate me from Allison.

"It was a slow realisation finding out the extent of my injuries and how much movement I might get back in my limbs. Doctors would say, 'We're going to have to wait and see over the next few weeks'. So each day I'd be thinking 'Is anything coming back? Any feeling, any strength?'

"After 2 or 3 months I realised it wasn't going to get substantially better. I thought I'm just going to have to try and make the best of my life as I can with this almost total paralysis of my limbs."

Long nights

"I've honestly never really felt angry at my situation. Just angry at myself sometimes.

"But I was in a low mood for a long time in rehab. There were long nights when I couldn't sleep, staring at the ceiling as some depressive thoughts came in.

"Rehab was very packed. There were lots of lessons about becoming more independent, readapting to society, how to drive your wheelchair using chin control, working with your support workers and how to direct them around your personal routines and advocating for what you like and don't like."



On their wedding day.

"You try to recover as much function as possible – in my case that was very little. Interestingly, while my arms have no real functionality, I have some limited strength in my legs and I can stand in the standing frame – it's crazy with my injury, but I am a bit upside down really!"

Back to study

In 2020, after a couple of years in a unit in Sutherland, Matt and Allison bought a house in Gymea Bay and icare helped with modifications, such as widened doorways and corridors, a ceiling hoist, ramps, a new bathroom and automated control for doors, aircon and TV.

Matt has now gone back to study at Sydney Uni and is in his second year of a psychology degree.

"I'm fascinated by the research around perception, personality, cognitive thinking and learning about what consciousness is. At the moment I'm not sure if I want to specialise as a clinician and work with individual patients or work in a research or policy area."

Allison is now lecturing at the uni and about to start a PhD investigating the management of large infrastructure projects. So the couple who met and fell in love at Sydney University in an engineering computing lecture are both back there. After 2 or 3 months I realised it wasn't going to get substantially better. I thought I'm just going to have to try and make the best of my life as I can.

"After 8 years we've come full circle," says Matt. "We got married earlier this year and we wanted to have the wedding at the uni. But COVID got in the way of those plans and we were married in a nearby church. Most of my groomsmen were my old uni friends."

In a good place

"Mentally I think I've adjusted well to my life," says Matt. "I still have problems with sleep and I still get some chronic pain in my lower back. If I'd had a more active, sporting lifestyle before the accident I might have felt different but I consider myself lucky that my accident wasn't more severe and that I am still alive.

"My main regret is not being able to hug Allison.

"And not playing video games. "But I'm in a good place at the moment. It's been great moving in together in our own home. "In myself I feel alright."



Mother and carer

All mothers are carers, but when a child has a life-changing accident your own life changes as well.



Tanya and Lewis.

Tanya Schmid

Tanya and her husband Malcolm met at university in Canberra but settled at Seven Hills in Sydney's north-west where they brought up their 4 sons.

In 2020, Lewis, the third of the boys, was in his last year at school and had applied to join the army. Wanting to get something for lunch, he hopped on his new motorbike.

"We don't know what happened exactly, because he doesn't remember anything and no one saw it, says Tanya, "but Lewis came off his bike and hit his head badly. He had few physical injuries but the ambos realised he'd had a bad head knock and put him on a breathing tube straight away.

"Over the next few weeks the diagnosis went from brain injury to traumatic brain injury to severe traumatic brain injury."

When he was able to return home 10 months after the accident, Lewis still had difficulty walking, rolling over in bed and doing ordinary tasks. Tanya, who works full-time as a swimming school supervisor, took on the job of organising all the resources Lewis needed.

Rapid progress

"Luckily, due to COVID, I was working from home. We had a physio, an OT, a consultant nurse, psychologist, speech pathologist and regular support workers. Lewis's progress over the last 18 months has been remarkable. "His therapy is no longer about specific skills like writing," says Tanya. "Now it's more about social skills, like how to order a drink and how to manage other people's expectations.

"He is still very active and doesn't have any real fatigue issues – unlike a lot of people with brain injury. And he's back to bike riding and bouldering – always one of his favourite activities – at the climbing gym."

Still improving

Lewis still has cognitive impairments and his speech and learning are still affected. "His recovery hasn't plateaued yet," points out Tanya. "He's still improving so we're always thinking how we can help him go a little bit further and keep his mind engaged.

"He's good around the house. He loves doing the washing and walking the dogs and he cooks satay chicken for everyone on Monday nights."

Lewis is looking at returning to work. He used to work at Gloria Jeans and he'll be able to go back there for short shifts. And there are other options like gardening or work in a factory. Tanya is resilient and pragmatic. With her job and other members of the family to think about, there's a lot of juggling. "Sure, I need to keep on top of things, to think ahead.

"I still make sure I can go out for coffee with friends. I think it's important to look after yourself and allow others to help you and give yourself a break.

"Malcolm and I make sure we go out to dinner by ourselves regularly. It's important to have time to plan, to reset, so life doesn't get out of control.

"The other boys still live at home so there's always one of them with Lewis if Malcolm and I aren't there, and the support workers help with that as well. And Malcolm is good at doing things with the other 3 so they get time as well.

"I don't think about the what-ifs. This is where we are now. You can't go back. If my children are happy and independent – that's always been my aim.

"My advice to anyone else would be, take one day at a time, seek support. The system is complex so don't be afraid to ask questions. Let people know how you feel.

"And be happy that your child is still here, still with you."





If there's any advice I'd give to other parents in my situation it's that you should enjoy every day. Find things of interest together. Make use of the support you can get - that's important.

Karen and Nick.

Nick with his Lego grand piano.

Karen Barwick

When Karen's youngest son Nick rode his new motorbike off the road outside their home town of Orange 14 years ago, both their lives changed.

In the third year of a baking and pastry apprenticeship, 18-year-old Nick never knew exactly what happened except that he was found by a passing motorist pinned under a fence.

"At first we thought it was a few broken bones and that he'd be out of hospital in a few days," says Karen.

Move to Sydney

But it was 4 months before Nick could even talk again. He'd sustained a severe traumatic brain injury and was in hospital and rehab for almost a year. Karen moved down to Sydney to be with Nick most of that time and if she wasn't with him, she made sure another family member was.

After Nick returned home he tried to go back part time to the bakery where he'd been before the accident.

"I did that for a couple of years," he says. "But I found it very noisy and had difficulty concentrating so I couldn't stay.

"I still have a lot of trouble with my memory. I use my phone to write down things and take photos. And I get tired and need a rest after lunch."

"But I still like baking. I bake a cake or biscuits for morning tea for my grandfather every week." On a side table are a selection of Nick's Lego creations. He's keen to show us the 3800-piece earthmover and an amazing grand piano that can play music through his phone.

"I started doing them in hospital, first smaller things and then they got bigger."

Nick keeps a book he calls his "Wow" book, full of photos and captions and notes from his progress since the accident. He uses it to tell his story to new people and it also reminds him of how far he's come.

Caravan travels

Once or twice a year, Karen, her husband Garry and Nick go away on a caravan holiday.

"It's a holiday that works well for Nick," says Karen. "He takes photos out the car window and he's in the same bed each night. We go places that aren't too crowded and we have whiteboards in the caravan so we can list where we're going tomorrow and the activities we're going to do. Nick's very much part of the planning."

Nick still keeps in contact with Narelle, the driver who found him under the fence.

"Every year on the anniversary of the accident," says Karen, "Nick meets up with her and gives her a bunch of flowers. It's important for him to keep in touch." Karen, who has lived in Orange all her life, has been a major part of Nick's recovery. She gave up her job as a cleaner in an aged care home after the accident. She encourages him to try new things such as the art classes he's now been doing for a couple of years.

Good support

"Nick's easy to get on with and we enjoy the same sort of activities," she says. "We just poke along. I don't feel I lack for support. I've got enough – especially through the family and the support workers who come to help Nick twice a week.

"He's worked very hard to get to where he is. He's done an amazing job really. And you can only do the best you can. Nick's been very fortunate.

"If there's any advice I'd give to other parents in my situation it's that you should enjoy every day. Find things of interest together. Make use of the support you can get – that's important."

The notice board

Sharing your news highlights, handy information and upcoming events.

Adaptive Movement

In July the Adaptive Movement website was launched.

The Adaptive Movement is a fully accessible website featuring providers of adaptive sport and recreation activities throughout NSW and the ACT. It's a one-stop shop for everyone who wants to get more active or have their sport adapted just for them.

The website is run by Wheelchair Sports NSW/ACT with icare support and a committee of disability advocacy organisations.

It has direct links to adaptive sports and recreation providers for boccia, cricket, remote control sports, AFL, hockey, dance, swimming, frisbee, netball, sailing, judo, gymnastics, surfing, golf, bowling, scuba diving, skiing and boxing and many more.

You can search the website by:

- activity type
- locations across NSW and the ACT
- type of adaptation (including brain injury, spinal cord injury, blindness, limb difference and many others)
- age
- gender.

Once you have found a provider that you think meets your needs, you can contact them directly. If you can't find an activity that suits your needs, you can sign up for an alert that will tell you if the activity becomes available in your area.

Lifetime Care participants Gabby Vassallo (featured in this edition of *Shine*, see page 2) and Stuart Jones (see *Shine* summer 2021 issue **here**) are advocates for the adaptive movement. On the website launch day they acted as panellists for a Q&A session where they shared their experiences of adaptive sports.

Both Gabby and Stuart have found sport a big help in building community connections and positive mental health.

During the panel discussion Stuart highlighted the impact of being able to cycle following his accident. "By being able to cycle again with adaptive equipment means I actually feel normal. I feel that I can do stuff, I think it saved me."

Gabby spoke about the power of social connections – "the friendship base and being connected ... nothing is better than getting involved and being with your tribe." To learn more about adaptive sports near you, visit <u>here</u>.

Gabby Vassallo and Stuart Jones at the Adaptive Movement launch.



Ageing with an injury

Last year we updated you on our work to support people who are ageing with a severe injury. In 2023, we'll be continuing this work to develop resources and supports to improve recovery, health literacy and outcomes for older people after severe injury.

We are keen to include feedback from our participants, workers and their families and carers as we develop these resources to make sure they meet the needs of older people.

If you'd like to be involved, please email us at <u>shine@icare.nsw.gov.au</u>





Remarkable Insights video podcast

The Remarkable Insights video podcast was launched in October.

This conversational series explores the future of technology at large and how disability drives innovation.

This series follows the success of the "Remarkable Insights" audio podcast launched in 2020.

Scan the QR code to access the podcast or click here.



icare's Reconciliation Action Plan

icare has launched its first Reconciliation Action Plan, setting out our path to provide better services and outcomes for the First Nations peoples and communities we work and interact with every day.

The new plan will help us:

- improve how we provide treatment, rehab and care to First Nations peoples
- expand the number of First Nations businesses and organisations we engage, and make sure our suppliers, partners and stakeholders see this increased focus and engagement
- foster increased diversity, inclusion and belonging, so that First Nations peoples feel respected, safe and supported in all interactions with us.

The plan signifies our commitment to improving the way we do things, and to play our part in achieving reconciliation and Closing the Gap.

If you want to share your ideas or experiences with us, please contact Carolyn Smith who is keen to listen to you and integrate the voices of lived experience into what we do:

E: <u>PAAenquiry@icare.nsw.gov.au</u> P: **02 7922 5531**



New journal for carers



The *wecare* program is launching a carer journal early in the new year for those supporting a loved one after their accident. It will contain tips and ideas throughout from carers who've been through a similar experience.

The inspiration behind the journal came from a carer, Lanie, whose daughter, Tahlia, sustained a traumatic brain injury in a motor vehicle accident in 2018. Lanie found the journal to be a really valuable tool to document her daughter's time in a coma while in intensive care.

"My best friend bought me a diary so that I could document everything," says Lanie, "from who came to visit, to what the doctor's confusing terminology was so I could google it when I had a chance. I was Tahlia's eyes and ears and I had to make life-changing decisions on her behalf.

"Every night I would write down her time in the ICU as I wanted her to read it one day and I felt like I had to fill in the blanks of her time in a coma.

"As time went on Tahlia improved. Each day I would document her appointments in the hospital as there were so many, even multiple, surgeries ... I felt a sense of being in control as I could look back in the diary and reflect on how far she had come and on her ability to push herself."

Lanie shared her journalling experience with other *wecare* family carers sparking the idea for developing a journal that could be gifted to new carers.

The *Carer Journal* was developed in consultation with the *wecare* carer advisory committee and icare's service development team.

The journal will be available in print for new carers and digitally on the carer resources page <u>here</u>.

wecare is a program of Carers NSW to provide support to family carers, including adults, young people and children. For any enquiries about the *Carer Journal* or the *wecare* program, please contact the *wecare* team at Carers NSW:

P: **02 9280 4744** E: <u>wecare@carersnsw.org.au</u>

Shining moments

Have you got something you'd like to share with the *Shine* community but don't think a full story is right for you at this time? We would like to invite participants, workers, carers and family members to send in photos of special events like birthdays, weddings, graduations, the moon cake festival, Diwali, Ramadan, performances, cultural ceremonies or any other significant moments you would like to share with Shine readers, for a new feature called "Shining moments".

Please send any photos and a brief description to <u>shine@icare.nsw.gov.au</u>



icare acknowledges the clans of the Dharug, Eora and Kuring-gai nations 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 <u>shine@icare.nsw.gov.au</u> or call **1300 738 586**.



Shine online



Scan the QR code to view the online edition or click <u>here</u>.

