



Shine

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

Winter 2021

Jess Stocker: from brain injury to motherhood

Jess is a Lifetime Care participant

Jess with Georgia, Joey and William.

Jess barely survived a terrible accident when she was 17. She is now the proud mother of a small boy.

"Jess and Ben" says the welcoming sign at the start of the long driveway to Jess Stocker and her partner Ben's house on the outskirts of Armidale. The house, in one corner of a large family hobby farm, looks out over rolling green farmland and bush.

Passion for music

Jess's parents separated early and she grew up with her mum Emily, her grandmother Cathy and Cathy's partner Angie.

"Both Mum and Grandma are musicians," says Jess. "Mum was a singer and teacher and is now a clinical psychologist."

Jess went to Armidale High where she enjoyed drama and art. "But it was music that was really my main thing."

"I was in a choir my Grandma conducted and the choir went overseas one year - to France, England and Canada. We also

I couldn't smell, taste, or even cry. I was depressed and just wanted to be home.



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met some great musicians who inspired me and three friends to start a band together. We were called 'Turkish Delights' and we played crazy gypsy folk music. My main instruments were cello and percussion.

"We played gigs at the Woodford Folk Festival and the Tamworth Festival when I was 15 and 16.

"It was a good childhood. I was happy and wanted to be a music therapist or teacher."

Year 11 party

But everything changed for Jess in October 2007.

"It was the end of Year 11. I was at a party with my best friends and having a great time. A group of us hopped in a car to drive to the service station.

"But we never got there. My friend didn't see a semi-trailer and turned in front of it."

Jess sustained the worst injuries of the group and had to be resuscitated five times by paramedics. She had multiple fractures, a punctured lung and, most worrying of all, a traumatic brain injury.

She spent a month at Tamworth Hospital, including more than a week in a coma, and then another three months in rehab in Sydney. "Mum and Grandma came down to Sydney and stayed in a little flat near the hospital. They'd come across and visit every morning. I don't remember a lot from that time. Every day I went to the gym and saw the occupational therapists and speech pathologists. The injury was mainly to the language part of my brain. I even forgot my name, how to write and how to hold a knife and fork. I had to start learning that all over again.

"For some months I spoke in jargon – made-up nonsense words. I lost most nouns so I couldn't name things properly.

"And I couldn't smell, taste, or even cry. I was depressed and just wanted to be home. I was so lucky to have the support of my family there. I don't think I would have recovered the way I have if it weren't for them."

Return of speech

Back in Armidale Jess continued her therapy. She became one of the first people to join Lifetime Care.

Her bones healed and her speech came back but the brain injury meant she was often very tired and had trouble understanding what she heard and read.

"I went back to school to finish Year 12. I couldn't do things that most of my friends were doing like reading, writing and maths. I ended up alone in a literacy and numeracy class.



Jess, Joey and Ben.

"Before the accident I'd had lots of friends but many of them dropped away. Turkish Delight disbanded."

Jess struggled with her mood - there was a period where she was chronically sad and anxious.

Her mum Emily says, "As a younger kid, Jess had always such a drive to be part of life. We were so lucky that drive was still there. She just wanted to be involved, and that really helped her recovery."

Luckily Jess's musical skills were not badly impaired by the injury and she was able to return to playing and performing.

Meeting Ben

Since the accident Jess has taught music at two local preschools and given talks about her experience at school road-safety programs.

Seven years ago, Jess met Ben, a cinematographer and animator with his own business. "I told him about the accident and the brain injury quite early in our relationship," says Jess. "He wasn't fazed by it at all. And he also plays guitar and sings. So that's a bonus!"

Ben says Jess's comprehension and memory are getting better all the time. "But she still finds reading hard work and, in a room with fast, overlapping conversations she can find it harder than most of us to process the information." Jess and Ben designed and built a house on the property where he grew up. Ben's parents and his brother's family all live on the property too.

"We call it the family commune," says Ben. "My two older kids also spend a lot of time here, and Jess gets on well with their mum. So it's a happy place!"

The accident is more than 13 years behind Jess now. Two years ago, she gave birth to their son Joey.

"She is really great as a mother," says Ben. "A natural!"

"Originally Jess's fatigue was something we were worried about," he says. "But icare have been great. In Joey's early days they provided us with cleaners and other help so that Jess could just focus on Joey. But Joey is a good sleeper and we don't need that help now."

An app to keep track

"I'm pretty good at working out medications and reading babyrelated stuff," says Jess. "I've got an app where I can record what he's eaten, and when I've given him Panadol and other things. If Joey's crying I can check back on the app at where I'm up to."

Jess and Joey have joined a group of other mums and their babies.

"Last year Joey and I started mini-minstrels every Thursday morning – singing, playing Sometimes I think I should be better than I am. But then I tell myself, that's who I am and that's OK. It took me a long time to get here, but I'm happy in my life.

instruments and reading books. I also take Joey to swimming lessons and kids gymnastics."

New cello

"I bought myself a new cello before I had Joey to encourage myself to keep playing. It's a beautiful instrument.

"Although I miss work a bit and the people and the fun, I don't want to go back yet.

"I just look forward to spending every day with Joey - teaching him. I feel that things are pretty complete right now, I'm not missing anything. I'm not missing studying - I'm studying Joey! Maybe later on I'll study or I'll go back to work.

"Sometimes I think I should be better than I am. But then I tell myself, that's who I am and that's OK. It took me a long time to get here, but I'm happy in my life."



Jerome Wong: wheelchair adventurer

Jerome is in the Workers Care Program

Jerome on his modified Ural motorbike with hand-operated gears and brake.

In his 20s, Jerome loved travelling to out-of-the-way places off the tourist trail. Despite an accident that left him with a spinal cord injury, Jerome's adventurous habits didn't change.

Jerome grew up in the 1980s and 90s on a two-hectare block at Mt Colah on the northern edge of Sydney.

Family camping trips

"I always remember being out and about from an early age," he says. "As a kid I loved my pushbike and riding it around the bush tracks near our house.

"My parents took us away on camping and road trips. We went all around Australia hunting for fossils. I guess this is what gave me an adventurous spirit. I always loved packing the four-wheel drive and heading off on unknown roads. It became a habit."

When he left school, Jerome studied network engineering at TAFE while working parttime in a car wrecking yard. He enjoyed being around



the cars more than his IT course, so became an apprentice mechanic with a car dealership. After finishing his apprenticeship, he moved into a service advisor role with the same company.

In 2008, Jerome headed overseas for three months on his first major adventure. He and a friend rode their dirt bikes through South East Asia including along 5000 kilometres of the Ho Chi Minh Trail in Vietnam.

Freeway accident

Back home, Jerome's employer promoted him to run a service department at Castle Hill and then a new dealership they were setting up.

One evening in April 2009, Jerome was riding his motorbike to Brooklyn after work to pick up some seafood. While heading home, the bike ran out of fuel. He hopped over the guardrail to keep out of the way of trucks roaring along the freeway. What Jerome didn't realise was that the slope on the other side of the rail ended in a 20-metre cliff. He slipped on some gravel and slid over the cliff onto the old road below.

"I think I was there for about an hour lying face down," he says. "My phone had flown out of my pocket, I couldn't move and I was having trouble breathing. I realised I'd probably broken my back as I couldn't feel my legs. I really thought I was finished." Eventually Jerome was found and airlifted to hospital. He had internal injuries and had broken

six vertebrae and numerous other bones. He was in ICU for some weeks and in hospital and rehab in Ryde for six months. "I was told I would never walk

again but I vowed I wouldn't let my condition slow me down.

Back on the road

"I got into gym work and built up my strength. I got my driver licence back while I was still in rehab – they said I was the first person to do that. I got an old Volvo modified while I was there as well. On weekends I could leave rehab and go for a drive."

It's my dream job really. I love it. I can mix the work up and move around which is best for my nerve pain.



You've just got to go out on a limb and throw yourself out there. There's always something else around the corner. It's up to you to have a productive and enjoyable life.

Jerome working on his Volvo at home under an icare-funded hoist.

A week after returning home, Jerome and a friend headed up to the Sunshine Coast and Fraser Island in a converted four-wheel drive.

"I felt I needed to challenge myself. We had to nut out all the difficulties that come with using a wheelchair on that sort of trip. I thought that if I can go for a week camping on the world's biggest sand island, the rest would be easy. And it was awesome!"

Work for Jerome wasn't going as well. The auto dealership told him his old job was gone and offered him a position in customer service. Jerome felt he'd been demoted.

"I stayed working there another two years but I didn't feel they were being flexible or accommodating."

Happier times

"By 2012 I was struggling with the neuropathic pain I still had from the accident. Eventually they made me redundant. It was devastating."

Jerome enrolled in a Diploma in Mechanical Engineering.

"It was a tough course but I was suddenly much happier – it was stuff that interested me."

Another ingredient in Jerome's increased happiness was meeting a young woman called Jess at a party. She was about to fly home to the UK the following day. But the two kept in touch and the long-distance relationship blossomed when Jess returned to Australia later in the year.

In 2014, with his diploma completed, Jerome and Jess set off on the biggest adventure of all.

"We rebuilt an old Toyota troop carrier and shipped it to the UK. We flew there and spent time with Jess's family before driving and camping through eastern Europe and Central Asia along parts of the Old Silk Road and back through Turkey, Greece and the Balkans. We organised it as a fundraiser for Spinal Cord Injuries Australia and set up a blog."

Hospitalised

The trip in the "troopy" was a great success although Jerome had to be hospitalised a number of times from complications relating to his injuries. In Turkey he needed a bladder operation. They cut short their adventure and flew back to Australia early in the New Year.

On their return, Jerome and Jess bought a house on a large bush block at Fountaindale on the Central Coast. But throughout the next year Jerome's health deteriorated and he needed back, bowel and thyroid operations.

"I still have some nerve pain and I still get urinary tract infections, but since then my health's been much better," he says.



With Jess in Samarkand.

Three years ago, Jerome got a job with PME Auto Conversions in Hornsby who do vehicle modifications for people with disabilities.

"It's my dream job really. I love it. I can mix the work up and move around which is best for my nerve pain. I work on the bench making the components and I also do their marketing and design work and certifications for new vehicles.

A big wedding

Jerome and Jess are not doing as much travel. "We're paying off the mortgage now," he laughs. "And we had a big wedding in 2019!"

Jerome has plenty to do at home.

"I love the garden. I mow the lawn on a ride-on and on my day off I've got a gardener who helps me with other stuff. I've even planted some Moreton Bay fig trees to help offset my carbon! And I'm restoring a bunch of old cars and doing lots of cooking."

His advice for others who have a spinal cord injury is "to go out on a limb – you've just got to throw yourself out there. There's always something else around the corner. It's up to you to have a productive and enjoyable life."

Alison Packwood: life and art after a brain injury

Alison is a Lifetime Care participant

After an accident 13 years ago, the country NSW art teacher was told she would never walk or work again. But she did, and she does. Alison talks to *Shine* about her long journey back.

Alison is a welcoming woman in her early 40s with a warm laugh as she greets us at the door of her house on the outskirts of Young. Ponyo, her 9-year-old French bulldog, has hidden a toy when we arrive and is requiring attention. "His name is Japanese for 'soft and cuddly'," laughs Alison, "but he's not!"

Teaching in the family

Alison grew up in nearby Cowra where her parents both taught at the local high school.

"Mum taught French and English while Dad taught metalwork and woodwork. They had met while teaching and still live in the house Dad built in town with his father. They both liked art and theatre so I remember lots of trips to Sydney – partly to see relatives but also to visit galleries and go to plays. "My two brothers were a lot older and had left home before I started high school so I grew up almost as a single child. It was a lovely upbringing, and I guess I was a bit spoiled. My parents always told me teaching was a great career – they worked hard during term and then enjoyed their holidays – so it's not that surprising I followed their footsteps."

Alison's favourite subject at school was art, and when she went to university in Wagga she studied a Bachelor of Fine Arts followed by a Dip Ed.

After some short-term and casual teaching positions, Alison landed her "dream job" in 2007 – a permanent position teaching visual arts and design at Boorowa Central School near Young.

I actually think my art got better after the accident. Before, I only worked in black and white and now I work in rainbow colours - it just happened that way. Alison with Ponyo in her garden.

It looked like rain

But the dream was rudely interrupted during the 2008 April school holidays.

"Heading home from Sydney, I was pulling out from The Fruit Bowl in Bilpin on Bells Line of Road, and the last thing I remember was that it looked like it was going to rain."

On a bend Alison met a rush of water coming across the road, crossed the centre line and hit another car head on. After being cut out of her vehicle she was transferred to Westmead Hospital and placed in an induced coma for a week. She had multiple fractures, a collapsed lung, lacerated liver and a traumatic brain injury.

When Alison first looked into a mirror she didn't recognise herself. "That image still haunts me to this day," she says. She was told she would never walk or work again.

"I said to myself that I would show them all. I would show them what I could do."

After five weeks at Westmead, Alison spent another three months in rehab in Young. She learnt to walk again although she still gets pain in her legs and back.

"And I still walk with a slight limp, especially when I'm tired." But the main legacy of the

accident is Alison's brain injury.





Alison and some of her artwork.

"I will have that for the rest of my life. Before the accident I was much more social and spontaneous, then afterwards I became a recluse and always exhausted, sometimes sleeping up to 17 hours a day. I felt lonely and hopeless and saw a string of psychiatrists and had a number of hospital admissions."

Room for a dog

"Eventually I was diagnosed with a form of chronic depression called dysthymia where you have a constant low mood. I now have regular treatment for that, and for the last few years I've been relatively good. Relationships with my family have got better and I have a good circle of friends. I don't travel that much, but we keep in regular contact. And Jane, an old school friend, now lives in Mittagong but comes to visit – which I really love.

"One of my brothers moved here four years ago. I wanted a pet so I needed to move out of my unit in town and he helped find this house which is wonderful. He has mental health issues himself so we keep each other in check and watch each other's back."

Alison's main goal and focus for her rehab was to get back to work.

"The school was keen to have me back and I loved my career and I loved the school but I just wasn't sure I could cope. "Returning to teaching really was the hardest thing I've done in my life."

Alison started back at Boorowa two days a week.

"Over a couple of years I got back to four days. I've tried five but it wears me out and I've had to tell myself I can't do it. I need to recover. So I've stayed at four.

"Despite the tiredness, I love the teaching. I love the school. The staff are so caring and supportive, and the executive have really gone out of their way to be flexible and meet my needs."

Four things

Alison says that the four things that keep her together are family, friends, teaching and art. "I actually think my art got better after the accident. Before, I only worked in black and white and now I work in rainbow colours - it just happened that way. Also, instead of painting things that were pretty or pleasing, I do more emotional, expressive work. I guess I'm using it as therapy. I get things out of my head and onto paper – it helps me deal with them in some way."

Alison has done a number of art commissions for icare.

"I've designed two of their recent Christmas cards, and when icare announced their inaugural *Shine* Art Prize last year I was really keen to enter."

I love the kids and the ideas they have, seeing the light bulbs go on and getting them to think bigger and enjoy art like I did at school.

Returning to work really was the hardest thing I've done in my life.

Her entry "April is still the cruelest month", referencing the physical and emotional changes following a car accident, was the prize's overall winner (see page 10).

Rewarding work

"I think my teaching has got better too," says Alison. "My empathy and understanding of people's difficulties and how they want to express hard and uneasy things. I love the kids and the ideas they have, seeing the lightbulbs go on and getting them to think bigger and enjoy art like I did at school. It's hard work but it's so rewarding and makes me so happy when it goes well."



Felicity Weal: return to the saddle

Felicity is in the Workers Care Program

Felicity with Fancy.

Felicity was following her life's ambition to work with horses. She was in a happy relationship, with her life ahead her. Everything changed when she fell through a roof on the family farm. Now the determined 24-year-old is putting the pieces back together.

"We grew up in the Southern Highlands," says Felicity. "Dad was a fencing contractor and my mum worked at a feed store. We had a few acres there with some sheep and horses.

Always around horses

"I'm from a long line of horse riders and both my grandparents are horse breeders. My older sister and I have ridden since we were babies – we've always had horses around us. We grew up doing pony club and lots of shows."

In 2011 when Felicity was 14, the family moved onto a mixed grazing property outside Cowra to be closer to Felicity's grandfather. The two girls continued with their riding competitions.



"When I finished school I had no interest in going to university. I loved the farm life and became a farm hand, working for my dad.

"I did all the general jobs on a farm, like fixing water pipes, building yards, fencing and looking after water troughs, but I preferred working with the animals – checking sheep, running the stock part of it.

Accident on a roof

"I met my partner Andrew here on the farm. He'd started working for my parents while I was at school. We got together in 2015 about a year after I finished school.

"I was pretty happy just working on the farm and not really thinking too much about the future."

The last day of August 2017 was a pretty typical workday. Andrew and Felicity were headed to her grandfather's place down the road to feed sheep. And there was also a shed roof he needed to repair. "We just had to go up there and measure some roof sheets to be replaced. "I was walking along the beam, like you should do when you're on the roof. I was stepping over one of the clear sunlight strips on the roof when I slipped – the strip was very brittle and cracked and I fell through. It was six metres to the ground.

"Waiting for the ambulance," says Felicity, "I was in a lot of pain and short of breath but, in between breaths, I remember telling Andrew that I couldn't feel my legs. I realised it was bad but just kept focusing on the pain and my breathing." A helicopter took Felicity to Royal North Shore Hospital where she was diagnosed with broken ribs, a bruised lung and a fracture of her T12 vertebra, resulting in an incomplete spinal cord injury. The paraplegia meant Felicity would need to

adapt to life as a wheelchair user.

Rehab routines

She spent two months in North Shore and then another three months in Royal Rehab in Ryde.

"I liked the structured system in rehab," she says. "You had the physio routine, then recreational stuff. You still had a lot of free time, but lunch and dinner was communal where you had to sit down with everyone.



They taught you all the practical things like going down the street, crossing the road and dealing with gutters. So when you got home, it wasn't such a shock.

Felicity dismounts onto the ute while her support worker Sandy holds Fancy.

"They taught you how to dress yourself, to transfer on and off your chair. And all the practical things like going down the street, crossing the road and dealing with gutters. So when you got home, it wasn't such a shock.

"If you were interested in particular things, they organised to get you back into that. They took me out to Box Hill where I got on a horse and rode around on my own."

Getting stronger

Back on the property at Cowra, modifications were needed to Felicity and Andrew's house so Felicity could live independently.

"When I got home I kept doing physio and we set up a gym in the house. I also started doing hydro in the pool."

Felicity says she's got stronger over time.

"I can stand up using my right leg. It's not really functional, but it helps with rehab and improving bone density.

The hardest thing when he was a baby, was putting him into the cot, but most of the things that you think would be a problem you work your way around. "Being in a wheelchair hasn't bothered me as much as it might some others. It's the cards I was dealt. You just keep moving forward. But I did have a lot of support, especially from Andrew. By 2019 Felicity was pregnant and Elliot was born in September on her

grandfather's 80th birthday – so Elliot is named after him.

"The hardest thing when he was a baby, was putting him into the cot, but most of the things that you think would be a problem you work your way around – you adapt and you just have to be organised."

Finding Fancy

Felicity was keen to get back into equestrian competitions.

"I knew to get back into the saddle I'd need a stock horse - they're quiet and sensible. So early last year I bought one with the registered name "Barnetts Fascinator-HSH" - we call her Fancy.

"And the lockdown last year was good for us because I could just practise, and Fancy and I could get to know each other. She's got the right attitude and has adapted easily.

"I can manage most of Fancy's maintenance. I can take her rugs off and brush her. But my support worker, Sandy, comes each day and saddles Fancy and holds her beside an old farm ute we use as a platform. I go up a ramp onto the platform in my wheelchair and I transfer myself onto Fancy with my arms.

"I don't really need anyone around when I'm riding her, but it's best if there is as horses do have a mind of their own.

"Dressage works best for my type of disability as my balance point is further back. I don't have the strength to get forward enough in the saddle for eventing or jumping.

"So I'm classed as a grade 3 para-equestrian. For that grade, there are specific aids that I can use – like I'm effectively tied to a modified saddle so my legs are secure, and I can ride with two whips.

"Dressage at my grade is only walk and trot. You need a powerful trot to get better marks. We've done some regional competitions since late last year against able-bodied riders. We're progressing well."

Paralympic hopes

Fancy turns five in August which is when she's allowed to compete in specific paraequestrian events. And Felicity is thinking about the Paralympics in Paris in 2024.

"But that might be too soon for us. And funding's a big issue for overseas events. So I might have to wait till 2032 when hopefully the games will be in Brisbane."

Connecting through Creativity

Your story through art

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



We were blown away by your responses to our first *Shine* Art prize and we're very pleased to present our 2020 winners. Thank you to

Shine

ART PRIZE 2020

> everyone who submitted entries, the judges had a very difficult time selecting the winners. Scan the QR code to view the full online exhibition or click **here**.



Overall Winner

Alison Packwood

Title *April is still the cruelest month* **Category** Drawing

Description "April is the cruelest month" is the opening line of the T.S Eliot poem "The Waste Land".

Alison uses this as a metaphor for how life feels following a car accident. The coloured sections represent different aspects of the artist's life since the accident including her physical and emotional health.



Sculpture category winner Craig Bridges

Title *Where's all my homes* gone

Category Sculpture and 3D

Description This abstract piece is Craig's tribute to the NSW bushfires and his liking for using opal. He lost his home in the bushfires and had been thinking about the animals that were killed in the fires, especially the koalas.



Drawing category winner Sally Crossing

Title Keep your eyes to yourself

Category Drawing

Description Sally describes her recovery as slow and extremely micromanaged.

"Keep your eyes to your self" represents her dislike of being the centre of all discussions and conversations.





Digital Category Winner

David Taylor

Title True Love

Category Digital and Photography

Description David suffered a severe traumatic brain injury 20 years ago. He struggled to find a way to express himself.

His love of art proved to be a wonderful way to create something that challenged him and gave him so much satisfaction. This collage, created for his wife, is evidence that love shines through.

Painting category winner

Asha Prasad

Title Skull with Butterfly

Category Painting

Description This watercolour symbolises fighting death. Asha felt trapped in her own body like a butterfly wanting to fly, but unable to.

She saw the death of who she was and of the entire life that she had built. The skull represents death. The butterfly symbolises hope, strength and determination.

Andrew Njemanze: wheelchair entrepreneur

Andrew is a Lifetime Care participant

Andrew on holiday in San Francisco.

The personal trainer felt a sense of hopelessness after his spinal cord injury six years ago. He is now building a video and photography business and has a renewed sense of purpose.

Andrew was born in Nigeria and migrated with his parents and younger brother and sister to Australia in 2001 when he was 13.

Loved the sport

"My first name is actually Chetachi, which means 'remember God', but I used my second name, Andrew, when we came here. My father was a politician back in Africa. I think he felt unsafe and wanted a better life for his family. We spoke English at home and Australia seemed a good place to go."

"I went to Ashfield High and loved it, but mainly for the PE and the sport. I played soccer mostly, although I had the height of a basketball player. It wasn't that I couldn't be academic, I just didn't care for it. Soccer was my jam until school was over.



"I did start a law degree, but after a year I thought this is so boring and got a job doing tech support at Optus. You wouldn't say it was fulfilling, but I stayed there five years. I guess I was trying to figure myself out. I learnt a lot about teamwork, how to persevere, how to deal with people in offices."

Fitness and photos

"But the real core of what I did at that time was fitness and body building. Then I thought, why not try and do that for a living?

So in 2011 Andrew started working at Fitness First in the city as a personal trainer. He did photography gigs as well.

"I was even a paparazzo for a while – staking out celebrities – but also did weddings and lifestyle shots. By 2015 I was 27. I felt I was at the cusp of becoming someone who knew what they wanted to do."

One morning in May that year Andrew was heading to work on his motorbike from the family home in Ashfield.

At an intersection Andrew had the green light, but confused signalling between two bus drivers led to Andrew driving straight into the side of one of the buses. "My head was pushed into my chest. I never lost consciousness and I remember the heat of the road and the terrible pain and thinking about my parents – like all immigrant parents – wanting so much for their children."

Andrew was in hospital and then rehab for nine months. The accident had severed his spinal cord at the T3 vertebra. He was now a wheelchair user with limited strength in his upper body.

A big toll

One of those Andrew met in hospital was a peer support education officer and also a Lifetime Care participant called Heidz Haydon (see Heidz's story in *Shine* Spring 2015).

Heidz recalls that she and Andrew just clicked. "We were the same age," she says, "we had the same injury level and were both keen bikers."

"The accident had taken a huge mental toll on him because he'd been so active, and with body building it's what you look like that's important. So being in a wheelchair was terrible for him. He was feeling, what's the point, what's the point of anything? It was very sad."



Directing a photo shoot.

"So he was reserved at first but then slowly came out of his box. He had a lovely sense of humour – in fact he was hilarious! And he really did well in rehab."

New home

But Andrew found it hard returning home.

"It was so disorienting – like a familiar environment you no longer belonged to. Before I was used to being tall, but now I was short and having to look up at everyone."

The rented family home needed modifications to accommodate Andrew, but the owner wouldn't cooperate, so the family had to move to a larger house in Concord.

"The rooms here are bigger so I can move around in my chair. But the only thing we've had to add is a ramp. I try to be as less obviously disabled as possible!"

"I felt I had no prospects, that I was starting at Year Zero again. I thought I can't go back to being a personal trainer; I can't do photography."

Learning about film

But Andrew had the time to work on it, and eventually he returned to both previous careers.

He wanted to go back to work at Fitness First and they were keen to accommodate him, but at first just the travel into the city terrified Andrew.



I've seen Andrew grow from someone who thought there was nothing to look forward to to someone who has got so much purpose. He's just a beautiful and successful person!

Working out at Fitness First six months after surgery.

"One day I just froze in my chair on the footpath. I couldn't work out how to go down the slope. I just stayed there for an hour trying to look as if I was enjoying myself. I was too embarrassed to ask for help and no one offered it. Eventually I just got a cab home.

"But I made myself go into town again. And now I go in most evenings to see three or four regular clients.

"With the photography, I knew I was going to have trouble lifting cameras. I've always liked creating images so I started watching YouTube videos about how films are made. I watched lots of indie movies. I really like the Coen brothers' films, their slow pacing, the way they do more with less. I did a bunch of online courses on cinematography – I'm still doing them."

It's my vision

"I started doing commercials for free. I'd organise the crew and the talent – often it was calling up friends.

"It's now starting to pay off for me, and my business, T-rex Productions, is taking off. I guess I'm more of a director. People come to me with an idea and I can conceptualise it. It's my vision that gives it value. I get a lot of fitness-based commercials and promotions and now I really want to go from commercials to film." Andrew now has a Batec attachment for his wheelchair that turns the chair into a motorised scooter.

"I first saw one ridden by Heidz when I was in hospital and I thought I want one of those! It's got big tyres so it can go over rough terrain. I can take it on the footpath or on the road, or on flattish hiking trails. I feel invincible with it. It makes me feel part of the human race!"

Andrew has gone overseas a number of times since his accident. "I love travelling and I love the great outdoors. New Zealand is my favourite place on earth. I love the fiords and the mountains – so beautiful and peaceful."

Heidz and Andrew keep in contact. "I've seen him grow from someone who thought there was nothing to look forward to," she says. "He's now someone who has got so much purpose. He's just a beautiful and successful person!"

To see Andrew's work visit www.t-rexproductions.com

Going home was so disorienting - like a familiar environment you no longer belonged to.

Jess Emeny: sister, daughter, young carer – her own person



Jess with Jarrod after his accident.

When Jess Emeny's brother broke his back in a car accident it changed her life too. She has written her own honest and emotional account of being the sibling of an accident survivor.

I feel different. Yet I am not the one with a physical injury. In most aspects of my life nothing has changed. I can still have the life I had always wanted. I can still have my planned career. I can have a family. But I feel the grief. I feel like I could never be the same person I was before 7 July 2018 when my brother Jarrod's life completely changed.

Feeling different

A severed spinal cord. He knew it before we'd even had scans. And he was okay with it. He wanted a green wheelchair he told us as we surrounded him in the emergency room.

I can walk. I can climb stairs, but I feel different. Every day I carry this weight. Some days I forget that it's there; other days it is all consuming. It's been three years since the accident and thinking of those first moments can still undo me.

Every day I carry this weight. Some days I forget that it's there; other days it is all consuming.

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I am a teacher now. I finished university as planned. I was determined to make my parents proud – as if my success would somehow lift the pain we all felt. I graduated with great marks and it was the best day of my life.

But these days I catch myself summarising my years of university with the traumas that punctuated my studies, rather than my personal successes.

A few weeks ago I was reading the novel "Wonder", a story about a boy with severe facial deformities, to my Year 5 class. We reached the section where Via, the boy's sister, explains what it's like to be a young carer and how our needs are often put on hold to support those around us.

Family dynamics

Of course, we understand this but at the same time find ourselves lashing out and becoming frustrated. It can be so isolating. I remember the first time I spoke to Mum about it and explaining that I felt I was no longer their child. There had been a big shift in our family dynamics. I could understand why, but I was also horrified at how resentful and angry I had become. Angry at my parents, my friends, my community. Everyone was always asking about my brother. The support was overwhelming for our family and yet I was uncomfortable answering their questions. It made me angry and I hated that I felt that way.

I started ordering my groceries online because I couldn't handle people asking me about my brother in the supermarket. When I'd hear the word inspiration I wanted to vomit.

My family was moving on with life but I was stuck. I was angry and I felt alone. Like no one was looking out for me.

I remember a discussion with a psychologist only a few weeks after the accident where I was explaining how I felt, and she cried. She was the first person who showed me that my feelings were justified and real.

I was so afraid of upsetting my family and drawing attention away from Jarrod that it wasn't for months that I spoke as freely again.

Then, with perfect timing, icare provided a wecare mentor. I found out about the structures in place to support carers. I could relax knowing Mum and Dad had other supports.



With her parents Carolyn and Michael.

Safe with a mentor

Mum and I have a wonderful relationship but there are things we can't talk about because our first instinct is to protect each other. That is what's so hard about being a young carer. Not only are we caring for a sibling but our parents – listening to them, running errands, keeping our own problems to ourselves. And at the same time they're looking out for you. It's a difficult situation to find a balance in.

Immediately I felt safe with my mentor. I learned there are a lot of other siblings out there who feel like I do. My mentor listened to me, allowed me to cry and process.

We unpacked my recent life events, my reactions, and every time she validated my emotions. My inner voice was telling me I was being dramatic and ridiculous, but I also couldn't control these emotions. I knew I couldn't ignore them forever. We developed strategies and made plans.

We met regularly. We spent a lot of time working on managing my new relationship with my family and community. My mentor prompted me to have conversations with my parents and to share how I was feeling.

In the classroom.

I am so proud of my family. We have come out on top after so much adversity. I can now recognise these triumphs because I've learned to be grateful.

I am still learning though. Occasionally the feelings of resentment return followed instantly by anger at myself for feeling this way. At these times I need to reflect on how well I have been looking after myself. Have I been giving myself space to feel? Have I been speaking up when something bothers me?

The burden remains

I am who I am today because I am a young carer. I care deeply for others and understand how important it is to speak up.

My brother lives a few hours away from me now but the weight that I carry is still there. Even if he lived on the other side of the world I'd still be a young carer. I'd still read Via's story and tear up because I understand how tricky a situation it can be. How wonderful it is to see someone you care for so deeply succeed and be happy for them. I now know I am not forgotten.

Each day I get up and I remind myself that I am resilient. I am a young carer and I am stronger than I think I am.

See Jarrod Emeny's story in *Shine* Summer 2020.

Supporting young carers

By Lizzy Bowles, Children and Young People Mentor – wecare program, and mentor to Jess.

For many young people it can be hard to manage emotions after traumatic events and often, like Jess, they feel alone or forgotten when other family members are consumed by the rehabilitation of a loved one. Every young person thinks and feels differently and will experience different challenges.

wecare: for young people

The wecare program supports icare families, with services for adults and young people.

The Children and Young People's Program provides tailored support for those aged 5 to 25.

Each participant in the program is assigned a mentor who uses age-appropriate resources to help the person:

adjust to additional roles and responsibilities with their loved one

understand and identify with their caring role

make informed choices, and

discover strategies to manage and regulate emotions during difficult times.

The program hopes to increase the wellbeing and resilience of young people and connect them with long-term support where necessary.

Find out more

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

Visit: <u>www.carersnsw.org.</u> <u>au/services-and-support/</u> <u>programs-services/wecare</u>, or talk with your icare contact.

Michelle and Terry

Happy and healthier with volunteering



Being a volunteer has lots of benefits. It can help you make friends, learn new skills, and even feel happier and healthier.

Michelle and Terry were both having trouble reconnecting after sustaining brain injuries, and both struggled with depression and loneliness. Their stories show the positive power of volunteering.

The 3Bridges Inclusive Volunteer Program

Funded by icare – 3Bridges, a community organisation – developed an Inclusive Volunteer Program for people with brain injury to do meaningful and worthwhile volunteer work.

The team use a "buddy" system - with every volunteer matched to a buddy. The buddy supports the volunteer every step of the way. Read on for how Michelle and Terry bridged the gap after brain injury.

See more at www.3bridges.org.au

Want to try volunteering?

- Talk to your icare contact about opportunities.
- People with a brain injury in Sydney and interested in the 3Bridges program contact:

P 1300 327 434

E <u>AlliedHealth@3bridges.org.au</u>



Michelle (right) and her buddy Erica.

Michelle - finding meaning and fun

Michelle left China at 15 to study as an international student in Australia and create a new life for herself. Her family remained in China and a host family in Sydney became her home away from home.

The intensive English lessons Michelle took before leaving China paid off. She enjoyed life in Sydney, settled in Year 10 at school, made friends and worked part-time as a waiter.

But Michelle's new life was unexpectantly turned on its head. Attempting to cross a busy road she was hit by a car, thrown into the air and struck by another car. She sustained a severe traumatic brain injury and physical injuries, and spent many months in rehabilitation.

Starting over again

Michelle faced big challenges – she was a young girl in a foreign country with a severe brain injury and a language she was still trying to master.

Her family had flown over to be with her but eventually had to return to China when their visas expired. COVID border restrictions mean they've not yet been able to return.

"I was depressed for a long time and the injury made me feel very low," says Michelle.

But, with the help of Lifetime Care, her rehab team, case manager and support workers, Michelle returned to her studies and continued living independently.

Things started to turn around when Michelle registered for the volunteering program with 3Bridges. "After my brain injury the volunteering program helped me open up more to other people." It makes me happy to meet other people, I feel like a normal person again.

Michelle was matched with a buddy, Erica. Together they spent 12 weeks at a charity, putting food hampers together for people experiencing homelessness.

"After doing the volunteering I found my value again as a person and my life became more meaningful."

Life is brighter for Michelle she's made new friends and still catches up with Erica.

"I'm better at talking to people now, and I can be social at volunteering without my buddy," she says.

Now 21, Michelle is much less nervous about meeting new people and getting out more.

"I have made friends and can have fun. I was more comfortable doing this because I practised with a buddy first. Volunteering makes my life more meaningful, and it makes me feel happier."

Michelle is looking forward to new adventures and possibilities ahead and, more volunteering!

It makes me happy to be helping other people. The important thing is doing something – it's much better than staying at home.



Terry's buddy Lee with Terry.

Terry – a need to work

Terry has always been a busy man – putting in long hours in the fast-paced world of logistics while working casually as an Uber driver.

Originally from Korea, Terry, his wife Julia and their two daughters, migrated to Australia a decade ago.

In 2017 Terry was hit by a car while walking, sustaining a traumatic brain injury that impacted his ability to plan, organise and complete complex tasks. He couldn't return to the high-speed world he knew and he lost a lot of his sense of connection and purpose.

For Terry it was important to go back to work. He knew his old job was now too challenging, but he needed something to do.

"My accident left me feeling very depressed," he says. "I want to work and to help others".

Terry tried a few trial work placements but found them challenging and he also struggled with language barriers. But things improved when he started the volunteering program with 3Bridges and worked with a buddy.

"Having the buddy was much better for me. Having someone to talk to while you do your work who cares for me is good."

Terry began volunteering once a week at Meals on Wheels in Willoughby with the support of his buddy Lee.

"Lee helps me feel like a normal person, she knows about my accident, she understands and that makes me feel better."

Growing in confidence

"My English is not good so I talk with my buddy to help me communicate. Before I had no-one to talk to, now I have Lee. I want to work with other people and be able to talk with them." Terry's conversation skills are picking up and he's growing in

confidence.

"Things are getting better, it makes me happy to be helping other people. The important thing is doing something – it's much better than staying at home."

Terry's still eager to get back to work and the volunteer program is helping him rebuild his work skills one step at a time.

"It makes me happy to meet other people, I feel like a normal person again. My main goal is to work but it's better being able to talk to other people."

The notice board

Sharing your news highlights, handy information and upcoming events.



Fred's captaincy honour

Fred Tabia was assaulted while working in security in 2013 and has been living with a traumatic brain injury ever since.

Fred was recently named captain of the Country Team in the NSW Physical Disability Rugby League competition. Fred regularly plays in the comp and the team has opened games for some of the first grade teams. They didn't win the big City v Country clash this year, but Fred led his team with pride and commitment - welldone Fred, and watch out for more of Fred's story next issue.

Interested in playing physical disability rugby? Check out their website **nswpdrla.com.au**



Jon's superstar award

We met Jon McWilliam back in our Shine Summer 2019. Jon shared how his volunteer work at Griffith Public School had given him purpose and fulfilment on the road back following his brain injury. In a community recognition and thankyou event last year in Griffith, with over 100 volunteers in attendance, Jon was awarded the "Superstar" volunteer's award, recognised for his outstanding service, and described as a person who "brightens the office". **Congratulations Jon!**

Helping younger adults with a brain injury thrive



Cerebral Palsy

icare has partnered with Cerebral Palsy Alliance to deliver a range of programs for people aged 18 to 35 years living with traumatic brain injury. Programs include one-on-one coaching, social workshops, structured peer support and group getaways.

The programs help participants connect with others while developing skills, building independence, confidence, and having fun in the process.

The first round of programs have recently finished with great feedback.

Interested in taking up the challenge?

Visit <u>www.cerebralpalsy.org.au/icar</u>e for more info or phone **1300 888 378** or email <u>ask@cerebralpalsy.org.au</u>

Support for families

The wecare program has expanded its range of family supports and is now offering:

- 1:1 mentoring and support programs for family carers
- online peer support meetings
- small group-mentoring sessions
- online carer education modules to access in your own time.

What people have said:

The group is such a great lifeline for me to have a laugh or a cry at whatever life is dealing us, in this crazy caring journey. I crave that hour every month to have time to get together. Zoom makes it so easy to join.

It's great to be able to discuss things with others and learn strategies to cope. I think being in a group situation gives us an opportunity to learn from others.

More information P: **02 9280 4744** E: <u>wecare@carersnsw.org.au</u> A message from the Agency for Clinical Innovation (ACI) pain management team.

Understanding chronic pain

Chronic pain is common after a brain injury or spinal cord injury, but it doesn't need to stop you, your child or your loved one from living life.

By developing an understanding of pain, and the connection with fatigue, sleep, depression, anxiety, and physical activity – along with using a few simple tools and help from the experts – you can learn to manage chronic pain.

The Agency for Clinical Innovation has developed specific resources to target chronic pain.

Be Pain Smart Clinics

- are available for children and adults with a brain or spinal cord injury in NSW
- are staffed by doctors, nurses, physiotherapists, and psychologists with a specialised background in pain management working together
- provide a full pain assessment and an individual pain management plan for all attendees
- are free of charge and telehealth services may be available for people in rural and remote areas
- contact for young people: Natasha Haynes – <u>natasha.</u> haynes@health.nsw.gov.au
- contact for adults: Regina Schultz – <u>bepainsmart@</u> <u>royalrehab.com.au</u>

Pain management resources and online support

For lots of easy-to-use information, resources and tools about managing and understanding chronic pain visit the Agency for Clinical Innovation's Chronic Pain and Brain Injury website: <u>aci.health.nsw.gov.au</u> > chronic pain > brain injury.

More information

If you're not sure if the clinics are for you, talk with your icare contact who can help with making a referral or finding out more.

icare has been working with ACI, the lead agency for innovation in clinical care in NSW, to support painmanagement initiatives for people with severe injury.

Junior Wheelies Holiday Camps

Remember Raphy from the last issue and how much he loved his day out at the the Junior Wheelies Holiday Camps? The camps are on every school holidays.



Who: for ages 6-18 to have fun and give wheelchair sports a try.

Where: Newcastle, Narrabeen & ACT

Visit <u>www.wsnsw.org.au/</u> junior-wheelies-camps or call Joe Shoebridge on **0439 743 777**.

Ricky Kemp: back at work

Ricky is a Lifetime Care participant

How Ricky found his spark after a spinal cord injury and was able to return to work.

Raised in a small rural town south of Cowra, Ricky married in his early 20s and started an apprenticeship in the local electrical contracting business run by his wife Julie's parents.

"I worked with my in-laws for 15 years before changing tack and going into the powerline maintenance industry with Essential Energy."

Ricky was driving to work in 2015 when he flipped his car. An incomplete C4 spinal cord injury left him with no use of his legs and minimal use of his arms and hands. He was in hospital for more than eight months.

"Essential Energy were good to me - they kept paying me for six months after the accident but eventually they had to medically retire me.

"I didn't think I could go back to work as there aren't that many opportunities for people in wheelchairs in country areas. And I can't really use my hands.

"But I got sick of looking at the same four walls. And there's only so many hours you can spend watching Netflix," says the 49-year-old.

When are you coming back?

"So in 2018 | started looking at possible jobs but never followed through with any applications."

Then two years ago his father-in-law Bruce left him a message: "When are you coming back to work with us?"

"I wasn't sure he was serious," says Ricky. "But I rang him back and he said he was extremely serious."

55 I got sick of looking at the same four walls. And there's only so many hours you can spend watching Netflix.

We'd love to hear from you!

Would you like to share your story or news in Shine? Email shine@icare.nsw.gov.au or call 1300 738 586.



Shine online

Scan the QR code to view the online edition or click here.



There were a few hurdles to jump before Ricky could start the new job.

"My spinal specialist needed to do some tests to give me the all-clear. And then the company needed to make workplace modifications which icare has paid for - like automated door openings and the appropriate heating and cooling since people with spinal cord injuries can't regulate their body temperature well.

"So instead of being a tradie, now it's mainly admin - taking calls, quoting and booking jobs, serving at the counter."

Help from an app

Ricky uses a stylus attached to his wrist to work on the computer.

"It's a bit slower but it works. "And a lot of the automation is run through my phone - like the app to operate the doors, the aircon, the remote mouse on my computer. Without the phone I couldn't do anything.

"I'm having a lot of fun with the job. It's full-time except I take every fourth Friday off.

"I've always loved the electrical business and this new role keeps me in the industry."



