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“I’m going to get up and write about my life.”
Meet Elise Speirs, page 4

Shine

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

Summer 2019



John Aloisi: adjusting to life with a spinal cord injury

John is a Lifetime Care participant

Dear all

As the recently appointed Group Executive Care at icare, I'd like to welcome you to the summer edition of *Shine* for 2019.

Shine, now in its ninth year, provides an opportunity for Lifetime Care and Workers Care participants to share stories about life after a motor accident injury or work place injury. These stories provide insight into what is possible and inspiration to keep striving for all that is achievable. They are also a reminder that we can never stop improving the support we offer.

We provide care and support to 1457 Lifetime Care and 322 Workers Care participants. We understand that for those living in rural and remote areas, it can be hard to access support services and maintain social connections. I hope these stories help break down some of the barriers created by geography and build connections with people sharing similar experiences.

In this edition of *Shine*, we hear many inspiring stories including Matthew, who received a Citizen of the Year Award for volunteering in his community of Narrandera, and Elise, who ran in the City to Surf race in Sydney. Each of you have a unique story to share and I look forward to hearing more in coming issues. It is through these stories that we grow a community of support and promote the possibilities that life offers.

With the Christmas season upon us, I'd like to wish you all a safe and happy holiday season.

Regards,

Dr Nick Allsop
Group Executive Care

John Aloisi was born in Griffith 58 years ago and the area has been his home ever since.

"My parents had come out from Italy as teenagers," John tells me in his house beside a large irrigation canal. "They were both from Verona. My dad worked as a truckdriver then bought a citrus farm." "After school I did a motor mechanic apprenticeship then worked as a mechanic for eight or nine years, but I knew I didn't want to do that all my life. I then worked at various things - in a bar, a slaughterhouse. My dad helped me buy a citrus farm like his."

He married Yvette when he was 24 and they have two children, Brooke and Blake.

Then about 15 years ago John started driving gas tankers - only daily trips around the Central West so he could look after the farm and maintain family life with his young children. He enjoyed the work.

Accident in the fog

Then in 2012, on the Lake Cargelligo to Condobolin road in a heavy mid-winter fog, John missed a reduce-speed sign. "I went straight through a t-intersection, over an embankment, hit my head and broke my neck."

“After what I went through in hospital, I can't complain at where I'm at now.”



Front cover: *Elise Speirs* (left) at home with her sister Denise, see story page 4.



He was taken first to Orange Base Hospital. “They were going to send me home on the second day. They didn’t realise that my neck was broken. I then went to Royal North Shore then finally to rehab at Prince of Wales for two and a half months. The staff there were just fantastic.

“ I’d been an active, outgoing person, and here I was having to take food from straws, being washed and crane-lifted everywhere. ”

“But I’d been an active, outgoing person, and here I was having to drink coffee through a straw, being washed and crane-lifted everywhere. And the accident had come only a few weeks after I’d lost my dad to cancer. So it was a hard time, I really felt I didn’t want to be alive. But Yvette was there 24/7, living out of a suitcase near the hospital, so that was very hard for her too – with a six- and eight-year-old at home. My niece moved in to help.”

When he came home, John had permanent screws between the C3 and C5 vertebrae in his neck. It wasn’t easy; he still needed help with basic tasks like getting dressed.

“I was off work for almost a year. I went back to driving but was only doing one day a week then slowly built up to full time. But I’m restricted in what I can lift, so about three years ago I moved to courier work. I do about three hours a day, and the rest of time I work on the farm – spraying, watering, organising the pickers for the oranges. It’s not that hard to manage.”

Nothing to complain about

“It’s still difficult for me to use my fingers for detailed movements like doing up buttons and I still can’t bend my neck back. I’ve still got pain in my right shoulder and hips, but it’s not major. If I drop things I tend to kick them around before picking them up. At least I don’t need drugs for the pain any more.

“But after what I went through in hospital, I can’t complain at where I’m at now. I can still drive. I can still work. And all four of us flew up to Cairns for a holiday earlier this year.

“Lifetime Care has been fantastic. They’ve organised all the modifications I need, like rails, and locks and handles that I can manage with my fingers. I can’t really complain about anything.”



Elise Speirs: putting her life back together

Elise is a Lifetime Care
participant



Getting back to yoga was one of Elise's first rehab goals.

Soon after returning to Australia following the end of her marriage, Elise had a car accident resulting in severe brain injury. Yet the South Coast midwife is keeping active and positive.

Elise Speirs greets me with a smile and a soft Scottish accent in her sister Denise's house in Ulladulla. Elise emigrated from Glasgow with her parents and four siblings in 1981 when she was 16.

"I was terribly homesick," says Elise, "but later when I went back to Scotland in my early 20s, my friends had changed and my family had either passed on or moved away. I thought, seriously? This was what I was crying about?"

They lived in the Illawarra area, and Elise followed her mum into nursing, later doing a masters in midwifery at Wollongong Uni.

She married a young GP named Tim in 1996, and they moved to the Southern Highlands where their first two children, Olivia and Alexander, were born.

“It's a stage
in my life and I'll get
through it one step
at a time.”

Moving overseas

Five years later Tim and Elise moved to the Middle East. "I didn't particularly want to go, but Tim was keen to work there and I figured I could do anything for two years."

They started off in Dubai, later moving to Saudi Arabia and a third child, Nathaniel, joined the family.

However the two years stretched into 17.

"I had a wonderful time in the Middle East," she says. "In many ways it was a great adventure. The Saudi landscape is amazing and I saw and did amazing things. But I was very trapped. I couldn't drive, I couldn't work. I did volunteer work in preventative medicine and ante-natal education and when I finally did get a job with John Hopkins Hospital in Dhahran, by then my marriage was breaking down."

With the older two children at university in Canada and the United States, Elise returned to Australia with Nathaniel in late 2017.

"Denise suggested I move to Ulladulla and stay with her and her husband Con. I was commuting to Wollongong Hospital where I'd got a job as a midwife but was keen to settle and work in Ulladulla."

On a mountain road

In March 2018, Elise drove Nathaniel to Canberra to catch a bus back to his new boarding school.

"The last thing I remember as I left the city to return to Ulladulla was waiting at the traffic lights and how beautiful and sunny the early evening was," says Elise.

But an hour later, with rain pouring down, Elise lost control of her car on a notorious bend of the mountain road east of Braidwood. It wasn't until the next morning, 13 hours later, that Toby, the driver of a Bunnings van, noticed the glint of a car down a ravine. He climbed down to the car and saw Elise inside. "I was a purplish-blue colour. He thought I was dead," said Elise, "and called triple-zero to report a death."

After hearing a groan and realising that Elise was still alive, Toby clambered into the car, held her hand and talked to her until help arrived.

Elise was taken to Canberra Hospital with multiple fractures and dislocations, lung clots and a severe brain injury. A day after admission, blood from the brain bleed had blocked up and the prognosis was "very negative".



VIP

Returning to work can be an important part of rehabilitation for people with a brain injury.

The Vocational Intervention Program (VIP) is for people with a brain injury, such as Elise, who want to go back to work – either back to their previous workplace or career, or into new work.

The program works by building networks between job service providers, people with brain injury and their families, and clinicians. It aims to reduce the barriers that arise when someone with a brain injury wants to return to work.

The benefits of VIP include:

- a focus on your interests, current skills and work goals
- tailored and graded work plans to suit your abilities
- supports and strategies to help you manage the job
- access to workplace modifications and equipment
- a coordinated approach for planning and managing your return to work.

Currently there are 20 VIP providers in the network providing services within 12 regions across NSW in partnership with local brain injury rehabilitation services. More than 100 people with brain injuries have been referred to the service with 21 already working, and many on the road to employment.

Contact your icare case manager for more info about how VIP could work for you, or visit www.aci.health.nsw.gov.au and search for VIP.

VIP is an initiative of icare and the NSW Agency for Clinical Innovation.

Elise at work in her brother-in-law Con's surgery.

But within a week Elise was sitting up and singing Queen songs. She spent a month in Canberra and another five months at Liverpool Hospital's brain injury rehab unit.

"I was incontinent for four months," says Elise. "And I was paranoid for a lot of the time in Liverpool, with hallucinations and vivid dreams. I gave the staff there a terrible time."

The brain injury means that Elise's memory, both short- and long-term, is still a problem. "But it's getting better," she says. "They say recovery from brain injury is a life-long thing." "And I always was a doer. To not be able to get up and go to work and do all the other things I used to do is incredibly stressful. So I rock myself a lot. It's a coping, soothing mechanism.

"And I've got diplopia, a sort of ghost or double vision in my right eye. The world looks to me like a Picasso painting. The doctors are hopeful that it will fix itself, but it might take a couple of years."

Keeping moving

Elise started running when she was in the Middle East. "I thought even if I can't work I can still use my legs, so I trained for a number of marathons starting with the Dubai Marathon in 2012 and completed it in just over four hours. I was so proud of myself! "This year my goal was to run in the City to Surf. It was hard

to organise as I'm not meant to run by myself. I had to arrange my physio and a friend to run with me in the actual race. But I finished in under two hours. I was overjoyed."

Writing her story

"When I was first discharged from hospital, I used to lie in bed and think, why am I alive? Then one day I thought, I'm going to get up and write about my life."

She has found the process of writing a great way to revive lost memories.

"It helps that I had told Denise a lot at the time about my life in the Middle East. She's been able to help me 'recover' some of the memories of what I did. And old emails and Facebook posts have helped too."

Elise has used icare's Vocational Intervention Program (VIP) – see box – leading to a day a week working at Con's medical practice in Milton. "I help set up the sterile equipment used in his procedures and also assist as a pair of non-sterile hands."

"One day I'd love to get back to nursing. But in the meantime, thank God for Green Slip insurance, for Lifetime Care and Denise and Con!

"It's been hard, it's been emotionally depleting, but I'm not depressed. It's a normal human reaction to what's happened to me. It's a stage in my life and I'll get through it one step at a time."

Wayne Churchill: dealing with chronic pain

Wayne is a Lifetime Care participant



Wayne was a successful builder until he broke his back in a traffic accident. It's been a long road for him and his family to pull his life back together.

Wayne grew up in Crookwell in the Southern Tablelands where his parents ran a small mixed farm. On leaving school he was offered an apprenticeship with a carpenter in Griffith where he worked mainly on commercial buildings. He met a local girl, Jenny, and they married when Wayne was 21.

"I didn't like the commercial work that much," says Wayne, "and when I finished the apprenticeship I started working with builders on the residential side. I just wanted to build houses."

"When I turned 30 I got my builder's licence," says Wayne, "and set up my own business. It was nearly all residential, some subcontracting to other builders, but mostly

custom-designed home and renovations. I've always found renos more interesting."

Jenny also set up her own business, as an accountant, and for over two decades the family prospered.

A bike ride to Sydney

But in 2011 everything changed. One of Wayne's daughters had moved to Sydney and Wayne was helping her fix up her unit. "I was going down to do the painting. I thought I'd take my motorbike as it was so much easier to park in Sydney. But I was less than an hour out of Griffith, near Harden, when I ran into the back of a car turning off the road."

Wayne says he can remember coming off the bike and hitting the road but the rest was a blur. He was flown to Canberra Hospital where he spent two months and was diagnosed with a break in his lower back. He spent another four months trying to build up his strength at Prince of Wales Hospital rehab unit in Sydney.

"I was just learning to walk with crutches when I finally got home," says Wayne.

While Wayne had limited mobility, it was the chronic nerve pain that was his greatest problem.

"It was just horrific," says Wayne. "I've got a type of paraplegia called Cauda Equina Syndrome. My lower vertebrae have been shattered and the nerves going to my lower body are just a jumble. The damage is too great for them to be repaired or to repair naturally. Even though I don't really have feeling in my feet it's actually my feet and the backs of my legs where I feel the pain rather than my back."

For six years after the accident, pain was the dominating issue for Wayne.

"It ruined my life for that time. When it was really bad I could be laid out for days, not sleeping or functioning. It was really tough on the family. There were times when I just wanted Jenny to put a pillow over my face."

Managing the pain

"I'd tried lots of ways to manage the pain without much success, and the heavy doses of pain medication left me drowsy and not really functional. Jenny was also worried about the amount of medication I was taking and started doing some research into a spinal-cord stimulator used as a pain-management tool."



Griffith is a major regional city in the Murrumbidgee Irrigation Area.

Population 19,144



“ The pain ruined my life for that time. When it was really bad I could be laid out for days, not sleeping or functioning. It was really tough on the family. ”

Wayne on his new three-wheeler Cam-Am Spyder.

The stimulator is a small battery device. Its wires run along the spinal cord and provide a pulse to different areas of the nerves and mask the pain signals going to the brain.

Wayne discussed the device with his doctors and took part in a trial to see if it might help him. After further consultation, the device was implanted in his lower back earlier this year. Wayne manages it with a remote control and was the first person in NSW to use one. “I haven’t had any bad attacks for quite a while now,” he says, “Although the device doesn’t remove the pain completely, it’s nothing like it used to be and I can now cut back on the medication.”

Back to building houses

It took Wayne a long time to adjust and come to terms with his injuries. He felt angry and depressed. And it’s really only in the last 12 months, since he’s been able to manage the pain, that his work has again become satisfying.

“ And when I’m on the back of that bike which I love the best, or when I’m in the water with that sense of freedom, I feel as normal as I ever did. ”

“I found that not being hands-on like I had been, not being able to lead by example, very difficult. The business of building houses is my passion but dealing with the disability and the nerve pain as well as managing the business was doubly hard. A few times I thought of getting out and said to my family that I couldn’t do the business any more.”

“But I’ve now got my head around it. I’ve adjusted to a more management and mentoring role. My family helps a lot and my youngest daughter now works in the company. And another daughter helps me in a new business I’ve set up organising clearance certificates for asbestos removal. Lifetime Care has helped a lot too – putting me through some useful courses.”

Back on the road

Wayne has always loved motorbikes. “But I don’t have the balance and the stability in my legs to ride a two-wheeler anymore,” he explains as he shows me his new three-wheeler Cam-Am Spyder. “Although my wife isn’t too happy,” he adds.

Earlier this year, Wayne set off on the bike by himself on a seven-day return tour to Adelaide. “Magic!” he exclaims. Apart from the bike, Wayne, now 63, didn’t have many hobbies apart from his family and work. “I was never one of those guys who played golf every Saturday.”

“But I’ve forced myself to develop other interests. I know you’re never indispensable in the building industry. I’ve collected bits of timber over the years from the building jobs and I want to build furniture for my kids and grandkids.

“I also work in the garden. There’s lots I can still do like hand-watering and riding the mower. I enjoy that, and there’s enough space for me to move around on my quad bike and do various jobs. “I’ve even built a cubby in the yard for the grandchildren.

“Lifetime Care has been really fantastic for me. If it wasn’t for them we would have been in trouble, big time. Jenny had her own business and was working hard but I didn’t earn a cracker for years! They helped us out where it counted.

“The pain used to be so bad for me,” says Wayne. “But when I read about others who are suffering nerve pain and can’t get out of bed all day, at least I know I can now get up and go to work. It makes me realise I’m so lucky.

“Although I can only walk about 100 metres by myself, I can do most things. I’ve got a modified car and I can drive down the street and buy a coffee. I can go to work. And when I’m on the back of that bike which I love the best, or when I’m in the water with that sense of freedom, I feel as normal as I ever did.”

Dean Walsh and family: living with the aftermath of severe brain injury

Dean is a Lifetime Care participant

Seven years ago Dean Walsh was a happy-go-lucky young farmer. Today he lives with round-the-clock support and can't speak, walk or eat. His family are doing the most they can to make his life as fulfilling as possible.

When we meet Dean, two of his support workers and his physio, Craig, are all working and joking with him. Dean, who lives in a specially modified house in Leeton, is in a minimally conscious state from an accident seven years ago.

Dean's dad Brian arrives and takes us through the background to Dean's story. Brian's father and grandfather were farmers in the area. "I've carried it on," says Brian, "and we've mostly stuck with rice and sheep".

A farmer at heart

Dean grew up on the farm about ten kilometres out of town, with his dad, his mum Jacqui and older sister Natasha. "He left school at the end of year 10," says Brian, "and mainly worked on the

farm. He was a terrific farmer – must have been bred into him. It just came naturally to Dean."

Apart from the farm, Dean loved fishing, music and riding motor bikes. "He was bit of a larrikin really," says Jacqui when I speak to her later. "An absolutely beautiful boy. And everyone just loved him. He was the sort of bloke who was everyone's groomsman."

Brian and Jacqui split up and Dean kept working on the farm with Brian.

"I remember my last conversation with him," says Brian. "It was the Christmas break in 2012 and Dean was heading away for a few weeks' fishing and camping with his partner. I was going to head off around Australia for three months the following winter and I would need Dean to stay on the farm, so I said to him: 'Have a good holiday, Dean, because you won't be having one next winter!' But of course it didn't turn out that way.

"Somehow the arrangement changed and Dean left the camp with a mate. We're not totally sure what happened, but it was a high-speed traffic accident and it was a severe brain injury."

Eighteen months in hospital

Dean was taken to the Griffith Base Hospital, then Woden Hospital in Canberra, and then Liverpool brain injury rehab unit. He didn't get back to Leeton for a year and a half.

"We had to make decisions at various stages about whether to have interventions or not," says Brian. "He got a couple of brain infections during the time in Liverpool and I reckon they did as much damage as the accident itself. But in truth he never regained full consciousness."

Dean lived out on Brian's farm when he came back to Leeton while a house in town was fitted out for him. icare funded all the modifications to the house and all the equipment that Dean needs.

While Dean is non-verbal, he can communicate with a few actions such as moving his head or raising his thumb.

“ He likes conversations about farming or fishing. He loves being touched and having people around him. ”



Leeton is in the Riverina region and is known as the "rice capital" of Australia.

Population 11,168



“ It might seem like a terrible life to some, but Dean’s extremely fortunate to have what he has. When he’s happy and it’s a good day, he really shows that. ”

Dean with his dad Brian and two of his support workers Krystal and Jayne.

“It’s hard to know how much Dean understands of what’s going on and being said around him,” says Brian. “Sometimes it’s really surprising what he responds to. Sometimes things from the distant past really brighten him up. He likes conversations about farming or fishing. He loves being touched and having people around him. “If you put the hours in you get better results.”

Communicating better

For the last couple of years Dean has been using a special electromyography switch called NeuroNode that sits on his skin. When Dean is asked a question, he can twitch a muscle to activate the switch, which sends an impulse to communication software on his tablet to say “yes”. “I think it’s made some difference,” says Brian, “but Dean still hasn’t progressed beyond yes and no answers.” Dean’s team of support workers have a special affection for him. One of them has been with him since he came back to Leeton from rehab. “He loves getting about,” she says. “We often take him out and he does *not* shut his eyes in the car. When the weather’s good we take him down to

the river or to the BBQs at Narrandera. He sniffs the beer – gets a kick out of that. And he loves the attention of kids, of them touching him. He’s got no anger.” “We’ve taken him to the pokies at the club. Once he stole my money I’m sure! Don’t know where it ended up.” “And he loves the Christmas lights. We do the whole Christmas thing here. Set up a tree and put presents for his nieces and nephews under it.” But Dean’s health is also fragile. “He lost some ground this past year,” says Brian. “Food was going back into his lungs causing aspiration. At one stage we had to bring in the palliative care team. “But he’s very resilient. I suppose it’s partly his age – he’s still only 33. And he was very determined as a young man. So I like to think it’s his determination or his spirit that keeps him going.”

Effects on relationships

“An accident like this destroys a lot of relationships. There’s no other way of putting it,” says Brian. “Dean had a lot of friends but you won’t see many of them now,” says Jacqui. “It’s too confronting for them. And his sister, his nieces and nephews, all suffer. We all miss the old Dean.”

“But one thing about a country town is you do get a lot of generosity and support,” she adds. “When Dean first came home we were able to raise funds in a few weeks to buy him a mobility vehicle. People we hardly knew were affected and helped out, and that has a flow-on effect. It helps raise the level of awareness of disability in the community and the rights of people who are disabled.”

Thanks for Lifetime Care

Both Jacqui and Brian are grateful for Lifetime Care. “The support from icare has been fantastic,” says Brian. “It’s an incredible scheme. You whinge when you have to pay your Green Slip insurance but when it comes to something like this you know its worth it.” “It might seem like a terrible life to some,” says Brian, “but Dean’s extremely fortunate to have what he has. When he’s happy and it’s a good day, he really shows that. “I come and visit him once or twice a day, and I think, how lucky am I. We don’t have the Dean who worked with me and went shooting and fishing but I’ve still got a young bloke whose spirit’s still there. I feel extremely lucky we’ve still got him.” “He smiles,” says Jacqui, “and we do the thumbs up. Nothing can replace Dean’s smile.”

Jon McWilliam: in love with life

Jon is a Workers Care
Program participant



Jon working in his home veggie garden.

Despite a serious accident 20 years ago that left him with a brain injury, Jon McWilliam has not let that stop him from being active and giving back to others.

Jon gives me a warm, enthusiastic greeting as he and Rob, one of his regular support workers, meet me at his front door.

Jon grew up in Griffith. His father and his grandfather were both winemakers – members of a well-known local wine family.

“I’ve always loved Griffith and lived here my whole life. It’s my home, my home town. I left high school in year 10,” he tells me, “to start a diesel mechanic apprenticeship”.

“For three years everything was good. I had a good life, with lots of friends. Although I guess I drank a lot and took recreational drugs, but I enjoyed living.”

A ute on a dirt road

“I was into the fourth year of my apprenticeship when the accident happened, although I don’t remember any of it. I was in a ute going out to a job with a tool box in the back. There’d been a lot of rain and I was about 20 kilometres out of town on a dirt road.”

John drove into a rut, hit a tree and was pushed forward into the steering wheel. The tool box flew from the back and hit him. At Royal North Shore Hospital he was put into an induced coma for 28 days. He’d sustained a traumatic brain injury with a damaged frontal lobe.

“There wasn’t a scratch on me, no broken bones,” says Jon. “Just the damaged brain. The doctors told my family that it would be a miracle if I came out of the coma.”

Jon did emerge from the coma, but he had no memory of his life before the accident. He spent a number of months in Liverpool Hospital brain injury rehab unit and needed a wheelchair to move around. He continued his recovery at a rehab centre in Albury.

Like two left hands

On finally coming home to Griffith, his old boss Tony offered Jon his apprentice position back.

“But it was like I had two left hands. I did it for a couple of months but told Tony I’d have to let it go. I was still in post-traumatic amnesia. I couldn’t remember things, my mind couldn’t process things. I’ve tried other jobs – with the family wine company, as a green keeper, pruning on a farm – but it just didn’t work out.”

Jon also struggled with drug and alcohol issues. “I’ve realised,” he says, “that when you have an acquired brain injury, any alcohol or drug intake can be a problem.”

Jon had another accident during this time. “I lost coordination and rolled the car into a ditch. So I haven’t driven since. I hope to get my licence again sometime, but at the moment I’m a fit man and Griffith isn’t that big. I walk a lot.”

Jon has support workers to assist him five days a week. Rob, who is with him today, says “Jon makes his own decisions. We’re just here to help him with things like grocery shopping and doctors’ appointments. We’re his wheels. And a prompt so he remembers his shopping list, his medications.”



Like Canberra, and the nearby town of Leeton, Griffith was designed by Walter Burley Griffin and Marion Mahony Griffin.



“ If I can save one or two drivers’ lives, I can sleep easier at night. ”



Jon and his friend Tristan at bsmartwise in Sydney.

A buzz from volunteering

While he has struggled to sustain paid jobs, Jon has taken on volunteer work in the last few years and discovered what a difference that makes to his sense of fulfilment and purpose.

Every weekday he turns up at Griffith Public School at 8.20 for the school’s Breakfast Club and makes toast, juice and smoothies for the kids. “There’s lots of disadvantaged kids coming to school without breakfast,” says Jon. “I love helping out as I come from a relatively well-off family, and I realise what they’ve missed out on.”

“He also does a lot of other jobs around the school,” says Rob. “One role has led to another. We do the BBQs at sports carnivals, he does some gardening, and he also helps some of the slower learners with their reading.”

“Jon brings an absolute warmth and energy to the school,” says one of the teachers, Lachlan Date. “Everyone here just loves him. He’s proactive with everything he does, and has a great rapport with the students, especially those who have some learning difficulties. We just love having him and it would be a really sad day if he ever left.”

Jon also works for Meals on Wheels twice a week. “We go to the supermarkets who give us the food that’s nearly out of date and we take it to Meals on Wheels where we put it in boxes for the families who need it.”

Talking about road safety

Jon gets a real satisfaction from giving talks about road safety, particularly through the Traffic Offenders Program run by the Police and Community Youth Clubs. He goes to events in local towns and also in Sydney where police, ambulance officers and other experts present a range of scenarios to year 11 and 12 students.

“I get up and tell my story about having an accident and living with an acquired brain injury. At the end I say ‘Nobody can go until I get five good questions.’ At first you could hear a pin drop, then one person asks a question and then it snowballs.”

“Jon’s got a lot of confidence and his talks go down really well,” says Rob. “Usually he overextends his time and we need to tell him to sit down.”

“If I can save one or two drivers’ lives, I can sleep easier at night,” responds Jon.

Jon with Rob, one of his support workers.

Through the Sydney events he’s made a new friend, Tristan, who is also a Lifetime Care participant with a similar story to Jon’s and they do joint presentations. Jon is keen to join Tristan in talking at bstreetsmart, an initiative of Westmead Hospital’s Trauma Service which has become Australia’s largest educational road safety program.

In a good place

At 39, Jon feels that he’s reached a good balance with his life.

“I know my memory’s shot but I’m working on it. I get stuck on words and speak slowly, and I find it hard to start a conversation and keep it going. I’ve still got lots of problems with my coordination, my memory, my thinking skills.

“But there’s lots of good things. I love helping out at the local school and reading to my nephew on Facetime.

“I enjoy cooking for myself, growing veggies in the back garden, fishing and going to the movies and out for coffee.

“I absolutely love icare. It’s made a big difference to my life.

“I have a new love of life. Everything’s going beautifully. As good as I can expect. As good as I can hope.”

“ I have a new love of life. Everything’s going beautifully. As good as I can expect. As good as I can hope. ”

Tiera Warren: coming to terms with a brain injury

Tiera is a Lifetime Care participant



At 32, Tiera Warren is fit, friendly and at ease, but for most of the last decade it hasn't been that way. We caught up with Tiera and her Lifetime Care coordinator Rosie at Tiera's North Coast home in Kingscliff.

"I grew up in Grafton," says Tiera. "As a kid I played a lot of soccer at a high level - I was a centre forward - until I was 16."

After school Tiera worked mainly in bars before going overseas - to Europe - for about 10 months.

She was 20 when she came back to Australia and settled in Yamba, working as a cleaner during the day and in a pub at night. She cycled a lot, to and from her jobs. But one night, returning home after visiting a tavern on the other side of town for dinner and drinks, she was knocked off her bike by a car.

Tiera sustained a traumatic brain injury, as well as lacerations and facial and foot fractures. She was in a coma for about eight days and after discharge from hospital went back to Grafton to live with her mum.

Downward spiral

The behavioural changes and mood swings associated with the brain injury led to Tiera becoming increasingly dependent on alcohol and other drugs. She had anger management issues, fought with her mum - her constant and main support - moved around a lot and had run-ins with the law.

"I was told I had a brain injury but I didn't believe it," says Tiera. "I thought I was fine. I thought I could do what I did before the injury, pushing myself and working two jobs."

"I normally work in hospitality but after the accident it was very hard for me to keep a job for more than three months. After about a week, the pressure would become too overwhelming."

Rosie has been Tiera's icare coordinator since soon after the accident. "I've been with Tiera for over ten years now, except when she's gone 'radio-silent'. Because she moved around a lot, we sometimes lost contact and it made the support we could offer very stop-start.

"For a long time, I worried that Tiera would end up in prison - she came very close - or even dead."

Turning it around

The middle of 2017 was a big low in Tiera's life.

"I broke up with my girlfriend of more than six years and I just spun out.

"Somehow I realised I couldn't keep living this way and went back to Mum's in Grafton. I just slept and read. My psychologist Paula, in particular, kept me sane."

Tiera had starting seeing Paula, a Sydney-based clinical psychologist, early in her rehabilitation but the relationship had broken down.

“

I know I have issues and I'm OK with telling people that I have a brain injury. It's the first time I've done that because normally I don't want to tell people. I'm better now at opening up about things.

”

“In the past I wanted to be living my life as I wanted, but my brain wasn’t capable. Relearning takes time. I didn’t want to be different but of course I was.”



Tiera with Rosie: working together for over ten years.

“It had gone well until Tiera got mad at us and sacked us!” laughs Rosie. “I had to persuade Paula to take Tiera on again. Since then Paula has stuck in there.”

“I Facetime her fortnightly,” says Tiera. “And at least once a year we meet face-to-face. I talk to her about the bad things in my life, although there’s less of that now. She really is my angel.”

Tiera moved to Kingscliff in 2018 so that she could study at TAFE. She’s now completed Certificate III courses in Swedish Massage and Fitness, and enrolled to complete the Fitness Certificate IV course this year.

“In the time we’ve supported Tiera,” says Rosie, “she’s always been good at getting jobs. It’s just keeping them that’s been the problem. And she’s started lots of courses but not completed them. What’s changed is that Tiera now knows what her limits are. She has the self-awareness to realise that noisy environments such as bars are a trigger for her and that it’s better if she isn’t around alcohol. She deliberately hasn’t taken a job in 18 months. That’s an insight into pacing herself as she knew she’d be up late at night studying. And the fact that she’s finished the massage and fitness courses is so special.”

The best it’s ever been

Rosie says that Tiera’s story is powerful because there was hope.

“Everyone responds to a brain injury differently. It takes a long time to adjust, especially when the injury happens in adolescence or early twenties. The period of development as an adult is arrested and completely derailed. I think when you have an injury at that age you get this absolute frustration and anger.

“Sometimes you just have to stick in there. Some of the progress for Tiera is just her naturally maturing as she gets older.”

Tiera says that life at the moment feels the best it’s ever been. “I’ve got a couple of friends here in Kingscliff now. My partner has just moved into the flat with me. I play indoor soccer and go to the beach. I go to the gym a lot – in fact I’ve turned my addictions into gym work. And I’ve lost about 20 kilos.”

Tiera is very close to her five nieces and nephews ranging from six months to 16. “It’s a testament to Tiera’s new-found responsibility and sense of herself,” says Rosie. “Her siblings trust her to look after their kids.”

“I know I have issues and I’m OK now with telling people that I have a brain injury,” says Tiera. “It’s the first time I’ve done that because normally I don’t want to tell people. I’m better now at opening up about things. At TAFE I’ve been using the Disability Support Services. They give me extra tutoring and extra time with assignments. It reduces the pressure.

“In the past I wanted to be living my life as I wanted, but my brain wasn’t capable. Relearning takes time. I didn’t want to be different but of course I was.

“I want to go on and become a personal trainer. I’d really like to work in a gym with people who have mental health issues. I’d like to give something back.”



Improving quality of life for those living with a severe injury



The Quality of Life Fund was set up by the icare Foundation with a \$3-million investment to find innovative solutions to improve life experiences for people living with a severe injury, their families and carers. We're pleased to announce the four successful recipients who will partner with icare to develop these solutions. We encourage Lifetime Care and Workers Care participants to get involved in these new programs.

Restoring hope

HammondCare is adapting a successful evidence-based course developed for people with chronic pain. They will modify, refine and pilot it to make it relevant to the specific experiences and needs of people with spinal cord injuries.

The course aims to restore hope through exploring the value of connections and purpose and making a meaningful contribution following a spinal cord injury.

Empowering young people

Cerebral Palsy Alliance (CPA) will develop and pilot an integrated framework of programs called CPA Challenger. Challenger programs include coaching, self-development and work skills workshops, peer-to-peer mentoring and camps and getaways designed to empower young people aged 15-35 years with a brain injury to develop the skills to become more independent and live their best life.

Volunteering

3Bridges Community will develop and pilot an Inclusive Volunteering Program to help adults with a brain injury find volunteering opportunities in an organisation that suits their preferences, skills and experience. The program matches each volunteer with a trained buddy volunteer who has similar interests and compatible personality. 3Bridges will partner with community organisations, local councils and corporates to support them in providing volunteering opportunities. Volunteering can contribute to a sense of belonging and purpose.

Communication tools

Sydney University is developing three new online tools to improve everyday interactions between people with a brain injury and their communication partners. The tools aim to address the problems many people have with communication after a brain injury and include:

- a short online course to help anyone unfamiliar with brain injury to increase their confidence and knowledge in interacting with people with brain injuries
- an online learning module to support people with a brain injury to engage meaningfully and safely in social media (in partnership with Brain Injury Australia), and
- an online portal for a communication skills training program (TBI ConneCT) guided by a speech pathologist between the person with the brain injury and their communication partner.

Interested?

For more information please see the cover letter included with *Shine*, or email the *Shine* team on: shine@icare.nsw.gov.au



icare regularly looks to improve services and supports for participants. The Quality of Life survey helps us to identify any gaps in services and allows us to develop programs that meet your needs.



Quality of Life survey

Each year we contact the people we support to ask you to complete a survey to help us understand your feelings about your quality of life. The survey we use is the World Health Organisation's Quality of Life survey.

Why do we ask about your quality of life?

We want to make sure your needs are better understood and the support you are being provided with is making the most difference to you. Doing the survey every year helps us understand whether your feelings about your quality of life are changing.

How and when is it completed?

You might be asked to complete the survey with your case manager or icare contact as part of your MyPlan. If you haven't done this, you'll receive a letter from icare every year asking you to complete the survey.

How do we use the results?

We use this information to understand how participants are feeling about their quality of life and if this is changing over time.

The information helps us to understand gaps in services and where we need to provide more or different supports. Past results helped us identify problems that led to the development of the new Quality of Life fund programs, as well as peer support and specific psychological support programs.

MindSpot: the pain course for adults with spinal cord injury

Chronic pain can be far reaching and impact many aspects of daily living. It can also reduce wellbeing – see Wayne's article on page 6 of this issue.

We funded a research trial to see if the MindSpot Pain Course was suitable and helpful for adults with a spinal cord injury. Those who joined the trial reported overall improvement in:

- emotional wellbeing
- anxiety
- depression, and
- pain.

About the program

MindSpot offers essential information and practical self-management skills to help you:

- understand pain
- learn skills that can reduce the impact of pain on daily activities
- continue to manage your pain and emotional wellbeing afterwards.

The course is freely available and delivered online. You can work through it at your own pace, and choose to receive weekly support from a MindSpot therapist.

To find out more talk to your icare contact or visit the Mindspot website mindspot.org.au/pain-course

Strength2Strength program for families and carers

Strength2Strength is a program by Royal Rehab in Ryde providing information, support and strategies for carers and family members of Lifetime Care and Workers Care participants dealing with changes and challenges following traumatic injury.

Previous workshop attendees have told us that they appreciated meeting other people in similar situations and hearing their stories. They learned that they are not alone, and that there is hope for the future. They were able to access resources and develop strategies to manage challenges, including making time to look after themselves.

When

The 2020 program dates are:

- Spinal cord injury: 10 April, 9 October
- Brain injury: 13 March, 29 May, 24 July, 6 November.

Where

The one-day workshops are run at Royal Rehab in Ryde. For more information, talk to your icare contact, email Royal Rehab: candice.unger@royalrehab.com.au, or phone: **9808 9205**.

Matthew Whiteman: giving back to the community

When *Shine* first spoke to Matt Whiteman more than three years ago, the 17-year-old Narrandera identity was looking forward to getting his P-plates.



Shine caught up again with Matt, now 21, and his mum Leisa in Narrandera recently.

Matt had a bad car accident when he was 11, leaving him with a brain injury and issues with his balance, short-term memory and attention to detail.

But Matt met a major goal in getting his P-plates earlier this year, and Leisa and his dad Col have bought him a second-hand red Ford Festiva. As the family lives on a farm outside town, the mobility gives Matt a lot more independence.

Helping at the gym

"I drive to the local gym three or four times a week," says Matt proudly. "I've made quite a few mates through there. I'm on the committee that runs the gym, I help out with fundraisers, and I help coach the kids' class sometimes."

"And where there's another kid with a disability, Matt helps out one-on-one," adds Leisa. "He's lost about 18 kilos since he started at the gym, improved his balance and coordination, and doesn't need as much physio anymore. His self-esteem and confidence have improved out of sight."

Matt has also got into athletics. "I'm concentrating on shot-put and discus," he tells me enthusiastically. And he has just won gold medals in both events plus in the 100 and 200 metres sprints in regional competitions. He also helps the kids in Little Athletics.

For the past two years Matt has gone to Yanco and Wagga to give Rotary-sponsored talks to year 11 kids about life with a brain injury.

"I show a slide show of myself in intensive care – there's not a dry eye in the room," laughs Matt. "Afterwards, they all come up to me and ask me questions."

Citizen of the year

In the local Australia Day celebrations last year Matt was presented with the Junior citizen of the year award for "the enormous amount of time he gives to volunteering in the Narrandera community".

Matt's looking forward to finishing his childcare course at TAFE next year. His car will come in handy for that too.

And Leisa and Col are now happy to let Matt drive his young sister Niesha the four kilometres down to the mailbox so she can catch the school bus – the same route Matt took 10 years ago when he had his accident. It's a measure of his growing confidence and maturity.



Narrandera on the Murrumbidgee River is part of the land of the Wiradjuri nation.
Population 3,746

We'd love to hear from you!

Do you have any feedback about *Shine*? Is there anything different you'd like to see in the magazine? Or maybe you'd like to share your story with other participants?

Email shine@icare.nsw.gov.au or call 1300 738 586.

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Web: www.icare.nsw.gov.au

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