

"I've taken ownership of my condition, and that really helps." Meet Luke Anderson, page 8

Shine

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

Summer 2020

Shine Art Prize

Ally West: learning to live with the new 'me'

Ally is a Lifetime Care participant

The importance of art

Art and creative activities are known to improve wellbeing, mood and self-esteem. They help people make connections. In recognising this we have established the *Shine* Art Prize.

An event just for you!

You may dabble with a brush, create with your hands, capture moments through film or digital, design or sketch your days away. Whichever way you create, connect or escape, we're interested to see and share what you do.

"Connecting through Creativity

- Your story through art" is this year's theme.

Categories include:

- photography & digital art
- painting
- drawing
- sculpture & 3D art
- children (under 15) any art form.

Did someone say prizes?

The overall winner of the *Shine* Art Prize will receive \$2000. Winners of individual categories will receive \$1000.

How to enter

Go to: www.icare.nsw.gov.au/ shine-art-prize

Entries close 31 January 2021. For more information email: **shineartprize@icare.nsw.gov.au** or speak to your icare contact. When Ally was 16, a car accident and a severe brain injury changed her life. She talks to *Shine* about her journey since.

Ally is a bubbly, articulate 25-year-old. She grew up in Wilberforce in the Hawkesbury area on the north-western edge of Sydney with her parents, Sandra and Rodney, and older brother Greg.

"It was a lovely place to grow up, and our family is very close - we're very much in each other's lives," says Ally.

A normal kid

"I went to the local public school only about three minutes walk from home. I think I was a fairly normal kid. I played softball for about eight years when I was younger. As I got older and went on to Hawkesbury High I stopped playing sport and hung out with friends more. I was interested in music, movies, shopping and fashion."

Accident on a dark road

"The accident was in July 2011 when I was in Year 11. I was with a couple of airlfriends not far from home and one of them was driving while I was in the back seat. I don't remember anything about it now. It was dark and the road was a bit greasy after rain. The car started to come off the shoulder of the road. my friend overcorrected and the car spun 180 degrees and slammed into a telegraph pole.

"The others were able to walk away with only bruises, but I took the full force of the impact. I was taken to the local hospital in Windsor and then on to Westmead and was in a coma for 66 days."

I fell in love with the centre, they offered me a job and I've been there ever since! I do one morning a week during term, and vacations as well.



Ally and her Mum, Sandra.



Ally with her parents, Sandra and Rodney, and older brother Greg.

It's been nine years since the accident

and I think I've very much reached a plateau.

This is me. I've learned to live with this 'me'

and I know how to navigate the world with

Ally had multiple fractures, collapsed lungs and, most serious of all, a traumatic brain injury. While her other injuries healed, Ally's neurological recovery was slow and she had to learn to walk and talk again.

"When I finally came home in December, I'd missed half of Year 11 but I went into Year 12 the next year – I did it mainly because I wanted to go to my school formal!" she laughs. "I took Legal Studies and did a partial HSC. The results weren't too bad in the end – a Band 3."

For the next two years Ally was at TAFE studying librarianship and business courses. Then in 2015 she ran into the boss of the local Out of School Hours childcare centre.

"I'd gone there as a kid and I knew her through other connections. She suggested I do some work experience at the centre. I fell in love with it, they offered me a job and I've been there ever since! I do one morning a week during term, and vacations as well."

A big development for Ally in the past few months has been the move into a onebedroom granny flat on her parents' block where she now lives with her dog Bailey, a 21st birthday gift from her parents. "My parents are amazing. They custom-built the cottage for me. I'm totally independent here, but they're next door if I need them." Ally has regular support workers provided by Lifetime Care, and manages the arrangements herself. "One of my biggest issues is anxiety. I was a cautious person before the accident, but the brain injury has amplified it. So the support workers are more a preventative measure – to stop me having a meltdown if something unforeseen comes up."

Some limitations

the way I am.

"I have a couple of really good friends I've had since before the accident. But my anxiety stops me meeting people and going places. It is a bit remote here and I can't drive myself since my vision is impaired. Also I still don't feel comfortable getting into other people's cars and public transport out here is not great – so all that limits your friends a bit.

"I have other ongoing issues from the injury. Balance is a problem – I'm still a bit unsteady on my feet. And I have a thing called left-sided hemiparesis – a weakness in my left side. I've got a bit of pain in my back, but it's not too bad and I don't need any ongoing pain medication.

"And I get cognitive fatigue. I'm much better in the morning than I am later in the day. It's been nine years since the accident and I think I've very much reached a plateau. This is me. I've learned to live with this 'me' and I know how to navigate the world with the way I am."



Jarrod Emeny: always looking forward

Jarrod is a Lifetime Care participant

Two years after a car accident that that left him with a spinal cord injury, Jarrod Emeny has lots of plans and is moving on with his life.

A high-spirited 19-year-old with a mischievous grin, Jarrod meets *Shine* outside his student digs in Wollongong. Moving quickly in his wheelchair he leads me to his local café where we talk about his life.

Jarrod grew up on a small farm outside Mudgee, the youngest of three children. His mother, Carolyn, was from a long line of wool farmers; his dad, Michael, from the city. His parents started a print and advertising business in town, briefly added a dive shop, and then eight years ago they set up Mudgee Lamb which delivers vacuumsealed bulk meat packs direct to the public from Port Macquarie down to Canberra.

"My brother's the head butcher," says Jarrod. "I was the farm's tractor driver and did a lot of the markets."



Worst moment of my life

His is a close Christian family and all three kids went to St Matthews Catholic School in town.

"I was a happy-go-lucky teenager. I had lots of friends and did a lot of partying. I loved playing rugby particularly – it was a great community and my rugby mates are still my closest friends. But by Year 11 I wasn't too happy at school. I guess I was rather aimless and thinking of dropping out."

One Saturday in July 2018, Jarrod was heading off early to play rugby in Orange. "I was in my first car – an old dual-cab Hilux that I'd got for my 16th birthday and which I loved. I was late, like I often am, and I still don't know exactly what happened. There might have been a roo on the road or I just took the corner too fast, but I spun off and flipped straight into a tree. "I don't remember anything about the accident itself. When I came-to for a few minutes I was still in the car with my head out the window and a neighbour was holding my hand and trying to calm me. I think that was the worst time of my life. Before I lost consciousness again I remember thinking – I've crashed my car! My parents are going to kill me! And then I realised I couldn't feel my legs."

Jarrod was airlifted to Royal North Shore where he stayed for six weeks. He'd broken three ribs, three vertebrae and severed his spinal cord at T7.

Emotionally prepared

"I knew that I wasn't going to walk again. But funnily I got over the shock of that quite quickly – faster than my family who really had trouble adjusting, and especially my Mum who was with me every day during the recovery. I think I was a lot more emotionally set up than others who have this kind of accident because I actually knew people in wheelchairs, people I looked

To be honest, I don't look back at what might have been, what I might have done if I hadn't had the accident. I've done things and learnt things I otherwise wouldn't have. I'm just looking forward.





I think I was a lot more emotionally set up than others who have this kind of accident because I actually knew people in wheelchairs, people who I knew had good lives.

A close-knit family.

up to and who I knew had good lives. I've got a friend called Ellie I've grown up with who has spina bifida and has been in a wheelchair her whole life. I've seen her struggles and I've seen her get over them.

"And through the family business I knew a guy called Grant Mizens. He had his accident when he was 16 and went on to do incredible things like be a gold medal Paralympian. I've never looked at Grant and seen a man in a wheelchair; I've always seen an Olympian. And he became a great mentor to me."

Peer support is tops

Recovery in Royal Rehab at Ryde was tough for Jarrod. "But the thing that made it easier was the peer support team, Dan, Jess, Lee and Emily, the other wheelies - people with a lived experience of spinal cord injury. people who could teach you about the real world. I found that talking to others, getting into their mind rather than always being in my own meant I forgot about myself for a while." Jarrod returned home in late October. "Thrown back into the real world," he describes it.

"On the first night home I went to a party and saw a lot of friends I hadn't seen for a long time. On the second day I surprised Mum by insisting on returning to school. Just half days at first, then full days."

On the court.

Although he'd missed half of Year 11, Jarrod decided he wanted to complete Year 12. "I had to drop some subjects and drop down a level in others. And at that stage I was thinking more of taking a gap year after school rather than going to uni. But I found out I could get an early entry offer into uni. I had good reviews from teachers and got an offer to do a Bachelor of Business degree at Wollongong."

A new passion

On graduating from school, Jarrod was given an award - voted by his peers - as the student who best demonstrated optimism, compassion and benevolence during their HSC year.

By the time he had finished school Jarrod had a new passion. He had played basketball at school before his accident, but it was in rehab where the seed of wheelchair basketball was planted.

"I started going in a bit early when we went back to school in 2019 because I realised I could use the basketball court. By the end of the year I was training like crazy. I'd get up at 5am three mornings a week, drive to school and train till 8.30. "Wollongong was a great place to come to. It's a good base for basketball and the Wollongong Rollerhawks are the best team in the national wheelchair league. I got some scholarships to help with accommodation and the building I'm living in is accessible for wheelchairs. I've got some mates here from home and I'm enjoying the courses."

Playing with the best

"I really want to play basketball for Australia. I'm currently on a low rung in the Australian Under-23 team and I'm getting a lot of experience with the Rollerhawks – learning a lot and playing with some of the best in the country.

"When I finish my course in Wollongong I've set myself a goal of a uni scholarship in the US – possibly the University of Illinois, which is where Grant went – on a basketball scholarship.

"After that I'd like to move to Europe and play basketball professionally. I'd love to make that happen.

"To be honest, I don't look back at what might have been, what I might have done if I hadn't had the accident. I've learnt things and done things I otherwise wouldn't have. I'm just looking forward."

Tim Hirst: from survivor to mentor

Tim is in the Workers Care Program

Tim sustained severe burns in a workplace accident 14 years ago and now mentors other burns survivors.

Shine met Tim and his wife Yvonne at their house in Raymond Terrace. Yvonne immediately offers us a slice of their layered anniversary cake from the day before. The affection between them is palpable.

A cheeky boy

The youngest of five children, Tim grew up on the Central Coast in the sixties and seventies. His dad worked mostly as a travelling salesman until he set up a car repair business in Warners Bay.

As a kid, Tim loved the cars and collected models of vintage brands.

"I was always getting into trouble for trying to start the cars in the backyard," he says. "He was a very cheeky boy!" adds Yvonne.



"I left school in Year 10," says Tim, "and got an apprenticeship with my dad as a spray painter as well as working on the car engines."

"We met on a blind date," explains Yvonne. "My car broke down and Tim was able to get it started. We ended up dating and got married in 1985."

The newly-wed couple lived with Tim's parents for three months. "Do not do that!" cautions Tim with a smile. They later bought a house in Warners Bay.

Spray painter

After working with his father for ten years until the business closed, Tim found another job as an industrial spray painter in Tomago – painting containers, waste bins and trucks.

In 2001 Tim and Yvonne moved to Raymond Terrace to be closer to Tim's work. They made friends in the community and joined a local church.

One afternoon in May 2006, Tim was at work painting the inside of a 20-cubic-metre waste bin. "I had no idea that an apprentice had shut the door and started welding the outside of the bin," says Tim. "It's against all the safety rules because the paint is so flammable. The fumes built up and there was an explosion. I don't remember any of it."

Tim sustained extensive burns to nearly 90 percent of his body.

"I got a phone call from Tim's work that he'd had some minor burns on his hands," says Yvonne. "On the way there I saw a helicopter, an ambulance and then the police. A policeman told me that Tim would probably not survive the night."

Terrible ordeal

As Tim was airlifted to hospital Yvonne said to herself: "I'm holding on to that first message about a minor accident. Tim is not going to die tonight." Yvonne was right, but it was a terrible struggle. Tim was in a coma for three and a half months and endured more than 20 operations, partial amputation of both hands and multiple skin grafts. Some of the grafting techniques - such as "spray-on" skin, developed by Dr Fiona Wood at Royal Perth Hospital to help the burns survivors of the 2002 Bali bombing - were a major factor in Tim's survival.



I want to help those burn survivors who don't get much ongoing assistance, particular those suffering from post-traumatic stress.

Tim and Yvonne at home.

"When Tim regained consciousness, he couldn't speak and he had to communicate by sign language - often it was just with his eyes," says Yvonne. "And at first his elbows were locked in, but by Christmas they had unlocked. Like a miracle! In fact the doctors and nurses called him the miracle man, as he shouldn't be with us today."

Tim spent seven months in Royal North Shore before moving to Royal Rehab in Ryde.

"It took me a good three months in rehab to get my legs to work properly. I had to relearn a lot of things," says Tim.

Yvonne stayed in Sydney the whole time. "Tim didn't want me to leave!"

"In rehab she got known as Nurse Yvonne," quips Tim.

Cold turkey

A year after the accident Tim finally came home. But the next few years were full of return trips to hospital to deal with complications arising from the condition of Tim's skin and the recurrence of surgical hernias. Tim and Yvonne have had to thoroughly educate themselves about skin care.

Soon after returning home, Tim decided to stop all his pain medications. "I hated my dependence on them and all the side effects," he says. "I just went cold turkey." "It was terrible for two weeks," responds Yvonne. "He really gave us curry during that time. I was thinking 'Where's my real husband?' The end result was good, but he should have done it gradually. He does have amazing pain tolerance."

A burns mentor

On one of his stays in Royal North Shore, Tim was asked by one of the nurse practitioners to talk to another burns patient. "He wasn't as severely burnt as me but he was very upset and crying and all the nurses were upset as well. I spoke to him and he calmed down."

Tim is now involved in the hospital's burns mentoring program and meets one-onone with recent survivors, discussing adjustment and rehabilitation issues.

"Peer support for burns survivors, especially adult survivors, hadn't really got off the ground here in Australia," Tim points out. "We started to bring people together. We have an adult Facebook group that's grown to 150 members, but it's hard to organise meetings because of limited sponsorship. We had a national meeting on the Sunshine Coast last year that went well - we even had ten people here from New Zealand - and we were planning one on the Central Coast this year but, because of COVID, it never happened."

In 2018 Tim and Yvonne went to a World Burns Congress in Michigan. "It was amazing," says Yvonne. "Survivors told their own particular stories and there was lots of discussion of new treatments and technologies and scarring issues."

While Yvonne is Tim's fulltime carer, the Workers Care program covers support workers to help Tim for about 16 hours a week.

Chaplaincy course

On top of his work with other burns survivors through online forums and peer support groups, Tim is doing a chaplaincy course through his church to give him skills in going into the community and talking to people.

"I want to help those burn survivors who don't get much ongoing assistance," he says. "There are a lot of suicides among this group – particularly those suffering from posttraumatic stress."

Beyond Burns

The Beyond Burns website **beyondburns.org** is a virtual hub that provides connections between survivors, information and support networks.



Luke with Kevin. his Jack Russell.

Luke almost lost his life in a motorbike accident. While still dealing with the injury to his brain, the 38-year-old has become increasingly active as a community mental health advocate.

Luke Anderson talks to Shine in his quiet apartment behind the beach dunes in Port Macquarie.

"I was born in Melbourne but Mum and Dad didn't want to bring me up in the city so we moved here when I was about three, before my younger brother was born. I've lived in 'Port' most of life apart from short stints elsewhere and some travel overseas."

Indigenous grandad

His dad, Joseph's, family is from Malta and his mum, Julie's, mother is from Scotland. "I only found out much later that Mum's dad was a Gunakurnai man from Gippsland."

"I had a generally happy childhood even though my parents separated when I was about ten. My stepdad Bret is a gentle giant and he's been



a big support in my life. Port was a small country town back then. I guess I was a boy's boy - skating, surfing and riding motorbikes. It's the sort of thing you do in a coastal town. It's what I did with my mates.

"School and I didn't really agree with each other and I left in Year 10. I joined the Navy but I wasn't there for long because my mum took her life and I came home. I was 19 and it was the first funeral I'd ever been to. The loss of Mum took me to some dark places. It also meant that I've done my own thing since then. I've always run my own race."

Offshore rigs

In his mid-20s Luke studied marine engineering in Fremantle which gave him a certificate to work as an Integrated Rating in the merchant navy.

"For the next eight years I worked in the oil and gas industry, mainly on offshore rigs. It was pretty diverse navigation, rust prevention and painting, emergency response, helping to land helicopters. It was hot and rough work but I loved it, and it was well paid. It was five weeks on at more than 80 hours a week, and then five

weeks off. Really, it's a young man's game. It's hard to settle down and have a relationship."

Luke finished a contract on the rigs late in 2014 and went snowboarding in Canada with his best mate. Soon after returning home in January he went for a motorbike ride in the mountains west of Port Macquarie with some friends.

"It was a beautiful day. The last thing I remember was putting fuel in the bike. I was cruising at the back of the pack on a mountain road with the mountain on one side and a cliff on the other when I had a head-on collision. It was with an off-duty nurse. That part was lucky!

"I almost lost my life but apart from some bad cuts to my leg there was hardly any visible damage. The damage was to my brain. I got air-lifted to hospital and spent six days in a coma. It was a couple of weeks before I could finally talk. But I was like Dory in Finding Nemo - my short-term memory was really shot. Also the traumatic brain injury meant I was very sensitive to loud noise or any stimulus and I'd get very anxious.



I was really hit by how healing it was for me. I was doing something useful again.

Luke receiving his Citizen of the Year award in January from local mayor Peta Pinson and Tim Conolan.

"In rehab I had to re-learn how to do basic things again like cook and clean, and navigate around a shopping centre.

"Just a week or so after I got home, I was offered a job I'd applied for before the accident which I'd totally forgotten about. It was working on a rig on the North West Shelf – a huge construction job. They didn't know about my accident of course, and they wanted me to start as soon as possible. I was in denial about how severe my brain injury was and I just said 'Sure'!"

Bit of a larrikin

"So I went back to work for eight months but I struggled. I've always been a bit of a joker, a larrikin. I masked the injury with humour. I didn't take the medication I was meant to. I had ulcers in my mouth and couldn't sleep properly. I thought I was OK but inside my head it was chaos. I was suicidal. Then one day I thought about my little brother, my friends, my family and went straight to my boss and said I needed to go home.

"Back in Port in 2016 I started to meditate, do yoga, focus on my health and actually listen to what the doctors said. I tried to manage my anxiety through breathing exercises. and I didn't drink any alcohol for two years. I began to read a lot. A lot of spirituality but also a lot of science. I was asking questions about life. I don't see myself as a Christian any more. I think I believe in the universe. If you're a good person then that goodness comes back to you."

Telling my story

Since 2017 Luke has increasingly involved himself in community work. He volunteered to be a facilitator in government student-safety programs. "I was someone with lived experience, someone who gets up and tells his own story. I put together a PowerPoint and spoke at big auditoriums in Port and Kempsey to a lot of kids about road safety, depression, suicide.

"I was really hit by how healing it was for me. I was doing something useful again."

A year later Lifeline asked Luke to be their regional youth ambassador. "Because of Mum, that was something close to my heart. And that work has led this year to bigger things."

In January Luke was named Citizen of the Year at the Port Macquarie-Hastings Australia Day ceremony for his work in the community to support people who have mental health issues.

"It really felt an honour. I got to stand with the mayor and give 52 new Australian citizens their certificates. And soon after I was headhunted by an Indigenous organisation as a 'future coach', a mentor to Indigenous kids coming out of foster care – a sort of big buddy to walk alongside them. It's a casual role but it's paid and I can get off the disability pension and be selfsustaining again."

Not fighting my condition

Luke has also started a nonprofit with some friends called 'Self Seen' to change the way we look at mental health.

"Things are good now. I've got this beautiful little unit I've had now for two years. My dad and my brother have both come back to Port from Queensland and come back into my life.

"It's taken a long time after the accident to get back to feeling myself. I'm exponentially better but I still have to be careful of my capacity and not overextend myself. Whenever I do too many things the brain injury takes me back a few pegs. I have to pre-think things. I've got lots of little strategies to deal with the unexpected.

"I've taken ownership of my condition. I'm not fighting it, and that really helps."

Luke has also started a non-profit with some friends call '<u>Self Seen</u>' to change the way we look at mental health.

Joel Vanderzwan: helping veterans with disabilities

Joel is a Lifetime Care participant



Joel was enjoying life in the Navy until a motorbike accident nine years ago left him with a spinal cord injury and in a wheelchair. The 31-yearold has worked hard to overcome his challenges and now advises other veterans with disabilities.

"I had a pretty normal childhood," says Joel. "I grew up in the Illawarra, the second of four kids. We did a lot together – mostly outdoor stuff. My parents had a tenacre hobby farm out west near Temora and we went there every fortnight. Mum was a nurse and Dad was in the Navy, then later a truck driver. Both my grandfathers, as well as other relatives, had been in the military too.

A 'business plan'

"By Year 11 I knew school wasn't working for me, but my parents had a rule that you either stayed at school or you went into a trade. They were very big on us having 'a business plan' so I left school and started a preapprenticeship as a carpenter.



"I really hated it, so I secretly applied to join the Navy and train as a marine technician. I even did the fitness test and final medical before actually telling my parents that I'd be leaving home the next week." After doing his basic training, Joel was posted to work as a marine technician on patrol boats in northern Australia, responsible for the boat's pump, fuel, firefighting, propulsion and sewerage systems. He finished his trade training, rose to the rank of Senior Able Seaman and got a posting back to Sydney.

Taking a risk

"I'd had a motorbike for a while and loved riding with my mates - mostly Navy friends. I was living in Carlton in southern Sydney and most Saturdays we would ride down south, and then I would peel off and see my parents at Shellharbour on the way back. One Saturday nine years ago I was following the usual routine, but when I left Mum and Dad's it was later than I planned and I was riding hard to get home. It wasn't uncommon then for me to take risks. I was almost home when I took off fast from the lights,

misjudged the change of lanes and hit a parked car. The police estimated that I had been travelling at near 150kph."

Joel was in a coma for about two weeks at Royal North Shore with a fractured skull, glass in his right eye, numerous fractures and abrasions, collapsed lungs, a bleed on the brain and a broken back.

"I had 36 hours straight surgery and when I regained consciousness the doctors told me I would never walk again due to a T6 break in the spinal cord. I was still only 21.

"The next weeks were terrible as I tried to come to grips with my future, but I told myself 'I'm going to get better and I'm not going to let this be the thing that breaks me'.

"From then on every day I wanted to do something new. I focused on breaking the larger goal of becoming independent down into lots of smaller goals – just little things like pulling my shirt on, or pushing my chair to the front of the hospital by myself."

In late 2012 Joel left rehab to go home to his parents' house which was being modified to be wheelchair accessible.



I'm a big promoter of the idea of people with disabilities getting jobs. I'm really keen to break down the stereotypes around us.

Joel at the launch of Veterans' Health Week in October.

"I left the Navy but I've kept a lot of the values and disciplines that I learnt from my time there. For example, I still like to be early; I believe that you don't excel without your team; that you own your mistakes. Also some of the skills I learnt help me now. I can drill down on what I need to know and what I must know."

Best trip ever

Joel went to TAFE to expand on his trade skills, but was unable to find work. He got a job as a debt collector and stayed there happily for five years.

During that period he built a house at Appin and married his long-term partner. But sadly the marriage didn't last.

By 2018 Joel had moved to Sutherland. He went on a holiday to the US that year with his new girlfriend, Alexandra. "It really was the best trip I'd ever had. One of the things I noticed was how much they love veterans over there. I met a lot of US vets and felt a real connection with them."

Training for Invictus

Back home, Joel got a new job as the customer service manager with a tech startup called WithYouWithMe that helps vets get jobs and skills.

"They were wonderful to me and even when I developed a severe hip infection and needed to be on a drip for five months they allowed me to keep working."

Joel had always been interested in sport and when the Invictus Games was held in Sydney two years ago he was inspired to train for the 2020 games to be held in the Hague.

"I trained hard for multiple events and was selected to play in the Australian teams for archery, indoor rowing and rugby, and as captain of the wheelchair basketball team. I wished I'd got involved with Invictus earlier. It was huge to be chosen to play in an elite sporting event at a level where you train six days a week."

Unfortunately the games had to be postponed because of COVID, but Joel is hopeful they will go ahead next year. Last year Joel was head-hunted by Deloitte as a technology enablement business analyst where he is part of their strategic innovation team and an advocate in the company for employing veterans and people with disabilities.

And earlier this year Joel and Alexandra got engaged.

He is also setting up his own mentoring program, Project JV, to help disabled vets set goals and find their own path. He already has a number of people he advises regularly.

Mentoring vets

"I'm a big promoter of the idea of people with disabilities getting jobs. I'm really keen to break down the stereotypes around us, many of which we put on ourselves – stereotypes about things we can do, things we can't.

"I stress the importance of goal setting. It doesn't need to be a 15-year plan, just a series of small goals that you can measure easily.

"Sometimes asking for help is all it takes."

From then on every day I wanted to do something new. I focused on breaking the larger goal of becoming independent down into lots of smaller goals.

Riding the roller-coaster of brain injury

A relationship built on time and trust.



Michael Dagiantis, his case manager Deb and icare contact Jo, have worked as a team in Michael's recovery. *Shine* spoke to them about their nine-year journey together.

Michael - the participant

In 2011, Michael Dagiantis was about to graduate from university. He was working three jobs and had a full social and sporting life.

One Friday night that all changed. Riding his motorcycle near his Strathfield home, Michael was hit by another vehicle. His new life, living with a traumatic brain injury, began.

Fiercely determined, Michael, now 32, is slowly pulling his life together.

What were the early days of your injury like?

I was in post-traumatic amnesia for a long time so I don't remember much. When I woke up everything had changed, it was hard to understand. I was still alive and still breathing but not sure what was happening.

What have been some of your biggest challenges?

I have lost a lot – a lot of years and friends. I can't get upset about it now – it's happened, and I have to think about the positives.

How is life now, nine years since your accident?

I still see a lot of doctors and therapists. You need a good medical team to get better.

I feel like I've recovered, recovered a lot. I'm back working which is important to me – in recycling computer products. And I'm exercising – cycling and swimming – and socialising. I'm proud my recovery has kept on going. I understand people more now and feel like I'm getting my respect back.

What would you like people to know about you and brain injury?

I'm still Michael but a little different Michael. I'm a 32-year-old man who wants to enjoy my life. I'm unique, not just with my injury.

I'm careful how I am with people and what I say to them. I prepare myself beforehand for what's going to happen. If I can see trouble coming, I walk away. I know the things I can't change and go a different path. Physically I'm OK, but things still hurt me.

Ten years from now what does life look like for you?

Married with kids and a permanent job. I'd like to meet someone who understands me, someone who knows what I've been through and sees my passion and determination. I'm living my best life.

Tell us about working with Deb and Jo

Deb and Jo work together to help me, they are extremely understanding. Deb's been around from the start. She has experience and knowledge and she's always there for me. They share my history and I don't have to tell my story over and over. They help me stay positive about my future.

I can't go back, but I'm catching up now.

I'm proud my recovery has kept on going. I understand people more now and feel like I'm getting my respect back.



Deb – the case manager

Deb's a speech pathologist specialising in rehabilitation. She has her own business providing communitybased rehab to people with a brain injury.



Can you remember when you first met Michael?

It was March 2012 and Michael had just been discharged from Royal Rehab. He was still in post-traumatic amnesia and was very clear on one thing – he didn't need any help. He was afraid to eat or to shower. He was easily upset and quick to anger. The Michael that came home from hospital was entirely different to the pre-accident Michael. Michael's family knew that he was going to need a lot of help. They have worked tirelessly to support Michael's recovery.

Tell us about Michael's rehabilitation journey

Michael's injury was very severe. He had difficulty communicating even basic concepts, couldn't read or write and was often confused about where he was and what was happening around him. Michael would wake up at 3 am and get dressed to go to work. It was a terrifying experience for him – he felt he was the same person but couldn't reconcile why things were so different.

I am astounded at how much he's achieved. When he got medical clearance to return to driving I thought he would never make it – driving takes a huge amount of cognition. Michael did months of driver retraining. He learned from his mistakes and never gave up.

Once he had his licence back, he turned to the other challenges – finding a job, re-establishing old relationships and finding new ones.

What are you most proud about for Michael?

To see Michael emerge as a man who is proud of himself, kind and caring of others, confident and looking forward to new challenges.

How do you keep motivated?

It's a privileged position to be invited into someone's life. A lot of people ask how I cope, but it's easy to stay motivated when you know you are part of someone's epic journey.

C I am astounded at how much he's achieved.

Jo – the community living facilitator

Jo's a social worker who works at Lifetime Care.

How long have you worked at Lifetime Care?



I joined Lifetime Care back in 2011 when it was much smaller. Before that I'd worked as a social worker – mostly in a community role.

What does a community living facilitator do?

I support between 25 and 30 participants – people who've moved out of the intensive rehab phase and are now focusing on living their life. For some this happens quickly and for others it takes years.

What would a typical week look like for you?

A typical week is never typical. Generally I'm talking with participants, their families and service providers to solve problems. Before COVID there was more opportunity for faceto-face visits – now we're all getting better at different ways of communicating. It is possible to teach an old dog a new trick.

A few words to describe Michael's rehabilitation journey...

Michael's story is one of tenacity, persistence and hard work. Everyone is different and everyone's adjustment to injury is different. Having a brain injury when your adult life is just about to kick off means a whole different level of adjustment for everyone – Michael, his family, his friends. Those who knew Michael when he was first injured would not believe where he is today – he is an absolute credit to himself.

How are good outcomes achieved?

The best results happen when a good team is established early on. We're involved with the person for life so it's important to establish good, honest connections.

Any advice you would offer?

Remember that the brain injury journey is different for everyone and comparing yourself to the next person doesn't help.

Those who knew Michael when he was first injured would not believe where he is today - he is an absolute credit to himself.

The notice board

A place to share handy information with you and let you know about past and upcoming events and programs.

CARERS 11-17 OCTOBER WEEK 2020

Caring for you while you care for someone

For *National Carers Week* we hosted a live event with Carers NSW, and family carers from Lifetime Care and Dust Diseases Care.

Missed it? You can still watch the event

To watch a recording of the event type this link into your web browser: **bit.ly/watch_wecare**

Or request a link from your icare contact.

Support for carers

The *wecare* program provided by Carers NSW is available to families across icare. It provides mentoring and support to people impacted by caring for a loved one.

Peer support groups for carers

The *wecare* team have also introduced peer support groups for icare families.

Sessions are held online and provide a supportive forum for carers to connect and a social outlet to discuss challenges. All carers are welcome.

For more information about *wecare* and the peer support groups contact: <u>wecare@carersnsw.org.au</u> or phone **02 9280 4744**.

Carers NSW top tips for looking after yourself:



- **1** Schedule time for yourself every day
- 2 Maintain good sleep hygiene
- **3** Get out of the house
- 4 Exercise
- **5** Improve your self-awareness
- 6 Journal at the end of the day

For more information visit the Carers NSW website **www.carersnsw.org.au**

Podcast anyone?

A podcast is like a radio show but instead of listening to it live on the radio, you can listen when it suits you on your own device.

Podcasts can be a great way to get Information.

We round up 5 podcast you might enjoy.

ListenABLE

Features Dylan Alcott chatting to people living with disability about their lives and asking the off-limits questions.

podcastoneaustralia.com.au/podcasts/ <u>k</u> listenable

Inform Podcast

People with disabilities sharing advice - finding work, moving house, dating, playing sport, finding a hobby and more.

informonline.org.au/listen 🔆

Disability Done Different: Podcast DSC

Conversations with people in the disability sector. Episode 25 features JENNIFER CULLEN, CEO of Synapse.

teamdsc.com.au/podcast 🔀

Brain on Nature

Explores the relationship between the natural world and the human brain.

brainonnature.com 🔆

Too Peas in a Podcast

Two mums chatting about parenting children with disabilities and the roller coaster it can be.

toopeasinapodcast.com.au/podcast 🛛 🔆 🔼

And don't forget to check out Jarrod's feature podcast on the 'Hear Them Roar' series.

open.spotify.com/ episode/4lQTDT8bkqRE1sOvhgmqjT 😽

Be Pain Smart Clinic

The Be Pain Smart Clinic is for people with brain or spinal cord injury with chronic pain.

About the clinic

Clinics are run by specialists in pain management and have been developed by NSW Health, in partnership with the icare Foundation.

The clinic provides:

- pain assessments and pain management plans
- consultation with your GP, health provider and case manager.

How can I access the clinic?

Clinics are available across Sydney metro area and by telehealth in regional areas.

For more information:

Call Regina Schultz on 0409 716 387 or email <u>bepainsmart@royalrehab.</u> <u>com.au</u>, or chat to your icare contact.

A flyer with more information is available **here**.

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Junior Wheelie Christmas Camps

Join the Junior Wheelie team for their Christmas Camp – now in its 39th year!

For kids aged 6-18 to give wheelchair sports a try. From **11-13 December** at the Sydney Academy of Sport in Narrabeen.

Interested? Visit <u>www.wsnsw.org.au/</u> events/74510/ or call Joe Shoebridge on 0439 743 777.

See Raphy's story on the next page.

ENGAGE – program for Spinal Cord Injury

Lacking direction or focus in your life? Not able to enjoy the same things that you use to?

ENGAGE explores:

- how the people and activities we engage with bring meaning and enjoyment to our lives
- how these are affected by a SCI
- how to build strong connections and find enjoyable activities that provide a sense of purpose.
- **ENGAGE offers you:**
- a structured, group-based program delivered by health professionals and people living with SCI
- personal support and coaching
- the opportunity to connect with others in similar situations.



Accessing the program

Engage is an online program you can do from anywhere with internet access. The next program starts in Feb 2021.

Interested?

Visit <u>engagesci.com</u> or contact Rebecca McCabe at <u>rmccabe@hammond.com.au</u> or **0425 331 771**.

Developed with support from the icare Foundation.

Disability Information Helpline



A free helpline about coronavirus

The Disability Information Helpline is available for people with disability and their families, carers and support workers, who need help because of coronavirus.

You can contact the Helpline on 1800 643 787 (freecall).

Volunteering opportunities

3 Bridges are looking for people with a brain injury living in Sydney metro area interested in starting a volunteer role.

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Providing volunteers with:

- social connection
 experience in the workforce
- potential opportunities for paid employment
- connection with a volunteer 'Buddy' who'll be your support person.

3 Bridges have 27 Buddies ready and waiting to be matched with volunteers.

Interested?

Call Linda Maher on 1300 327 434 or email alliedhealth@3bridges. org.au

Connections

A place to share your news with us



Raphy (left) at his first Wheelchair Sports Holiday Camp.

Having a wheelie good time!

Raphael Plummer, affectionately known as Raphy to his friends and family, is a young boy achieving big milestones.

Raphy was in kindergarten when a car accident left him with a complete spinal cord injury and the need to learn a new world as a wheelchair user. Home-life, school and birthday parties were suddenly very different.

He recently celebrated his seventh birthday – his first at home since the injury – and went to his first Wheelchair Sports Holiday Camp in Narrabeen.

Raphy's grandmother Eloise took him to the camp. Eloise spoke about the day and what it meant to both her and Raphy.

C Raphy had an absolute ball, he was grinning from ear to ear all day.

"Raphy had an absolute ball, he was grinning from ear to ear all day, it was his first time, and everyone was so welcoming.

"It was great for him to see other kids like him, see them still doing things and having fun and not being restricted."

"Raphy tried everything, basketball, tennis, soccer and AFL – he had a go at it all. A lot of the kids had been before and they really welcomed Raphy and helped him. And the coaches were wonderful and very patient," Eloise recalls.

Eloise thought the experience was a wonderful opportunity for Raphy, who not surprisingly was worn out by the end of the day.

"He went to bed early that night and wanted to know when he could go again! I'd encourage any parent to take their kids if they have the opportunity. It's a fabulous day and Raphy got so much out of it."

See previous page for more info on the Junior Wheelies Christmas Camps.



Michael and Eimear welcome a baby girl

We met Michael and Eimear back in 2019 when Michael wrote his own story for the winter issue of *Shine*, 'Reflections on stroke recovery'.

We're pleased to share that Michael and Eimear are now the proud parents of a baby girl – Fiadh (a Gaelic name).

Michael told Shine they are all doing well and even though Fiadh is only a few weeks old this picture is almost out of date!

Congratulations Michael and Eimear!

We'd love to hear from you!

Would you like to share your story or news in *Shine*? We're always looking for people to be involved, or any feedback you might have.

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

General Enquiries: **1300 738 586** Web: <u>www.icare.nsw.gov.au</u>

