



**Doctor, councillor, quadriplegic**  
We meet Steve Peterson, page 2

# Shine

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

Winter 2022

# Steve Peterson: no slowing down

Steve is a Lifetime Care participant



Before his cycling accident Steve Peterson was a committed member of the Orange community – a well-regarded doctor and an active member of the local mountain bike club. While he now lives life in a wheelchair, it's a life that is full.

Steve Peterson is a busy man. When we meet at his home outside Orange, the 36-year-old is just back from a council meeting and his support worker Anita is helping him hurriedly eat a pizza. And for the next 90 minutes our discussion is occasionally interrupted with calls from one of the 30-odd small rural hospitals he works for as an online consultant GP.

## An itinerant childhood

Steve grew up in an “army” family. He was born in Hong Kong and went to high school in Beijing. “As far as I recall,” he says, “I always wanted to be a doctor.” He studied medicine at the ANU in Canberra and it was at medical school where he met his future wife Deb.

After graduating Steve and Deb kept moving. “We went to Darwin where we did our internships, then worked as GPs in other country areas like Cairns, Innisfail, Newcastle and the Kimberley. We’ve never really been interested in living or working in big cities.”

By 2014 the couple were keen to raise a family so they settled in Orange where Deb had grown up. They now have two boys, Luke and Tim aged 8 and 6.

Steve worked in a range of medical areas – with the Orange Aboriginal Health Service, at a local drug and alcohol detox centre, and in the emergency department at Orange Hospital. He’s always liked outdoor sports and became active in the local mountain bike club. As well as taking part in their rides, Steve helped out in working bees and organising medical teams at events.

“I guess I’ve always been a joiner. I was president of the student society for my medical school. I like organising events and making things happen.”

In March 2018 Steve was riding his bike to work at the emergency department when he was hit by a car.

He jokes that he still arrived on time to work that day. “My colleagues were expecting a major trauma patient and were worried they were understaffed. They kept asking ‘Where’s Steve, why isn’t he here?’ I did turn up, but it was in the ambulance.”

## Hospital and rehab

Steve broke all the bones in his neck and one of the fractures was bad enough to damage his spinal cord. He also had other fractures and internal bleeding. He was airlifted to ICU at Royal North Shore.

“In all it was 269 days in hospital,” remarks Steve clinically. “About 2 months in ICU, 3 months in rehab and then another 4 months back in Orange.”

“I don’t remember the accident nor much around the early recovery period. I’m not sure when it was that I knew I would be a quadriplegic. I never felt particularly angry about my situation. It was more sadness and regret. I was more focused on looking forward than on thinking too much about what had happened.”

“My colleagues were expecting a major trauma patient and were worried they were understaffed. They kept asking ‘Where’s Steve, why isn’t he here?’ I did turn up, but it was in the ambulance.”





Steve standing for council.

Steve says the rehab was pretty relentless, but he stuck at it. “I wanted to get out of hospital and back to work. I was always hoping to return to being a doctor but I didn’t really know in what capacity I could do it.”

### Back to work

He started back in his job at the drug and alcohol centre as soon as he could. Then it was trying lots of different things to see what worked and what didn’t. At one stage he had 14 different jobs.

“One of the things that works best for me is small rural hospital telehealth, where there are nurses but no doctors on the premises at the time. I can’t really do face-to-face consultations because of the mobility limitations. I also do some GP training and write and mark the exams for trainee GPs.

Steve works between 30 and 60 hours a week and reckons he’s the only quadriplegic working as a GP in Australia.

As we talk, Steve is getting phone calls from the hospitals where he is employed.

After each call Steve shouts to the voice recognition software on his computer: “Wake up!” then dictates some clinical notes before calling out again: “Stop listening!” All the while he deftly maneuvers the cursor around his screen using his “quadjoy” – a mouth-controlled joystick that acts as a computer mouse.



Using his mouth-operated “mouse”.

While we are chatting, Steve operates his chair to lift himself into standing position. “To be truthful, I’m never really comfortable in any position, but this chair lets me alter my posture. Sometimes I work standing as well.”

Steve says he’s had minor neurological improvements since he left hospital. But mainly it’s been a matter of getting better at coping with his limitations.

### A new home

With some assistance from icare, Steve and Deb have built an accessible house on the farm of Deb’s parents on the rural fringe of Orange. In the autumn sun, overlooking pasture and bushland, it feels idyllic. There are wider corridors, lots of automation and sensors, and 3 hoists so that Steve can be lifted when necessary. “I’m very happy with the house – although there’s lots of things I’m still learning about it. This is still a working cattle farm and the kids love living here – lots of animals, lots of areas to explore. “I’ve got a rough-grade wheelchair – a sort of quad bike – that I can get around the farm on. It can go on sand and through the bush and over small obstacles.”

“ I’m not sure when it was that I knew I would be a quadriplegic. I never felt particularly angry about my situation. It was more sadness and regret. ”

Although no longer riding, Steve remains active in the mountain bike club. “I’m the grants officer now. We just got \$325,000 from the state government for a mountain bike track around Mt Canobolas.”

And as if he didn’t have enough on his plate, last year Steve decided to run for local council. After his recovery he felt that as a quadriplegic he could offer a different perspective.

“Not just because of my disability – also as a younger person, as a person with young kids, as a doctor.”

He organised a ticket of candidates under the “Refresh Orange” banner, was elected and now chairs two council committees.

“I’ve dropped the jobs I have now down to 8 but I think I’d like to cut down a bit more, to rationalise. I know I’ve got lots of options.

“But I enjoy the work. I find it useful. I’m helping people.”



# Paul Davison: from sportsman to artist

Paul is in the Workers Care Program



Paul was a keen athlete and also worked as a stone letter cutter. The discipline and perseverance needed for both have left him in a good place to deal with the effects of a brain injury.

A neat townhouse with a camellia-hedged garden in Terrigal is home for 65-year-old Paul and his wife Janette. They're coming up to their 40th anniversary and both remember clearly their first meeting when they worked in the same bank in the late 70s. Four decades later, with the family unit expanded to two adult sons and their families, the couple tick-tack in conversation – finishing each other's sentences, challenging the other's perspectives and periodically bursting out laughing together. Paul says that, since his accident, they've swapped roles – “Janette was the feisty person. Now I'm the outspoken one – when I see someone approach a roundabout incorrectly, boy do I let them have it – while she is positive and calming.”

After a decade working in the bank, Paul became a monumental mason, inscribing stone in his father-in-law's funeral business. He describes the patience and detail of shaping each letter, getting the balance of each word right, checking the spelling and then chiselling it into the stone.

## Sports mad

And all through his youth, Paul was a committed athlete. He played first grade cricket for Petersham-Marrickville, batting at number 3 against many top-class cricketers.

He went from jogging around the block to running marathons – his first race being on the Sydney Olympic marathon track in 2000. Still smiling at the memory, Paul describes the route taking the lycra-clad runners along Oxford St in Darlinghurst where leather-clad blokes called out encouragement as they emerged from nearby clubs. He's also twice run the challenging Six Foot Track in the Blue Mountains (motto “46 kilometres of pleasure and pain”).

In 2014, Paul was knocked down by a cyclist on the pavement while at work in Randwick. He hit his head and lost consciousness. Diagnosed with severe bleeding on the brain, he was in St Vincent's Hospital for more than 3 months enduring multiple operations and complications, and then a further 6 at Royal Rehab at Ryde. From a slow start, the fitness and determination that had made him a dedicated athlete kicked in.

“It was about getting my dignity back. I was chasing my independence,” he says.

Paul set himself a challenging path. From a few steps walking around the ward, to around the quadrangle at Rehab in Ryde – just once then a dozen times – and later the daily challenge of climbing the hospital's 52 steps without holding the railing.

“The doctors reckoned I was a walking miracle.”

“I had 3 choices,” says Paul succinctly. “I could let the injury define me. I could let it destroy me. Or I could let it strengthen me. And that's the one that I chose.”

## New granddaughter

Further motivation came with the arrival of his first grandchild, Vogue, who was born in May 2015 shortly after he emerged from rehab. Watching Vogue learning to walk and lurching towards him across the room, was further inspiration for Paul to also work at strengthening his stride.

The effects of Paul's brain injury continue to be with him.

“I just have to accept that,” he says. There is a constant pressing pain in the side of his head, short-term memory loss and mood swings.





“ After a brain injury, many people think that it’s gone. But it doesn’t disappear. They don’t understand that I’ve had a change of character. Brain injury is with me every waking moment. It’s not invisible to me. ”

“If you’ve had cancer, other people always look at you sympathetically. But after a brain injury, many people think that it’s gone. But it doesn’t disappear. They don’t understand trauma, they don’t understand that I’ve had a change of character. Brain injury is with me every waking moment. It’s not invisible to me.”

Paul says “I now call things as they are”. Janette counters that he now filters things better. “We’ve got this commitment to remove all negatives out of our life. We focus on meeting positive people and doing positive things.”

### Losing his bike

Before the accident, the couple took long trips to Tamworth, to Coonamble and beyond on Paul’s BMW 1200 motorbike. Paul is nostalgic when remembering their trips. “They are wonderful memories.”

While he got his car licence back after the accident, he can’t get his bike licence reinstated. “It’s taken me years to admit that I won’t get medical clearance to ride again. I’m fine with that now. I recognise that it was a joy Janette and I once shared, but it’s not for now.”

With that acceptance, Paul sold his bike and used the money to buy bracelets for Janette, his two daughters-in-law and his granddaughter, Vogue – a concrete reminder of moving on.

### Starting to paint

Moving on has also meant channelling his discipline and patience into new pursuits.

Picking up a paintbrush was Janette’s idea. She suggested that she buy some oil or acrylic paints for him, but he asked for watercolours: “They’ll be more of a challenge”.

After he’d posted some of his early efforts on Facebook, the encouragement he received inspired him to keep experimenting with colour and form. He found that painting while listening to music with headphones created a calming space and allowed his frustrations to dissipate.

Now Paul applies a mason’s discipline and an athlete’s determination to painting. “Both letter cutting and watercolour painting give you no second chances. One wrong stroke and it’s ‘Goodnight Dick!’” he laughs.

After the accident, Paul struggled to write his name but now he signs “davo” on the many canvasses he generates in regular painting sessions in his garage studio.

He captures small scenes of places that he and Janette visited in their travels over the years, and larger canvasses of the curved female form in brightly coloured Picasso-esque shapes. He entered one of his works into the last *Shine* Art Prize, and plans to do so again this year.

Paul’s outlook is generally sunny. “I feel like everything is a privilege – being involved in art, being able to gift it, it’s such a privilege.”

Janette finds it hard not being able to discuss all the things they used to. But she says they’re in this together. She drove between the Central Coast and Ryde every day for 6 months to be with him during rehab. She describes her job as being there to absorb the downs and keep Paul on an even keel. “Our biggest connect is our loyalty to each other and our love. He never gives up and that sets me up with hope. He’s my Paul.”

“ I had 3 choices. I could let the injury define me. I could let it destroy me. Or I could let it strengthen me. And that’s the one that I chose. ”



# Disability support workers: essential but undervalued

For many Lifetime Care and Workers Care participants, the support workers who regularly come into their homes to help them with daily tasks are an important ingredient in being able to live their best lives. We talk to some participants and support worker providers.

## A COVID challenge

Danielle Bennett from All About Caring says that the early COVID period was an opportunity to learn more about responding quickly.

“We had to think how to do things differently so that participants could still receive the services they needed. We had to respond quickly to risk.

“Our support workers were amazing. They were hands-on in the trenches working with participants not knowing what the significance of COVID was going to be.”

“COVID at first was the great unknown,” says Damon Ashton of Care1. “We didn’t know how it would affect our organisation, our workforce or the participants.”

Sam Ball from Acquired Brain Injury Services says that for their support workers the pre-vaccine period was particularly challenging.

“Trying to reassure our participants and keep the communication going was hard when there was so much stress and anxiety.

“We did quite well keeping our support workers relatively COVID-free during the lockdowns but, since the end of last year, with the prevalence of COVID in the community it has really exploded among our support workers.”

## Shortages

Damon points out that the perfect storm of low unemployment, reduced access to workers from overseas and the stresses of COVID forcing many support workers to reassess their careers has led to difficulty in finding workers to meet the needs of participants.

“The market is now very thin,” says Danielle.

## The providers



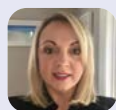
**Damon Ashton**  
Founder,  
Care1

“I guess I fell into the disability sector. I was studying fine arts and found some work with Homecare on the Northern Beaches. I really liked the work and ended up full-time with the Cerebral Palsy Alliance. I started Care1 in 2006 and we now provide services across the disability sector through NSW and Qld.”



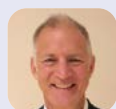
**Samantha Ball**  
General Manager for Services,  
Acquired Brain Injury Services

“I worked in marketing and comms, then as a teacher. I had an accident myself, got interested in rehab and trained in community services. I started 10 years ago as a support worker at ABI and I’ve had various roles here. I now oversee all our individual support services.”



**Danielle Bennett**  
Founder,  
All About Caring

“I worked as a support worker when I was completing my health science degree at uni. There were lots of complaints about service delivery and I thought I can do this better. I guess I had a real passion. I started All About Caring in 2001 to provide community-based support to help people live independently in their own homes.”



**Antoine Casgrain**  
General Manager of Operations,  
All About Caring

“I was in the financial service industry for many years and I wanted a legacy that was about more than improving someone’s share portfolio. I felt I could bring some structure and rigour, some protocol and process to the care industry. I’ve been in the industry now for 4 years.”

## The participants



### Brigitte Bullen

**Brigitte is an LTC participant who lives with a brain injury.**

“When you are living with a disability it’s hard when you see what needs to be done and can’t do it yourself, or knowing that the effort and brain power to do it would take hours compared to 15 minutes for someone else.

“I have to say I don’t enjoy having support workers do things for me, but this isn’t a conscious choice. It’s not like having a maid.”

“I like a familiar rapport but I also want boundaries. I just want them to do physical things – to help with a load of washing, unpacking the dishwasher, pull up the beds, sweeping – to just see what needs to be done and to do it.

“Now I have the best support worker – a 19-year-old with amazing instincts.”

**Advice to others:** “It’s not about years of experience. It’s about intuition and initiative. You need to get the right person.”

See *Brigitte’s story in the last issue of [Shine, Summer 2021](#).*



### Simon Page

**Simon is in the Workers Care program and lives with a brain injury.**

At the moment Simon has round-the-clock care and he’d like to work towards having some time by himself.

“Aphasia has taken a big chunk of me. Suddenly my life was filled with clinicians, case managers, psychologists, neuropsychologists, speech pathologists, doctors, fitness specialists, music therapists.”

“I’m never alone. I would like the nights alone. Saturday. Sunday. Alone.”

See *Simon’s story on page 16*.



### Steve Peterson

**Steve is an LTC participant who lives with a spinal cord injury.**

“I’d prefer not to have support workers – it’s always hard having other people working in your house. One of our challenges is trying to minimise the unintended impacts on privacy and my family.

“But my support workers are essential for me to live a normal life – getting me out of bed and driving me around. I have 2 who arrive about 7am to get me up and give me physio. They leave by 9 or 10, then someone usually comes around the middle of the day and then another 2 come in the evening to get me ready for bed. There are 6 carers in the team and some of them have been with me from the beginning.”

**Advice to others:** “It’s challenging but, ultimately, support workers are a positive. Be positive, respectful and flexible yourself and it will provide the best outcome for everyone.”

See *Steve’s story on page 2*.



### Jack McBride

**Jack is an LTC participant living with a brain injury.**

“In the 3 years since my accident, I’ve had 4 good support workers who taught me what good caring means and who’ve inspired me to work in the disability care and support area. I now have a support network to help me grow.

“I got angry with some of the others and got into trouble about that.

“It’s good for me that I don’t need support workers anymore.”

“Having support workers in the home was more an issue for Mum. She was still adjusting to the new me, and it was hard having the support workers there. She felt that because I had these greater needs that she should be doing that work and looking after me and not have someone else do it.”

See *Jack’s story on page 10*.

“There is a real shortage. It’s a lot harder for us to get the right people, to get people with expertise in brain or spinal cord injury.”

“Even just staff through the door for recruitment is getting harder and harder,” says Sam. “We’re certainly feeling the squeeze right now.

Damon has been working in the disability industry for 30 years and says this is the most challenging time for staffing he can remember. “We now have two full-time people working on recruitment, looking at inventive ways to get and retain staff.

“We’re having to get better at marrying the interests of support workers and participants – not just with the right skills,” says Danielle. “That way the relationship can be sustained longer and we can reduce the turnover.”

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## Working with icare

Antoine Casgrain from All About Caring says they have been working with icare since 2011. "icare appreciate us as essential to making the lives of participants better. The collaboration is synergistic and flows beautifully. It is a great relationship."

"We've been working with icare 9 to 10 years," says Damon. "They have been very supportive during the pandemic. They've helped providers with care coordination and other common issues. They have become more consultative."

Sam says that about half her agency's work is with icare. "The refreshing thing about them is that they are very willing to engage and listen to us and open to feedback so it's very much a partnership."

## What of the future?

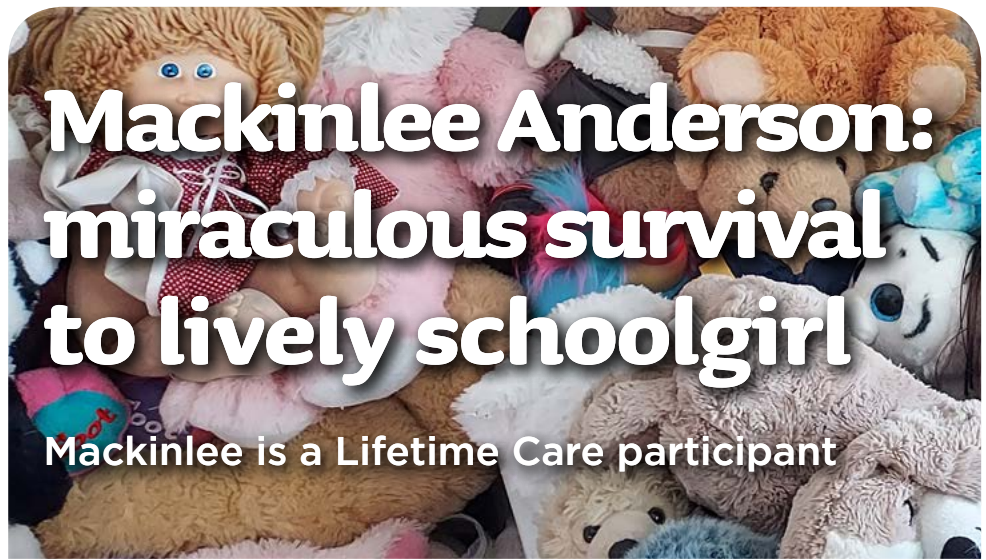
"I think we all need to talk more with our participants," says Antoine, "and regularly check in and ask how they would like something done. 'What are your expectations? Please show me or guide me.' This is how we can keep meeting the needs of each participant."

Support workers are very undervalued by society, Sam points out. "And we'd love to see them more valued for their skills and the hard work they put in."

"It's not just an unskilled job that anyone can do and I'd love to see more people attracted to the role, particularly men."

"But I'm hopeful for the future of the industry and just hope we can keep up with demand."

"It all comes down to communication," says Danielle. "It comes down to listening."



Mackinlee endured a near fatal car crash when she was 6. Not expected to survive the accident, she has had a remarkable recovery and is now looking forward to the arrival of a French bulldog puppy.

Mackinlee is at the front door with her mum Kylee, eagerly awaiting our meeting at her home in Nerang in the Gold Coast hinterland. She lives with her parents and 3 older brothers and a large collection of stuffed toys and live animals. "Three dogs, 2 cats, a bird and a fish!" she tells me proudly.

## Accident driving home

Five years ago Mackinlee was 6 and in her first year at Ashmore State School. "She was a normal, happy child," says Kylee. "I loved doing lots of things," adds Mackinlee, "like dancing, singing and face-painting. And I liked playing with my Nan."

In the September holidays that year, Mackinlee and her family drove to Wollongong to visit Kylee's family. On the return trip they travelled in convoy with Kylee's parents. But near Port Macquarie the car Kylee was driving collided with two other cars and a semitrailer coming in the other direction.

Mackinlee's Nan, Kay, was killed in the accident and Mackinlee was badly injured while her mum and brother Riley were relatively unhurt. Emergency workers said they were amazed that any of the occupants of the car came out of the wreckage alive.

Mackinlee was taken to ICU at John Hunter Hospital in Newcastle with her pelvis broken in 3 places, a ruptured bladder, broken femur and severe brain injury. After a 13-hour surgery, doctors told Kylee that they did not expect Mackinlee to live as her brain was not responding and, if she did live, she wouldn't be able to walk, talk or eat again.

But on the second day, her brother Riley squeezed Mackinlee's hand and she squeezed back.

It was some days later that she sat up and smiled.

"The first way I could talk to people was with my eyes," says Mackinlee. "If I blinked

“ The first way I could talk to people was with my eyes. If I blinked two times it meant 'yes' and one time it was 'no'. ”





“ Every day the doctors would say she can’t do something and the next day she could do it. Mackinlee just constantly amazed us with her determination and positive attitude. ”

*Mackinlee and her mum, Kylee.*

two times it meant ‘yes’ and one time it was ‘no’.”

“And by day 32 she was speaking,” says Kylee.

“Yes!” adds Mackinlee excitedly, “my first words were ‘Mum’, ‘Dad’ and ‘Riley’.”

“Everyone was gobsmacked that she was talking again,” says Kylee.

Mackinlee’s progress continued. Soon she was eating again. “Eleven cans of tuna in one day!” she says. “It’s still my favourite food.”

Mackinlee moved to Lady Cilento Hospital in Brisbane for rehabilitation. She was able to join her family at home for Christmas before it was back to Lady Cilento for ongoing rehab.

After 8 months Mackinlee was walking. “By myself, down the hall,” she says.

### **We were all amazed**

“Every day the doctors would say she can’t do something and the next day she could do it,” says Kylee. “Mackinlee just constantly amazed us with her determination and Riley was wonderful in helping her by doing arm twirls and bed curls with her beside her bed.”

She was able to start at the hospital school in February before returning to Ashmore State later in the year where she would go 2 to 3 days a week depending on her fatigue levels.

### **Full-time at school**

“At first I had a wheelchair taxi to take me to school,” Mackinlee tells me.

“icare paid for extra teachers that she needed,” says Kylee. “Overall if it wasn’t for icare, Mackinlee wouldn’t have made the progress she has. And then in 2019 she was able to move into year 3 full-time.”

Mackinlee still needs to keep up her rehab exercises. She regularly sees a physiotherapist, an occupational therapist and a speech therapist.

“All the extra therapy is helping to keep her up-to-date at school,” says Kylee. “Learning how to run, and swim and hop again.”

“And read!” adds Mackinlee.

Her left side was initially paralysed after the accident. It is still weaker but it continues to improve.

“And apart from that we’re not sure that there are any ongoing brain injury issues,” says Kylee.

“I reckon her mindset is remarkable. She really encourages and inspires other children.”

Mackinlee has recently had tendon release surgery on her left foot and has the foot in a surgical boot. The surgery was needed to lengthen a tendon that had become too tight due to a growth spurt combined with the brain injury. The prognosis is good.

Now an animated 5th grader, Mackinlee enjoys a lot of the things that other 10-year-olds enjoy. She goes to the beach, she loves art, gardening, sharing updates on social media, seeing her friends and making cupcakes.

“And I love animals! My dad was a dog breeder. When I see animals they bring me joy.”

“She pats all the dogs on her walks,” adds her mum.

### **New puppy**

She is about to get a French bulldog puppy provided through the Make-A-Wish Foundation. “I’ve decided to name her Katie after one of my favourite doctors at the hospital,” she tells me. “I want a dog to grow up with me.”

Mackinlee still thinks about her grandmother who died in the accident. She has a painting of a sunflower on her arm. “My Nan loved sunflowers,” she tells me softly.



# Jack McBride: looking to the brighter side

Jack is a Lifetime Care participant



Before his bike accident, Jack worked hard and partied hard. Now, still living with the effects of a brain injury, he is trying to be the best version of himself and to help others.

Twenty-four-year-old Jack lives with his mum Andrea and their old kelpie cross Gemma in a house behind the beach at Noraville on the Central Coast. It's the region where he's lived his whole life.

When Jack was 17, his dad died suddenly. "That was a difficult time for me," he says. "It just didn't seem fair. I didn't see the point of doing things right as Dad had, only to die young. I started using cannabis and drinking more. By the time I was 21, I was a heavy user. I was living for the weekends. I also had depression and anxiety."

When Jack finished school he started working as a scaffolder. "I thought jobs were something you had to put up with, not enjoy. But I liked scaffolding and was half-way through a TAFE accreditation course when I had the accident."

Jack was heading to work on his motorbike in March 2019 when he collided with a SUV travelling at 80kph.

## Fighting for life

"I don't remember it at all. I was very lucky that the first person at the crash was an off-duty paramedic who knew not to lift my head."

Jack was left fighting for his life in John Hunter Hospital with multiple skull fractures and a traumatic brain injury.

"I was in a coma for 2 days, and then for 2 months in the hospital and brain injury unit.

"Initially I was not talking, not walking, not eating. I had to learn them all again. I also had double vision. I needed to defrost!" he laughs.

"I felt I had to do everything they told me to do if I was ever going to get out. I had to do the exercises - I even broke their sit-to-stand record."

Slowly Jack regained most of his pre-accident abilities.

But back home with his mum, Jack knew it would be some time before he would be well enough to work again. He exercised hard to lose the 20 kg he had put on in hospital. He also volunteered at Arafmi, a non-government mental health support network.

Jack's 18 months at Arafmi had a big impact on him.

"David and Rhonda from Arafmi told me not to stress about things I couldn't do but urged me to focus on relationships, as the most important things in life. Their advice helped build my confidence and I owe them a massive thankyou. It also meant I could initiate some cool stuff for them. I helped set up a bike riding group and I facilitated a men's group where the blokes could just chat about their week and their lives. I even got them a vending machine so they could raise money by selling drinks."

Jack regained his driver licence and completed a TAFE Certificate III course in disability support.

And he had other unfinished business. Jack had had an old school friend, Kyle, who'd given him a guitar in hospital to help him practise his memory skills. But Kyle took his own life on Father's Day, two weeks after Jack came out of rehab.

## Ride for Kyle

"The loss of Kyle made me think about how precious life was and that not everyone gets a second chance like me. I thought, I can cry about it or I can do something with my life. I knew Kyle would want me to choose the second one.





“ I feel I have to pay back all the people who’ve had faith in me. I want to show them that their time wasn’t wasted. ”

Jack with Nathan Haywood, his case manager from the Hunter brain injury unit.

“I thought I would do a ‘Ride for Kyle’ up the coast to Brisbane. I would go to all the places Kyle never got to see and raise some money for the Hunter brain injury unit.”

The first ride was in March last year, the second anniversary of Jack’s accident. Over 16 days, he cycled to Brisbane through beach townships and along smaller roads to raise money for mental health. He mostly stayed in youth hostels and caravan parks. His mum was his support driver.

“I’m now preparing another fund-raising Ride for Kyle for March next year. It’s a lot of organisation but I’ve already got a commitment from a local bike shop to provide the support vehicle.”

Jack still has ongoing problems from the brain injury including short-term memory deficits.

“I still see an occupational therapist who helps me with time management and sorting out my preparation for any events. I’m getting much better.

“Mum and I also see a neuropsychologist. She helps me with how to cope with things, and she helps Mum to see how far I’ve come. The sessions where Mum hears things from the specialists, not just from me, have helped so much in getting us on the same page.”

### Better each day

Jack and his mum have also done an online course in “convers-ABI-lity” at Sydney University. “It’s really helped us work together better – to communicate more collaboratively,” he says.

“I try and get one percent better each day. If I can do that then I’m winning!”

Jack feels in many ways he is better than before the accident.

“Now I see a brighter side of life. I like getting up early to make the most of the day. I do meditation and yoga every day and I try and learn something from every person I meet.”

Last year Jack got his first paid job since his accident, with Coast and Country Primary Care who provide mental health services on the Central Coast.

“I applied for 19 jobs in the care sector. The 20th one, I got the job. It’s casual, but I’m mostly working 5 days a week and I’ve now been there 9 months.”

The job involves Jack providing support to people with brain injury or mental health issues.

“I use a lot of the strategies I’ve learnt during my own recovery – music therapy, showing how not to stress out too much, good little sayings.”

“Everything he said he’d do, he has done,” says Nathan Haywood, Jack’s case manager from the brain injury unit. “The ride to Queensland, losing weight, getting his licence, finishing the TAFE disability course, getting a job. He always follows through. He always finds the answer. He’s got the will.”

“I feel I have to pay back all the people who’ve had faith in me,” says Jack. “I want to show them that their time wasn’t wasted.

“And I’m just starting. That’s the best thing about being the age I am. I want to pay it forward to help show people what they can do and what I can do to make the world a better place.”

“ I thought jobs were something you had to put up with, not enjoy. ”



# Your feedback to us




## Participant survey 2021

We have been surveying Lifetime Care participants since 2009. Your feedback helps us understand what we're doing well and what we can improve in the way we provide services to you.

### Since 2020, using your feedback, we have:

- published our **Health Literacy Framework** to help you manage your own health, rehabilitation and wellness through increasing the accessibility and availability of services, programs and information – for [more information](#) or download the [Health Literacy Framework PDF](#)
- implemented the schedule for equipment repairs and maintenance to address delays
- changed the **My Plan toolkit** to provide you with plan preparation tools to make it easier to participate in the planning process
- increased regional recruitment to our **Case Management Panel**
- developed innovative and immersive training for our support worker providers to improve the way support workers interact with and understand you.

**90%** satisfied  
with how Lifetime Care meets their needs



### Findings from the most recent survey in 2021

We were excited to have the opportunity to run the participant survey last year, after having to postpone the 2020 survey due to the impact of the COVID-19 pandemic. 90% of the people surveyed were satisfied with how Lifetime Care meets their needs.

Over the last few months we've presented the findings from the 2021 survey to Participant Reference Groups across Lifetime Care. Feedback from the groups so far has been positive.

#### What is going well

- We have a good understanding of your injury and priorities
- We communicate clearly with you
- We treat you as an individual, with empathetic, inclusive and accessible communication
- You are satisfied with the services provided by Lifetime Care especially:
  - occupational therapy
  - equipment
  - exercise and gym
- Your support workers are reliable, skilled and respectful of you
- More participants than ever before had a My Plan and found it useful when setting their goals.

#### Where there is room for improvement

- Letting you know that you can choose or change your provider, including your support worker agency
- Improving your ability to find out information about services and supports available without having to speak with us directly
- Being more open to finding new or different ways to meet your needs
- Providing you with timely updates to support you to make decisions
- Doing more to help you advocate for your needs
- Exploring opportunities to help you with vocational goals after injury
- Improving the communication between you and your support worker agency.





# My Plan

Working together to plan your supports and services

## Improving our future service to you

From your feedback this year, we are looking at these particular areas:

- how we communicate with you or your nominated person when you choose icare-funded supports to make sure you have the information you need
- current vocational support programs and how they can best meet your needs
- regular communication to you from the agencies who provide your support workers. We also want to make sure you have all the information you need to choose who delivers your care.

We look forward to continuing to improve our service to you.

“ My case manager gives me the option to say no ... I would have a problem saying no if they didn't let me know it was ok as I would assume I have to do it. ”

Brain injury participant

## My Plan

We want to work closely with you to plan supports and services that help you achieve goals that are important to you. We launched the new My Plan toolkit in May to help us do this.

### What is My Plan?

My Plan is the planning tool used by Lifetime Care and Workers Care to help you identify and document:

- the things you want to do
- the assistance and support you need
- what you will do to work towards the goals you have set.

### What has changed?

You told us that you like My Plan and want to choose the ways in which you are involved in developing your plan. We have created some new tools to help you be more involved in your My Plan if you want to.

#### Preparation tools

You can now access these tools to help you prepare for meeting your case manager to discuss your My Plan. These tools help you think about your services and supports, what progress you've made and what you might like to include in your next plan.

#### New My Plan template

This is available to help you write parts of the plan yourself if you want to. Find the new Lifetime Care resources [here](#) and new Workers Care resources [here](#).

### How do I get a My Plan?

If you don't have a My Plan but would like one, contact your case manager or your icare contact.

### What if I don't want a My Plan or don't want to be involved?

We think developing a My Plan with you is the best way for us to understand what's important to you and what services and supports you need to live life your way. However, you don't have to be involved in developing a My Plan if you don't want to. We will still work with you to organise services to provide the assistance and support you need with or without a My Plan.

# Chris Love: a passion for trees

Chris is in the Workers Care Program

Chris relished his work as an arborist. But a bad fall in 2017 and the resulting injuries meant he could no longer work with trees. He maintains his other passion – for collecting.

Chris lives in the hamlet of Kentucky, between Tamworth and Armidale in northeast NSW. His cottage was once a butcher shop when the whole area was given over to orchards after World War I. Now Kentucky is merino country and the village consists only of a shop with petrol pump standing guard outside, a church and primary school.

## Shiny treasures

The seemingly empty village is at odds with the treasures Chris displays in his neat cottage – a red 1935 Coke dispenser, a 1907 ice cooler, a sunflower-yellow petrol bowser, an old wall telephone with windup handle. Each item in the collection is brightly polished.

“As an arborist I sometimes refused to cut trees down. They’d have to find someone else for the job.”

An energetic wood fire adds to the welcoming atmosphere. Chris is just back from riding pillion with a mate to nearby Uralla. Frustratingly for him, his motorbike licence was cancelled after his accident because of his loss of peripheral vision.

Chris was born in Armidale and moved with his family to New Zealand at age 3. Returning for a change of scenery at 16, he started work in the local abattoir, then worked around the country in gold and aluminium mines.

But then he developed a love for trees and became an arborist. Gesturing with both hands emphasising his passion for the work, Chris says, “I understand the biodynamics of trees. They’ve got to be cut the right way. You have to know the cambium layers. There’s hardwood at the centre then layers and layers. When you cut the cambium layer it lets disease in.

“As an arborist you understand a tree’s weakness. You use a special drill called a resistograph to tell the tree’s life – to show its defects.

“I’ve removed a lot of trees because people plant them in the wrong place and they get into the plumbing. It’s not the tree’s fault. But, after all the trees I’ve worked on over more than 25 years, one finally got me!”

## Fall from a pine

Chris describes his accident 5 years ago in a matter-of-fact tone. “I was 5 or 6 metres up a pine tree, preparing to take it down. I had to take it down in pieces because there was a high-voltage power line nearby so I couldn’t just drop it. I was harnessed to the tree and my offsider was handing me ropes from the ground.”

The offsider didn’t see Chris fall. He only heard him hit the ground. A man across the way saw Chris trying to get up and lay on top of him to stop him moving.

“He knew I was in trouble.”

No one knows exactly what happened, but Chris thinks his lifeline rope slipped. He was in John Hunter Hospital in Newcastle on life support for more than 2 weeks. About a month of rehab in Tamworth Hospital followed.

Chris still does the rehab exercises he was taught for his back and for his vision. He compressed 5 vertebrae in his lumbar spine and ruptured his aorta. “I lost 1.5 inches and still have problems with my





“ I do my exercises almost every day. I’m trying my hardest and I won’t give up.”

*Chris with his vintage Harley Davidson.*

left leg but I prefer caring for myself. I had a cleaner. Now I do it myself.”

“I do my exercises almost every day. I’m trying my hardest and I won’t give up.”

### **Anxiety**

Because of the impact to the front part of his brain responsible for managing his emotions, Chris developed severe anxiety. He says he’s a feisty sort but reckons it got much worse after the accident and now he relies on heavy medications to stay calm.

Chris’s parents live 40 minutes away in Armidale and Chris’s tenacity extends to caring for his mum who has advanced dementia.

“It’s a big job. People don’t get it. Dad’s busy with groceries, cooking, cleaning. Mum doesn’t always recognise me but I go there every second day to keep her company and help Dad. It’s very tiring but it’s good to be there so Dad can go out.”

“I hate that dementia. It robs people of everything. Before, no one could put one over Mum, but to see her now!”

Chris’s love for trees persists and the discussion winds back to the job he relished.

“As an arborist I sometimes refused to cut trees down. They’d have to find someone else for the job.” Chris’s voice trails off as he pictures trees he

has loved. “There was an old bunya pine – nearly 200 years old – at the University of New England. A huge tree. It was in danger of dropping its massive cones on graduates who, every year, gathered to have their photos taken under it.”

Chris queried why photos couldn’t be taken to the side of the tree but the risk of injury was too great and Chris had to take the tree down.

### **Vintage collector**

Trees aren’t Chris’s only passion and his face lights up animatedly when describing his old motorbikes. He started riding bikes when he was 12, and still buys, restores and sells them – always American ones. “I love their cars too – big limos from the ‘20s like Elvis drove. They all look good – Cadies, Fords, Oldsmobiles, Chryslers. They look like they’ve got a face or something.”

Chris is now looking for a 1935 Harley Davidson. They are rare – with the gear shift on the tank and a foot clutch. “They’re buggers to ride. A fellow interstate has done one up. It’s beautiful. I’ll be going up to see it before we do the deal.”

### **Value and loss**

When a new project arrives, Chris and a couple of mates list what they need, order the parts and work on the engines, gear boxes, clutches, frames.

“We rebush the fork, replace the rubbers. It’s a real art. Other mates do the electricals and we contract the painting out.”

Chris has a clear sense of what’s valuable and of what he’s lost.

“After the accident, I asked myself what the hell am I still here for. I’ve lost so much – including my partner, Jenny. I miss her. She said the brain injury changed me.

“And the business – I just closed it down. I was the best around – climber, roper, rigger. Fellows today get 5 metres up a tree and their knees are banging together – I used to do 25 metres.”

“Only health is valuable. You’re a poor man without it.”

Chris is still a fit and youthful 52-year-old. “It’s the trees that’ve done that,” he says wistfully. “They keep you young.”



# Simon Page: in love with music

Simon is in the Workers Care Program



A fall and a brain injury brought an end to Simon's busy career developing and managing nightclubs. But the creative 62-year-old has now turned his talents to composing music.

Simon Page is cool and still lives in the heart of cool territory in Darlinghurst, central Sydney. His apartment is a stone's throw from the party stretch of Oxford Street. With shaved head and bright orange designer spectacles, Simon opens the front door with a flourish – his equally welcoming Lhasa apso dog, Georgie, at his heels. Behind them are artistic posters Simon has created. On the floor along another wall are 350 music LPs of all eras and genres.

Simon came to Australia from New Zealand in his twenties. He was already a committed musician who had played the piano since age 8. He and his former wife, Susanah, began developing and running nightclubs. Their first club was the subterranean “Sublime” in Pitt Street and then “Home”, a three-floored waterfront space overlooking Darling Harbour featuring top DJs from around the world.

## Boutique hotel

A perfectionist in everything, Simon attended to every detail, right down to the design for advertising posters. Hence the funky art on his walls.

The couple also developed the 5-star boutique Moog Hotel in Surry Hills where Bill Gates once stayed. It featured a recording studio and a pool with underwater speakers.

In 2010, Simon blacked out while up a ladder inspecting a sound speaker. He fell and injured his head severely. He was in a coma in hospital for 10 weeks before moving to Ryde Hospital for 9 months of rehab.

The talkative workaholic who bubbled over with creativity and ways to motivate his employees had been struck down with aphasia – a condition affecting his ability to express and understand written or spoken language. Simon becomes emotional as he describes the feeling of being no longer able to inspire people. “All respect for my insights has disappeared and no one listens. In my head, the words fine. No problem. But can't get them out. Bizarre. Bizarre.”

Some of Simon's sentences flow fluidly and then he stumbles into a more staccato delivery while trying to capture a word. “No problem what to say. No problem understanding. But saying. Frustrating.”

He frowns and growls to demonstrate the effort of trying to make himself understood.

## Using a code

“January, February, March” he mutters softly to himself and then pounces on “APRIL” when he arrives at the month he's trying to name.

Or he uses a readily picked up code to depict time: “Monday Sunday, Monday Sunday, Monday Sunday,” he says to describe 3 weeks. Or “January December, January December,” to capture 2 years.

At other times he explains a thought by drawing on a notepad. Or he spells words and numbers he's struggling to say, tapping on the table as he says “Three. Five. O” to describe how many records he has.

“All respect for my insights has disappeared and no one listens. In my head, the words fine. No problem. But can't get them out. Bizarre.”





“ If Simon has an idea, he’s staunch about it. I might suggest a chord but he knows where he wants it to go and is passionate about pursuing his idea. ”

Simon takes a laminated card out of his wallet. His speech therapist gave it to him to help explain to people why he can’t clearly say what he wants. On one side, the card explains that he has aphasia:

*“I am intelligent but need some help with my communication. This can be frustrating for me.”*

The other side lists ways to help:  
*“Please give me time to talk.*

*Please give me a choice of two things if you know what I want to say but the word is stuck (eg tea or coffee).*

*Speak slowly in shorter sentences.*

*Ask clarifying yes/no questions to help me.”*

The card has been a great help. People say, “Wow! This is different.”

Simon breaks into a beaming smile: “Bruce Willis. Cool.” He then quickly pulls up an article on his phone about the actor Bruce Willis being diagnosed with aphasia. He’s enthusiastic about the publicity Willis’s diagnosis has brought to the condition.

## Working with music

Being attentive to every detail of anything he does, has made the impact of Simon’s accident especially frustrating. The words are there for him but he struggles to articulate them, periodically looking to Vic, his musical collaborator,

to fill in the gaps. Vic has known Simon since late 2016 when he began helping Simon master the complexities of composing music online using an electronic keyboard and computer with giant monitor.

Vic describes being blown away seeing Simon struggle to articulate his thoughts and yet expressing himself on a keyboard with flare or tapping out a groove on his drums. He says that while Simon’s analytical skills may be compromised, his creativity is dynamic.

The two have a warm rapport and Vic is enthusiastic in recognising Simon’s perfectionism. “If Simon has an idea, he’s staunch about it. I might suggest a chord but he knows where he wants it to go and is passionate about pursuing his idea.”

Sometimes Simon has a melody in his head and just needs to capture it on the keyboard. Other times he noodles along, trying different riffs until he works it out.

They might start with some piano chords making a simple melody. Next some string parts, then woodwinds, brass, percussion, ending, perhaps, with a choral overlay. Each section might take a week as Simon’s perfectionism demands that he refine and refine.

*Enjoy one of Simon’s compositions [here](#).*

Simon dreams of one day sharing his compositions with his 8-month-old granddaughter Lulu. He envisages sitting with her at his keyboard, instilling in her his love of all things musical. He’s also started working on gathering material to write his story. Plastic-sleeved notes and photographs are readied in neat piles – the beginnings of capturing: “All the story. The good. The bad. Both. Unfortunately.”

## Solace

A look of sadness clouds Simon’s face – “aphasia has taken a big chunk of me”.

Simon finds peace and solitude in music. Every night he chooses an album from his collection and plays it during dinner. At night the phone next to his bed delivers Spotify with its endless offerings of music types and eras. Asked which he prefers, he answers, “All of them. Everything music.”





# The notice board

Sharing your news highlights, handy information and upcoming events.

## We care

Having a loved one involved in a serious injury or accident can be a challenging time for families. *wecare* is a program that partners with Carers NSW to provide support to family carers, including adults, children and young people. *wecare* recognises the experiences and challenges which informal family carers face and provides individualised support to help these carers foster their own health and wellbeing.

### What's new?

The program has expanded to include a range of groups that meet monthly via Zoom:

- **small mentoring groups** for carers to connect with other carers while accessing the program resources.
- **peer support group** for adult carers to express themselves with confidence in a friendly, safe space and connect with other carers living in similar situations.
- **peer support group** for young adult carers (18 to 25) wanting to connect with carers of similar ages who have the shared experience of caring. The group discusses self-initiated topics, self-care and mindfulness.



## Mindfulness for Everyday Living sessions

These upcoming 6 online sessions are suitable for carers over the age of 18 years.

Mindfulness is the ability to be in the “present moment” with the focus on what is happening right now rather than what has happened in the past or what may happen in the future.

The sessions will provide information, practical tools and resources to bring the principles of mindfulness into everyday life.

**When** Wednesday 6 July, 10 August, 7 September, 5 October, and 2 and 23 November. All 10:00-11:00am.

**To find out more** about *wecare* or to register for the Mindfulness sessions above, contact the *wecare* team directly at Carers NSW: P: **02 9280 4744**, E: [wecare@carersnsw.org.au](mailto:wecare@carersnsw.org.au)

## Remarkable Insights podcast

In 2020 our charity partner, Cerebral Palsy Alliance's accelerator program, Remarkable, launched an online conversational series called “Remarkable Insights”. The series brought together a panel of experts, advocates and innovators working in the disability-tech sector to discuss the importance of harnessing technology to build social and economic inclusion of people with disability.

These conversations have attracted a global following and now Remarkable is adapting future episodes into a Remarkable Insights **video podcast series**.

The series will explore how disability drives innovation. The first season launches later this year and will include 8 episodes with a stellar lineup of guest panellists.

To hear more about the podcast launch, sign up to the mailing list at: [bit.ly/RemarkableInsights](https://bit.ly/RemarkableInsights)

I N  
S I G H T S  
PODCAST  
COMING  
SOON



## Social Brain Toolkit

### New resources for people with a brain injury

icare has provided funding to support the development of this toolkit – a new suite of online resources to support communication after a brain injury.

The resources include:

- **interact-ABI-lity** an online, self-guided short course on how to communicate successfully with people with a brain injury. For family, friends, support workers, and professionals working in brain injury.
- **convers-ABI-lity** an online platform for people with brain injury and their communication partners to improve conversations together, with the support of a speech pathologist – see more about this resource in Jack's story on page 10.
- **social-ABI-lity** an online, self-guided short course for people with brain injury about using social media successfully and safely.

### Online launch

Find out more about these new resources at the online launch for people with brain injury, family members and organisations: Friday 21 July 11am-12pm. [Register here](#) to attend the launch, or to receive a recording after the event.

For more information about the Social Brain Toolkit, [visit](#) or contact the University of Sydney project team at [abi.communication-lab@sydney.edu.au](mailto:abi.communication-lab@sydney.edu.au)

## 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 the changes and challenges following traumatic injury.

Workshop attendees have told us they appreciate meeting other people in similar situations and sharing their stories. The program also offers information on social and economic resources available.

Groups are run as:

- in-person one-day events, or
- online 1.5-hour sessions over 5 weeks.

### When

The remaining 2022 dates are:

- Spinal cord injury: in-person, 16 September
- Brain injury: in-person, 29 July
- Brain injury: online, weekly, 10 August to 7 September
- Brain injury: in person, 11 November.

### Where

The in-person groups are run at Royal Rehab in Ryde. For more information, talk to your icare contact, or email: [erin.mitchell@royalrehab.com.au](mailto:erin.mitchell@royalrehab.com.au), or phone: **0423 756 159**.

## Carers Way Ahead

### Managing challenging behaviours in a person with brain injury

The Carers Way Ahead is a free online and step-by-step program for family carers provided by the University of New South Wales and funded by icare. It offers support for families who are managing challenging behaviours in a person with a brain injury.

### Take part

We're inviting family carers to take part in a pilot of the online program over a 10-week period. Support is provided to the family member to work through the program.

### Contact

Email Kim Wallis: [k.wallis@unsw.edu.au](mailto:k.wallis@unsw.edu.au)  
[redcap.link/thecarerswayahead](https://redcap.link/thecarerswayahead)

## Are you a First Nation person, or from a Culturally and Linguistically Diverse Background?

We understand that your cultural context may be a big part of who you are and where you draw your strength from. We are updating the way we do things so we can consider your cultural identity in the way we interact with you.

We want to improve how we provide services, and want to hear from you so you can help shape this change.

We would really value your expertise and guidance as we make changes.

### Join one of our Participant Reference Groups

These informal meetings are a chance to hear directly from you about how you feel about your services.

To find out more, contact Carolyn at icare.

E: [PAEnquiry@icare.nsw.gov.au](mailto:PAEnquiry@icare.nsw.gov.au), or P: **02 7922 5531**.

# Shine Arts Prize 2022

Enter and help us  
spread the word!



Artwork by Alison, Lifetime Care participant.

## The Shine Arts Prize has returned!

The prize is open to Lifetime Care participants and those in the Workers Care Program. You don't need any prior art experience to enter.

The prize recognises and encourages artistic practice in people of any age and highlights the role of artistic activities in maintaining wellbeing and engaging with community.

## What's new?

The three categories for this year have been expanded to include film and music:

- **visual arts** (including photography, digital, painting, drawing, sculpture/3D and film)
- **music** (including singing or instrumental)
- **children** under 15 years old (any art form).

## What are the prizes?

The overall winner of the *Shine* Arts Prize will receive \$2000 and will be offered optional mentoring sessions through Accessible Arts NSW. The winners of the individual categories will receive \$1000 each.

## How do I enter?

Entries can be submitted online until 5pm on 30 September via the [Shine Arts Prize 2022 webpage](#).

Also on the *Shine* Arts Prize webpage you will find links to:

- inspiring short videos (provided with Accessible Arts NSW) to help you with your entries and art practice. Topics include:
  - how to transform your ideas into an artwork
  - how to turn your art practice into a business
  - interviews with professional artists
- submission guidelines, and terms and conditions for entry
- the previous *Shine* Art Prize 2020.

Artworks submitted for the prize will feature in an online exhibition. There will also be an in-person exhibition at the icare office in Sydney at the end of the year for short-listed artworks - we will contact entrants to provide more information.

## Any questions?

Contact Nerita on **(02) 7922 1115** or email [shineartsprize@icare.nsw.gov.au](mailto:shineartsprize@icare.nsw.gov.au).

We've a limited number of starter kits with some basic art materials like pencils, paper and paint for new artists to help you prepare an artwork for entry. Just ask Nerita (above) for one.

“ Art is something anybody can have a go at, you don't have to be great. It's therapeutic. ”

Kerry, Lifetime Care

“ I feel like everything is a privilege - being involved in art, being able to gift it, it's such a privilege. ”

Paul, Workers Care Program

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

## We'd love to hear from you!

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

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

SCAN ME



## Shine online

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

**icare**<sup>™</sup>  
Insurance and Care NSW