

Man about town and winner of this year's *Shine* Writers' Prize. Meet Dom Goodwin, page 11.

Shine

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

Summer 2023

Kelly-Anne Kerley: back on the bike

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Kelly-Anne is a Lifetime Care participant

Kelly-Anne had a busy and balanced life – good job, good relationship and a love of cycling. Three years ago that all changed in an early morning accident. But with her optimism and determination she is now enjoying life again.

Kelly-Anne Kerley's story begins and ends with cycling. One autumn morning in 2020, the fit 41-year-old left home on her new Focus Izalco Max bike at 5.10am and joined her friend for a spin to see the sun rise at Manly and enjoy a coffee. She planned to be back home and ready to work in her HR manager role by 9am.

In a coma

That day Kelly was hit by an inattentive driver while cycling along the Manly esplanade. She has no memory of going jaw first into the car's windscreen and rolling over the bonnet.

It was 6 days later that she woke distraught to find herself in ICU at Royal North Shore with her Adelaide-based mum at her bedside. She later found out her Dad was there too but, with only one visitor allowed because of COVID restrictions, he spent much of the next few weeks waiting in the downstairs hospital coffee shop. Kelly sustained an incomplete spinal cord injury, facial injuries, and a traumatic brain injury. At first she was unable to move but, after 6 weeks of twicedaily physiotherapy, she started to walk with assistance. Moved to Prince of Wales Hospital to continue rehabilitation, she was eventually discharged 13 weeks after the accident.

Living in a third-floor unit in Leichhardt in inner-west Sydney, Kelly had to conquer the challenge of climbing and descending stairs while persevering with her rehabilitation.

"My tenacity was fierce," she says. "I really wanted to get my life back on track."

With the "wonderful support" of a recreational therapist, Kelly used a slowly-slowly approach to get back into cycling. "Small steps are undervalued," she says, "but they get you places."

Seven months after the accident, she tried a recumbent bike with her body in a laid-

The hard things never get easier; you just get stronger.

back position. Then a mountain bike with flat handlebars riding around netball courts, weaving in and out of cones for a few weeks. Next it was time to haul out her old road bike and venture out to the nearby Bay Run around Iron Cove.

Celebrations

The step after that was to put on her lycra bike kit and cleats. For 4 months, Kelly drove herself to Lane Cove National Park to cycle before cars were allowed in at 9am.

After a lot of hard work, Kelly was able to celebrate the second anniversary of her accident by cycling an average of 70km a day with 3 friends around France, Italy and Spain. In an article, "Breaking up with

my wheelchair," she writes that "the hard things never get easier; you just get stronger. My determination to keep moving forwards and live my best life is well underway."

Yes, there were setbacks, such as when she fell off her bike and her body went into shock.

"Cycling still isn't easy. My arms and neck ache and my muscles are still rebuilding due to the damage to my spinal cord and nervous system. However, I'm driven by my love for the sport and the rush it gives me." While Kelly's then-boyfriend had been supportive throughout her time in hospital, he wasn't ready to settle down.



My injuries are mostly invisible which means people generally think I'm OK, and often I am not.

Kelly-Anne at home.

"My life wasn't on hold just because I'd had an accident. I still wanted to live life to the fullest."

"I still wanted kids at that point - but the accident had stolen that from me. It's taken three years of my life."

Dating again

She ended the relationship and a few months later started dating again. "The dating scene was hard. I wasn't working and rehab is all-consuming. Plus, I was struggling with my identity and purpose – trying to figure what I wanted my life to be.

"I had to wear braces. I'd worn them when I was 15. You don't feel good wearing them again at 42!

"But then, I was grateful to have my own teeth. I'm lucky that even though my face is not like it was, it could be so much worse. In the big scheme of things, all this is nothing. It's important to change your dialogue so it's positive."

Kelly approached dating as she would an HR recruitment process at work – exchanging multiple messages followed by phone conversations to test the banter before arranging to meet and go for a casual walk.

Work represented another challenge for Kelly.

"I had been in a senior management role, earning good money and all of a sudden I'm learning how to walk again, dealing with a brain injury, living off of a portion of my salary and not knowing what my future looked like."

But when she transitioned back to work after 18 months, she could only manage 2 half-days a week.

"I was grateful for the support from my colleagues, but work was no longer the most important thing. Physio and being back on my bike, and living and juggling a life that revolved around appointments had become my priority."

New horizons

Working with vocational therapists helped her to consider other options that have recently led to casual work with NSW Health as a lived-experience educator.

She won a \$5000 scholarship from Forward Ability Support to write a book about her experience and now she is part of the Authorpreneur Boot Camp, a writers' group which meets fortnightly providing support and guidance.

Kelly says of herself, "the person staring back at me in the mirror these days is a strong, courageous, brave, resilient and kind woman."

"Those little messages to myself make all the difference when things feel traumatic. It's not about whether the glass is half full. It's about appreciating that you have a glass at all." So where is Kelly at now? "My injuries are mostly invisible which means people generally think I'm OK. Often, I am not, yet I try to get on with enjoying life while being grateful and proud of what I have achieved. I keep working hard at the gym, and managing chronic pain, fatigue and my overall wellbeing."

And her advice to others: "Keep asking questions. Be curious and keep moving forwards."

"Allow yourself to have down days – just don't stay there, be kind to yourself."

As for her dating project? Her first walk with Adrian was around Iron Cove and they've now been together for 10 months. Kelly will be moving in with him soon. She beams: "I'm super excited!"

Her final words to others: "Focus on what you get to do, not on what you don't. I get to ride!"



Daljinder Singh: strength and determination

Daljinder is a Lifetime Care participant

At the age of 18, Daljinder came to Australia to study engineering. A bad car accident and traumatic brain injury derailed his plans. But he never gave up.

Daljinder grew up in Punjab in north-west India as part of a large extended family. Every year his family, including uncles, aunts and cousins would holiday in one of the Indian hill stations where the climate was cooler. "When I was younger I used to help my dad in his electrical services shop and I'd also go with him to building sites, watch the construction and chat to the builders," says Daljinder. "I think I always wanted to be an engineer."

Study in Australia

In 2012, when Daljinder finished high school, his father encouraged him to study civil engineering in Sydney where Daljinder's older brother and cousin were already living.

"My school results were good and I was accepted into the University of Sydney. There were not so many Indians at university then and it took me 6 to 12 months to feel settled."

I wanted to finish the course for my father who I believe is watching me from up there.

Daljinder got a job working in an Indian restaurant in Bega on the South Coast.

"I'd go down every weekend - 5 hours each way - and also work there during the holidays. It was a good job and I didn't mind the travel."

But Daljinder was hit by family tragedy when, early in his second university year, his father died suddenly of a stroke.

"I felt my world almost broke. My father had always encouraged me, and had urged me to come to Australia."

Roo on the road

His father's death at first affected Daljinder's studies, and he had to repeat a semester. Then, in September 2015, his third year at university, Daljinder was driving with his cousin back to Sydney from Wagga. "We were outside Gundagai, he was driving and I was asleep. Suddenly there was a kangaroo on the road. My cousin swerved to avoid it but crashed into a parked truck." Daljinder had skull and other fractures, damage to his left optic nerve and a traumatic brain injury.

"I've got no memory of the accident or the period around it. I was in a coma for 10 weeks. The doctors couldn't tell my mum, who was there with me the whole time, if I was going to be OK, or even survive.

"I was in Canberra Hospital for 3 months and then the Liverpool Brain Injury Unit for rehab for another 3. By that stage I was walking, but my left arm had been so badly broken I felt I would never to be able to use my elbow again.

"I moved from the brain unit to a transitional living unit about a kilometre from the hospital. I walked to the hospital every day.

"That time I even failed their walk test. The nurse and OT monitoring me reported that I was walking into trees!"

Almost 10 months after the accident, Daljinder was able to return home to the unit in Revesby that he shared with his cousin.

Daljinder says that his medical specialists advised him that given the level of his brain injury he shouldn't return to university study too soon.

But he was determined to complete his degree - "I wanted to finish the course for my father who I believe is watching me from up there."

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Daljinder and his new work team.

He went back to university in 2017 – to do just one unit – but when he failed that unit the university excluded him.

Persistence

It was a bad period for Daljinder. Although he had recovered from most of his physical injuries, he was in a poor state mentally and was seeing his psychologist weekly.

"I was really angry and sad. I felt I hadn't been given a proper chance and that if I couldn't do the degree then I didn't want to live anymore. At one stage the police even came to check on my welfare."

Daljinder persisted. He applied for as many engineering courses as he could and was accepted by Western Sydney University where he started part-time in 2018.

"It was hard. Hard to concentrate, hard to focus. And I had very little sight in my left eye. But the university was very supportive."

Not only did Daljinder graduate as a civil engineer in 2022, he graduated with honours – almost 10 years after he'd first started his degree. His final thesis was on the use of lightweight foam concrete which creates fewer carbon emissions.

2022 was a big year for Daljinder. He was also a semifinalist in the NSW Young Achiever Awards receiving



With his mum, Kulwinder.

media coverage for his determination to finish his degree while still living with the effects of a severe brain injury.

Over the last few years Daljinder has had 3 internships organised through the Australian Network on Disability (AND).

"AND has been great in helping me get access to big engineering firms. I especially enjoyed my 3 months with the Hunter Water Corporation. It was a very supportive team and I learnt a lot."

Legacy of injury

Daljinder now lives in Milperra in western Sydney with his mum, who spends most of her year in Australia, and his brother and cousin. He still lives with the legacy of the accident.

"I have very little sight in my left eye, my balance and my left elbow are still a problem, and I can't remember faces easily. I don't have any sense of hunger or smell and so I need to remember to eat.

"And I'm still on antidepressants - but I think they're working OK."

Daljinder has a few thoughts that keep him moving forward.

"Hope is the first step to a positive and happy life, but better than hope is acceptance. I have accepted that what has happened to me has been given to me by God and I must live with it. Since no one

It was a long journey, but what got me through it was hope and acceptance.

has control over an accident I am just thankful I have been granted a second life."

In September Daljinder started his first job as a graduate engineer. He will be working in the design team for a large renewable energy project. He is over the moon. "I'm confident I can perform well because I told them in the interview about my brain injury and I succeeded in the recruitment process."

It's early days but Daljinder is enjoying the work and says that his manager and the team are all very supportive.

"I keep reminding myself that when I was in rehab I was given 5 words each morning to recall at the end of the day and I used to fail every time. And now I'm a full-time civil engineer.

"It was a long journey, but what got me through it was hope and acceptance."



Scott Priestly: still smiling

Scott is in the Workers Care Program

After a motor bike accident in 2006, Scott wasn't expected to survive. Although he is still living with the effects of his physical and brain injuries, he is enjoying lots of new activities.

When *Shine* meets Scott at his home in Barnsley, just west of Newcastle, he is with his Mum, Sharlene, and one of his support workers, Tash. The conversation that afternoon was full of jokes and banter.

A sense of humour

Scott has a mischievous wit as is fitting for a man with a huge collection of t-shirts with amusing, but often risqué messages.

"We've got to check him when we're about to go out," says Tash who has worked with Scott for more than 18 months. "Just in case he's wearing a shirt that's a bit inappropriate. He's got a wicked sense of humour."

"My quietest boy ended up my wildest one," sighs Sharlene.

I tell them that even when you're a good driver or rider that bad things can happen and change your life in an instant. Scott, now 51, grew up in nearby Holmesville with his parents and two brothers. His dad worked at the Newcastle coal loader.

When he was 16, Scott left West Wallsend High School to take up an apprenticeship as a carpenter and joiner with Stockton Hospital.

After his apprenticeship he wanted to work in the building industry but, as Scott says, "joiners do neat, detailed work. When you're putting up a house you want to get the timber up quickly. I found it hard to find a job."

He got a sales position with a timber company where he thrived, winning salesman of the year award.

When he was 24, Scott married Paula and they had two girls, Samantha and Casandra.

Apart from his family, Scott's great love was Ducati motorbikes. He was a founder and first president of the Hunters Ducati Owners Group, a club for local riders. He also raced bikes for the Ducati Bears Team.

In 2006 Scott was riding home from a new job as a workshop manager for a motorcycle dealer near Newcastle.

Scott out on the lake with Sailability.

He'd only been there 9 days. "It was Melbourne Cup Day and I didn't even have any bets on," jokes Scott. "In Cardiff they had just hosed down a section of road from a recent car accident but there was still oil left on the road. My bike slipped and a telegraph pole stopped me. That accident took a large chunk of my life."

Memory loss

Scott was taken to John Hunter Hospital with a traumatic brain injury as well as spinal, leg and shoulder fractures. He had also severed the nerves running from his spine to his left arm leaving it permanently unusable.

He was in a coma for 10 weeks and doctors told his family that even if he survived he would be unlikely to walk again.

Scott was transferred to Royal Rehab at Ryde. He had survived but had difficulties with attention and processing information. He had ongoing pain and no movement in his left arm. But most significantly he had forgotten the last 10 years of his life including the fact he was married and had two daughters.

Sharleen remembers that Scott rang her one day from Ryde. "'Mum,' he said. 'You know those two young red-haired girls who come into my room all the time? They're mine! And did you know that I was married?'"



Sharlene, Scott and Tash.

"He had to learn to do everything again from scratch," says Sharlene, "to eat, walk, talk, use the bathroom."

After 13 months in Royal Rehab, Scott went to Toronto Private Hospital nearer to home. One of his first carers there, Jude, asked about his accident.

"When I told her the story she started crying. She said she'd realised that she had been one of the first on the scene of my accident as she lived close by and had heard the noise. Jude told me that she never thought I would survive."

Coming home

It was more than 2 years after the accident that Scott was finally able to return home.

"I thought I'd be able to go back to work, but it hasn't really turned out that way. I did some sales work for friends and I've done some commercial photography as well – weddings and family portraits."

Paula and Scott split up. Their girls are now adults and live in Brisbane and Wollongong. Scott has large pictures of both of them on the wall and is obviously a very proud dad.

Since 2011 Scott has been involved with Sailability, a charity that helps people with disabilities get involved in sailing. "I started going with them on small trips out on Lake Macquarie. Now I'm a registered volunteer and I take



Scott in earlier days racing his Ducati.

other people out and teach them how to sail."

"The boats are just big enough for two people. I can manage both sails with one hand. I just need a lift to get in and out."

"Sailing is one of the best things he's done since the accident," says Sharlene. "He's free, he's not restricted. He's helping others and he loves it."

While Scott needs support workers around the clock, he still manages to see local bands once or twice a week. He tells anecdotes about concerts he's been to and about musicians he's met. He's partial to a dance as well and can get up from his wheelchair for a few minutes to join in on the dance floor. Tash often accompanies Scott to the concerts to provide support – "I quite like hanging out with Scott and his bands."

Scott has given talks to traffic offenders at meetings organised by local PCYCs.

"I talk about the accident, how it's affected my life and about the need to be careful. I tell them that even when you're a good driver or rider that bad things can happen and change your life in an instant. Sometimes people cry."

As for his lost memory, Scott says little things come back over time. "Sometimes people mention something to me or tell me things that happened and it comes back to me." Sailing is one of the best things he's done since the accident. He's free, he's not restricted. He's helping others and he loves it.

On the high seas

About 4 years ago, Sharlene took Scott on a cruise for a week to Noumea and Port Villa. "I felt he needed a holiday from everything. A holiday without his support workers.

"It was a great time. We shared a room and talked and talked. And he just did what he wanted to do. He made so many friends. People I'd never seen were coming up to me and calling me 'Mum'. Although I had to save him from the dance floor a few times!"

As *Shine* is about to leave we have the feeling we're not at all essential to the lively conversation between the 3 of them and that it will continue without us for some time.

"We've probably been burning your ears off," says Sharlene.

"Have a safe trip home," says Scott gently. "Drive carefully."



Shanae Taiepa: looking to the future

Shanae is a Lifetime Care participant

Surviving a bad accident at the age of 6 has given Shanae many challenges. But she is now looking forward to high school next year.

A few days before she meets with *Shine*, Shanae Pani Taiepa celebrated her 12th birthday with her mum, Kelly; dad, Wayne; her siblings and their partners – who all live in or near their happily busy household in Wentworthville, in western Sydney.

Shanae describes with relish the roast beef with gravy plus mashed potatoes and hot chips with which her mum delivered her birthday wish.

And even better, as twin brother Whatanui was away on camp, the birthday dinner had to be repeated a few days later.

Accident out walking

Six months after the family moved to Australia from New Zealand, Shanae was walking with her mum when she was struck by a car, leaving her with spasticity and weakness in her legs. She now needs a walking frame or manual wheelchair to get about. The injury to her brain has also left her with cognitive challenges and some vision impairment.

In spite of these difficulties, Shanae has an inspiringly positive outlook. She describes her 10 months in Westmead Children's Hospital in glowing terms. "It's the best hospital in all the world. I love it because the people are so nice – especially the clown doctors. And the Starlight Room where you go to paint or play games organised by people like Captain Fuzzy. Sometimes I wish I could go back!"

Kelly remembers the 3 operations Shanae needed on her brain and still gets emotional at the memory of her daughter wearing a helmet to protect her head and of her perseverance in learning to walk, and speak, and eat.

Shanae is still buoyed remembering a clown doctor completely wrapping her and her wheelchair in toilet paper. "I had to rip it to get out!"

Shanae readily lists all the people who continue to help her rehabilitation.

"I'm a busy bird with appointments to a physiotherapist, OT, exercise physiologist, psychologist, dietician and speech therapist. I really like them because they make a difference for me."

When Shanae was preparing to leave the hospital after 10 months, she came home for day visits to adjust to being in a home environment.



Shanae at home.

Kelly describes how icare assessed the house they lived in as unsuitable to be modified and helped them find a new place, which the landlord was happy to alter. Lifetime Care (LTC) installed a ramp, railing and renovated the bathroom.

"Best of all," Kelly says, "LTC let me slow down and not rush choices. They gave me so much guidance."

Foot operation

Shanae did get her wish of going back to Westmead Children's Hospital - for 5 days. Her right foot had gradually rolled so that she stood on its side. To fix it, her medical team tried straps, massage and Botox. But in March this year, she had an operation to adjust her knee and tendons to correct how the foot landed. She mentions the Parramatta Council Christmas party. "The best part," says Shanae, "was that there were other people with a disability. That tells me that I'm not the only person with a disability in the whole, entire world."

It can be uncomfortable when no one else around has a disability. That makes me unhappy, anxious, even scared sometimes.



With her mum, Kelly.

There's also a new school friend, Fariah, who recently arrived in Australia.

"My teacher has asked me to help her with words and maths because she is still learning English."

There's also Mrs Maemar, Shanae's Student Learning Support Officer who has guided her classroom learning for 4 years.

Earlier this year at school when Shanae walked on stage unassisted to receive the principal's award for "Outstanding work ethic" there was much clapping. "The school was really stoked," says Kelly.

Making speeches

This year Shanae's class have focused on researching, writing and delivering speeches. Shanae describes how she feels when she has to give a speech.

"My heart goes very quick and my breathing goes crazy. But now I look at a wall instead of at the people. Or I look at the people and pretend they have no clothes on. So now I'm better at public speaking. My last speech on multiculturism went well."

There's also the excitement of moving to high school next year with the prospect of "new friends, new teachers and new stuff to learn".



Shanae with twin brother, Whatanui.

But it's not all upbeat for Shanae. With great clarity, she describes the challenges of living with a disability.

"It can be uncomfortable when no one else around has a disability. That makes me unhappy, anxious, even scared sometimes."

Dealing with bullies

"I feel worried that people are talking about me. They sometimes look at me in a funny way and point or stare."

Asked how she responds in those situations, Shanae describes her coping mechanisms.

"I look at something else – something fancy like a shop window, or something interesting like the cosplay bumble bees in a ball at the shopping centre – to distract myself.

"I don't like bullies or people being mean. If they do it to me, I try to just walk away and ignore them. But if they are mean to other people, I say, 'Hey, don't do that. You should never be mean to anyone if they're not hurting you!'"

Kelly becomes emotional listening to her daughter and says she is inspired by her all the time.

"When people stare, I want to set them straight. But Shanae's taught me how to send a message without being intimidating or negative."

No matter what disability you have, you are always special to the world. Don't let people get you down.

"Now I just try to bring their focus to me by staring back or even pulling a funny face.

"I also remember that it's my job to remind Shanae how amazing she is and to give her time to express herself to me about what she's feeling."

There have been times when Shanae has wanted to go home if she's feeling vulnerable. But then mum and daughter talk through their feelings and sometimes choose not to head home right away after all.

Shanae's clear on what her wishes for the future are.

For herself: "I can sometimes take a few steps without my walking frame but I'd like to get better at walking independently."

For other people experiencing disability: "No matter what disability you have, you are always special to the world. Don't let people get you down."

For the whole world: "I wish everyone was kind."



The right support at the right time

working with an icare coordinator and an external case manager

As a Lifetime Care participant or worker in the Workers Care program, you have a dedicated icare contact to help navigate the ways we can support you. Your icare contact may be a coordinator, rehabilitation case manager or community living facilitator.

Depending on what support you need, you may also work with a case manager external to icare who coordinates your treatment and rehabilitation. This manager is more likely to be based geographically closer to your local area than your icare contact. They have knowledge of services and supports closer to your home.

Bronwyn: case manager

For case manager Bronwyn, the support she provides is working with participants and workers to help them identify and troubleshoot their injury related needs, connect them with the right services at the right time, and develop and support a person to achieve their My Plan goals.

To see someone move through rehab and be as independent as possible is really rewarding.



Bronwyn



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A typical week may include following up with service providers or meetings with care teams. She spends a lot of time on the road checking-in with the people she is supporting.

Someone may contact Bronwyn with new requests or for help with their therapy, equipment or supports. Her role also includes working with families to support her clients. She may work with a participant from months to years depending on the complexity of their needs and goals.

"It's so great knowing you've helped someone progress towards their goals," says Bronwyn. "To see them move through rehab, be as independent as possible, and live their life in other areas like parenthood or work is really rewarding."

Nasrin: icare coordinator

Nasrin is a Workers Care coordinator giving advice and reviewing service requests while working with case managers to make sure a worker is feeling supported while achieving their goals. She also visits workers to check-in and provide a human face to icare.

I am a good listener and I think they find it refreshing that I talk and listen to them without rushing through the call.



A typical week for Nasrin involves liaising with case managers to review and clarify requests for treatment approvals and equipment servicing. Workers mostly contact Nasrin to understand what is happening with their treatment or to report issues with services or care.

"I am a good listener and I think they find it refreshing that I talk and listen to them without rushing through the call or just talk about their injury," says Nasrin. "I really enjoy meeting my workers in their environment or home."

Sometimes Nasrin and external case managers like Bronwyn will visit workers together to see how treatment and care is going and to look at ways to help with any challenges.

Introducing the winner of the Shine Writers' Prize



Dominic is a Lifetime Care participant

Dominic Goodwin is the winner of the inaugural 2023 *Shine* Writers' Prize. Dominic, known as Dom to his friends and family, impressed the judges by exploring his comic side in a storyboard of himself describing special moments in his life before and after his accident, titled "This is me, Neon".

Dom's visual story shows that after leaving hospital, his zest for life has continued.

Combining text and pictures, his story tells us about his love of music, shuffle dancing and sport, and he shares some of his recent adventures.

Shuffle dancer

Dom loves a particular style of dancing called "shuffle".

Going by his shuffle name, Neon, he loved how shuffling made him feel and he continues to watch shuffling videos.

As a shuffler, Dom also loves sneakers and plans on buying himself a fresh pair of Nike TN shoes with his prize money.

Dom communicates using facial expressions and a communication device which he accesses using eye and head movement. Dom worked with a speech therapist and support workers over many months to develop his visual story.

Sharing his thoughts

Starting with printed photos of all his adventures, Dom used a "talking mat" to share his thoughts and develop a shortlist of what he wanted to include in his story.

The speech therapist worked with Dom and his support workers to develop customised communication grids and vocabulary on his communication device. These were based on events shown in his photos.

Dom could then make choices about the words or phrases to write his story and the process continued to evolve from there.

Dom shares his story "This is me, Neon" on pages 12 and 13.

Years ago I had a head and spinal injury. Since then, I've had to try different things. My speechie says I have a better social life than her!



Shine Writers' Prize

This *Shine* Writers' Prize was developed to showcase the talent of participants in Lifetime Care, workers in the Workers Care Program, and clients in Dust Diseases Care.

The prize celebrates the role of writing and storytelling in promoting and supporting emotional well-being and social connection.

This year's theme was "Who I am". It invited entrants to explore identity, reflect on how identity can be redefined, or find meaning through exploring another identity.

This initiative was run by icare NSW in consultation with Accessible Arts NSW, the peak arts and disability organisation in the state.

This is me, Neon

Dominic Goodwin, winner of the Shine Writers' Prize 2023

This is me, Neon



I was a shuffler. I love how it used to make me feel.

I used to shuffle at Central Station.

I shuffled until I had my accident



Years ago I had a head and spinal injury. Since then, I've had to try different things. My speechie says I have a better social life than her!

I like to go on holidays



The drive to Coffs Harbour was a bit crazy, but it was worth it.

I like to relax



I got to swim in the ocean. A seal even slobbered on me! I also swam with the stingrays and sharks.

And I enjoy close encounters



Recently, I went to Swansea. Like my snake?

Have you ever heard of DEFQON?



I like listening to the music. They wanted to carry my wheelchair into the moshpit!

l'm famous



The thing is, my contagious personality has meant I have met a few stars in my time.

Actually, she's famous



Like when I met Delta at *The Voice*.

But I reckon I scrub up alright



I was the best man at my brother's wedding. I even gave a speech using my eye-gaze device.

Yeah ... I try to get out and about



l'm a West Tigers supporter.

At all sorts of venues



Before COVID, I used to head out to Sefton Playhouse. The topless waitresses were awesome.

That's just who I am



Richard Poole: seeing himself in new ways

Richard is a Lifetime Care participant



Richard and his icare contact, Libby.

It took a traumatic brain injury for Richard to be more accepting of himself. The time in recovery also gave him a perspective on his friendships and allowed him to confront issues he'd been denying for years.

Richard Poole was struck by a car in 2017 while crossing the road near his home in inner-west Sydney. He has no memory of going over the car's bonnet and his head hitting the road, but he does remember that he was unhappy and distracted. His wedding loomed 3 days away and he was grappling with doubts about the marriage as well as problems he was having as a secret gambler.

Induced coma

Immediately after the accident, he was convinced he was fine and that he should just head home. Fortunately, the attending paramedics insisted they take him to St George Hospital where he needed to be placed in an induced coma for 2 months due to bleeding on his brain. His treatment continued in the Liverpool Brain Injury Unit for 4 months and for another 2 in Royal Rehab at Ryde.

More than 6 years later, Richard walks with a slightly uneven gait caused by nerve damage in his right foot. Coordination, memory, balance and fatigue are a challenge and he sometimes finds it hard to express himself.

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"It can be difficult to get the thoughts out that are clear to me inside," he says.

Richard takes his appearance and fitness seriously. Even on an unseasonably hot spring day, the 57-year-old is planning to go for a run through the 35-degree heat.

Scattered around the sitting room of his Dulwich Hill apartment, there are weights, an exercise mat, a darts board and his dad's framed jersey commemorating his captaincy of the winning Australian team in the 1957 Rugby League World Cup.

After the accident, the wedding plans with his partner were postponed. And with his brother managing his finances, he was forced to tell his family, his fiancée and his adult sons about his 10-year addiction to poker machines.

"I was kind of relieved because I was forced to do something about my gambling and it wasn't a secret anymore." The engagement continued for 4 years but it is with a sense of relief that he describes it ending. "I finally confronted my lack of assertiveness."

A burden lifted

Richard started therapy around his gambling. "I loved it because I could finally speak honestly. A huge burden was lifted."

"The accident gave me proper independence and, ultimately, the space to live in tune with my introverted self – to go to bed early when I'm tired and to get up at 2am to watch TV, write and perhaps go for a run."

Another bonus of gaining a new perspective on his life was recognising that he'd lost touch with his friends during his engagement – some of whom he'd known since primary school. His sons encouraged him to reconnect with them and now they regularly go to the footy and play golf.

At the time of his accident, Richard worked in IT and loved it. He had started in the mail room in an insurance company straight after school, working

I was kind of relieved because I was forced to do something about my gambling and it wasn't a secret anymore.



The accident freed me up to be honest - with myself and with other people. I don't care if people criticise me, just as long as they're being honest. I love honesty.



Richard at home.

his way into IT and finally to the position of development manager at a global finance company. He reckons he had a natural instinct for information technology.

After the accident, he returned to work in a business analyst role for just 4 hours a week, building to 29 hours a week until August this year when his company was taken over and his team was retrenched.

Scriptwriting

But Richard sees the end of that position as the possibility of something new. At the moment he's enjoying the break and is taking time off for a week away with his sons to see a band in Melbourne. And then he's heading off with his friends for a golfing week.

The work pause also means more time for his new passion - writing a script for a movie, a task he devotes time to every day. His new self-awareness has shown him how much he enjoys being creative.

Describing his new sense of self, he says, "For me, now it's all about truth. The accident freed me up to be honest – with myself and with other people. When I was young, I didn't want to be criticised so I suppressed my creativity. Now I don't care if people criticise me, just as long as they're being honest. I love honesty." The writing brings him great joy. "After my sons, the highlight of my life will be having someone read my script."

Richard is also keen to educate others about what it's like to live with a brain injury. "It's only those who have had one who can really understand what it's like."

Royal Rehab's Wall of Fame inspired him when he was a patient. "I wanted to be on the wall too because being there would mean I'd recovered."

When he too was welcomed to the Wall of Fame, he had to give a speech. "I was anxious about reading it," says Richard. "But afterwards, I felt good about myself."

Richard is troubled by the invisibility of people with a brain injury. Because he wobbles slightly as he walks, he's several times been denied entry to a pub or refused a drink before he's even had one. Richard has tackled significant challenges to reach a place of self-insight, understanding and contentment reflected in his commitment to his sons, his friends and his love of writing.

Gambling no longer has the hold it once had. A turning point for Richard was at a pub watching the State of Origin. He had a card inviting him to use the pub's poker machines. His son said, "Just cut it up, Dad." And he did.

WALL OF FAME

Richard was recently celebrated as a Wall of Fame ambassador at Royal Rehab in Ryde.

Ambassadors are chosen for their determination, resilience and personal achievements following brain injury. They often volunteer to support current patients at Ryde and their framed stories are hung on the walls.

"I've wanted to be an ambassador ever since I left Royal Rehab," Richard said.

Richard's icare contact, Libby, has been a partner supporting him to achieve his goals.

"Most people don't realise Richard is living with a brain injury, so one of his challenges is that people often expect too much of him, or not enough."

"It's meant a lot to me," she says, "that I got to see him achieve his goal of being a Wall of Fame ambassador."



Martin Young: staying connected

Martin is a Lifetime Care participant

Martin Young is 85 and still recovering from the effects of a recent road accident. But his life is full of family and community despite the challenges of dealing with a late-life traumatic brain injury.

After raising their children in Sydney's northwest, Martin and his wife Rachel were enjoying their retirement – delighting in spending time with their 5 grandchildren, and celebrating birthdays and festivals such as Christmas and Chinese New Year.

Crossing the road

Martin, in particular, was in good health and the couple played bridge, grew vegetables in their large garden and socialised with the Sydney Chinese community. They both had late careers as movie extras and actors in commercials.

But two years ago, Martin was crossing the road near their home in Rydalmere when he was hit by a car.

"We were going for a walk before lunch," says Rachel. "Martin was crossing the road and I can remember watching it happen right in front of me. He was thrown about 5 metres by the car and was just lying there, not moving. He finally stirred but his face was bleeding."

Martin was taken to Westmead Hospital with a broken leg, a spinal compression fracture and a traumatic brain injury. He was in a coma for several days. "When I woke up I thought I was in the morgue," says Martin. "I thought I was dead."

After a month at Westmead, Martin was transferred to Royal Rehab at Ryde where he spent another month.

This was all during the COVID lockdown and his family couldn't visit him.

Martin was born in a town near Shanghai, the oldest of 5 brothers. He grew up in the shadow of the Japanese invasion of China and his family moved for safety to the French section of Shanghai.

While the family was still in Shanghai, Martin's father started an import-export business in Hong Kong and, after the 1949 victory of the Communist Party in the Chinese Civil War, the whole family moved there.

"I did most of my schooling in Hong Kong and when I finished I went to Taiwan to study chemical engineering," explains Martin. After finishing his degree he came to Australia at age 25 to do a Masters degree. "I never finished the Masters. Instead, in 1966, I got a job as a scientist with the CSIRO where they trained me as a fuel technologist. I can remember my first pay packet. It was in dollars and cents because Australia had just changed over to decimal currency."

The following year he married Rachel. She was also Chineseborn but had family roots in Australia going back to the goldrushes. Her family migrated here when she was only 2.

Double celebration

The couple had 3 children and Martin continued working with the CSIRO doing research into coal and then iron ore. He retired as a mineral engineer in his late 50s. Rachel spent 20 years working in office admin.

When Martin came home from rehab in October 2021 he was still in a spinal brace and walked with a frame. His balance was poor and he had memory difficulties.

"He was discharged on the day of our son Victor's 50th birthday," says Rachel.

1've loved growing vegetables all my life. It's my exercise, my daily sun exposure.





But I think things are still getting slowly better. After all, it's not a short race. It's a longdistance one.

With Rachel in the garden.

"Victor died from cancer when he was 40 but every year we celebrate his birthday. That year we had a double celebration. We had a big banquet at Carlingford and invited all the relatives."

Martin maintains a busy and active lifestyle – playing and organising bridge games, acting in commercials, gardening, and connecting with his family and friends. Martin had started playing lunchtime bridge when he was at the CSIRO. He still plays and Rachel plays with him, although he is now mainly a bridge director or umpire.

"People get intense and worked up with bridge," he points out. "Sometimes I think there are no friendships at the bridge table."

Martin is also active in an Australian alumni association for graduates from his university in Taiwan and is the president of a Chinese community organisation. "I have to organise functions and things like visits to the graves of ancestors."

"No one else really wants the job!" jokes Rachel.

Films and commercials

One of their 2 daughters, Susan, is an actor. It was through her and her agent that Martin and Rachel started a late-life career acting in commercials and as film extras. Martin in Pepsi-verse commercial by Pepsi.

"We have to audition for the commercials," says Martin. "We have an area set aside in the lounge room where we can make an audition tape." "Martin finds it fun while I find it more like work," laughs Rachel. Between them they've worked as extras in some of the Marvel movies and done ads for Woolworths. Audika and Pepsi. In one ad, made as part of a Pepsi YouTube campaign last year, Martin sits wearing a wig and an oversized blue suit at a large desk in a paddock and, in his distinctive Chinese-Australian accent, describes how "in the Pepsi-verse, phones have more than one life" and "awkward dates aren't awkward for long".

"They made that suit specially for me!" says Martin.

Far-flung family

Martin keeps in contact with his 4 brothers and their families who have all ended up in North America.

"Sometimes they come here, and we've also been to see them in New York and Toronto.

"We also went back to Hong Kong with the whole family about 5 years ago."

Martin has a raised garden bed where he grows tomatoes, strawberries, cucumbers, bok-choy and Chinese cabbage. "The raised bed is a real bonus to me because I can't bend down easily now. I worry about falling," says Martin. "I've loved growing vegetables all my life. It's my exercise, my daily sun exposure. Chinese veggies are cheaper in the markets but I just like growing my own."

Martin talks about the ongoing effects of his injuries.

"I've still got balance problems, which I think come from the brain injury, so when I go out I take a walking stick to feel safe. I can walk about one kilometre before my foot and ankle start to hurt.

"And my short-term memory isn't as good as it was before the accident – I often get names wrong – but my long-term memory is fine. But I think things are still getting slowly better."

His advice to others in his situation is to stay optimistic. "After all, it's not a short race. It's a long-distance one."



The notice board

Sharing your news highlights, handy information and upcoming events.

Jarrod realises a dream

After a car accident that left him with a spinal cord injury, Jarrod Emeny found a passion for wheelchair basketball.

He was playing in the national league with the Wollongong Roller Hawks while studying at university when he featured in the Summer 2020 *Shine* magazine.

It's now more than 5 years since his accident and he hasn't looked back.

Jarrod graduated with a business degree from Wollongong University and is on the path to becoming a professional basketballer.



He recently moved to America with a scholarship to play college basketball at the University of Illinois and now juggles a busy training schedule alongside studying for a Masters in Finance.

First Nations Cultural Project Consultation results

Thanks to the First Nations people in Lifetime Care and Workers Care who took part in our consultation in March.

The consultation was part of our journey to making icare a culturally safe place for our First Nations people.

We found 5 themes in the stories and suggestions you gave us. These themes have been shared with key people in icare so we know what is important to you. icare staff have been trained on how to respectfully ask about your cultural identity and needs.

The First Nations consultancy KARI is helping to train icare staff in cultural awareness and support our learning and development.

We invite First Nations people in our schemes and programs to help us in our journey to becoming a culturally aware and safe place. If you want to contribute, please contact us at

PAAenquiry@icare.nsw.gov.au.



Shine readers survey results

A huge thankyou to those who responded to the readers survey included with the last issue of *Shine*. These are the highlights of what you told us.

- Overall, we are doing a better job of making *Shine* what you want it to be than when we asked you in 2019.
- One third of people who responded expressed an interest in being in *Shine*, and we have been able to include 2 of you in this issue.
- It is important that we continue to print and mail *Shine* to you, which we will.
- You asked for more stories about the staff that support you and we have one in this issue.
- Some of you found the Noticeboard pages hard to read so we are trying a new format. Let us know if this is an improvement for you.
- You sent us heartwarming messages about how important *Shine* is in keeping you connected with each other.

Please let us know your thoughts any time at shine@icare.nsw.gov.au

Assistive Technology Hub ready for you

The Assistive Technology (AT) Hub is a new service to help people with brain injuries access and use assistive technology. After a successful trial in late 2022 the AT Hub is now ready to take referrals.

There is a growing range of mainstream and custom-designed AT available. These technologies can improve your independence, community participation and rehabilitation while reducing reliance on family, friends, and caregivers.

An AT Hub clinician can work directly with you and your family to:

- help you work out which technologies are useful for you
- support you with a technology trial
- provide tailored product recommendations
- help you with funding applications
- provide set-up and training.

For more information, contact Brendan Worne, the Assistive Technology Hub Manager at E: <u>athub@inghaminstitute.org.au</u> P: **0475 983 299**



More podcasts

Cerebral Palsy Alliance's Remarkable Insights podcast features conversations with disability-tech pioneers who are pushing the boundaries of innovation and social norms.

Following a successful first season, the podcast returned this year with new episodes.

The podcasts explore how disability drives innovation and highlight the importance of harnessing technology to build social and economic inclusion of people with disability.

For a list of current episodes and more information, just google "remarkable insights".

New consumables agreement

Did you know that icare has a Consumables Panel that supplies single or short-term use products to manage continence, wound care, skin integrity, respiratory and nutritional needs of participants, workers and clients?

We have increased the scope of the panel and now have two approved providers for the supply of healthcare consumables for people in Lifetime Care and Workers Care. The panel is also available to support clients through Dust Diseases Care and CTP Care.

We have also made changes to the forms that are used to prescribe and order healthcare consumables. If you have questions, please contact your icare contact or email the equipment team at equipment@icare.nsw.gov.au.

The new providers are: Brightsky Australia P: 1300 88 66 01 Email: icareCC@brightsky.com.au

Independence Australia P: 1300 793 133 Email: icare@iagroup.org.au



Vindependence





One of Huntah Hawkins' winning entries for the Shine Arts Prize 2022.

We're very excited to announce the *Shine* Arts Prize returns in 2024!

The *Shine* Arts Prize aims to recognise and encourage artistic practice in people of any age and highlight the role of artistic activities in maintaining wellbeing and engaging with community.

Entries will open from 1 May 2024. The prize is open to Lifetime Care participants and workers in the Workers Care Program. Participants do not need to have prior art experience to enter.

This initiative is brought to you in partnership with Accessible Arts NSW.

Theme: my favourite things

Do you have something that you can't live without? Something that you really like or is special to you? This could be related to an activity you enjoy doing or that you consider your "thing".

Categories

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

How do I enter?

You can submit up to 2 artworks online from 1 May via the *Shine* Arts Prize webpage: www.icare.nsw.gov.au/shinearts-prize.

Entries close on **31 July 2024**.

Entries must be your own original work and completed within 12 months prior to the opening of the competition.

- Physical artworks must be under 1.2m wide x 1.2m long.
- Film and music entries must be under 4 minutes in length and files under 5MB in size.

Prizes

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

We're also introducing a \$500 People's Choice award where people can vote for their favourite artwork.

Starter kits

We're putting together a limited number of starter kits with some basic art materials like pencils, paper and paint for new artists wanting to create their entry.

Email Nerita (details below) to let us know if you are interested in a starter kit.

Got a question?

Contact Nerita on (02) 7922 1115 or email shineartsprize@icare.nsw.gov.au

icare acknowledges the clans of the Dharug, Eora and Kuring-gai nations as traditional owners of the land on which *Shine* was created.

We'd love to hear from you!

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



Shine online



Scan the QR code to view the online edition.

