

From freak accident to loving life again. We meet Asha Prasad, page 4.

FROM

Shine

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

Winter 2023

Huntah Hawkins: seeing the world from above

Huntah is a Lifetime Care participant

Since he was 4, Huntah has lived with the challenges of a brain injury resulting from a car accident. Yet the young man is already making a creative mark on the world.

The school motto for Manilla Central School is "I begin. I strive. I achieve". Huntah Hawkins is one of the few students who has been at the school from kindergarten through to year 12 and he's clearly taken the school's motto to heart.

Spreading his wings

Year 12 has 7 students due to graduate in a few months. Huntah is considering what the move into adulthood means for him and what opportunities to look for in the years ahead. He is animated when describing what he enjoys and, like other 18-year-olds, he's keen to spread his wings – with a range of dreams from movie nights in Tamworth to cruising round the world.

Huntah relies on a powered wheelchair and communicates through an assistive communication device, Tobii, which uses eye tracking to trace out letters and a joystick to move a cursor. He also communicates with an array of up, down and swooping eye signals, and a range of facial expressions – often with his eyes sparkling. Manilla is a small town just north of Tamworth. Huntah moved there with his mum, Tina, and older sisters Reece and Drew to be closer to family after the accident. Tina runs a candle-making business and is a dedicated advocate for Huntah.

Living in a small town has both pluses and minuses, notes Huntah. "Everyone knows everyone, which is both good and bad – mostly good. But it's far from the beach. And from live football games."

Drag-queen bingo

Huntah's sisters now live at Baradine and on the Gold Coast, and Huntah is now an uncle to Drew's 3-year-old, Lois.

He's recently visited the Gold Coast where he got to watch a drag-queen bingo contest – not something you generally get to do in regional NSW!

A team of aides, Amanda and Taylor, have supported him all the way through his school years, helping him participate in science, maths and business studies – not favourites – and English, food technology and art classes – favourites. Huntah describes Mr Rowe, the English teacher, as cool and funny and says he encourages discussion among the students. Huntah appreciates that, while communication can be challenging, his classmates try their best to connect with him and that his school has been so accommodating.

Creative works

In Design and Technology, Huntah has created a dog coat and is working on a bed cover with the symbols of 17 football teams. In the cooking class on the day of *Shine's* visit, the students tackled pavlova with passionfruit curd and cream – a winner with any teenagers.

But it's focusing on photography in art class that most inspires Huntah. He was introduced to drone photography by his art teacher, Mr Galloway, who arranged for Huntah to try photography to express himself and suggested he use the school drone to capture a cross-country meet. Huntah immediately loved the considerations of light, angle, movement and framing, both when taking the picture and editing afterwards.

G Just do it. Have fun. Express yourself.







Huntah at school.

He is now buying his own drone and, as for art students all over NSW, he's required to identify his sources of ideas. He lists the German Bauhaus movement, known for its focus on angular and geometric shapes, and English pop art painter and photographer, David Hockney, as inspiration.

He's also required to keep an art journal. Huntah does a lot of planning, using social media platforms to share ideas and using a whiteboard to brainstorm his emerging concepts. And once he's taken a photograph, the work begins to edit and develop it using Lightbox and Photoshop tools.

Speaking through pictures

He is inspired by nature, by trees photographed from above the canopy rather than under the branches, and by the shapes and angles laid out below of rooftops and fences. He likes to speak through his images and demonstrate his autonomy through his creativity. To be interesting and provocative. To show others things they may not notice. To reveal new angles and perspectives on the world from a drone that others haven't previously considered. To use the drone's height to show people lines, textures and colours in a new way. To encourage people to slow down and think.

With his cat Socks.

In 2022, Huntah was the overall winner of the Shine Arts Prize for his suite of three artworks a wonderful achievement for an artist with much creativity still to be explored. His plan to put the \$2000 prize money towards a cruise to New Zealand is now part of a package of dreams for life beyond school. He'd like to study at TAFE - perhaps photography or videography. And he's currently planning for life beyond that - talking to a vocational counsellor about his longer-term options.

Future dreams

Huntah's dreams include being closer to the beach and ideally working on the Gold Coast, perhaps photographing sports. Most of all, he'd like to see his beloved North Queensland Cowboys play a live NRL game.

But his loyalty is not just to one team. He also likes the Redcliffe Dolphins now coached by Wayne Bennett and during State of Origin matches, it's Tina, his mum that he's up against. She goes for NSW but he's a Queensland supporter. Origin nights are both fun and tense at home.

Huntah's loyalty is reflected in the name of one of the family's two ragdoll cats – JT or Johnathan Thurston, the former Cowboys player. Happily for Huntah, JT (the cat) has fathered a litter of kittens of 5 girls and one boy – Socks and Peanut are his favourites. **C** Everyone knows everyone here, which is both good and bad – mostly good.

Good advice

Huntah's advice to others is to try one's best. And also, not to be afraid to ask for help. "Just do it" he says. "Have fun. Express yourself."

And his reminder to himself, "I can achieve anything that I put my mind to." Winning the *Shine* Arts Prize proved that. And that determination is the motto of his school in action.

At 3pm the school gong sounds and a Bruno Mars song starts playing through the loudspeakers in the playground. And with that, Huntah's keen to be gone. School day is over and Mum's waiting in the car park to take him home.

In no time, the school year will be over too and with it goodbye to the caring Manilla Central School community and hello to a whole new array of opportunities.



Asha Prasad: from a dark plac to a calm one

Asha is in the Workers Care Program

Asha (right) with one of her support workers, Saveda.

Asha had come to Sydney for a new job. She was 26, single and loving her independence when a freak accident changed her life forever. After many frustrations she has learnt to be kind to herself.

Asha is from Otorohanga, a small town south of Auckland in New Zealand's Waikato region. "A beautiful rural area," she says.

Of Fijian-Indian and Cook Islander background, Asha grew up in a supportive family and close-knit community with her 2 younger siblings. She went to local schools then moved to Auckland to do a business degree.

New job

After graduating, Asha landed a job in Sydney in a small advertising agency in Neutral Bay as an account coordinator.

"I was living in a new city, shopping, clubbing and loving life."

In October 2006, a few days after a free neck and shoulder massage offered at her work, Asha began vomiting and feeling dizzy.

"That night I fell asleep on the couch and when I woke in the morning I couldn't move. Literally. When I tried to shout no sound came out. All I could do was blink."

Asha was terrified.

"When my flatmate woke up and found me unresponsive, she raised the alarm. I just lay there as everything unfolded - the ambulance, the hospital tests, my family arriving from New Zealand."

Locked in

Asha was told that a blood vessel in her neck had ruptured as a result of the massage and she'd had a stroke. It had caused a neurological disorder often referred to as "locked-in syndrome" where a person is aware and fully conscious but is paralysed and can't move anything except their eyes.

At first she was only given a week to live. She needed a machine to help her breathe and was fed through a tube.

But, defying her prognosis, Asha was soon able to breathe on her own. And by the time she could move her head she was able to start rehab.

The effect of Asha's injury on family and friends was complete shock and disbelief. It shook her community of Otorohanga, and her family and neighbours organised fundraisers and garage sales. A fundraiser was held in Sydney too. However, soon after her injury Asha returned to New Zealand. Although she was now closer to her family, Asha spent much of the next few years unhappily trying to navigate the medical systems in both NSW and New Zealand.

"I had to learn to eat again, talk again and write again. I regained some movement in my right hand and, although I knew how to spell, I had to relearn how to write letters.

"It felt so dark and lonely and I was grieving for the loss of my able self and the life that I had. Then I got angry. Angry that when I was just starting my life, it was taken away.

"I can't walk so I'm dependent on a power wheelchair. I've got a speech impairment, incontinence, and problems with balance and coordination and swallowing food. And I have fatigue and anxiety issues and bouts of depression, although that's better now."

66 I've had to re-learn to love life and myself with an injury.



Asha at the Shine Arts Prize.

Change of attitude

"I need help from support workers 24/7. They are my arms, legs and voice. They help me shower and dress, they do my housework, they assist in driving. They help me in my grocery shopping or speaking to people on the phone."

Asha's attitude started to change after her father died of a heart attack in 2011.

"His death was so sudden and such a shock," says Asha. "It taught me that life is precious and short, so live it and experience everything that it has to offer."

In 2016 Asha went on a holiday to Hawaii.

"I booked it 9 months ahead to give me time for preparation. When you've had an injury like mine there's a lot of planning.

"I booked all my tours myself and did something everyday. The whole trip was magical."

In 2018 Asha moved back to Sydney. Although missing her family, she was now able to access a wide range of medical services and specialist rehabilitation following the introduction in NSW of the Workers Care program.

Asha is now living in a sunny unit in Schofields in Sydney's west. Many years of rehabilitation, therapy and specialist services have helped her get to where she is now.



C I just lay there as everything unfolded – the ambulance, the hospital tests, my family arriving from New Zealand.

With her support worker, Kelly, on her trip to Hawaii.

"I'm 42 and my focus has changed to looking after my mental health and keeping things as calm and peaceful as I can.

"I try to stay positive. I don't fret about petty things and I try and surround myself with positive and uplifting people who love me for who I am."

Out of my comfort zone

"I enjoy music, I love learning new things, going to shows, going out for dinner, being in nature. I love being at the beach. Doing things out of my comfort zone."

She even went indoor skydiving in Penrith.

"I was so scared. But I did it, and I want to do it again."

Asha has also entered the 2 most recent *Shine* Arts Prize competitions. She won the painting category in 2020 with her watercolour, *Skull with Butterfly*. "The butterfly represents hope and determination," she says. "I sometimes think of myself as a butterfly trapped in my own body – wanting to fly but unable to.

"I love painting because I can escape and let my mind go free, but also I can focus on something else apart from medical appointments or carer rosters. "Writing was an interest I took up to cure my boredom in hospital – initially it was just a diary of events. It's interesting how a new skill can arise from a dark place in your life."

Keeping in touch

Asha keeps in regular contact with her family in New Zealand and has just come back from a trip to her cousin's wedding where she met her 2-year-old niece for the first time.

"Being kind to myself has really helped in my recovery. Sometimes it's just a matter of a bit of self-pampering – like doing my nails, going to the hairdresser.

"I've lost so much but I've also achieved goals, met inspiring people and had amazing experiences.

"I've had to re-learn to love life and myself with an injury."



Jamal Amer: an inspiring outlook

Jamal is a Lifetime Care participant

In the face of injuries from a serious accident 2 years ago, Jamal has been sustained by the support of his wife Amal, his wider family and community, and by a discipline he learnt on the sports field.

Jamal, now 53, was born in Syria where he worked in the family business as a supplier in the construction industry. In 1996, his older sister encouraged him to move to Australia where she had lived for 20 years.

A couple of years later he met 26-year-old Amal, the daughter of another Syrian family who had emigrated from the same province when she was a baby. He'd found his soul mate. The couple married and moved to western Sydney where they have raised their 3 sons, Fayez, Shadi and Laith, close to their extended families.

He'd cry. I'd cry. But then I'd remind him that he's strong and fit and determined and that will help him walk again.

Football fan

Jamal has always loved soccer. He is one of 5 brothers, three of whom played for the premier team in Swaida, their Syrian home town. When he moved to Australia, he remained very fit, playing soccer in a competition for older men and working in the building industry for over 20 years.

It was as a soccer player that he learnt the importance of a collaborative attitude – an outlook he has instilled in his sons and, in particular, in soccerloving Laith. Jamal taught him from the age of 5: "Never swear, get angry or talk back to the coach. Don't complain or make disappointed faces when substituted off the field."

Unconscious

It's the discipline of sporting fitness and a positive outlook that has motivated Jamal in the long struggle to recover his movement and strength after a motor vehicle accident in April 2021. Amal and Jamal.

Jamal had been working on a building project in Canberra. His boss asked him to drive their ute back to Sydney. On the Hume Highway outside Goulburn, the vehicle flipped 6 times. His boss was lifted out, but Jamal was trapped and had to be cut out of the vehicle.

The boss had been wearing a neck cushion, which protected him, but Jamal had to be helicoptered unconscious to Canberra Hospital. He had a spinal cord injury and had also suffered a stroke when his C4 to C6 vertebrae crushed an artery to his brain. Doctors were unable to treat the stroke because he had bleeding on his brain – a delay which has resulted in continuing weakness in his left side.

The next day Jamal was moved to Royal North Shore Hospital for an operation to decompress his spinal cord. He was in ICU for 2 weeks, suffering hypersensitivity to touch and terrible nerve pain.

Amal took their 3 sons to the hospital the morning after the operation, but seeing their father covered in tubes and in a neck brace was too challenging at first and they had to leave the room. After the initial shock, however, they resolved to see their father every day.





We're close. We rely on each other and have been through everything together. I wasn't going to let him go through it alone.

Working hard in rehab.

Amal dropped them at school each morning before driving 45 minutes to the hospital to be with Jamal. In the afternoon, she collected the boys from school and returned to the hospital – driving 3 hours each day so that the boys could support their dad.

"I had to do it," she says. "We're close. We rely on each other and have been through everything together. I wasn't going to let him go through it alone."

Homework in the car

Sitting next to Jamal on their porch, Amal has a warm energy. But she remembers the dark days of having to encourage her husband. "He'd cry. I'd cry. But then I'd remind him that he's strong and fit and determined and that will help him walk again."

Their extended families and friends also visited. Amal chips in again: "He's a very lovable person. Everyone was supportive." The boys did homework in the car while relatives delivered meals and helped in many ways.

Jamal was moved to Prince of Wales Spinal Injury Unit and over a few months slowly learnt to sit again. "That's where the really hard work started." Jamal with his sons on coming home.

Jamal was allocated an hour in the gym each day but, with the determination that had kept him disciplined and focused through decades of playing soccer, he wanted to do an extra hour. He remembers always being competitive with himself and setting personal bests in the gym. The staff nicknamed him "King of the Hospital" for his tenacity and can-do attitude. He was determined that when he left there he would be walking out.

Jamal readily acknowledges that it was a combination of his own determination and his family's support that made all the difference for him. But then came COVID and he was only able to see one person a day for several weeks. And then there was a strict lockdown and no-one could visit.

The family FaceTimed for hours each day and the everresourceful Amal devised a way of getting the food Jamal loved to her husband. Every second day she drove to the hospital with his favourite dishes all chopped up. She parked near the lift and one of the nurses would pop down to swap food containers with a bag of washing. And sometimes Amal was treated to seeing Jamal brought down in the lift too.

Special delivery

On Father's Day, she couldn't visit but arranged for a delivery of the dishes he'd said he most wanted when he got home: warak anab or vine leaves with green beans, lamb and rice followed by roz bihalah or rice pudding. And as an extra treat for him and the nurses, macarons and strawberries dipped in chocolate.

The time finally came for Jamal to leave hospital – 5 months and 10 days after the accident. A physio and occupational therapist brought him back to a home festooned with balloons and a waiting feast.

But Jamal's return wasn't all smooth. The man who came back was very different from the man who had last been home nearly half a year earlier. There were tears but the boys stepped up to help their dad with his catheter and urinal jug.

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Jamal earlier this year - on the sand for the first time after the accident.

Jamal still does physiotherapy and hydrotherapy to strengthen his left side and to improve his gait. An occupational therapist sets exercises to help him strengthen his left hand. At Royal Rehab he used an exoskeleton - like a robot strapped to his body - to support and guide his walking until he reached his stability target. The spasticity in his left leg has to be treated with Botox to reduce the spasms and he needs to wear a glove and rubber rings to stop the fingers of his left hand from further contracting.

And he still sees a urologist, hand surgeon, spinal pain specialist and a psychologist from time to time.

Improved mood

Improvements are now not as marked as in the first 6 months, but there are incremental shifts all the time. His left arm is significantly more mobile and he hopes to do away with a catheter entirely.

He needs a sleep apnoea machine at night because he stops breathing about 120 times an hour.

And short-term memory loss is still a challenge.

But his mood has lifted, with support to attend Laith's early morning soccer training. Having Jamal there has lifted Laith's spirits too and he relishes his dad's support from the sidelines. Jamal had been the family organiser of weekend trips to the beach for swims, soccer games and BBQs. Not being able to do those things was confronting.

Catching fish

On the family's first trip away to the sea, Jamal was able to walk with help to the rockpool but couldn't balance because his legs kept floating to the surface. Instead of returning home refreshed, he felt moody and depressed with an overwhelming despondency about what his future looked like.

But on Australia Day this year, his sister's family rented a house at The Entrance as they had done in the past. Jamal was hesitant but was encouraged to give it a go and, with the extended family for support, was once more able to go fishing on the beach at night. His nephews and sons carried him across the sand to a rock. A nephew cast a line for him and they fished until 4am – Jamal the only one to catch anything.

Seat by the sea

The next day, the family again carried him across the sand to the water's edge where they sat him in a sand well. The sea came rippling over him and with Amal sitting beside him, his spirits soared.

Jamal is reminded of a picnic at Bronte Beach 2 weeks before the accident. He was there with many of his extended family. They stayed on into the summery evening to play soccer on the grass not knowing it would be the last game of soccer Jamal would play.

The memory of that game sustains Jamal, just as his determination and discipline and the love of his family and community does. He is committed to continuing to improve, no matter how incremental each step is.

Asked what technology has helped him, he replies without hesitating: "Amal's my help and my hero. She does everything for me."

And sitting next to him on the porch, she smiles with joy that her Jamal is back in the family home with them all.



Troubleshooting problems with a spinal cord injury



"With good health there is a path for happiness. For hope." Person with a spinal cord injury

The **Spinal Cord Injury Health Maintenance Toolkit** is a guide to help you understand and troubleshoot problems you experience in managing your life after a spinal cord injury.

The Toolkit was developed by people with spinal cord injury, general practitioners and clinicians. The Toolkit provides tips and tools to help you proactively manage your own health in 6 key areas – mental, bladder, bowel health, skin health, pain, and autonomic dysreflexia.

The Toolkit has 3 free and complementary products:

BOOKLETS

You can ask for printed versions of the Toolkit from your spinal service provider.

You can also access the PDF documents for these booklets **here**.

WEBSITE

The website has interactive elements that you can use anonymously. You can also access the website **here**.

SMARTPHONE APP

The app keeps all your personal information secure within your phone and is not shared with anyone else. You can get it by clicking on or scanning these QR codes on your smartphone.







Tania's story

Tania's life changed forever when she sustained a spinal cord injury. She became reliant on health professionals for management advice but found it hard to get appointments. Tania also had to do daily self-care checks and often had to ask friends and family for assistance.

Despite her early recognition of symptoms, Tania experienced autonomic dysreflexia, a condition causing a sudden and severe rise in blood pressure and other complications, which could progress rapidly and quickly become scary. The onus was on her to tell her GP and community nurse if her condition deteriorated.

Tania started using the Health Maintenance Toolkit. This improved the consistency of her daily self-care checks and allowed her to quickly recognise autonomic-dysreflexia-related bladder issues.

When Tania had to go to hospital emergency the Toolkit also helped her communicate with the doctors and nurses. They were able to see Tania's diagnosis and intervene more quickly and effectively.

Tania's confidence to manage impending crises by herself increased. Using the Toolkit meant there was less stress, better communication, fewer people to contact, faster interventions and better outcomes.





Health checks: good for body and mind

We are more than our injuries, so regular check-ups are important to staying well.



We all get older and over time our bodies change. How they change depends on many things including our gender, genetic background, past injuries and lifestyle.

As we age we are at risk of health issues and diseases that can reduce our independence or shorten our lives.

When someone has had a severe injury they spend a lot of time with medical and health professionals to manage the impacts of the injury.

But general health needs are different.

Seeing a doctor can seem hard

It can be hard to remember or feel motivated to see a GP about our health because we:

- are not sure how seeing a GP now will help in the future
- might feel embarrassed about what the GP will ask
- might be worried about the news we'll get
- might not know what questions to ask.

Why we need our GP

Everyone's health is complex. Trustworthy advice and support can help us stay healthy, avoid disease, and live our best life. And that is what a GP is for. Regular health checks with a GP help us stay in charge of our health.

A regular health check is separate from talking about your injury. The GP can recommend things that help you understand how your body is changing and the risks of becoming unwell.

Sometimes these things are simple like:

- a short conversation
- a blood test, or
- a blood pressure check.

Your GP chooses which tests you could have. And remember, most of the chronic conditions older people get are preventable. You are less likely to get them if you look after yourself.

Making changes

Once you know the results of the tests, your GP will support you in making any changes you need to keep having the life you want. Some of these changes might be medications or other treatments. But often they are things you can manage yourself like:

- exercising regularly
- eating and sleeping well
- learning ways to improve your mental health.

Helping the future you

Getting your regular health check and acting on the GP's advice is a good thing you can do now that you will be grateful for later. Maybe there are things you have done in the past or have already started that you are enjoying the benefits of now? Maybe you:

- started an art practice that makes you more relaxed and able to communicate with your family better
- made a habit of exercising and now need less medication
- improved your sleep routines and now have more energy and can focus better
- quit smoking and can now breathe easier and do more exercise
- made a point of spending time with friends and now you feel more relaxed.

Remember, it is often the simpler things that you can incorporate into your current daily routines that are the most achievable and therefore likely to be the most successful.

Most of the chronic conditions older people get are preventable.



Get more good info Go <u>online</u> to or ask your GP or chemist for advice.

Use the postcard included with this issue of *Shine*. Write things on it you want to ask your GP. Ask them to write things on it you need to remember.



Josh Powderlys from roofs to hoofs

Josh is in the Workers Care Program

A heel in the wrong place caused Josh to fall. The accident led to the loss of his business and changed his life, but has also allowed him to focus on his first love of horse training.

Josh is quietly spoken with a shy, thoughtful smile. He's waiting for us in his wheelchair as we arrive at the property where he lives with his family on the outskirts of Young.

He grew up in the town, went to the local high school, played rugby league with the Young Cherrypickers and began an electricial apprenticeship.

Love of horses

"I didn't really want to be an electrician," he says. "We had some horses that I learnt to ride as a kid and I decided I wanted to be a horse trainer. But I knew a trade would be more secure."

Josh finished his apprenticeship and moved to Sydney. He worked for 2 years as a maintenance manager for a restaurant in the Rocks.

"I married Chloe who had family in Young and we bought this house. I always knew I'd come back here." While running his own electrical business he became an accredited solar panel installer. It was the mid-2000s, there were subsidies for solar systems and a lot of uptake so Josh's business boomed.

"I put on a couple of workers and we could do 2 systems a day. First just in Young, and then all over the state. We did a lot particularly in the Snowy Mountains area."

Josh and Chloe started a family – they have 2 sons and a daughter aged between 15 and 18 – and Josh re-engaged with his local community, becoming president of the Cherrypickers Rugby League Club.

And while still running his solar business, he managed to go back to his first love - horses. In particular, training and racing harness horses.

"Harness horses are less flighty than racehorses. We would be training about 6 at a time. It takes them about a month to get used to the gait and then the rest of the training is just getting them fitter, stronger.

• I was trying to hide my emotions when one of the nurses told me it was normal to be crying. "This is a passionate harnessracing town. Young's got around 17 race meetings a year and a lot of trainers live here."

In January 2022 Josh had a solar installation job in Tumbarumba.

"It was a fairly basic job like any other. A flat roof with a ridgecap in the middle. One side of the roof looked a bit frail so I told the boys not to go on that side."

Josh walked across the roof to help one of his workers straighten a panel.

Couldn't feel my legs

"As I stood up I must have put my heel back onto the weak side of the roof. It crumbled and down I went. It wasn't that far - less than 3 metres - but my back hit the ground first." Josh had broken 12 ribs, had dislocated others and was having trouble breathing.

"That was when I realised I couldn't feel my legs."

He was taken to Royal North Shore with a burst fracture of his T9 and T12 vertebrae.

"The cord wasn't severed, but they told me I'd never walk again."



You really have to stay positive. If you're not, then no one around you is either. It's a flow-on effect.

Josh with a racing harness.

"It was COVID time and I was only allowed to see Chloe once a week. And I could only talk to the kids on the phone.

"For the first month I think I cried every day. Mourning the loss of my past life I suppose. I was trying to hide my emotions when one of the nurses told me it was normal to be crying but also that I had no choice but to do what I needed to get better."

I'm going to get well

"The next day I was sitting outside and I thought I'm not going to let this ruin my life. I'm going to get as well as I can. That's when I started hooking into physio and using the gym to strengthen my upper body, work on transfers and learn how to live in a wheelchair.

"You really have to stay positive. If you're not, then no one around you is either. It's a flow-on effect.

"The local league community and harness racing community were very good to us, raising money to help with expenses when we weren't working."

Josh finally came home 6 months after the accident. By then he was getting some small movement in his hips.

While he was in rehab, modifications had been done at home.

"Chloe was managing it all – getting ramps put in, widening doorways, making changes to the bathroom and cupboards. And the support of icare has been fantastic."

It's still less than a year since Josh returned home. An allterrain chair has recently arrived that allows him to get around the property and his car has been modified.

However, Josh is also dealing with a brain injury resulting from the accident.

"We weren't aware of it at first. Then, a month or so in, I realised I was forgetting short-term stuff – like I couldn't remember filling in my breakfast or lunch order. It's getting better but I know it's still there. I'm still forgetting things, especially when someone rings me and I forget what I've said I would do."

What I miss

"I do miss the independence, being able to do things at whim, the fast-paced lifestyle. I miss kicking a football with my kids, coaching their teams. Everything is much slower now.

"Chloe has been amazing. I hate that I've had to put all this extra pressure on her. She says I haven't, but I know I have."

Josh has had to close his solar business but he is keen to make the harness training a viable enterprise.

"We can keep up to 8 horses on the property, although it's often an industry with more losses than winnings." Josh is also getting a new vegie garden.

"I've always loved the peace of gardening. The new one will have raised beds and wider spaces between them. I'll grow lots of tomatoes, zucchinis, pumpkins.

"I think I'm getting better in that I've become more accepting of my condition. I'm doing more physio and I think it's slowly making a difference and I'm getting more independent.

"I want to be as good physically and mentally as I can be. They say the first 2 years are full of appointments and rehab work. I'm only half way there. It's still early days.

"I think it helped that I had a positive attitude from early on. I never showed the kids that I might want to throw in the towel. They're not too worried about me. To them I'm still the same person – just I'm not walking."



Andrew Cowley: still busy and living with a brain injury

Andrew is a Lifetime Care participant

A busy suburban bloke in his early 50s and the dad of three teenage daughters, Andrew worked long hours in his job as a building services manager. He was competitive and driven, but then his life was turned upside down.

Andrew was also a serious golfer and cyclist. He rode 40 or 50 km most weekday mornings from his Five Dock home in inner-west Sydney, and often more on weekends.

No memory

It was while riding with two friends in West Ryde on a spring morning in October 2016 that he was hit head-on by a turning car. Andrew has no memory of the accident. He only recalls coming round about 10 days later "in a spaceship", which was the high-dependency unit at Westmead Hospital.

As well as smashed bones in his legs, ribs and shoulder, Andrew had a punctured lung, split spleen and a brain bleed. He was in hospital for a month before moving to a private hospital in Ashfield for 3 months of rehabilitation.

C Letting go of the 'luggage' is fantastic advice ... Otherwise it will consume you. "But, hey, I was lucky," he says. "If I hadn't been wearing a good helmet, there wouldn't have been any rehab. I wouldn't have been here."

While the breaks and tears are healed, his struggle continues with short-term memory loss.

"My old memories are on my mental hard drive but there's nowhere to store the new ones."

He laughs describing chats with friends. "One of them calls me 'Riddler' because I jump around in conversation and can be hard to follow." But Andrew doesn't let the label get him down. He repeatedly interrupts himself to say, "You've no idea how lucky I am!"

A different outlook

When playing golf at Strathfield Golf Course after the accident, Andrew has looked across to Rookwood Cemetery and felt grateful to be working on his putting and not pushing up the grass on the other side of the fence. While once competitive about his golf, Andrew now has a different outlook. "Losing the ball is no sweat these days. At least we're all still on this side of the fence." But things weren't always so sunny after the accident. Andrew became severely depressed and says he sprayed anger about when anything didn't go his way. The cancellation of his driver licence as a result of having had a seizure infuriated him. He was eventually able to get it back but, more importantly, with help, he overcame the depression, cancelled his anger and recovered his inner peace.

Andrew worked with personal trainers on his diet and physical fitness. He took the advice of his neuropsychologist, Nicola, and read the books of paraplegic and triathlete John Maclean which encourage people to see the value of persistence, balance, humility, community, friends and self-belief.

Andrew had been struggling to recapture the details of the accident. He'd been angry and preoccupied with questions about the future. But then he got thinking about forgiveness and realised that the accident would also have affected the driver of the car that had hit him. He messaged the driver to let him know he was OK. All his anger and hate disappeared. "Letting go of the 'luggage' is fantastic advice from Maclean. Otherwise it will consume you."





Feeding the homeless, helping others, reminds me how lucky I am and it's also helped my daughters appreciate how lucky they are.

Not the old me

Nicola asked him what his future looked like. At that point, he hadn't realised he wouldn't be going back to work but over a series of appointments she steered him to tune more into what he liked doing.

"I carried on like a chump chop before the accident, but now I look for the best in people," he says. "I'm not like the old me anymore. I see how lucky I am. The rehab doctors said I should be dead but here I am and I can still walk and talk."

Andrew has now dropped the dosage of his anti-depressant medication – "my happy pills" as he calls them. "It makes me more accountable as I'd got to the point of not caring about anything."

He is mindful that being a different person is a big adjustment for the whole household. His long work hours meant much of the family organisation had been left to his wife, Mary-Lou. She had had to juggle her work in secretarial administration with parenting.

So every day Andrew looks for meaning and purpose wherever he can. He donates plasma to Red Cross Lifeblood as a way of giving back, and volunteers as a mentor at Let's Get Going, a community centre in Concord that helps people living with a disability with socialising and exercising. Andrew with his wife and daughters.

Before the accident, when his daughters were at school, Andrew took them on night patrol for the Matthew Talbot Hostel for homeless people in Woolloomooloo. His daughters have finished school and moved on with their studies, but Andrew is now back volunteering at the hostel – this time with some old school mates.

A big shift

"Feeding the homeless, helping others, reminds me how lucky I am and it's also helped my daughters appreciate how lucky they are."

The accident has meant that he is no longer caught up with the busyness of work but with the busyness of volunteering, golf twice a week, gym sessions, swimming at the local pool, regular catch-ups with his brother and coffee in a nearby coffeeshop with the two mates who were cycling with him on the day of the accident.

Andrew acknowledges the shift from work busyness to health commitments must be difficult for his family. "Mary-Lou still works and I don't. That's hard."

A big shift has been Andrew's willingness to ask for help. "It wasn't in my DNA to reach out to anyone for support before. But I see that there's no shame in getting help to navigate through life." The support of icare in taking care of accidentrelated health issues has removed stresses and reduced the burden on his family.

"I'm a better person in some ways. But I've had help and the family hasn't. There's not as much support for them."

The family's exuberant 9-monthold labradoodle, Poppy, is running about the garden, burning off energy. On the weekend, he will take her to the family's holiday house at Fingal Bay with Mary-Lou and daughter Annabel. Poppy will swim in the sea and they'll go walking in the bush and he'll do mountain biking. Next up, Andrew is off on a cruise to New Zealand with youngest daughter Emily to celebrate her 21st.

"We've got so many good things to look forward to, rather than looking back."

Andrew's still a busy suburban bloke in his 50s – just a different kind of busy.



Jake Tucker: determined and resilient

Jake is a Lifetime Care participant



Jake and his partner were expecting their first child when a car accident left him with serious spinal and brain injuries. He needed to relearn so many tasks and 5 years later he is still working hard to rebuild his life.

One of 4 brothers, Jake grew up in Cootamundra where his dad was a mechanic and ran a repair garage. His mum helped with the admin work.

Active sportsman

Jake enjoyed his boarding school in Campbelltown where he played lots of sport.

"I loved being active. I played basketball, tennis, rugby league, rugby union and touch football. And occasionally also volleyball or beach volleyball. I was a pretty social person and hung out with lots of friends." Jake liked horses too.

"I was working with horses from about when I was 14. And after I left school I worked for a cutting trainer. Cutting is a sport where a horse and rider separate a cow from a mob of cattle and keep it apart. I used to break in young horses and train them for this event."

While I've still got trouble with my memory, I use a diary to help with my appointments. After some bar work in Sydney, Jake worked for a couple of years in mines in Western Australia driving machinery where his team's job was to make and maintain all the roads across the mine.

Jake returned to Cootamundra and took a job with NSW Railways spraying weeds and slashing or mowing the grass alongside the tracks. He used to drive with his team along the line between Melbourne and Sydney, staying in different towns along the way.

By early 2018 he was 28 and his partner Melanie had recently become pregnant with their first child.

In a coma

On 25 May Jake was driving to work near Cooma when he had an accident.

"I have no memory of it at all. I was told my car came off the road, rolled 3 times and wrapped around a tree. Nobody knows what caused the accident although some people think maybe a kangaroo jumped in front of me."

Jake was flown to Royal Canberra Hospital. "I'd broken bones in my arms, legs and face, mainly on the left side of my body and my spine was fractured in 5 places, but the main thing was I had a traumatic brain injury.

"The doctors told me my brain had got shaken up so much inside my skull it was like jelly. To begin with I had a tube to help me breathe and I came in and out of a coma for a while. I was also paralysed and couldn't feel or move my arms or legs and couldn't talk, eat or drink."

Jake was in a post-traumatic amnesia for 86 days before he was transferred to the Liverpool Brain Injury Unit.

"I think it was hard for my family as the doctors didn't know if I'd wake up and survive or not.

"My daughter Casey was born in September while I was in the coma. So it was a huge shock when I discovered I was a father! But also it's probably the best present I'll ever receive."

"When my memory started to come back the following month I thought it was Boxing Day 3 years earlier! I thought I was 25 and then suddenly I'm 28."



Jake with daughter Casey.

Jake is particularly grateful to his neurological physiotherapist, Rheem, in the brain injury rehabilitation unit at Liverpool.

"She was a huge help to me. She did a lot of work to help me talk, walk and use my arms and hands again. Basically I had to learn to do everything again."

Jake is proud of what he's accomplished. "I wish I could say it was easy but it was very difficult."

Move to Albury

Jake and Melanie have separated and she has moved to Albury. So Jake has moved there as well so he can be close to Casey. He is living independently in a unit in town.

Jake is keen to tell his story to other people and to ask them to drive safely. He has given a talk at a specialist disability business near where he lives and is keen to do more public speaking.

"I want to get back to work too. It makes me feel useful."

Jake has been doing some supermarket shelf-packing which he likes and he's keen to do more.

It has been 5 years since Jake's injury.

"I still have a big team of people helping me. I really want to thank my speech therapist,



Practising his basketball.

Sam, my case managers Donna and Madeleine, my personal trainer at the gym, Nathan, my occupational therapist, Virginia, and my social worker Zoey. And of course my parents Bill and Carol have been a huge help and ongoing support for me."

More independent

"When I first went home I needed full-time care to help me with all the jobs around home and managing my appointments.

"I don't need 24/7 care any more but most days support workers help me with cooking, travelling around town and shopping. While I've still got trouble with my memory, I use a diary to help with my appointments.

"Walking and running are hard because of my balance issues. But I've learned to play golf, basketball and tennis with one arm. It's difficult but doable."

Jake shows us his impressive one-armed golf swing. He had a golf handicap of 3 before the accident and he's working hard to get a new handicap.

"I have to do most stuff with my right arm because it's awkward using my left arm and hand. I'm unable to drive a car and I don't think I'll ever be able to, but that's not the end of the world." My daughter Casey was born in September while I was in the coma. So it was a huge shock when I discovered I was a father!

Giving 110%

"I've also got blurred and double vision but my glasses help.

"Talking is difficult for me but I always try my hardest. Same as anything I have trouble with – all I can do is give it 110%.

"I've had to learn to do everything again. I still have a good and happy life and I improve in something every day."

I've had to learn to do everything again. I still have a good and happy life and I improve in something every day.



The notice board

Sharing your news highlights, handy information and upcoming events.

Working toward cultural safety



Our **Reflect Reconciliation Action Plan** is underway. icare is committed to working with First Nations people toward reconciliation, creating a culturally safe environment, and supporting Closing the Gap. We understand that a person's cultural identity and their connection to community and Country are central to who they are. Lifetime Care and Workers Care are changing the way we work to include what we are learning through this plan. When you enter our schemes or request services you can now share your cultural identity if you choose.

We are continually learning about what cultural safety means in practice and have begun a staff training program so that First Nations people we engage with can feel confident their cultural needs are being accommodated where possible.

Thank you to the First Nations people who took part in our recent consultations and shared what cultural safety means to them. If you would like to tell us how we can work toward creating cultural safety for you, please **email** us.

Carers Way Ahead

The **Carers Way Ahead** is a free web-based education program for family and carers supporting a person with a brain injury.

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The program can help you understand how having a brain injury can affect a person's emotions, thinking and behaviour, and provide information on positive and helpful ways to respond when difficulties arise.

The program was developed in partnership with UNSW and is available in English, Mandarin, Arabic, Korean, Vietnamese, Spanish, and Slovakian.

Access the program <u>here</u>.

Assistive Technology Hub

New assistive technology service

The **Assistive Technology Hub** is a new service which supports the delivery of technology for people with a brain injury.

If you have had a brain injury, you will know that cognitive skills such as information processing, memory, organisation and planning can be affected.

Assistive technology can be a useful support in these areas and increase your independence and participation.

A Hub therapist can work with you to understand if you might benefit from technology and can support you with an equipment trial, requests for funding and set-up.

For more information on how to access the service, contact Brendan Worne: <u>email</u> or phone **0475 983 299**.

Caring for carers

Many people don't see themselves as carers. However a carer can be a partner, a relative or a friend who cares for someone close to them or is a part of the person's support network. Having a loved one who has been seriously injured is challenging. There are times when you, as a family member or friend, might need help to manage and adjust to the changes in their life.

These are places you can go for help and support as a carer:

The **Carer Gateway** is an Australian Government program that provides free assistance to carers to find services and supports tailored to your needs in your local area.

Phone **1800 422 737** or <u>visit</u>. **Carers NSW** provides information, education, training, resources and referrals for carers. Here you can also find the *Carer Journal* developed for people supporting loved ones following injury, including insights from carers who have shared a similar journey. Phone (**02**) **9280 4744** or **visit**. **Strength2Strength** is a group program for families and carers of people with either a spinal cord injury or a brain injury. It is run both as faceto-face and online group sessions at various times throughout the year. It aims to help you develop greater resilience while building on your existing skills.

Email or phone **0478 488 568**.

New Attendant Care Panel

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The new Attendant Care and Nursing Panel started in February with providers appointed for services in the categories of physical assistance, high clinical needs, and cognitive and behaviour support. The panel will be in place for 3 to 5 years.

Many of the providers you are already working with have stayed on the panel. There are also some new providers. There are now more attendant care providers available across more of NSW.

Some new providers are still undergoing certification and will come on board in the coming months. Following certification, provider details will be added to the attendant care finder on the icare website. Talk to your icare contact or case manager if you want to know more.



Ease chronic pain The Be Pain Smart

program is now being delivered by Royal Rehab in Ryde. The program helps manage chronic pain following a brain injury or spinal cord injury. When you attend the program you will have an assessment by a multidisciplinary team of health professionals who will design a program specific for you.

Talk to your icare contact, case manager or <u>email</u> Deborah Mcconnell if you or a family member would like more information about the program.

Vale Joan McDonough

We would like to acknowledge a remarkable woman and Lifetime Care participant, the late Joan McDonough, who celebrated her 100th birthday last August surrounded by her loving family.

Joan was in her late 80s when she was hit by a car as a pedestrian, sustaining a traumatic brain injury. Despite the challenges that life threw her way, Joan never lost her spirit or her determination. She was a survivor in every sense, and her fierce independence and resilience were an inspiration to those around her. A devoted mother of 4 children, she loved gardening and spending time outdoors.

Joan passed away in October but her legacy will live on in the memories of all who knew and loved her.



Are you a bit of a poet or song writer? Or you have an idea for a short story? Or perhaps you express yourself through pictures?

If this is you, then why not enter the *Shine* Writers' Prize. Following the success of the *Shine* Arts Prize, we're excited to launch this new prize. This year's theme is "Who I Am".

The Shine Writers' Prize was developed to showcase the talents of Lifetime Care participants, workers of the Workers Care Program and active clients of Dust Diseases Care. It celebrates the role of writing and storytelling in promoting and supporting emotional wellbeing and social connection.

First-time writers are encouraged to enter.

Categories

Adults A written work between 750 and 1000 words OR a storyboard (visual story)

Children (15 years and under) A written work up to 500 words OR a storyboard.

Format

- Your submission can be a short story, a poem, or a storyboard. A storyboard is a visual story where you use pictures or drawings in a series of boxes to tell a story – like in a comic strip.
- Your writing will be a response to the theme "Who I Am".
- Only 1 entry per person.

Prizes

Adults

- Winning entry \$300
- Runner up \$100
- Highly commended \$50

Children

- Winning entry \$300
- Runner up \$100

In addition to the prize money, winners will have the opportunity to publish their writing or storyboard in the next edition of *Shine*.

How do I enter?

Send us your entries by 5pm on **26 July 2023**.

Get your entry form online <u>here</u> or <u>email</u>.

More info

Check out the submission guidelines <u>here</u> or by scanning the QR code.



If you have any questions, please <u>email</u> us at or phone **02 7922 1115**.

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 or click <u>here</u>.

