



Family and community is important.
Meet Mathew and Elva Barker,
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Shine

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

Summer 2024

Tomas Newlands: never give up

Tomas is a Lifetime Care participant

Tom with Jess and 9-week old baby daughter, Leilani.

Tom had a major brain injury as a pedestrian 10 years ago. After intensive rehab, he returned to his home town, Narromine. He now has full-time work with his previous employer and has ticked off many other goals.

Tom says a large part of his recovery is down to his family and the tight-knit Narromine community. And he's now looking forward to life with his partner and baby daughter.

Family

Tom, his partner Jess and 9-week old baby daughter, Leilani, are in the front garden of his parents' home in Narromine, about 30 minutes drive from Dubbo. They are taking family photos for this edition of *Shine*. Tom is thrilled to be a father, calling Leilani 'My Princess', having called Jess 'My Queen' since they met nearly 2 years ago.

Family is very important to Tom - his partner and child, as well as his parents, siblings and extended family. In fact one of Tom's nephews is there on the day we gather round the kitchen table. Tom repeatedly refers to his family's support during his hospitalisation and the gruelling years of rehab.

“A lot of things I do now, I thought I would never do again.”



Tom sustained a major brain injury plus arm, shoulder and jaw fractures when he was hit as a pedestrian in January 2014. He spent 7 months in Westmead Hospital in Sydney followed by 3 months in Lourdes Hospital in Dubbo, re-learning to walk. He then came back to Narromine where his rehab and recovery continued. He credits the ongoing work of his physio Lisa, his family and community with helping him reach his goals. "Mum and Dad were there in Westmead with me the whole 7 months."

His family was told that he would never walk, eat or talk. Tom says, "A lot of things I do now, I thought I would never do again."

Fitness goals

As a youngster, Tom grew tall early but says he wasn't so confident, wasn't the goal-setter he is now. In sports he says he "often felt like I was a grade below." However, he joined Little Athletics, did high jump, represented his region at the NSW championships, won B grade bowls and played first grade rugby league.

In 2020, 6 years after his accident, Tom won Narromine's [Senior Sportsperson of the Year](#) for running, touch footy and rugby league. He was aged 26 - hardly a 'senior' but certainly out of the junior ranks.

He met his physio Lisa when he returned to Narromine in late 2014. Her steady but tough approach helped Tom set, and exceed, some fitness goals.

"She shook me up when I told her I couldn't do this or didn't want to do that. She had more confidence in me than I did."

She didn't just want Tom to get back into running but suggested that they run together in the 2015 City-to-Surf in Sydney. Tom says he thought "Wake up to yourself, Lisa. I'm going to go guts up." But they did it. Ticked that goal off. And at the top of Heartbreak Hill were some Narromine friends to cheer them on. Tom has since done a half-marathon (21.5 km) which he considers one of his greatest achievements.

Tom also set a goal to dead-lift 200 kg. He went to a gym in Dubbo, worked with trainer Donna and can now tick that goal off too. He has another tick for a 100 kg bench-press.



“ Sometimes it is best not to rush, and things will turn up. When things are tough, take a step back and think. Reassess. ”

Tom has fitness goals.

The Narromine community

Although Tom was born in Canberra, he grew up in Narromine, completed his schooling in 2012 and joined the workforce there. He started a traineeship with Narromine Council in their Water and Sewer team, quickly completing a Certificate II in Water Operations.

Both Tom and his mother, Elisa, say the tight-knit Narromine community was a strong support network and a key part of Tom's recovery. "Narromine Council, and the community too, were great when I had my accident. Setting up a Tom Newlands Support Group and doing fundraisers, even in Dubbo."

Tom commenced a return-to-work program with the Council on 27 February 2015, initially 3 hours per day for 3 days per week. He developed seizures and so reduced his work hours until medications could stabilise the seizures. Tom and Elisa say in unison "And he hasn't had a seizure since 2016." Tom has completed a number of workplace certificates - in backhoe operations, work safety at heights, working in confined spaces, asbestos awareness. Proudly, Tom was part of the Narromine work team that won the national Water Industry

Operator's Association Team of the Year Awards in 2023 for their work on a cutting-edge ceramic membrane water-treatment plant for the small community of Tomingley.

Recently, Tom has secured a full-time position as a Utilities Labourer, still in the Water and Sewer team at Narromine Council. It is a 9-day fortnight, so Tom lives with his parents at Narromine during the week and in Dubbo with Jess and Leilani at weekends.

So, there are some more goals he's ticked off. A family. A full-time job. Driver licence.

Looking ahead

Tom is looking forward to settling down with Jess and Leilani, and is determined to "give Leilani the life she deserves." He is thrilled about the security and opportunities of his new job. They hope to buy a house someday, probably in Narromine.

When asked to look ahead 5 years, Tom sees himself still working with Council having gained more certificates. And travel is on the agenda. Perhaps shorter trips while Leilani is small. But Jess lived in the NT for a while and Tom has a good mate up there. The broad plan is to take some time to drive up there with Jess and Leilani, and look around.

Tom has had setbacks, like his epilepsy. And continues to need to pace himself to manage the general fatigue of brain injury plus the additional fatigue of fatherhood. And there are limitations, like not playing rugby any more because of the risk of a head knock. But Tom has picked up ways to still be involved in community sport, as a volunteer safety trainer with the Narromine Jets senior rugby, where he is responsible for the check process if a player hurts themselves.

Tom's motto in hospital was 'Never Give Up'. He wants other people to believe in themselves and not give up. "Sometimes it is best not to rush, and things will turn up. When things are tough, take a step back and think. Reassess. Think of the positives in life - family and friends. You've always got them there."



Mark Marchiori: establish your own life

Mark is in the Workers Care Program



Mark left home straight after school, went off to explore, and became a timber-cutter. A workplace accident in the forest resulted in a brain injury and paraplegia. He uses a wheelchair, gets out and about on his rural acreage and still works with timber.

Shine meets Mark and has a cup of tea on the back deck of his property at Bilambil in far north NSW near the Queensland border. Mark says he made the outdoor table we are sitting at, about 12 years ago using his own design. “I made it up, worked out how to brace it and make it strong. I like things to last. Its heavy, made out of hardwood which I’ve been familiar with all my life.”

Mark grew up in Cobbity, south-west of Sydney when it was a rural area. “We grew up in the bush, right in the middle of it. The bush is what I understand.”

“ I’m not working in the forests now but still working with timber. ”

Timber-cutting

Mark has an adventurous streak – he was the one in the family who left town, packed his bags and went off to explore. On leaving school he moved to Willow Tree, having done work experience there during high school. “I’ve tried North Queensland, but I love the north-west of NSW best, around the Liverpool Plains. That’s where it all started. I established farms, got into the timber industry, started timber-cutting and built everything up.”

In 2003, Mark was working in the forest when a machine hit a tree, pushing the tree over and it fell on his head, resulting in paraplegia and a brain injury. After the accident he moved between Cobbity and Manilla with his wife and child. About 8 years ago, he made a conscious decision to get back to the country, moving to Bilambil. It’s smaller than the farms he had in the past but “It’s quiet, private, peaceful. There’s room for some chickens, some cows and the dogs. There are neighbours but they are far enough away.”

Independence

A strong thread in Mark’s life has been independence. He left town straight after high school; he developed his business, managing properties and cutting timber; he got his car licence back while still at Royal Rehab; and he organised the renovations at Bilambil, becoming an Owner Builder so he could make things happen exactly as he wanted them to. He renovated the barn to become a studio for his daughter, doubled the size of the deck and roofed it, and built a self-contained pool house so he can be independent before and after swimming.

The Owner-Builder course added to his existing business and planning skills. He made easy timelines for the tradies but was always very clear about his need for involvement in decisions and any change of plans.

This independent streak extends to his approach to his disability. “You need to accept you’ve had your accident, realise this is how I am going to live now. It’s your life and you have to establish it.” Part of this independence is keeping fit. Mark attends a gym in Tweed Heads twice per week with a personal trainer, to keep toned and strong. He regularly does a 5 km push along the boardwalk track on the coast. He also swims in his pool at home.



“ There is a big difference between living it, knowing what it feels like and researching or studying disability. ”

Mark at the table he made about 12 years ago using his own design, and at home in his garden.

The voice of lived experience

Mark puts very high value on personal experience, particularly the importance of a voice for people with lived experience of disability. He has been very disappointed at different times with his contacts with insurance staff and providers, saying “There is a big difference between living it, knowing what it feels like and researching or studying disability. Book work is only a guideline.” He found many providers might “have a banner on their name badge” but didn’t listen, and gave the impression that they knew best. Mark says that good providers are civil, explain things and treat you like a human being. They’ll make the time to meet you, talk with you and explain things, whether good or bad. In particular, he says “They own their mistakes; they don’t just ‘tell’ you things, but explain, so you can decide things together; and they listen.

“I grew up in the bush and became a timber-cutter. This is a very different background to most of the people I was dealing with. They may think they sort of know about farm life, but they don’t know the life of a timber-cutter. No-one really asked me, wanted to know how you are, who you are, what you are and what would work for you.”

Mark appreciates his interactions with Workers Care and having his ‘voice’ on the Workers Care Reference Group which meets about 4 times per year. Workers can share experiences and insights and discuss topics of concern. Mark says, “They actually want to know what you think, what you see. It gives them more understanding, and a better feeling about what you’re living with. You can agree or disagree.”

Mark is passionate about ensuring the systems that support people living with injuries have staff who listen, understand, and meet their needs. In particular, he emphasises the need to recognise that everyone is different. Everyone is an individual, with differences in upbringing, age, lifestyle, injury, and help needed.

Establish your own life

“You learn the basics at rehab but you need to go out and establish your own life” says [Mark](#).

He has certainly established his own life - attending to his fitness, asserting his voice, building the country life he values. He acknowledges he has had some low times but focuses on opportunities and having a go, saying his thinking is “I could do this, I like this, I am interested in this.”

He used to like helicopters so tried *Wheelies with Wings* in 2011, a light plane course where he reached the stage of take-off, fly, touch-down, take-off. At home, he has built raised garden beds to grow his own veggies. He fitted out the garage as his woodworking shed and has since produced large pieces like tables as well as many smaller items like bookshelves, side tables, plant stands.

Mark says, “I’m not working in the forests now but still working with timber.”

“ It’s your life and you have to establish it ... This is how I’m going to live now. ”



Connecting through Creativity

Theme: My Favourite Things



The *Shine* Arts Prize showcases the artistic talent of people in Lifetime Care and Workers Care, and recognises the role of art in maintaining wellbeing.

Shine Arts Prize is an icare initiative presented in partnership with Accessible Arts NSW, the peak arts and disability organisation in NSW.

This year's theme celebrated 'My Favourite Things', referring to the things that provide enjoyment, inspiration, or reflect who we are. These things might keep us going in difficult times or be what we seek out to promote healing and recovery.

A panel of 3 judges assessed the artworks for their creativity, originality, connection to the theme and how well the artwork was composed and created.

Thank you to everyone who submitted entries. The judges had a challenging time selecting the winners due to the high calibre of the artworks.

Overall winner ►

Zac

Title: *Everything is possible*

Description: "Perry Cross is a very inspirational and motivational human being; he reminds me every day that a life with disability is a life worth living. He has gone above and beyond, proving to everyone that you can still have goals and dreams and pursue them even if your life takes a path you never expected. Surrounding myself with people who motivate me is one of my favourite things as it helps me to stay positive and remember that with determination, everything is possible..."

See the [full online exhibition here](#).
View video from the exhibition opening [here](#).



[Listen to Wayne's song here.](#)

Music winner ►

Wayne Williams

Title: *Warwick Farm*

Description: "Warwick Farm song. This song is about growing up in Warwick Farm surrounded by my family and friends. It brings back happy memories of growing up. Music is my happiness."



▲ **Visual arts winner**

Paisley Flower

Title: *The ocean*

Description: "It heals me every day in every way"

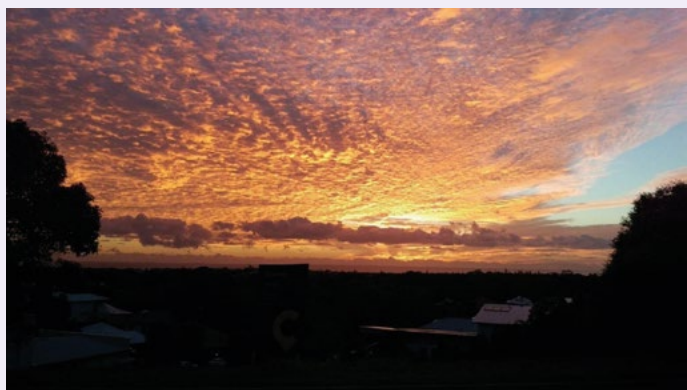


▲ **Visual arts highly commended**

Brigitte Bullen

Title: *Juxtaposition*

Description: "My sculpture is called 'Juxtaposition' (my favourite word) which reflects my favourite thing: Nature. Which is both reflected in verdant colour and the red earth of these Aztec structures in my sculptures. Aztec structures are my favourite shapes. Corokia plant being beautiful yet tragic, is one of my favourite plants. Sculpting is my favourite way to spend my time."



▲ **People's choice award winner**

Liam Raybould

Title: *Sunset*

Description: This photo speaks for itself. Natural beauty in one shot. Liam loves photography and seems to capture nature at its finest. Calming, beautiful natural photo.

The People's choice award was a new award this year and the winning artwork was the one that received the most votes by the Shine Arts Prize community including artists, their supporters, icare staff and other people in the community.



▲ **Children under 15 winner**

Isla Davies

Title: *Felted fairies and unicorn*

Description: Soft floating fairies and unicorn. The accompanying playmat includes a flowing stream with footbridge and a little fairy hut.

Introducing the Winner of the 2024 Shine Arts Prize

Zac is a Lifetime Care participant

Zac is the winner of the 2024 *Shine Arts Prize*. Zac had an artistic interest from a young age. After a 13-year break while he was building a career in the finance industry, he returned to drawing in 2018.

Zac was absolutely thrilled when he heard he had won the *Shine Arts Prize* for 2024. "I was walking on air. Walking in some metaphorical sense. I really was on cloud 9 for a few weeks."

He says he is always going to do art regardless of competitions or winning. But he also acknowledges he was quite a competitive person in the past, particularly with his career and with basketball back in New Zealand. "I am essentially working with a new body now, so it's nice to know there is a platform where I can be competitive. And that is art."

“ I love my work being out there ... otherwise it is going to be in a closet collecting dust. ”

Zac's Art

Zac has always had artistic interest. He went to boarding school as a child and felt the only way he could reach out to his mother from a distance was through art. His first image was 'Scar' from 'The Lion King'. "I've always had a flair for the dark rather than the hero" says Zac. "My niche is off-centre. That is partly why I do a lot of my art on black paper."

He entered two pieces in this year's *Shine Arts Prize*, having previously entered three pieces in the *Shine Arts Prize* in 2022. One of those previous pieces, titled 'Life is worth living', was Highly Commended. Zac has since sold this piece, and he says "I enjoyed the fact that it sold more than I thought I would. I feel grateful and honoured."

Zac received another Highly Commended for his piece 'Black and white' in another competition in *Artful* – a website community that helps people explore, learn, and connect with others who share a love for art.

Art as therapy

Zac says he came from a very stoic upbringing and his art is a form of therapy. He is not just talking about practical therapy for his hands and fingers. He notes a deep personal satisfaction and happiness arising from his art, and links it with the release of serotonin and dopamine. He feels re-finding art has been like a rebirth. He found himself as a person with a new body and has had to learn how to use that body. In *Artful* he refers to his art as a "method of journaling through paralysis." He notes "As a male who struggles to express emotions, navigating my injury has been incredibly difficult. Painting is my method of journaling."

He says initially he drew anything and everything he could see and imagine, including designing tattoos, but now he feels his talent is in faces and portraits. Currently, he is doing some commercial work and has taken commissions for pet portraits and human portraits, whether living or deceased. Work comes through word of mouth and social media.



“ As a male who struggles to express emotions, navigating my injury has been incredibly difficult. Painting is my method of journaling. ”

Above: Zac's Highly Commended entry in the 2022 Shine Arts Prize, 'Life is worth living'.

Practical matters

Technically, he describes his winning portrait 'Everything is possible' as comprised of black paper with white charcoal for the portrait, and gold paint mixed with black splashes for the background.

"I have always believed an artist works with his eyes not his pencil. I try to do as much as I can with the limitations I have. Some days my hands are not so cooperative. I work at a table and accept help where I need it for small dextrous movements like sharpening pencils, taking a cap off."

Art, publicity and the future

In relation to his Instagram page, Zac says "I love my work being out there ... otherwise it is going to be in a closet collecting dust." He holds a very firm view that art does speak for itself.

The descriptions of the pieces he submitted to the *Artful* competition provide some further insights about Zac and his art. In relation to 'Colours of an Indian' he says "I am an Indian that has been raised in Oman, immigrated to New Zealand as a young adult and now lives in Australia. I'm light skinned in winter, turn black in the summer. My accent is British due to my influences, yet I only relate to black American humour."

In relation to 'Stallion out of water', he says "Given my compulsive positive outlook on life, I refuse to think of myself as a fish, so I depicted myself as a stallion instead. The way I remember my former self."

Zac says he's developed resilience and is fiercely protective of the things he can enjoy. "It's like Noah's ark. I only have on board with me the people I want on board, carefully selected. No one unwanted is on board. Then you can weather the storm."

His self-described positive outlook certainly comes through in the titles of both the 2024 winning artwork 'Everything is possible' and the Highly Commended artwork he submitted to the *Shine Arts Prize* in 2022 'Life is worth living'. Zac has a message for anyone who is questioning themselves about whether they should take up art in any form: "Detach yourselves from the validation. Forget the external, just pursue your art."

More of Zac's artwork below.



Title: *Black and white*.



Title: *Stallion out of water*.

“ I only have on board with me the people I want on board, carefully selected. ”

See Zac's winning artwork 'Everything is possible' on page 6.

Tony Wright: humour helps

Tony is a Lifetime Care participant



Focussing on his fitness.

Tony was cycling when he was hit by a distracted ute driver. Since his injury, Tony acknowledges he's had low periods and has sought professional help. He has a great sense of humour and is grateful for his family and community.

Tony says, pre-accident, he was the sort of guy who didn't really have goals. "I was more along the lines of 'That seems good. Let's go and do it.'" But he admits that when he moved to Port Macquarie in 1996 without a job, he did have a 'loose cunning plan'. It was to "join the surf club, join the SES, then the Bushfire Brigade. You get to know people and you find out about jobs."

He went out and did just that, and got a job as a lifeguard at Town Beach during the day and running a motel bar in the evening. Contacts grew and he became a school bus driver, which suited him when the summer lifeguard season was over. At various times he was also maître d' at different restaurants, worked for *A Man with a Ute* and taught swimming to kids.

When he lived at the Gold Coast previously, Tony used to run, ride and surf and he was involved with triathlons. In Port, he became coordinator of water safety for the local surf club, and area Swim Director for Iron Man Australia. So, he was very well-known in Port Macquarie. The town was shocked when, while out cycling one day in 2017, Tony was hit at 100 kph by a distracted ute driver. He was flown to Newcastle with a brain injury and multiple fractures, including to all four limbs. He spent a month in ICU, a month in the trauma ward, 5 months in rehab at Newcastle, and another 3 months in rehab back in Port Macquarie.

When *Shine* meets Tony at the airport, he is walking without his stick. He says he doesn't need it in open spaces but will use it at events that are crowded or where people are moving around a lot. He has had multiple surgeries over many years including having both elbows replaced. At one point, surgeons seriously considered amputating his left leg.

Tony says the hardest thing is still the head injury and resulting fatigue. He has a nap every afternoon, often reminded by his wife, Leanne, who Tony describes as "The brains of the outfit."

Adjustments

Tony says "The biggest challenge is just life. Everything has been an adjustment. Sometimes it works, sometimes it doesn't. It's as simple as that." There are big and small adjustments. He has had to adjust his swimming stroke. And wears elbow braces while on the exercise bike at the gym. He has had to adjust how he butters his toast because his left forearm bones are fused and don't rotate.

He is more cautious now. "I used to be: Get up and go. Now I'm: Get up, think about it and then go. Leanne is good at reminding me."

“ You never know unless you try. ”



“ I used to be:
Get up and go.
Now I’m: Get up,
think about it and
then go. ”

Tony has a specialist ‘Pink Lady’ role.

Tony appreciates all achievements, big or small. “Little bonuses are a good thing like the first time I could sleep on my side.” Or swimming a lap of the pool. Big achievements are important to Tony too, not just for himself but for what he can do for others. Learning to walk again. Getting his driver licence back. He was particularly pleased to get back his rigid vehicle licence – this means he can drive a minibus if needed to help with ‘away’ surfing carnivals.

He has retained a focus on his fitness. He has regular sessions at the gym and the pool. And he’s grateful for the opportunity to cycle with mates on quiet roads, or to do some hiking. “You never know unless you try.”

He acknowledges he’s had low periods and has sought help from a psychologist a few times. He tells people to “Be patient. Just be patient. The biggest thing is that you’re trying to get everything back together; nothing happens straight away; you get the sh*ts, you get depressed.”

Humour

Tony certainly has a sense of humour and he credits this as a key factor in his current contentment with life. He laughs when he shows me his name badge saying, ‘Pink Lady, Tony’.

He tells *Shine* the uniform is “White pants and pink shirt – the same outfit I used to wear working in a bar on the Gold Coast 40 years ago in the 80s!” Pink Lady volunteers deliver services that provide extra care to improve patient experience. Tony has a special Pink Lady role, transporting people around the very sloping hospital carpark in a golf buggy. He brings his humour to this role – hat on sideways, music playing in the buggy, saying ‘Wanna Ride?’ in an accent.

He says he’s always looked on the silly side of things and that is evident when he refers to the golf buggy as ‘the billy cart’, the staff roster at Busways as ‘the leader board’, the walking sling at rehab as ‘the Thunderbird costume’.

He is very, very proud of Leanne and his family but jokes “At one time the kids were doing HSC and Leanne was doing Uni. We didn’t see the surface of the kitchen table for about 6 years.”

Perhaps humour runs in the family. When there was a serious likelihood that Tony was going to lose his leg, his daughter and Tony talked about how much he’d save on pirate outfits. And Leanne priced getting a parrot.

Giving back

Tony talks frequently about ‘paying back’. He is very grateful, not only for the many medical teams who saved his life, but for all the known and unknown folk who have helped him find a new life and beat its ongoing challenges. Old employers, mates from work and from sports.

He is back doing some teaching at the surf club and undertakes traffic management for triathlons and ultramarathons. And he has his ‘Pink Lady’ volunteer role at the local hospital.

Tony also attends [Self-Seen](#), a walking and talking support group helping people with mental health issues. He hopes his experiences will help someone else. His humour shows through again, referring to *Self-Seen* as like *Men’s Shed* but “for men who don’t have the talent to do shed-type things.”



Jonti Dimond: mixing individual and team sports

Jonti is a Lifetime Care participant



Jonti enjoys the sit-ski experience.

Jonti finds sport is a way to learn about yourself and your new body. And parasport might be his new passion. He is giving it a ‘red-hot crack’.

Jonti is just back from the gym when *Shine* meets him on the deck of his 2-acre Hawkesbury riverfront property at Wilberforce, north-west of Sydney.

Even sitting in his wheelchair, it is clear that Jonti is a tall guy. He says he is hitting 2 m in height and 120 kg. Gym is a regular part of his schedule, part of recovery from a motor bike accident in April 2022 which resulted in an incomplete spinal cord injury at T12/L1. The gym is also part of his path to considering whether his future might be in paralympic sport.

Jonti moved to Australia from New Zealand about 8 years ago to ‘get ahead’ and he started a concrete-pumping business. “The accident was pretty life-changing. I didn’t know what was around the corner.” He spent 3 weeks at Westmead Hospital, 3 months at Royal North Shore Hospital and 3 months at Royal Rehab at Ryde before coming home in November 2022.

“One of the best advocates for yourself is yourself.”

Sport and fitness

Jonti has always loved sport and was very fit, with a busy sporting and social life in NZ. He had a boat and a couple of motor bikes, and loved snow skiing and snowboarding, water skiing, golf and cricket. He was in the NZ men’s under 23 netball team.

Despite not knowing what was around the corner after his accident, he has found “Sport is a way to learn about your new way of life and your new body.” He says “I was a workaholic in my 20s. In a way, I’ve become a ‘rehabaholic’ with a combination of gym work, physio and sport.”

Jonti won’t be returning to concrete-pumping but wants to find a purpose. Right now, he is “giving parasport a red-hot crack.” Since his accident he has spent 20 days on the snow in 2023 and 20 days this year. He attended a couple of para snowsport development camps with *Snow Australia* plus an adaptive sports festival in Queenstown run by *Snow NZ*. He really enjoys the sit-ski experience as it has full suspension like a motor bike and you can go up to 90 kph.

He successfully competed in NSW and national downhill mountain biking events. Races are held on regular, but slightly wider, mountain biking courses using an adapted mountain bike.

In watersports, Jonti didn’t like rowing or wave-boarding but is a keen kayaker. His eye is on K1 200 m and 500 m events. He regularly trains with a squad on the Nepean river and joins 8 km races.

He has also tried wheelchair tennis (both singles and doubles) and seated throwing (shotput and discus).

Jonti believes a mix of individual and team sports is good. In relation to individual sports, he says “What you put in is what you get out” but he also values teams sports for their morale and team banter. “Sporting communities are super friendly.”

Getting moving

Soon after his accident, Jonti heard about advanced leg braces worn externally that have microprocessors controlling movement at the knee, ankle and foot. Jonti committed to an intensive program over a lengthy trial period to determine the functional benefits and their limitations.



“ Have faith in the people around you. Create a team you can trust. ”

Keeping moving has added health benefits.

After 6 months he could walk 90 m with crutches and the brace, and go up and down small slopes. He was able to stand up at his 31st birthday party for 2.5 hours.

Jonti is focussed on moving his body as much as possible, which has the added health benefits of improving bone density, skin integrity, avoiding muscle wasting, and improving bowel and bladder function.

Approach to risk

Jonti knows he’s never been a risk-averse type of guy, but also knows he now thinks a little differently about risk. He notes that “A big sporting crash humbles you” but reflects that safety is partly about concentrating in the moment. “If your mind is on the consequences of the risks, you are likely to make mistakes.”

He suggests finding a sport that suits your ability and passions, then getting yourself set up with the right adaptive equipment, the right guide and lessons. “Slowly push the boundaries of your comfort zone. Learn from guides, coaches, carers, people with experience. Have faith in the people around you. Create a team you can trust.”

**See also the article by Dr Steve Peterson about using Living My Way on page 14.*

Taking charge

Jonti was very keen to get his driver licence back. He had lessons when he was an in-patient at Royal Rehab in Ryde, went for the driving test and passed on his first attempt. “It’s been great to have that independence driving again” but he notes that it took a lot longer than he expected with wait times for lessons, for approvals, for installing modifications. He used portable hand controls for 2 months on his existing car, and then decided to downsize his vehicle and get permanent hand controls.

In terms of his sporting hopes, he says “I’ve been inspired by people I’ve met like Curtis McGrath, current Paralympic kayak winner. And by meeting the first sit-skier in the world to do a double backflip.”

And if you are interested in parasports as a career, his message is “Educate yourself, and advocate for yourself. Development paths are not clear, particularly when you are starting out. Pick one sport, the rest are hobbies.” Jonti recently joined the supported self-management program [Living My Way](#) to help him have more control and flexibility with his supports. It has been a bit of a slow start, as he reports learnings about how to advertise and find the care supports he needs.*

In terms of taking control of his day-to-day living, Jonti has listened to other folk in wheelchairs at rehab and in sporting groups. From them, he has “learnt about life after hospital and things like transfers, skin care, infections.” His personal reminder to others is, “One of the best advocates for yourself is yourself. I’m the squeaky wheel that gets oiled.”

Looking forward

Jonti acknowledges that he is a recovering ‘rehabaholic’ who needs to enjoy some time away from rehab and training. For Jonti, this means spending time with family and friends. He has made trips back to NZ and joined a 2-week Contiki tour. He and his girlfriend recently went on a trip to Bali with friends. Trip-planning is important, but his advice is “If you are going to Bali, have some strong friends able to carry you upstairs. Bali is not super accessible.”



Freedom with Supported Self-Management

Steve is a Lifetime Care participant

Living My Way support has given Dr Steve Peterson the right balance between choice and control, and responsibility.

Steve is a 38-year-old man, working as a GP and local city Councillor, living in Orange with his wife and two sons. He was injured in 2018 while riding his bicycle to work at the Orange Emergency Department, sustaining a spinal cord injury resulting in quadriplegia. He shares his story...

“Over the last 6 years, I’ve had quite the journey when it comes to managing my own care and support workers. It hasn’t always been easy, but I’ve found taking a more hands-on approach has given me the flexibility and control I need to live the life I want.”

Managing his own care program

Engaging and maintaining a care program in regional areas can be challenging. Steve said: “Initially, I struggled to maintain a consistent roster, and there were far too many days when my support workers wouldn’t show up. When I switched providers, that made all the difference, and now I manage a wide range of shifts myself, which means I directly coordinate with my support workers.”

An alternative care solution

The *Supported Self-Management* initiative offers Lifetime Care participants the option to engage off-panel providers in remote regions, or to hire and manage their own support workers. icare’s partnership with *Living My Way* is intended to give participants more choice and control in how they engage and manage support workers.

An icare contact will let participants know if *Supported Self-Management* might be a suitable option for them. Steve shared: “I have a long relationship with icare, and a Case Manager. They recommended that I connect with *Living My Way*. I’m really glad I did. The team there has been incredibly helpful in ensuring I meet all employment law obligations, and with the onboarding of new carers. Their expertise has been a game-changer for me, as I don’t have a lot of experience in that realm.”

Gaining new skills and building a stronger team

Steve received training from *Living My Way* to manage his own team of support workers. He said: “I found that building interpersonal relationships with my support workers is key for the success of my care program. I try to be a good employer by giving them advance notice of any changes and discussing concerns right away. They appreciate that I have their back, and they go the extra mile for me, so it’s mutually beneficial.”

“It’s crucial to build a strong network of support workers and maintain open communication.”



Steve with his wife Deb and family.

Self-management is not for everyone

Self-management involves a fair bit of responsibility. *Living My Way* takes on some of the administrative tasks and manages invoice payments; however, there is still a lot of work involved in managing a care program. Steve advised: “For anyone thinking about taking a more active role in managing their own care, make sure you have the right skills, and mindset, to be a responsible employer. Things like keeping on top of timesheets, approving hours, and ensuring your support workers are paid correctly are all important. It’s crucial to build a strong network of support workers and maintain open communication, and I’m proud of the progress and the relationships I’ve built.”

Empowered to give back to community

“I see my unusual position as a doctor with a disability as an opportunity to contribute positively to the lives of others and to advocate in my local community. I serve on the Board of *Spinal Cord Injuries Australia* and I’m working to bring a disability-focused gym to our regional town. I’m passionate about these projects.

“I want to inspire others to take a more active role in their own care and use their experiences to make a difference in their local community.”

Dr Steve Peterson,
Doctor, Advocate,
City Councillor,
Lifetime Care Participant.

Living my way.

Working with *Living My Way*

Living My Way have had experience in supporting individuals to live a self-directed life since 1992.

They can provide the assistance and guidance required to manage supports with less administration required by the participants.

Living My Way can help participants select, train and organise their own care team, or purchase services through an experienced agency or online platform.

Talk with your icare contact to discuss if *Supported Self-Management* is suitable for you. It is available to participants who are over 18, have been accepted into Lifetime Care and whose care needs are stable and predictable.

“ Taking a more hands-on approach has given me the flexibility and control I need to live the life I want. ”

Easy to use

Living My Way uses technology that allows you to:

- Approve payments and track your budget online
- Manage staff rosters and communicate with workers easily



Mathew and Elva Barker: in their community

Mathew is in the Lifetime Care Program



After a major motor bike accident, Mathew needed 24-hour care. His mother, Elva, is the matriarch of her extended family with caring roles for Mathew, other family members and people in her community.

Elva Barker grew up in a tin humpy on the banks of the Culgoa River on Weilmoringle Station outside Bourke. Her remaining brothers and sisters still live in Bourke, but Elva now lives in Dubbo which is where *Shine* meets Elva and her son Mathew.

Shearing

The family has long worked in the shearing business. Elva's dad was a presser, her mum a cook, 8 brothers were shearers and one a roustabout. "My sister did a [wool] classing course, and we were a full shearing team!" says Elva proudly.

It was natural that Elva's sons, Kevin and Mathew, became shearers too. In an interview 10 years ago, Mathew said, "The shearing game is tough, back-breaking work but it's in my blood. I like shearing, I like the shed, I like the people in the shed. It's a competitive game and you earn good dollars." He averaged 180 to 200 sheep a day, at his fittest.

“ I couldn't see any other way than having Mathew home with me. ”

Voice

Listening to the old radio interview during *Shine's* visit, one of Mathew's support workers chokes up: "I've never heard his voice before!"

Elva refers to a voice recording she had on her phone. Mathew had changed song words from 'We've got golden fingers' to 'I've got burrs in my fingers.' Some years ago, Elva's phone broke – a sad loss as Mathew can no longer speak or sing.

Accident

In June 2015, at age 30, Mathew was hit by a bus while riding his motor bike. He was flown to Canberra Hospital with significant brain injuries and remained there for many months before moving to the Liverpool Brain Injury Unit. He was non-verbal, had very limited movement and needed 24-hour care.

Elva stayed near Canberra hospital while he was there. When Mathew moved to Liverpool, Lifetime Care assisted Elva with motel accommodation. But after 18 months it was time to go back home to Bourke.

"In our culture, family is very important. Everyone steps in to help everyone else. No one goes outside the family to be looked after. Our loved ones belong at home. "I couldn't see any other way than having Mathew home with me."

Lifetime Care assisted to bring a group of support workers from Bourke to Liverpool, to meet Mathew's support team and learn about his care before Mathew returned to Bourke in 2017.

"Never be frightened to bring your loved one home. When I saw the change in Mathew's face once he came home, I knew I'd done the right thing."

In November 2022, flooding in Bourke made it even more difficult than usual to manage Mathew's care roster and meet his needs. Elva decided to shift the family to Dubbo to access more support services. But Elva needed to stay in Bourke until she could make new arrangements for Mathew's four children who were in her care.

Lifetime Care assisted Mathew to move to Dubbo under the supervisory care of his aunt and uncle, while Elva visited Mathew on weekends and school holidays.



“ I’m proud of what I’m doing for my family and the kids. I want to stand mighty for them and for my community. ”

Elva

Family is important.

Mathew and family

Mathew has two daughters and two sons. The boys now live in Brewarrina with their maternal grandmother and the girls with Elva.

Elva was finally able to move to Dubbo early in 2024 when Aboriginal Housing organised a home accessible for Mathew’s specialised reclining wheelchair. Mathew usually lies quietly but he becomes animated when his daughters come nearby, stroke his hand or hair, and chatter to him. He communicates by nodding and rotating his eyes and head in a language his mother and daughters understand; if he doesn’t like something, he kicks out with his left leg.

“His biggest smile is for his sister who used to do the night shift,” Elva says. “I get a lump in my throat seeing it.”

Caring

The Dubbo home is a full household with Mathew and his daughters, many of Elva’s grandchildren coming and going, plus visiting support workers. Elva plays down her role in caring for everyone, but then lists school interviews, medical appointments, looking out for her siblings and community in Bourke, and organising care rosters among her obligations.

Several of Elva’s siblings have passed away and she is now the matriarch of her extended family. “I’m proud of what I’m doing for my family and the kids. I want to stand mighty for them and for my community.”

When asked about how she cares for herself, she replies “Elva looks after Elva. And without the family, kids and grandkids to look out for, I’d probably go down.”

Alongside her caring role, Elva is also the regular cook for son Kevin’s shearing team, where a contract may be for a weekend or a fortnight, depending on the number of sheep to be shorn – but she always prepares all of Mathew’s meals before heading off. While the shearing cooking is tiring, Elva enthusiastically describes being in the bush and the long days: “I start preparing breakfast at 4.30 am for maybe 12 rousies, shed hands and shearers – chops, sausages and eggs. Extensive spreads at morning tea and lunch follow.” Tea is trays of sandwiches and dinner at 6pm is soup, beef pie and mash plus sweets. “They’re working hard. You have to keep them fed.”

She says, “I learnt from my mum that cooking for the family is important for gathering and for nurturing. And for keeping the stories.”

As well as sustaining and nourishing her large household every day, and Kevin’s shearing team quite regularly, there are other occasional events requiring cooking. In NAIDOC week, Elva and her daughter organised a gathering in Bourke for 60 elders with abundant food prepared for a day of singing and speeches.

Elva has plans to take Mathew back to Bourke sometime soon.

“We might go to the shearing sheds if there’s any shearing going on. He loves it.

“Otherwise, I just sit him near by the river where we have always gathered. We’ll do some fishing. Visit the weir. Someone will put a guitar in his hands. He can’t play but he likes it. And we’ll keep passing on the stories.”

Listen to more

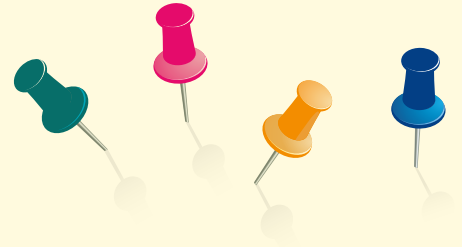
[2014 interview with Elva](#)

[2014 interview with Mathew](#)

[Shearing runs in the family](#)



The notice board



Sharing news highlights, handy information and upcoming events.

Support and Advocacy Service

We understand that it can be difficult to speak up when you disagree with a decision we have made, or are dissatisfied with how we have communicated with you, or with the services delivered by providers we fund. If you have concerns with icare, or a service provider we fund, we want to know about it.

If you are in Lifetime Care or Workers Care, you can access a panel of independent advocacy providers for support. The type of support they provide is up to you and can range from having someone speak on your behalf, provide support to help you write letters or make phone calls, or go to meetings on your behalf. An advocate can provide both practical and emotional support throughout the complaint process.

An advocate can provide support through the dispute process as well. Complaints and disputes are different things and icare has different processes to handle them.

A complaint

A complaint is when you are not satisfied or are unhappy with our services. Anyone can make a complaint and there is no cost associated with making a complaint. Complaints might be about:

- the level of service provided to you
- the services we pay for

A dispute

A dispute is when you disagree with a decision we've made about your medical, hospital, rehabilitation treatment or care; eligibility for Lifetime Care, or acceptance into the Workers Care program.

A dispute is resolved in a different way to a complaint.

icare fact sheets can help

icare has a range of helpful fact sheets. Some apply to Lifetime Care, some to Workers Care and some apply to both programs. For more information about what an advocate can do for you and how to access them, refer to the fact sheet '**Advocacy**' included with this edition of *Shine*. Other fact sheets that might be helpful are '**Support and Advocacy Service**', '**Your Feedback, Workers Care**' and '**Resolving disputes about medical, hospital and rehabilitation treatment**'. These fact sheets and other information can be found on the icare website: www.icare.nsw.gov.au

For Lifetime Care
[Support and Advocacy Service](#)

For Workers Care
[Services and support for severe workplace injuries](#)

icare Support and Advocacy panel

They are the three providers on the icare Support and Advocacy panel.



SCIA notes their policy and advocacy experts can help you resolve issues that impact your independence or ability to live the life you choose. They have staff with lived experience of disability on their Policy and Advocacy team, so they understand the challenges you face.



Synapse advocacy services notes they work to ensure that rights, interests and needs are upheld across a range of disability systems and services.



Disability Advocacy NSW notes they support people with disability to get a fair go. They stand beside people with disability to help them know their rights, sort out issues, and be fully included in the community.

Have you thought about sharing your story with *Shine*?

Many icare participants have shared their stories through *Shine* over the last 12 years.

Here's how to share your story

Previous participants have said they weren't sure what to expect ... but were surprised how easy the process is.

The *Shine* team does an initial interview by phone, before the *Shine* writer contacts you to arrange a meeting place that suits you. It's all organised around what is convenient for you. You are welcome to have your case manager, friends or family with you at the discussion.

You and the writer usually chat for an hour or so about your life and your story. The chat is informal and friendly and you don't need to talk about any issues you don't want to.

If you are comfortable, the writer will take some photos of you and any friends or family members you'd like to have in your story. You can also send through your own photos.

You'll see the draft story, so you can tell the writer anything that needs to be changed. You will also see and approve the photos that *Shine* plans to use in the final story.

See what previous participants have to say...

"That was easier than I thought. I was worried because I've never done public speaking before but it was just a kitchen table chat."

"It was good to get things off my chest and feel that my story might help someone else."

"They really listened to what I had to say. The chat was informal and we had lots of laughs."

We'd love to hear from you!

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

icare's Support Worker Reward and Recognition Program update!



Above: The top words across all the nominations.

Thank you to those who supported the first round of the new icare Reward and Recognition program. There were 35 nominations for support workers who had delivered exceptional service.

The top 10 nominees received an award and gift voucher for their hard work and dedication.

Winning nominations included the following comments:

“Hands down one of the best involved support workers. Supports all of her goals and enables her to work on her speech and getting back out into the community. The improvement is amazing! Makes my day every single time.” *

“Her calm and consistent presence has helped him, and his entire team, navigate difficult SCI health issues. She deserves recognition for her capacity to provide such a high standard of care to a grateful participant, family, and team.” *

**Responses have been edited for support worker and participant confidentiality.*

Hear what support workers say about their role. [Here](#).

Why nominate your support worker?

If you have a support worker who is consistent, caring, amazing and genuine then let us know! This is your chance to express appreciation for their exceptional efforts. It might just make their day. Here is some feedback from a nominated support worker.

“Thank you, it really makes my day. So grateful and thankful for being nominated to this Recognition Program. My heartfelt thanks as well to everyone involved.”

How does it work?

It's simple! As someone who receives support services, you can nominate your support worker for their outstanding contributions. To be eligible, the support worker must be from one of icare's attendant care panel providers and working with a person in Lifetime Care, Workers Care or Dust Diseases Care.

Nominate now!

Nominations are always open. A round of judging took place in November 2024. If your nomination missed the cut-off for the November round, don't worry. Your nomination will automatically go in the next round.

Step 1: Complete the online nomination form by using the QR code below. Share your story about how exceptional service has made a difference in your life.

Step 2: Feel good knowing your support worker will be recognised by icare. Celebrate the nomination together!

Benefits

Nominated support workers receive recognition and a certificate, confirming their nomination. Submissions are judged by a panel of experts, including a care recipient. The top nominees receive an award plus a gift voucher.

Reward and Recognition program online nomination form. [Here](#).

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

Shine online

View the online edition [here](#).

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Insurance and Care NSW