

# THE Advocate

A VOICE FOR ACCESSIBLE, EQUITABLE AND EMPOWERED LIVES | 2022 SUMMER ISSUE

## BACK ON THE TOOLS: JACQUES FINDS THE WAY

Accessible gaming  
levels the playing field

Rodeo riding...  
and raising two boys

Throw a line in  
with inclusive fishing

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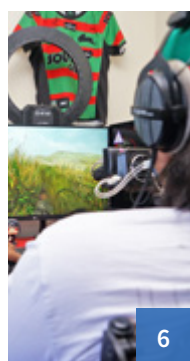
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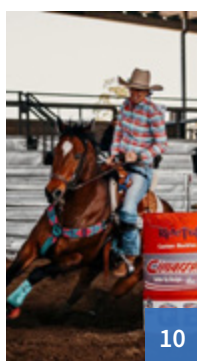
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When reading the member stories in this issue of *The Advocate*, I immediately thought of our recent campaign, which was all about how Spinal Life can help you to 'take life back'.

This message sums up our summer issue perfectly – it's all about how people who have sustained spinal cord damage have rallied to take their lives back, and get back to doing something they love.

Whether it's horse riding, gaming, fishing or returning to work as a mechanic, this is just a small snapshot of what's possible, which can be hard to see especially if you've been recently injured, or experiencing challenges.

While these activities may not be right for you, it's a reminder to explore what's out there and to ask for support if you need it – a few ideas may be all you need to get started.

Our closed Facebook groups – Peer Support Spinal Life Australia and Spinal Chatter – are great places to hear suggestions from others, and I encourage you to join at [facebook.com/groups/peersupportspinallifeaustralia](https://facebook.com/groups/peersupportspinallifeaustralia) or [facebook.com/groups/Spinalchatter](https://facebook.com/groups/Spinalchatter).

As we go to print, Spinal Life Australia's Annual General Meeting has just taken place on 14 November, providing the opportunity for members to have their say on the future of the organisation.

This year, members voted in the election of Board Directors and also approved proposed changes to the Constitution that will strengthen our organisation.

## Taking life back

The successful candidates were all current Board members, including myself, Gerard O'Brien and Michelle Wilson, after being required to submit for re-election following a three-year term.

I'm honoured to have the opportunity to continue to lead Spinal Life Australia in 2023, and thank all members for placing their trust in us, and for participating in the AGM. You can read more about the outcome on Page 28.

Finally, we will soon be sharing more about our Research Committee, which is developing an exciting program with Griffith University to seek tangible results across a range of areas aimed at improving the lives of our members and community.

In the New Year, we will be seeking your input on what these priorities should be, and asking if you would like to be involved in the research, so keep an eye on your email for updates.

As always, I encourage you to share any feedback at [chair@spinal.com.au](mailto:chair@spinal.com.au) to help us make Spinal Life the best it can be.

From my family to yours, I wish you all the very best for a wonderful Christmas and New Year. I look forward to sharing more updates with you in 2023. [A](#)

GYL STACEY

## DO YOU HAVE A STORY TO SHARE?



Email us at [theadvocate@spinal.com.au](mailto:theadvocate@spinal.com.au) – we'd love to hear from you!



## 3 QUESTIONS WITH THE CEO

# Mark Townend



### What are you most excited about right now?

The Queensland Government has just declared that 2023 will be the 'Year of Accessible Tourism', after we submitted a proposal earlier this year to the Premier and Tourism Minister.

This will significantly boost efforts to raise awareness of the benefits of accessible tourism for travellers and their families, as well as operators, who can not only improve their community for the better, but also reach more potential customers.

As part of the announcement, the Government will be providing a \$10 million Accessible Tourism Fund for small to medium businesses to build infrastructure and install technology to provide more inclusive travel opportunities.

The Government has also pledged \$1 million to raise awareness of accessibility needs and services, and \$1 million to promote accessible Queensland visitor experiences.

I would like to congratulate our Advocacy team, who have been hard at work behind the scenes to promote this important issue, working with councils, regional tourism organisations, operators and businesses in both Queensland and Western Australia to create real change in the industry.

As we go to print, we have also successfully passed a recent independent audit, which covers all our NDIS supports and services. This is a rigorous process that we welcome, to ensure we are continuing to meet (and exceed) requirements set by the NDIS Quality and Safeguards Commission.

### What's happening with the Disability Doesn't Discriminate campaign?

A law firm, Mitry Lawyers, is launching class action proceedings against the Commonwealth Government on behalf of people who are 65 years and over who have a disability, due to their exclusion from the NDIS.

Mitry Lawyers is currently calling for expressions of interest from individuals to participate in this class action, including spouses and family members who have also been affected by this exclusion. Visit [mitry.com.au/ndis](http://mitry.com.au/ndis) to find out more.

The class action follows in the footsteps of our Disability Doesn't Discriminate campaign, which commenced last year, aiming to address the severe inequity of funding for people with a disability aged over 65, who are unable to access the NDIS.

Despite many discussions with political candidates ahead of the federal election, and more than 25,000 people signing our petition, we still have not received a clear commitment on how this issue will be resolved.

We are also closely following the recent announcement by the Commonwealth Government about the upcoming review of the *Disability Services Act 1986* and will engage with our members to contribute submissions throughout 2023.

### What are you most looking forward to in 2023?

I can't wait to see our organisation continue to grow and deliver more services to help people with spinal cord damage and other physical disabilities to reach their goals.

We have a passionate team who are focused on working with individuals to provide tailored solutions that truly suit your needs and what you wish to achieve in your life.

It's been a great privilege to lead Spinal Life again for another year, and I thank all our customers for choosing our services. I'd also like to thank our staff and volunteers for their valued contributions to our organisation.

On behalf of the entire team, I wish you and your loved ones a safe, happy and healthy festive season. [A](#)




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**Bookmark it today**



Gamer extraordinaire,  
Tyson Te Maro

# Ready, player one

**How a mouth-operated controller helped a young dad get back to gaming**

“I grew up playing video games,” says Tyson Te Maro, 34, a former scaffolder from Thornlands in Brisbane. “I always loved them, but I didn’t always have time to play. And then I had my accident.”

The accident was a car crash that left Tyson with C4 quadriplegia and a seven-month stint in the Princess Alexandra (PA) Hospital.

“I remember staring out from the balcony in the hospital and just crying,” he reflects. “Growing up, I always thought my 30s would be the best years of my life. And then I had my accident... at age 30. I can remember thinking, ‘I’m still young –



I've got maybe 30 or 40 years left to live – and I'm going to spend most of my adult life in a wheelchair. I don't know how I'm going to get through this."

At that point, Tyson says, "I didn't even care if I got my legs back, I just wanted my hands. I used to get jealous of the people in hospital with paraplegia; the ones whose injuries were a bit lower so they could move their hands and transfer in and out of their chairs when they wanted to. I wished I could do that."

Happily, he gradually regained some movement. "I can't feel anything from my chest down – my triceps and my forearms are all basically numb – but I have almost normal sensitivity in my face, neck, shoulders and the tops of my arms," he explains. "A lot of people are quite surprised when they see me, because I can move my arms pretty freely now and I've learnt to adapt and can do a lot of things by myself, like eat, hold drinks and other things with my palms, and even use a manual chair. I've come a long way."

“A lot of people are quite surprised when they see me, because I can move my arms pretty freely now and I’ve learnt to adapt and can do a lot of things by myself.”

As his movement increased, so did Tyson's desire to get back to gaming. "I used to think every day, how can I play video games?" he says. "Most games require you to push a number of buttons, all at the same time, so I'd be lying in bed thinking, 'How can I make it work?'. And then I found the QuadStick."

The QuadStick is a mouth-operated game controller specifically designed for people with quadriplegia so that they can play video games hands-free.

Tyson learnt about it via YouTube. "When I got home from hospital I did a bit of research about game controls and stumbled across this guy called RockyNoHands. He's had his injury since he was 19, and has been using the QuadStick for a long time.

"He's amazing and has even broken two Guinness World Records for the game Fortnite. He was the one who inspired me to get a QuadStick and learn how to play." >

Tyson's super-sweet gaming setup



*Tyson loves the South Sydney Rabbitohs nearly as much as his QuadStick*



Playing involves sipping and puffing on holes in a mouthpiece to operate a joystick; different combinations of sipping and puffing in the various holes result in different actions. And while RockyNoHands plays games using only his mouth, Tyson is able to use his hands as well.

It took Tyson about a year to master the QuadStick, staying up late every night as he tried to improve the way he played. “When I first started I was like, man I suck, I’m never going to get good at this,” he says. “But because I knew RockyNoHands could do it, I knew I’d eventually be able to as well. I play against people with fully functional hands and these days, I really feel like I’m at no disadvantage. If you watched one of my games, you wouldn’t even know that I was playing it using a QuadStick.”

US developer, Fred Davidson, is the man responsible for the QuadStick.

“He’s the only person who makes them and if he stopped, I don’t know what I’d do... I can’t even imagine it,” says Tyson. “That’s how important the QuadStick is to me: I can’t live without it. I’ve actually bought two, just so I’ve got a backup if one breaks and I have to send it away for repairs. Ideally I’d like three!”

There are three different models of the QuadStick, which all connect to PCs and game consoles via USB or Bluetooth. The most expensive controller sells for US\$549, plus there are accessories such as a mounting arm, which can cost up to US\$229.

“It’s expensive, but it’s changed my life,” says Tyson, who bought his QuadStick out of his own pocket, not realising that he was eligible for funding. “I eventually got all my money back, which was great,” he says, “but it wouldn’t have bothered me if I’d had to pay for it myself – it’s so worth it.”

His family think it’s amazing how far Tyson’s come in such a short time. While his wife, Kristel, isn’t into video games herself – plus she hasn’t had time to play in recent years anyway, as she’s been so busy training to become a nurse – his children all love playing just as much as their dad.

“I’ve got four boys, aged 8, 11, 12 and 15, and they’ve adjusted to things really well,” says Tyson. “They help me out heaps and they don’t look at me any differently than before. In their eyes I’m still the same person I was when I could walk. But I can’t do the things I used to do with them, like throwing a rugby ball around and wrestling. I’m on the sidelines now, so playing video games has really helped me to connect with them.”

On an average day Tyson will drop the boys off at their school, which is fortunately just up the road, so he can travel alongside them in his powerchair. He then heads home to spend a few hours playing video games and watching YouTube, before heading back to pick them up at the end of the day.

“After school the boys will play video games, but I’d rather just hang out and watch them play. Weekends and school holidays are when we play together the most,” explains Tyson. “My Dad’s in New Zealand and I’ve even got him





Tyson's life-changing QuadStick


into playing my favourite game, Call of Duty – it's a great way to catch up regularly and we chat while we wait for games to start."

It's this ability to connect with people that Tyson really loves, and has got him planning for the future.

"I want to try and build a community, a family outside of my family, of people who want to play video games and make connections with other people who are in a similar position," he says. "I'm going to start by making my own YouTube videos about the QuadStick, because there are so many people who would benefit from it, but don't even know it exists."

Tyson's goals also include a career change.

"I'm quite a shy person and a bit of an introvert, so it's hard for me to make connections with people," he says. "It's not because of the chair or my injury – it's who I've always been. But I want to push myself beyond my comfort zone and eventually become a peer support worker, and go back to the PA Hospital to speak to people who are new to the injury, and try and help them. I think that would be a great new purpose for me; it would satisfy my soul."

And as for the immediate future? "Well, the new Call of Duty game comes out soon," he laughs, "so I'll be busy playing that!" 

For more information, go to [quadstick.com](http://quadstick.com)

## Tyson's top tips

- Be patient – it's going to take a while to master this new way of playing games
- Don't worry if your breathing's not very good or you don't have good head movement – pretty much everybody can use the QuadStick
- It's compatible with the PS3, PS4, Nintendo Switch, Windows PC and Mac computers. You can also use a USB adapter to use Xbox 360 and Xbox One consoles
- It's for absolutely everyone, no matter what your age, and you don't even have to be a gamer – you can use it as a mouse and a keyboard, use it with your phone, or connect it to your TV and use it like a remote
- The forum on the QuadStick website, where other users post answers to all sorts of questions, is a great resource
- YouTube videos of people that use the Quadstick, like RockyNoHands, are also really helpful

## How Spinal Life can support you

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During your session, our Assistive Technology Mentor or Occupational Therapist will work with you one on one, providing impartial information and guidance about assistive technologies available.

The service is available at our Brisbane and Cairns Healthy Living Centres, at your home in select locations and via telehealth.

### Looking for more on gaming?

We're planning more gaming-related events, activities, and services in the future. To sign up for updates, visit [info.spinal.com.au/gaming](http://info.spinal.com.au/gaming) or call us on **1300 774 625**.

*Kristy with her husband Dale, eight-year-old son Nash and latest addition to the family, Nova*

# Back in the saddle

How a simple seatbelt allowed former jockey Kristy Banks to ride again

Kristy Banks could ride horses almost before she could walk.

"Horses have been my life," she says. "My Dad got me into riding and I've just always loved them."

So much so that she made a career out of working with the majestic animals: "I knew I wanted to be a jockey from a young age, so I left school at 14 without even completing year nine," she says. "I just knew that riding horses was what I wanted to do. I was so passionate about them, and had a pretty successful career as a jockey."

Kristy rode professionally for about 15 years until, on New Year's Eve 2011, she had a fall that ended her career.

"It was during a race at Clifford Park Racecourse in Toowoomba," she recalls. "I wasn't knocked out so I remember everything, and from the very start the prognosis

wasn't good. They did X-rays and scans, and saw that my spinal cord was completely severed. So they flew me to the Princess Alexandra Hospital in Brisbane where my back was screwed and pinned back together. I also had a broken rib and a collapsed lung, but those things weren't really a big deal – the major thing was my back. I ended up with complete paraplegia at the T11/T12 level, and the prognosis was that I would never walk again."

Kristy moved from the hospital's ICU to the Spinal Injuries Unit, and later to a motel for a transition period to see how she would cope when living out of the hospital... but the only place she wanted to be was back at home.

"I just wanted to be with my husband and all my animals," she remembers. "I eventually made it home about eight weeks after my fall."



A simple seatbelt has let  
Kristy barrel race again



For someone so used to being outside and on a horse all the time, it was a massive adjustment. “My world was totally flipped upside down and I basically had to learn to live my new life in a wheelchair,” she recalls.

Then Kristy came across a girl in the US who also had a spinal cord injury, but did something called barrel racing.

“It’s what the ladies do in a rodeo,” says Kristy. Three barrels make a cloverleaf pattern, and whoever races around the barrels on their horse in the fastest time wins the money.

“The girl I saw racing was able to do it thanks to a seatbelt on her saddle,” explains Kristy. “When I saw it I sort of perked up and went, ‘Oh, I think I can do that!’ So I got a saddle, put a seatbelt on it and started riding again.”

Simply adding a seatbelt may seem like a very minor adjustment, but it made a major change to Kristy’s life.

“When I’m in the saddle, if you didn’t see the seatbelt you wouldn’t know that I was paralysed,” she says.

Thanks to this additional piece of hardware Kristy’s not only riding again, but even competing in races in the Queensland Barrel Racing Association.

The magic all happens on her beloved horse, Bob. “He’s a really good horse and I’m lucky that he’ll run as good for me as he’ll run for my sister, who isn’t paralysed – that’s just the sort of horse he is,” she says.

Together, they’ve won three barrel racing titles – and that’s competing against people without spinal cord damage. “I don’t get any favours,” she laughs.

Kristy got Bob six months after she got hurt. Twelve months after her injury another beautiful boy came into her life: her son, Nash.

“My husband, Dale and I were worried about the possibility of having kids as we didn’t know whether my injury would affect our chances, but I was lucky enough to fall pregnant just a year after my fall,” reflects Kristy.

Dale and Kristy met at a racetrack in 2007, were married in 2009, and live on their 100-acre farm in Yalangur, about 15 minutes outside of Toowoomba. Dale is a horse trainer, and they have a small stable where he trains the horses in their care.

“I’ve got a four-wheel-drive electric wheelchair that I use around the farm – I’ve actually got two of them because they are so good and I’m lost without them,” says Kristy.

“I’ve also got a little foldable power chair which is good to take shopping, and a Kia Carnival that’s fully modified so I can take any chair I want without having to pull it apart. It’s probably one of the best things in my life, because it lets me be really independent.” ➤



Kristy with her beloved Bob

The farm is not only home to horses but also a small herd of the tiniest, sweetest mini cattle imaginable. It's all thanks to Nash, who's now eight years old. "He's a great little horse rider but he's also really into mini bull riding and competes in the 7-11 age group. He gives everything a go – he's a little bit like me, he doesn't know fear," laughs Kristy.

"Thankfully he's not quite as mad as me – being paralysed and riding with a seatbelt is probably a bit extreme! But at the end of the day, it's something that I enjoy doing so I take that risk. I think I'm as good a rider now as I was before my injury," she says.

Another injury, caused by a bucking horse in 2020, left Kristy with a broken wrist and a cracked sternum. "They screwed and pinned my arm, and told me not to put any pressure on it," she says. "It was a pretty hard time because being in a wheelchair you need both arms to wheel, plus I couldn't do transfers. It slowed me up a bit for a few months and made me realise I've got to be a bit more careful than someone who's not paralysed."

Luckily, she can rely on the exceptional Bob for a safe ride. "Of all the horses he's by far the best. He never bucks, and I'm so lucky that even though he's 15 now, he doesn't have any

## A barrel of fun

Kristy's tips for anyone with a spinal cord injury wanting to give barrel racing a go:

- It's not for everyone, but it's so good!
- It's also very challenging and is probably best suited to people who were into horses before their injury and want to get back into riding
- It costs a lot of money! Among other things, you have to find a horse that won't spook, and get a saddle made for your specific requirements
- Barrel racing suits people with good balance and a little bit of core strength: the lower the injury, the better. I'm able to ride and be competitive as long as I have my seatbelt on. If I've got even a little bit of movement, my balance isn't there
- That said, I have a friend who's a C5 and 6, and she does power reining (guiding her horse through a precise pattern of circles, spins and stops), so there are also options for people with quadriplegia who love horses

issues. Hopefully I'll be able to ride him for a few more years. He's been such a blessing – I don't know if I'll ever get another one like him."

In the meantime, *another* beautiful boy has joined the clan. "Nash has been begging us for a baby brother ever since he was a little boy," says Kristy. His wish was granted when Dale and Kristy's new son, Nova, was born on 16 May this year. He's growing at a rate of knots, and will no doubt be riding before he can walk, too!

Kristy kept riding until she was about six weeks' pregnant, and it didn't take her long to get back on her horse after the birth of Nova, either: "It was about three or four weeks later," she says. "I just wanted to get back on and see if I could still do it. It took me a while to get my groove back, but I'm getting there."

Indeed, in late September when she competed once again in the barrel racing finals, she came in third. Not bad for a new mother with paraplegia! [A](#)

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# Gone fishin'

How a brilliant service in Cairns is helping ardent anglers get back to doing their favourite thing

There's nothing Jason Lettice likes more than fishing.

Growing up in the Hunter Valley, he would regularly go fishing and camping with his friends and family. "Even after my accident, they'd drag me through paddocks in my wheelchair in order to get to creeks and rivers," he says.

The accident happened when Jason was 17 years old and celebrating the end of school; sustaining quadriplegia in a 33-foot fall from a bridge.

Jason's life changed dramatically over the following years, yet he managed to turn things around, first with the support of his sister in Ipswich, before relocating to Cairns to live with his brother and nephews.

It proved to be a very wise move. Not only does the tropical weather really agree with Jason, but living in such a renowned fishing destination has also opened up a world of experiences for the avid angler.

"For a while there I was doing a lot of fishing by myself," he says. "I don't have a 'normal' schedule, so I'd get up at 2am and head down to the Esplanade in my power wheelchair to drop a line off the pier. Part of my quadriplegia is that I don't have any finger movement: my hands literally do not work. So once I lost my bait I'd have to wait for someone to walk

past and help me out – and there aren't many people walking around at two o'clock in the morning!"

But then, about two years ago, Spinal Life Supports Coordinator Alice Schiller introduced Jason to Lindsay Payne from Disability Support & Tours Queensland, and the rest is history.

"Lindsay takes people fishing, bush walking, camping and all sorts of things," explains Jason. "But if I'm with him, we've got to have a line in the water, that's all there is to it."

Where they go all depends on the weather: "I'm happy to fish anywhere that's not on a pier or a jetty – I've done too much of that in my life," he says. "So if it's rough, we'll do a bit of land-based fishing. If not, I'm definitely on that boat. We're so lucky here in Cairns, everything's in our backyard. We live in paradise up here."

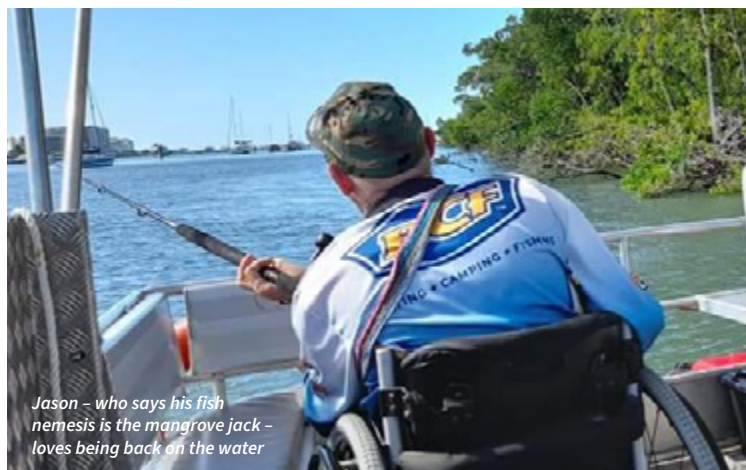
After a full day's fishing, Jason's driven home – but the service doesn't stop there. "If I've caught anything they'll fillet it for me and even cook it for me, so I get to eat the freshest fish straight out of the ocean," he says. "Sometimes they'll even cook fish right on the beach."

Everything is covered by Jason's NDIS plan, which he started receiving about four years ago.





Jason's great catch at the barramundi farm near Cairns, held by his nephew, Trent



Jason – who says his fish nemesis is the mangrove jack – loves being back on the water

"I never had any support until the NDIS," he says. "It's the best thing that ever happened; it's brilliant."

A few of Jason's neighbours also go fishing with Disability Support & Tours Queensland, and he loves talking to them about their own adventures and seeing the expressions on their faces. "They just light up," says Jason. "I guess my face looks just the same when I talk about it, too!"

Seeing expressions like this is a daily perk for Lindsay, who started Disability Support & Tours Queensland after 20 years working in healthcare, including a decade in the disability sector. It was his interest in this, combined with his love of the outdoors, that prompted Lindsay and his wife Emery to pack up, sell up, and move to Cairns.

"We'd been living on Kangaroo Island for three years and I didn't want to go back to Adelaide, where I'd lived for 30 years before that," says Lindsay. "So we sold our house and invested all our savings into starting this idea up – including importing a very expensive four-wheel drive wheelchair bus from Japan. And for the first eight weeks I didn't even get a single phone call. I was really starting to wonder, what have I done here?"

But then a guy called Steve rang, and everything changed. "We started taking Steve, who has quadriplegia, out one day a week," says Lindsay. "We explored *everywhere*: you name it, we went there. From there, I got another phone call, and then another one. Fast-forward to now, two years later, and we've got five staff and are assisting about 40 participants, with a variety of disabilities, on a regular basis. And Steve still comes out with us every week – our goal is to get him camping again. He misses it so much that he'll even burn wood chips on his stove at home to replicate the smell of a campfire!"

The business idea for Disability Support & Tours Queensland is simple and splendid: to help people with disability get out and enjoy the great outdoors, all against the glorious backdrop of Cairns and Tropical North Queensland. Tours are

customised, based on a person's interests and goals, and everything is funded completely through the NDIS.

"Whatever people want, we'll pretty much make it happen – we don't want any barriers," says Lindsay. "Everything we do is risk-assessed, but to live life you've got to take some risks and we don't want our participants to not get enjoyment out of their life just because they can't take a risk like the rest of us.

"It brings back a bit of normality and gives them the opportunity, just for a few hours, to maybe forget about being in that wheelchair. We do heaps of different activities and travel all over: we've taken participants everywhere from Mission Beach and around Dunk Island, all the way up to Port Douglas and Cape Tribulation in the Daintree Rainforest."

The most popular activity is, of course, fishing. "We go beach fishing, jetty fishing, boat fishing: you name it, we'll take people there to fish," Lindsay says.

"One of our clients, Rob, went out to the Reef recently and caught two tuna. A few weeks before that a couple of my team took him up to Port Douglas and Snapper Island, and he caught himself a coral trout and a red emperor. When they dropped him off at the end of the day he was apparently grinning like the Cheshire Cat!

"We also take people fishing around Double Island, at the local barramundi farm, and of course in the Trinity Inlet here in Cairns. It's a magnificent estuary system that extends for 96 kilometres and is home to lots of different species of fish, including big blue salmon, threadfin, barramundi and mangrove jack.

"Obviously we're up here in croc country, so it's taken a bit of mapping out as to where to take people safely, but we've got some awesome spots where we fish." >



The all-time, four-wheel drive Toyota Regius Ace that Lindsay imported from Japan

As well as transportation, local knowledge and endless enthusiasm, the team also offers an adapter that turns a power wheelchair into a fishing chair and electric reels that will make it a bit easier for anyone who doesn't have the strength to reel in their catch.

They also run respite trips, designed to give participants a bit of a break from their normal routine.

"Spinal Life's Healthy Living Centre in Cairns is a great example of an accommodation option, and we're looking forward to sending clients there in the future," Lindsay says.

"The longest respite trip we've done so far ran for two weeks, when we took a guy all the way from the Daintree down to Mission Beach. It was his first holiday in 20 years and he passed away not long after, so it was absolutely beautiful that he was able to experience it."

Lindsay and his wife Emery are loving living in this patch of paradise, getting to enjoy the great outdoors every day and running their own business, but their greatest reward is being able to help others.

"We can see how much it's changing some people's lives and we're so grateful to be able to do what we're doing," says Emery. [A](#)

For more information, check out the [Facebook page: Disability Support and Tours Queensland](#)



Rob [left] and his epic tuna, held by Lindsay's son and trainee, Kody

## Jason's top fishing tip:

"Just try it once. Get out of your shell and try it. It's almost a guarantee that you'll want to go back."

## Accessible activities in Cairns

Tourism Tropical North Queensland recently published a great itinerary covering two days of accessible activities in Cairns, featuring our very own Spinal Life Healthy Living Centre. The itinerary also includes attractions including the Cairns Aquarium, the Night Markets, the Esplanade Lagoon and more.

All apartments at the Spinal Life Healthy Living Centre in Cairns feature ceiling hoists in the main bedroom, an electric hi-lo bed, height-adjustable benches and shower head, and a smart tablet console to operate the doors, lights, blinds, air conditioning and TV.

Visit [tropicalnorthqueensland.org.au/plan-your-trip/accessible-travel](https://tropicalnorthqueensland.org.au/plan-your-trip/accessible-travel) to plan your next trip.





# WIN a 4-day stay at the Spinal Life Healthy Living Centre

Experience stress-free, accessible accommodation in the heart of Cairns

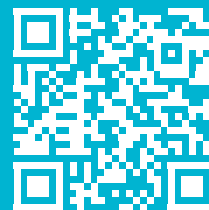
Being away from home doesn't have to be an overwhelming challenge. That's why Coloplast has partnered with Spinal Life Australia to give you the chance to win a trip to tropical Cairns. Take a break from your routine and try new therapies and services, meet new people, and explore the area!

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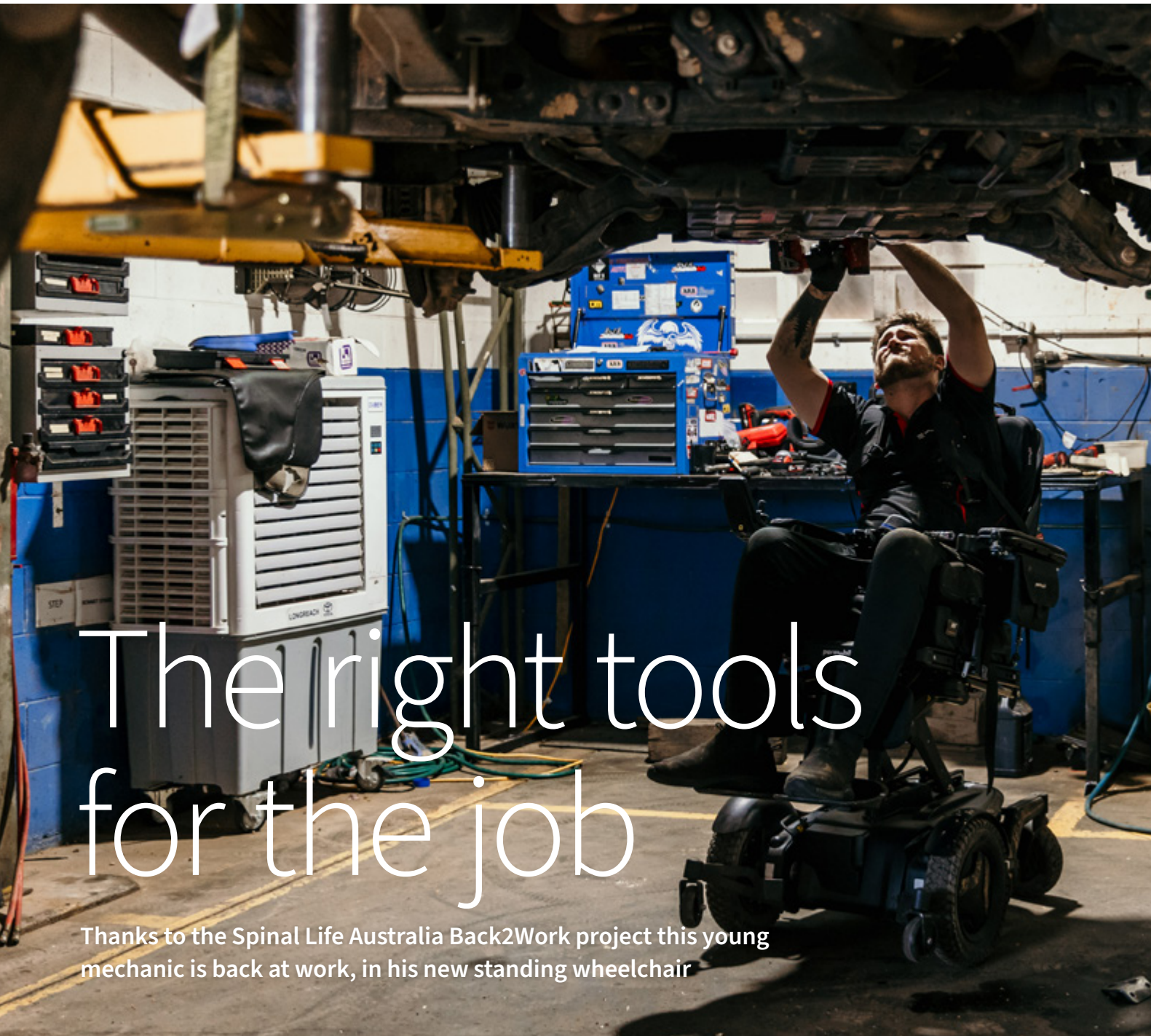


Entries open 12:00AM AEDT 02/10/2022 and close 12:00AM AEDT 08/01/2023. Open to all Australian residents aged 18+ only. Limit one entry per person. Drawn at Coloplast Ltd, ABN 57 054 949 692, Level 4 1 Acacia Place, Notting Hill Victoria 3168 at 12:00 noon AEDT on the 09/01/2023. Winner name published online at [coloplast.to/HealthRetreat](https://coloplast.to/HealthRetreat). The total prize pool is valued at \$2,723.98. Full terms and conditions are available at [coloplast.to/AU\\_TermsandConditions](https://coloplast.to/AU_TermsandConditions). Promoter: Coloplast Ltd, ABN 57 054 949 692, Level 4 1 Acacia Place, Notting Hill, Victoria, 3168. Ph:1800 333 317.

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# The right tools for the job

Thanks to the Spinal Life Australia Back2Work project this young mechanic is back at work, in his new standing wheelchair

*Jacques back on the tools  
at Longreach Toyota*

"I never really knew what I wanted to do with my life," says Jacques Jacobie, 25. "But then when I was 20 I was offered an apprenticeship as a mechanic and thought, why not? Because I didn't want to be sitting behind a desk; I like being hands-on. As long as I'm actively busy with my hands, I'm happy."

Jacques was enjoying his life as a grease monkey when, on one fateful day in mid-2020, he went for a motorbike ride after work.

"I couldn't get hold of any of my friends, so I just went by myself," he says. "But I took a route that I wasn't too familiar with. I forgot that there was a turn and a fence at the end, and just went too fast and ran into it."

He sustained paraplegia in the accident, leading to months of rehabilitation at the Princess Alexandra Hospital's Spinal Injuries Unit (SIU).





“I worked hard at my rehab, especially when it came to wheelchair skills and gym work, just to make life a little bit easier so I could be as independent as possible,” says Jacques. Indeed, he was the 'wheelchair skills' champ at the SIU – he even featured on the brochure!

After the SIU, and six weeks staying in Brisbane as part of the transition from hospital, it was finally time for Jacques to head back home to Longreach.

“My family and friends played a big part in my recovery because they kept me positive and supported me where they could,” he says.

Jacques’s brilliant attitude also played a significant role in his recovery.

“When I first woke up in the hospital, I said to myself, yeah this sucks, but there’s no point just sitting around doing nothing. That’s when I have time to think about things – and when things can start to go downhill,” he says.

“I kind of just kept going after I left the hospital,” he continues. “I didn’t want to be sitting at home all day every day. I had to keep myself busy. I know that the busier I am, the more positive I stay.”

It was lucky, then, that while he was in the SIU, Jacques had met a key member of the Spinal Life Australia Back2Work project, Vocational Rehabilitation Counsellor, Belinda McLeod.

“We just got along right from the start,” says Jacques. “Nothing ever felt forced and I never felt that I *had* to do something. We got to know each other first, instead of just getting straight to the point. She’s helped me so much.”

The admiration is mutual: “He had all this excellent mechanical knowledge and we needed to work out a way to get him back on the tools!” says Belinda.

Pre-injury, Jacques had been working full-time as a mechanic at Longreach Toyota, and while he was initially uncertain how he might be able to return to his job, he was very open to exploring options.

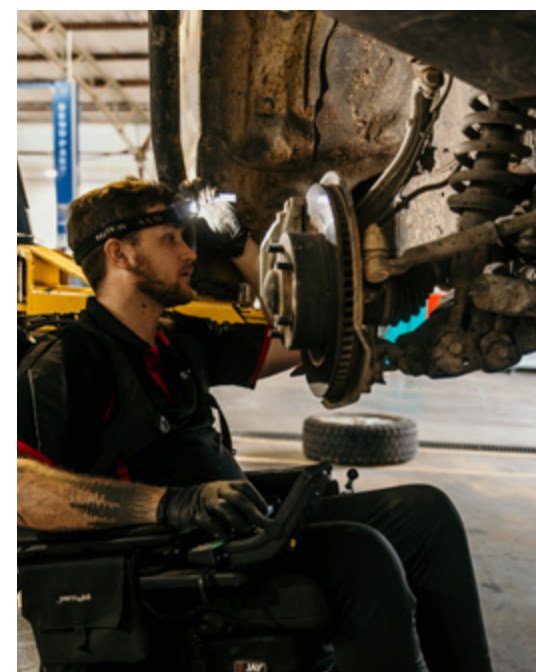
“We identified early that among other equipment, a standing wheelchair would be helpful in addressing some barriers,” says Belinda.

For Jacques, it was a revelation.

“At that stage I didn’t even know that standing wheelchairs *existed*, let alone that Spinal Life could help me out with all the necessary paperwork and the funding,” he says. “If it wasn’t for Belinda’s help, I wouldn’t be where I am right now.”

So where *is* he right now?

Back at Longreach Toyota, as part of a team that includes two other qualified mechanics and an apprentice. ➤





He returned to light duties in January 2021, while waiting for his standing wheelchair. Given that he'd only been discharged from rehab in Brisbane the month before, it was an extraordinary achievement.

His standing chair arrived after Back2Work, on behalf of Jacques, successfully applied to the Australian Government's Employment Assistance Fund, through Job Access, for funding for assistive technology.

Luckily, Jacques's spatial awareness is, in his own typically understated words, "pretty good," and he took to it easily.

"I just feel like I'm such an outdoorsy, hands-on person that when it comes to physical activities I tend to catch on to things quite quickly," he says. "Don't get me wrong, I was working the other day and put a hole in the wall by accident – I'm not perfect, but I'm getting there!"

He uses his standing wheelchair in a variety of positions, including lying back while under a vehicle. "I still have some access issues in the engine bay," he says, "but it's definitely made things a lot easier."

And it's not just high-cost equipment like this that makes a difference. Jacques has been hugely innovative when it comes to finding new ways to do things. Simple things like laser pointers, a modified wheelchair tray and portable air compressors have all made his work day that little bit easier.

"I came up with the idea for the lasers while I was trying to point out something to our apprentice and couldn't

reach," he says. "I bought a cheap laser online and it's been really helpful."

The modified wheelchair tray came about because every time Jacques would go underneath a vehicle, his tools would fall off the tray whenever he changed his angle. "My sister's partner is a qualified welder, so he helped me make a new tray out of metal. Thanks to some strategic welding, nothing can fall off now."

No wonder Jacques has garnered a bit of a reputation as a problem-solver.

"What's impressed us the most is Jacques's willingness to give things a go and come up with his own solutions. His attitude and patience throughout the process has been fantastic," says Belinda.

“I think being a mechanic has helped me to think more outside the box – and not just for work, but for life in general.”

"I just feel like there's always an easier way to do something," Jacques says. "I try to stay open-minded and think, is there another way to do a task? Am I going to struggle the whole time to do it? I think being a mechanic has helped me to think more outside the box – and not just for work, but for life in general."

Jacques is excelling in his job, but credit also has to go to his workplace, which has been incredibly supportive and accommodating regarding his return to work.

"Longreach Toyota has helped out a lot, and in so many different ways," he says. "When I was still in the SIU they came down to see me and brought me Toyota jackets and other merch. They helped me buy some of the equipment to make my job easier, and even gave me a bit of a discount for my car. They've been brilliant and are just continuously helping me as I go. Honestly, I couldn't ask for any better. And they all still treat me the same, which is great!" <sup>A</sup>

Back2Work is a specialist project that provides early intervention vocational rehabilitation to patients in the Princess Alexandra Hospital's Spinal Injuries Unit, funded through the Motor Accident Insurance Commission (MAIC). For more information, go to [spinal.com.au/back2work](https://spinal.com.au/back2work)





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# Keep your cool

Our nursing team shares their tips on regulating your temperature during the warmer months

For people with spinal cord injuries and other neurological conditions, or the late effects of polio, temperature regulation (also known as thermoregulation) can be a constant challenge, particularly in the summer months.

Signals usually sent between the brain and body via the spinal cord are often disrupted, preventing automatic responses that would cool the body down, such as sweating.

Generally, the higher the injury to the spinal cord, the more likely it is that a person will have issues with regulating their temperature, in both heat and cold. Having a complete spinal cord injury also makes a difference, as there is more disruption to the signals between the brain and body.

Here are a few strategies from our nursing team on how to stay cool this summer, if you haven't tried them already.

## Top tips

### Hydrate

Drink plenty of water and stay hydrated.

### Shelter

Don't stay out too long in hot weather and stay in the shade as much as possible – and try to plan outdoor activities early in the morning or late in the afternoon/evening.

### Dress

Wear loose, breathable and light (both in weight and colour) clothing whenever you're outdoors, plus a hat of course.

### Wrap

Use ice vests, wet towels or gel packs straight from the freezer by draping them around your neck when you need to cool down. There are also options like cooling bands and ice neck wraps.

### Mist

Have a spray bottle filled with cold water in the fridge to create a cooling mist – if it's too humid, use it in front of a fan or any natural breezes.

### Freeze

Supermarkets are a great place to quickly cool down, especially the freezer section! If you're outdoors, keep an eye on where you can find air-conditioning nearby if you need it.

### Precool

If you know you're going to be active in the heat for a long period of time, try lowering your core temperature before heading out – by taking a cold shower, drinking something ice-cold or sitting in an air-conditioned room with the temperature on low. [A](#)

Visit [spinal.com.au/nursing](https://spinal.com.au/nursing) to find out more about our Community Nursing service and how we can support your health and wellbeing. Telehealth consultations are available.



# Getting ready for storm season

As we move further into summer, it's important to ensure you are prepared in the event of an emergency, including storms, cyclones or bushfires.

Below are some resources that you can use to plan ahead, just in case:

- The 'Get Ready Queensland' website ([getready.qld.gov.au](http://getready.qld.gov.au)) has a range of resources available, including fact sheets and templates for putting together an emergency kit, planning with your neighbours, preparing your home and staying informed during a disaster. In Western Australia, you can also visit the Emergency WA website ([emergency.wa.gov.au](http://emergency.wa.gov.au)) for tips.
- The Australian Red Cross also has a RediPlan template ([redcross.org.au/prepare](http://redcross.org.au/prepare)) which you can complete to have all your information in the one place, including contacts, evacuation options, details on your medical conditions or disability, insurance and more.
- The Bureau of Meteorology ([bom.gov.au](http://bom.gov.au)) provides information on cyclone, flood and storm activity, and will keep you up to date on any evacuations in your area.

We are contacting all Personal Support and Home Care Services customers to ensure your emergency plan is up to date, which covers what to do if your services are disrupted and whether you have access to any additional assistance. [A](#)

Visit [spinal.com.au/stormready](http://spinal.com.au/stormready) for more tips.

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## A WOMAN'S RIGHT TO SHOES

How advocacy helped a polio survivor gain access to funding

Fiji in the 1950s might sound like an idyllic time and place to spend your childhood, but for Tai Florian (*pictured*), it was tough going. At the age of three she contracted polio, a virus that attacks the muscles and causes muscle wastage and nerve damage.

"It affected my right leg, so I used to wear a calliper when I was at primary school," remembers Tai. "The other kids were very cruel and would trip me up, so when I was about nine or 10, I ditched it."

She managed brilliantly without the calliper, and would wear trousers all the time so most people never even realised she had polio. At age 28, with a husband and a seven-year-old son in tow, Tai moved to Australia where two daughters were subsequently added to the clan.

Tai lived in Coffs Harbour for many years, before first heading to Hervey Bay for work, and then making the move to Toowoomba with her new husband, Max, earlier this year.

While she cherishes her new home, things have definitely been changing for Tai in recent times.

"Until recently, I've managed to live a 'normal' life. I could walk unaided most of the time, and really only started using crutches in the last two years," says Tai.

"Before, whenever I heard people talk about post polio syndrome, I'd think, 'I'm so lucky I don't have any of those aches and pains'. But now, not only do I feel ancient, I also have all these new medical experiences. I get terrible backaches and headaches, pain in my hips and my right knee, and thermoregulation issues that mean I really feel the cold and the heat."

Tai's limp is also more profound these days. "Thanks to polio, my left foot is a size nine, but my right foot is only a size five," she explains. "Over the years, to compensate for the difference in size, my right foot has formed a sort of 'high heel'. But the bone is now very close to the surface and I have to wear shoes every minute of the day, except when I shower and sleep. It's very painful."

For Tai, who's just turned 67, coming to terms with the effects of post polio syndrome has been a challenge. But it's nothing like the challenge she initially experienced when applying for the NDIS.



"Years ago, when I was still living in Coffs Harbour, my doctor said to me, 'Tai, polio is a permanent disability. It's never going to be cured, it just gets worse. You're getting older and you're going to need some support. You need to apply for the NDIS, because once you turn 65 you won't be eligible.'"

So they filled in the forms and sent in all the necessary information... only for the NDIS to reject Tai, on the grounds that, "you do not meet the access requirements".

Then, after she moved to Hervey Bay, Tai met a physiotherapist who again encouraged her to apply for the NDIS. When she informed him she had already tried, he advised her to seek advocacy support.

And so Tai rang Spinal Life Australia.

"They worked on my new application before it was sent to the NDIS and edited it down to a clearly worded brief document that my GP was happy to sign off on," says Tai. "I think it might have been the smallest application in history – and it worked! I was accepted into a self-managed plan, just five months before I turned 65. It was just amazing and I was so grateful."

But when her second year on the NDIS came around, everything went pear-shaped when she received her new plan and it wasn't the same as before.

"The assessor had changed it from self-funded to plan-managed, saying that I was at risk of spending money on unnecessary stuff," says Tai. "They also said that the NDIS was not going to cover my shoes, as they weren't a 'necessary and reasonable' item, and 'everybody wears shoes'. But not many people have to buy two pairs of shoes at a time, in two different sizes, and then throw away the spares!"




A plan needs to have been in action for three months before an appeal can be lodged to have it reviewed, so 90 days later Tai did exactly that. After a couple more months, she was shocked to discover that while she'd heard nothing, her Local Area Coordinator had received a letter stating that a review had already been done and the new plan would stand; nothing was changing. The *coup de grâce*? Tai had 21 days in which to respond – and that time that had long since lapsed. “I was ropeable,” says Tai. “And that's when I spoke with Spinal Life Australia again.”

They opened a case with the Administrative Appeals Tribunal (AAT) and offered to guide her through the process.

“I just wanted to be self-funded, and to get some shoes,” says Tai. “That's all I wanted. But Spinal Life said I should also think about Supports Coordination as I'd just moved to a new area. And thanks to their help, after six months of stress, a mound of paperwork and three case conferences on the phone, the AAT awarded me everything we'd requested.”

So after all this, what was the difference in Tai's funding from the previous year? Just \$7,000. “That included \$500 for my shoes, plus funding for the Supports Coordinator – everything else was pretty much the same as the previous year,” she says. “All the lawyers and countless hours and fuss for just \$7,000. I'd love to know how much my court case actually cost and how much the solicitors made – solicitors employed by the government. I would imagine six or seven times this amount at least. It just seems like such an unnecessary waste.”

Tai is, however, incredibly grateful for the funding she gets from the NDIS: “It's a good system, with support services that really help you, and people that are so lovely,” she says, “but ultimately you are in a system, and I just couldn't fight it anymore. If it wasn't for Spinal Life Australia, I would have walked away because they absolutely drained me. I'm a pretty resilient person, but they wore me down. I'm so grateful to Spinal Life – it's a wonderful organisation that really helped me get results. I feel like I've accomplished something. I was *heard*.” 

## Tai's advice to people needing help with the NDIS

- If you feel there's an unfair change in your plan, you've got to fight
- Make sure you have a good advocate; someone who really understands the system
- Provide them with comprehensive information about your case
- Be aware that the NDIS is going to question you, and maybe even make you feel like they doubt your disability
- Make sure you're strong enough to go through the entire process, because it's not easy – after all, you're fighting the government!

## The late effects of polio

Polio survivors can experience symptoms decades after their initial recovery, known as the late effects of polio or post polio syndrome. These symptoms include:

- Increased fatigue
- Muscle weakness
- Joint pain
- Increased sensitivity to cold
- Difficulties with swallowing and sleeping

They're often mistaken as a sign of ageing by medical professionals, so it's vital that you discuss your history with your doctor.

Spinal Life provides a range of resources for polio survivors and is also working to educate GPs about the condition, aiming to increase their knowledge so they can provide better diagnoses and treatment.

For more information visit [spinal.com.au/polio](http://spinal.com.au/polio)



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# A stunning debut

**How writing about his extraordinary life as a globe-trotting athlete – and the accident that ended his career – helped Brad Smeele make peace with his new life**

In 2014, Brad Smeele was living the dream. The then-27-year-old professional wakeboarder was at the top of his game: winning world titles, travelling the globe and loving life as a thrill-seeking adrenaline junkie and part-time model.

He'd spent the previous decade "chasing the summers" – dividing his time between Florida and his home country of New Zealand, and competing in Europe, Australia and Asia in between.

He was finally granted a five-year working visa that would let him stay in Florida permanently... but then just four months later had the accident that would change his life.

Brad was practising a wakeboard trick that he'd pioneered – a ramp-to-ramp double backflip, with a 180-degree rotation and backwards landing – when it all went catastrophically wrong. "Usually if you fall you're just behind the boat and you crash into water," he says. "But I went head-first onto a ramp." His C4 vertebrae was shattered, and he was paralysed in all four limbs.

For someone who was such a physical person, the diagnosis of quadriplegia was a bitter pill to swallow. It led to an extraordinary journey that Brad has documented in his debut book, *Owning It: The Ride That Changed My Life*, which was released in August this year. We spoke to Brad from his home in New Zealand, to discuss being a first-time author, how he tapped out half a million words using his mouth, and why merely accepting his new life just wasn't enough.

*Brad with his best friend, Jesse James, on the last day of a "100 days of standing" challenge in 2019. To celebrate, Brad did his final stand at the top of Auckland's Mt Victoria – after his tilt table had been carted all the way to the top!*



## What inspired you to write your memoir?

"If I had to sum it up in as few words as possible, it was that I wanted to help people learn what I've learned, without having to go through what I've been through. I started writing before I even knew where my journey was going: I'd pictured it ending with me walking again. I was very determined to get there, and coming to terms with not regaining movement ended up being a huge part of the book.



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It became part of my healing journey. But that's not why I wrote it; I just wanted to tell my story. I had an amazing teacher, a kinesiologist called Suzie, who sort of became my life coach. A lot of what I was learning from her – about the connection between emotion and how it impacts the body, and vice versa – was blowing my mind. I wanted to share it, because I realised that none of it was exclusive to being in a wheelchair."

### Can you describe your writing process?

"My writing process was: 'I don't know what the hell I'm doing, so I'm going to put my whole story down on paper, and I'll let the editor decide what gets cut and what stays in!'. Thanks to the recommendation of a friend, I got a publisher when I was about halfway through – which was lucky, because I ended up writing half a million words [most published books are only about 80,000 words]. I didn't have any experience with how to plan and shape and structure a book, so I needed lots of help, but the amazing thing I discovered is that I'm actually quite good at writing. When it came to actually getting the words down I tried a few different options, but I ended up using a lightweight stylus in my mouth which I used to point at letters on a screen and type into a Word document on my phone."

### How long did it take to complete, from start to finish?

"About six years, from when I started writing until the day it came out. That included about a year to edit and proofread it. The proofreading stage was the toughest for me. When I read the sections about my life before the accident I'd have tears streaming from my eyes. I wrote it from a first person, present tense angle, so it's from the perspective of me at that time, not of me now. So it meant I had to really put myself in that time. But, as I discovered, the more time we spend in the past, the more we drive ourselves into a depressive state. So writing about that time was also really tough, but it was also great because it helped me to break down all the things I was struggling with."

### How did you feel about the book being published?

"I was a bit nervous because I really put my whole story out there. It's very raw and very real – I haven't left much out! I also worried that I'd left myself open to be judged. But then I thought, this is my life, this is the truth, I'm confident in

who I am and I know that I'm a good person, so if people want to judge me, that's up to them. As one person said to me: 'you can't write a book for everyone'. And that's what it came down to. The people who will enjoy my book will really enjoy it, but there might be others who turn their noses up at certain things, such as the amount of sex I've written about. People are intrigued about sex post-injury, so I felt I needed to include the full story of what my life was like before my accident, so that they could get a feel for how it changed and how much it affected me."

### What do you hope readers will take away from the book?

"I think most of all just how powerful acceptance can be. I've actually taken things a step further, like the title of my book says: 'Owning It'. Rather than just accepting things I've decided to own every part of who I am and what my life is. It's quite an empowering feeling as opposed to acceptance, which feels a little submissive."

### What has the response to your book been like?

"Amazing. I've been getting loads of compliments from people saying that they couldn't put it down, that it was captivating and such an easy read, and things like that. For someone who had no experience and really had no right to be an author, to get that sort of feedback is really cool. I've also had a lot of messages from people telling me how they really connected with the learnings I shared, and how they feel like they can apply them to their life. Those responses are exactly why I was so vulnerable and open, and really put myself out there."

### What are you most excited about, looking to the future?

"I've been convinced that I should write another book... but I'm not going to spend six years on the next one! I've just started as a peer support worker for Spinal Support New Zealand and the idea of being able to help in some way to make a person's journey less daunting is really rewarding. I'm also really excited about my next project, which relates to my new passion for freediving, and is going to help me get in front of more people and spread my message further. [A](#)

*Owning It: The Ride That Changed My Life* (Allen & Unwin), is out now. Follow Brad on Instagram [@bradsmeele](#)



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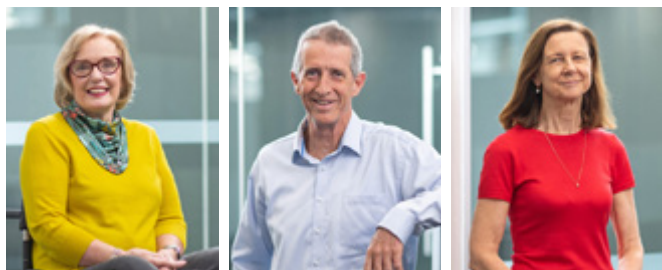
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# Votes pave the way for success



At this year's Annual General Meeting (AGM), held on Monday 14 November, members voted to have their say on our organisation's future.

Three existing Board members were re-elected to their positions for another term: Chair Gyl Stacey and Directors Gerard O'Brien and Michelle Wilson.

At the AGM, members also approved proposed changes to the Constitution that will further strengthen Spinal Life's Board by creating two new definitions for Directors – Elected Directors and Appointed Directors.

## So, what do these new definitions mean?

Elected Directors will continue to make up the majority of the Board, to share their lived experience with spinal cord damage (which may include immediate family members), giving valuable insight to inform discussions and decision-making. Members will vote to elect these Directors at each AGM.

Appointed Directors will be chosen by the Board when required, after searching for candidates with specific knowledge and skills that may be needed. The search will be based on a wide-ranging skills audit of the Board, recommended by the Australian Institute of Company Directors.

Visit [spinal.com.au/agm2022](https://spinal.com.au/agm2022) for more frequently asked questions.



## CATCH UP WITH YOUR COMMUNITY

Our Peer Support catch-ups are held across Queensland and Western Australia. Keep an eye on Facebook and our website for updates on upcoming events.

If you'd like to connect with our Peer Support, Post Polio or Transverse Myelitis Groups in your region, please use the contact details below.

### Spinal Life Peer Support Groups

**BRIBIE ISLAND:** Ross Duncan on 0475 077 080.  
Combined with Post Polio group.

**BRISBANE:** Fred Nitz on 0412 190 585.

**BUNDABERG:** Steve Richter on 0413 457 284.

**MACKAY:** Debra Reaves on 0487 021 735.

**MORETON BAY:** Ross Duncan on 0475 077 080.

**ROCKHAMPTON:** Robynne Clifton on 0473 576 107  
or Anne Guthrie on 0407 116 035.

### Post Polio Groups

**CAIRNS:** Joy Hay on 4055 5795.

**GOLD COAST:** Lyn Glover on 0448 206 856  
or Joan Radanovic on 0413 178 073.

**SUNSHINE COAST:** Cathy Newman on 5447 6608.

### Transverse Myelitis Group

Contact Jodi Gallon on 0451 235 860.

Join our community today at [spinal.com.au/membership](https://spinal.com.au/membership) or call 1300 774 625 to find out more.



## Tourism reviews open up travel opportunities

Reviews of tourist hotspots in Western Australia have made it easier for travellers with disabilities to plan their next adventure.

The accessibility reviews were undertaken in Mandurah, Rockingham and Geraldton to give insight into the accessible tourism options in each region and provide feedback to operators, local councils and regional tourism organisations.

The information has also been added to Spinal Life Australia's Accessible Australia app, a free online resource for people with disabilities to read and share first-hand experiences of the places they visit.

Spinal Life's Community Advocacy Officer, Karen Harvey (*pictured*), has conducted reviews of tourist destinations, cafés, accommodation and more.

She says being more inclusive is not just about physical accessibility, and often the first step is to improve attitudes and increase understanding of what it means to have a disability.

"I know what it's like to spend hours, if not days, researching destinations, which is why having comprehensive, accurate information regarding the accessibility of a particular location is essential, to know exactly what to expect," she says.

"The accessible tourism reviews of Mandurah, Rockingham and Geraldton aimed to identify, review and promote accessible tourism offerings that already exist in these regions. Through our efforts, we aimed to help educate tourism operators and small businesses on the steps they could take to improve accessibility for those living with disabilities.

"The reviews have revealed that these local councils have done a great job at improving accessibility in each region, with effort put in to make not only tourist experiences more accessible for people living with disabilities, but also public spaces such as beaches and parks."

Karen is encouraging more councils and tourism operators nationwide to follow suit, by reviewing and enhancing their accessibility efforts for travellers with a disability.

Spinal Life has also conducted accessibility reviews in other tourism hotspots around Australia, including in Cairns, Mackay and the Sunshine Coast, in partnership with councils, tourism organisations and partner agencies.

Visit [accessibleaustralia.com.au](https://accessibleaustralia.com.au) to read first-hand reviews and experiences.



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# CPR train-ing...

## How a young Spinal Life staff member saved someone's life on a train

When Alanah Dunstan caught a train into work on 22 September, she had totally forgotten that it was a public holiday.

The 18-year-old had just started working as an Administration Officer at Spinal Life's Perth office. When she realised the office was closed for the National Day of Mourning for the late Queen Elizabeth II, she quickly made plans to spend the day with her boyfriend.

As she was racing to catch a train to meet him, a man ran past her on the station platform: Alanah would later discover he was 45-year-old Colombian Gustavo Berna, who had only arrived in Australia three months earlier.

"I wasn't even supposed to be on that train, and it was pure coincidence that I got on the same carriage and sat down across from Gustavo," she says. "I thought he maybe had asthma because he was gasping and really struggling to breathe. But then, about two stations along, he collapsed and fell to the floor, onto his face."

Alanah initially thought he was having a seizure, but quickly realised it was a heart attack. Taking charge of the situation, Alanah had someone alert the train driver, and another person call triple zero. When Gustavo's faint pulse disappeared she began CPR, using the skills and knowledge she'd acquired when obtaining her first aid qualifications the previous year.

Thanks to the train driver they were soon reversing at breakneck speed, heading back to the city centre where an ambulance met them and the paramedics took over.

"I was hysterical at that point," says Alanah. "I'd given CPR to Gustavo for 15 minutes and he still had no pulse. In my head I was convinced he was dead."



Later, Alanah was informed that Gustavo had been taken to the intensive care unit at a nearby hospital, but it took about a week for her to learn the full story. Thanks to the wonders of social media, she was put in touch with Gustavo's sister-in-law, Nicola, and then his twin brother, Victor, who has lived in Australia for 16 years.

"The doctors had told Victor to prepare for one of three outcomes: that Gustavo would die within 48 hours while still in an induced coma; that he would die a little later, once they took him off the machines helping him to breathe; or that he would wake up, but be severely brain damaged," says Alanah.

But Gustavo regained consciousness and is perfectly fine. He's had five stents inserted into his heart, but in what seems like another miracle there are zero signs of brain damage.

The incredible story attracted a huge amount of media interest, with more than 40 different news outlets publishing the story in Australia and around the world.

However, the beautiful postscript to this extraordinary tale has only happened recently, when Alanah, accompanied by her boyfriend, parents and grandparents, headed to a brewery in Fremantle to meet up with Gustavo and his Australian-based family.

"It was so lovely," says Alanah. "We all hugged, and I really feel like they're a part of my family now. Victor told me that he's going to get a tattoo on his arm of my name with angel wings, and my grandmother has even invited them all around for a roast dinner!"

After such a profound experience, Alanah says she is thinking about studying nursing in the future – and continuing to work as part of the Spinal Life team. [A](#)





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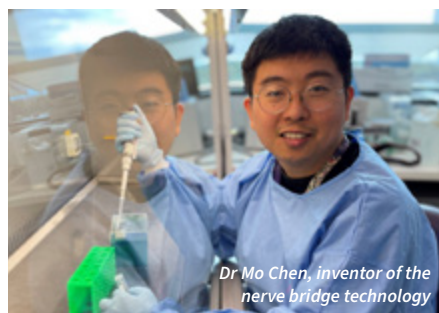
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# The latest

Information, inspiration and inclusivity



## CLINICAL TRIAL ON THE WAY FOR SPINAL INJURY PROJECT

Queensland researchers are preparing for human clinical trials to test a groundbreaking therapy that transplants cells from the nose into the spinal cord to repair the nerves.

The Spinal Injury Project team, from the Clem Jones Centre for Neurobiology and Stem Cell Research at Griffith University, involves more than 35 engineers, medical doctors, biological scientists and educators.

They're building on research that has been conducted over the past 25 years around the world and are now closer than ever to success, thanks to advances in technology and discoveries about biology.

### What is this therapy?

The therapy uses the patient's own cells from the very top of their nasal cavity, which are called Olfactory Ensheathing Cells, or OECs for short. The cells are the supporting cells of the olfactory (sense of smell) nerve that help the nerve cells to grow and repair. They have a range of exceptional properties that make them particularly suitable for repairing other regions of the nervous system including the spinal cord.

In 2002, the use of OECs for treating spinal cord injury was shown to be safe in a clinical trial in Queensland led by the 2017 Australian of the Year Professor Emeritus Alan Mackay-Sim. Since then, other research teams around the world have continued to test and improve the therapy. However, while the therapy has shown promising results in some studies, the outcomes have been inconsistent over the years.

Thanks to major funding support from the Motor Accident Insurance Commission, the Clem Jones Foundation and the Perry Cross Spinal Research Foundation, in 2017 the Griffith University team embarked on targeted translational research to solve the problems of the therapy and to make it more effective.

The team has been successful in creating a world-first technology that can be summed up in just two words: nerve bridge. These nerve bridges are built with OECs and have

made the therapy better, safer, more effective, and more clinically relevant. The team has extensively tested the olfactory nerve bridge therapy in the lab and in pre-clinical models and they are now ready to take the improved therapy to clinical trial.

### Nerve bridge plus rehabilitation = maximum effect

While repairing the injury site is essential to start the regeneration process, the team has realised that rehabilitation and physical activity is also essential to drive effective repair. Once the nerve cells have grown across the injury site, the body needs to be stimulated through rehabilitation activities so that the nerve cells know they are making the right connections to activate the various motor, sensory and autonomic processes.

How much rehabilitation is needed and how much can people cope with? The Griffith University team has just completed a clinical trial to test a program of intensive rehabilitation in which five people underwent six months of rehabilitation. The results are pending, with a second trial about to start to test some other aspects of the rehabilitation program.

### What's next?

With these encouraging results, the Griffith University team is now planning for the next stage – the full cell transplantation plus rehabilitation trial. This trial will be conducted in Queensland and will test the nerve bridge transplantation therapy.

As part of this planning process, the team is conducting a survey of the spinal injury community to find out people's attitudes to cell transplantation therapies and whether they would be interested in receiving a nerve bridge transplantation treatment. The survey will help the team determine what support people would like before they would volunteer for the clinical trial. [A](#)

Visit [pcsr.org.au/spinal-cord-community-survey](https://pcsr.org.au/spinal-cord-community-survey) to share your thoughts or [griffith.edu.au/clem-jones-centre](https://griffith.edu.au/clem-jones-centre) to find out more.



## SEEN A PROBLEM? SNAP IT!

Snap Send Solve is a handy app used by our Advocacy team and members, to report hazards and accessibility issues to their local Council.

This includes things like trees, footpath problems, dumped rubbish, broken streetlights, water faults or any other areas of concern in the community.

The free app allows you to take a photo of the offending hazard or issue and send it directly to the relevant council to investigate, and we often hear positive feedback on the outcomes.

You can find Snap Send Solve on the App Store and Google Play. [A](#)

## MAKING LIVE MUSIC ACCESSIBLE

We were proud to support this year's Valley Fiesta in Brisbane and the first ever Access All Areas Stage, with a free event held on Saturday 26 November.

The event featured Auslan interpreters and a wheelchair lift to access the stage area, aiming to make live music more inclusive for everyone. We hope that this will also encourage other venues to make their events more accessible too!

Our very own Tim McCallum (*pictured*) also took part in the festival program, sharing his vocal talents at a VIP event.

Valley Fiesta is a three-day celebration of music, culture and community, presented by Brisbane City Council and produced by QMusic Network. [A](#)



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## ON THE ROAD AGAIN

**After a fundraising trip through Queensland, this Spinal Life superstar is planning to travel around the entire country**

The Last Word this issue goes to Bevan Kearsley who, a few years ago, came up with the idea of raising money for spinal cord injury research by taking off on a round-Australia trip... on a 150cc modified wheelchair scooter.

When the 2019/20 bushfires and then pandemic-inspired lockdowns delayed his plans for a nationwide adventure, Bevan decided to travel around Queensland instead – and so last year took his wheelchair scooter on a three-week trip around the state, visiting Mackay, Cairns, Mount Isa, Winton and Charleville, before returning home to Brisbane.

Now that things are “back to normal,” Bevan is gearing up to finally take his long-awaited journey around Australia, again on his specially adapted scooter, which he’s able to manoeuvre onto directly in his wheelchair via a ramp, without the need for transferring.

He’s always loved bikes, even after sustaining paraplegia in an accident on a motorbike 29 years ago.

But nothing could stop this qualified chippy who, following his injury, started a small business selling building supplies. Earlier this year, Spinal Life pulled him out of early retirement in order to take up a position on

the Advocacy team, consulting on accessibility issues. He’s also studying to receive accessibility qualifications and is set to finish his Certificate 4 in Access Consulting next year – hopefully before he sets off on his Australian odyssey!

### **How’s your itinerary looking?**

“I’m hoping we’ll depart in April next year and be on the road for around 66 days. We’ll travel south before it gets too cold, and then across to Perth before heading to Broome, Darwin and Uluru. By that time it should be winter – I don’t want to be up there when it’s too hot! One place I’d really like to see is Kakadu.”

### **Who will travel with you?**

“Unfortunately my support team from the Queensland trip can’t make it this time, so I’ve got to find a new crew – someone to handle the social media side of things, and someone to drive the support vehicle. It’s a wheelchair-accessible campervan that I built myself.”

### **What were the biggest challenges on your Queensland trip?**

“The bike broke down once, just outside of Mount Isa, but we were able to get it fixed pretty quickly. The biggest challenge was dealing with ‘accessible’ caravan parks that really weren’t.

One had just spent \$30,000 making a bathroom ‘accessible’ but the vanity bench was about a foot higher than it should have been, there wasn’t enough room next to the toilet to allow for transfers, and they didn’t have a fold-down seat in the shower. This is where Spinal Life’s Advocacy team can help – we can provide advice to businesses and share our own experiences, so there’s no confusion and things can be done right, the first time.”

### **What are your goals on this trip?**

“I’m hoping to raise \$100,000 for spinal cord injury research, and to influence more businesses to consider people with disability as customers. I also want to do a lot more wheelchair-friendly activities to really raise awareness of inclusive tourism. Just like on my Queensland trip, I’ll be uploading reviews and photos of these experiences and the places I visit to Accessible Australia [Spinal Life Australia’s free online resource]. By mapping Australia like this I hope to be able to help other people living with a disability to be able to travel and explore more.” **A**

For more information, visit [accessibleaustraliaride.org.au](http://accessibleaustraliaride.org.au) or follow Bevan’s journey on Facebook.



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