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THE ADVOCATE IS THE OFFICIAL **PUBLICATION OF** 



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Cover photo: Paralympics Australia

#### **FROM THE CEO**

Have your voice heard in 2021



Welcome to the winter edition of The Advocate.

To celebrate the Tokyo Paralympics, we hope you enjoy our special sports focus, including interviews with two incredible wheelchair rugby players. Four-time Paralympian, Ryan Scott (page 6), reflected on past Games and gold-medal glory, while Michael Ozanne told us what it means to him to take part in his first Paralympics (page 8). We'll be supporting all of the Aussies at this fantastic event, but the fact that Michael is a Spinal Life member will make watching the wheelchair rugby even more exciting than usual. Good luck, Michael, we're behind you all the way!

On the advocacy front, our efforts have kicked into a new gear since last issue. Working alongside other organisations from the age and disability sectors, we've been successful in securing changes to the National Construction

Code. It means that, from 2022, all new buildings will be required to meet the silver standard for accessibility. You can read more about this big win on page 23 - and stay tuned as we continue to strive for the Gold standard just like in the Olympics.

We've also kicked off our campaign to support our over-65 members who are dealing with significant disparities in funding compared with those who are eligible for the NDIS. We've been engaged at most senior levels of government on this important issue, and have designed and funded the campaign to put maximum pressure on government to give better support to our over 65s. Visit DisabilityDoesntDiscriminate.com.au to sign the petition.

Finally, we extend a huge welcome to two new Board Directors, Dr Dinesh Palipana and Rebecca Tweedy. You can read more about them in the 'Message from our Chair', Gyl Stacey, on page 27. Their appointments further enhance the Board's mix of skills and experience and we look forward to their contribution to the organisation over the years ahead.

Until next time, I hope you enjoy this issue of The Advocate - and supporting our athletes at the Paralympics. C'mon Aussies!

MARK TOWNEND

# Do you have a story to share?

Email us at theadvocate@spinal.com.au - we'd love to hear from you!









Our new Accessible Australia app features reviews of a brilliant program that lets you experience the joys of sailing, whatever your ability

Imagine... the freedom and adventure of heading out on the waters of a beautiful bay, on a boat driven entirely by wind.

Sailing is the perfect mix of physical activity, socialisation and getting out into nature, and at some clubs in Australia it's available to absolutely everyone, thanks to a program called Sailability.

Equipment and support are available, as well as an established team of volunteers who are passionate about welcoming people of all abilities to the joys of sailing. It means that even landlubbers with zero experience on the water can enjoy time on the high seas, all the while building up their skills and expertise.

Sailability is an international program that was first introduced to Australia in the 1990s, and is today available in every state and territory.

It makes sailing inclusive by incorporating such things as equipment to assist people with limited mobility getting into and out of boats; instructors who can adapt their teaching methods to suit individuals of all abilities; different types

of boat, including the easy-to-sail Hansa Class; and even modified, accessible docking areas.

And once you've been bitten by the sailing bug and mastered the basic skills there are plenty of opportunities to get on the water for recreation or competition, such as:

- Participating in inclusive club competitions
- · Obtaining formal and informal coaching
- Competing in inclusive competitions (state, national and international)
- Competing in disability-specific competitions (national and international)

66 A beautiful way to start the day. >>

Spinal Life Australia has several members who participate in this fantastic program – and a handful of reviews on the new Accessible Australia app, singing its praises:

"On a weekly basis during the sailing season, places on boats are provided to give people with a disability the opportunity to sail," explains Karen H on the app. "Participants can be from agency networks or live independently within the community. They can be assisted by a support worker or family member, or be completely independent. They sail in easily accessible, stable and safe boats under the control of an experienced

skipper. The Hansa two-person dinghy Class has been specifically designed to be extremely stable and simple to operate. Several larger yachts are also utilised, which can accommodate more participants. Hoists are available to transfer wheelchair users into the boats provided. All volunteers are trained in safety and first aid, and a support powerboat is provided for all activities. There's also a stable motorised pontoon called *Nev Thomas*, owned by Fishability that is operated once a week for a limited number wheelchair-bound participants."

Reece Wallen's review focuses on sailing in the waters off Cairns: "The Cairns Yacht Club's Sailors with a Disability Program runs each Tuesday and Thursday, subject to weather conditions," he writes. "Tuesday training starts at 12noon till 5.30pm, and Thursday starts at 3pm and finishes at 5.30pm. The program operates in the sheltered water of Cairns Harbour and out into Trinity Inlet. The Sailability program offers a great afternoon opportunity for visitors to the Spinal Life facility on a casual 'Experience Sailing' basis."

And finally, there's a short but sweet review from Fiona Qoronalau: "A beautiful way to start the day. Open Mondays and Thursdays, bookings are required. There's friendly, helpful staff and a hoist is available for boarding boats. Can't wait to sail on a warm winter's day."

Well, winter is officially here, so if you like the sound of a day on a bay, get in touch with Sailability to find your closest participating club. And don't forget to listen to some Jimmy Buffett songs to really get in the mood for sailing!

Learn more about this amazing program at:

discoversailing.org.au/para-sailing/sailability – and
then once you've tried it, be sure leave a review on our app:
accessibleaustralia.com.au



# **Vehicle Mobility Solutions**

- Accessible Vehicle Hire (Short/Long Term)
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- www.drivingmobility.com.au







Photo: Paralympics Australia

The Tokyo Paralympics are set to commence on 24 August 2021. Thanks to COVID-19 they're a year late and, as we go to print, still not 100% locked in. But whatever happens, we wanted to pay tribute to the extraordinary effort of athletes, past and present, who have worked so hard to represent Australia at this event.

One such athlete is wheelchair rugby legend, Ryan Scott, OAM, who played international wheelchair rugby for 17 years before his retirement in 2018. Ryan took up the sport in 1998, as part of his rehabilitation after he became a quadriplegic following a car crash when he was 16. He excelled at the game and made his debut for the national team, the Australian Steelers, in 2001.

Just three years later he was on his way to his first Paralympics, in Athens. Four years after that he was part of the team that won a silver medal at the 2008 Beijing Games. Four years after *that*, at the London Games in 2012, he co-captained the Steelers to their first gold medal. And then in 2016, at the Rio Paralympics, the Aussies won gold again after defeating longtime rivals, the United States by just one point. The game was a double-overtime thriller for the ages.

So who better to speak to about the Paralympics than someone who's competed in no fewer than *four* Paralympic Games (not to mention five Wheelchair Rugby World Championships)? We asked Ryan to take us on a little trip down memory lane...

# How did it feel being selected for your very first Paralympics [Athens in 2004]?

It's so long ago I can barely remember! But I know it was a great time for my parents. They'd been through the worst part of my life, after the accident, and I was really happy that I could give them something positive back. I just wanted to make them proud.

# From a playing point of view, do you have a favourite Paralympics?

They've all been great, but winning gold for the first time in London was obviously special. And then there was Rio. The Australian team has a long rivalry with the United States. We lost to them at the Sydney Paralympic Games before I joined the team; we lost to them again in Beijing; and then we didn't even get to face them in London because they were beaten by Canada in the semi finals. I wanted to win a gold medal knowing that we had beaten the US at some point during the event. We finally got to do it in Rio, when we beat them in the final, by just one point, in double overtime. It was an amazing game; an amazing experience.

#### What's the best piece of advice you ever gave as captain?

Our coach would tell us to not get distracted by our families in the crowd, but privately I'd tell the guys how important it was to acknowledge them. They'd seen us go through the worst time of our lives and were such a big part of the journey to get us to the best time. Many of them had experienced moments when they thought their son or husband wasn't even going to live, let alone get to represent their country. So it was a big, emotional moment and I always encouraged the guys to acknowledge their loved ones when they entered that court.

#### What's it like in the Paralympics Villages?

They've all been slightly different, but they had things like games halls with Xboxes and arcade games, outdoor BBQ areas and swimming pools (for hanging out, not training). The dining halls were like all-you-can-eat buffets with food from all over the world, and always a highlight! We had to be very disciplined and remember what we were there for. It was quite hard because everything was free and all-you-can-eat. And every Village had a 24-hour McDonald's!

# What's a Paralympics memory that always makes you smile?

Playing the Brazilian team in Rio was like one of those massive soccer games, with the crowds booing and jeering us whenever we had the ball. It was deafening, unbelievable. But they'd be booing us, and then you'd look into the crowd and everyone would just be laughing and have the biggest smiles on their faces. They weren't being nasty, they were just supporting their team. And because our team colours are green and gold like Brazil, after they were knocked out they supported us at every other game throughout the rest of the tournament. It was just fantastic.

#### How does the classification system work?

In all Paralympic sport you get classified on your level of ability. Or, if you want to look at it the other way, your level of disability. Players get classified from 0.5 up to 3.5, going up in half points. The higher the number, the more function that player has. You're only allowed to play with four players and you can't exceed a total of eight points – for example, two 3.5 players and two 0.5s. Your two 3.5s are going to be your fast, dominant players who carry the ball, while the 0.5s are the defensive players who set the blocks and screens to try and make passes for the offensive players.

# Which Australian players are you looking forward to seeing play at the Tokyo Paralympics?

All of the Aussie guys are great to watch. I'm really looking forward to seeing one of our Queensland guys, Michael Ozanne – who's actually a Spinal Life member – at his first Paralympics. He has worked his butt off. And of course you can't go past the two 3.5 guys in our team, Ryley Batt and Chris Bond – they're both really fast and hard-hitting.

# Who's your hot favourite for the gold medal?

I think this will probably be the toughest Paralympics ever. I can't call it. But Japan beat us on Australian soil to win the World Championships by one point in 2018, so it's only fair if we beat them in their home country!

# What are you up to these days?

After I retired I had a development role for Paralympics Australia, helping recruit players, but I had to give it up when I started having some shoulder issues. These days I'm a stayat-home dad with two little girls. I also run a fun social rugby program here on the Sunshine Coast. [Read more about the Suncoast Spinners on page 9.]



Michael Ozanne has ticked just about every box on his wheelchair rugby wish list. He made his debut with the national team, the Australian Steelers, in 2013, having taken up the sport shortly after injuring his C6 vertebrae in a diving accident when he was 19 years old. Since then, he's represented his country many times – including the time Australia won its first gold medal at a world championship, at the World Wheelchair Rugby Championships in 2014.

But there's one thing Michael hasn't done yet: represent his country at a Paralympics Games. That's all set to change as, COVID-permitting, he's on the verge of making his debut at the Tokyo Games. It's such an exciting moment, and a just reward for a decade of hard work.

Like his hero Ryan Scott, Michael is a 0.5 classified player, and we were overjoyed when we had the chance to speak to both players for this issue. Michael kindly found some time between endless training sessions to tell us about his journey to the Games...

# Congratulations, you must be so excited to be going to the Paralympics!

I just missed out on the last Games, in Rio, so making my debut as a Paralympian has taken a long time. That's why I'm so happy the Tokyo Games haven't been cancelled! Everything's still a bit up in the air, but from everything we've heard, they are going ahead. We're updated constantly about what the protocols are going to be, and things are definitely going to be different.

#### Like what?

Well, this is the first time that we'll be playing in the first week of the Games. And it's nothing to do with COVID! I think it's just because the sport is becoming so popular, which is great. But it means we'll miss the opening ceremony, as our games start so early.

#### What about changes due to COVID?

We're not allowed to leave the Paralympic Village unless we're competing... but even in the Village we'll be taking extra precautions, like eating in our rooms rather than in the dining hall. With so many athletes from so many different countries, everyone says the dining hall is the best place in the Village, so it's disappointing to miss out on it. But I'm more than willing to take that hit if it means limiting my chances of getting COVID.

#### Have you been to Japan before?

Yes, we've played in a few competitions over there and I've been four or five times. I really like Japan. In fact, before COVID hit, the plan was for my family to join me for a little holiday during the second week of the Games. We were going to visit Tokyo Disneyland and the newly opened Super Nintendo World. Obviously that plan got shut down, but I'll definitely be organising a return trip in the future.

#### Will any of your family be there to watch you play?

No, there will no international spectators at all. Apparently they'll all be locals, they'll all be wearing masks and there will be no cheering. The first time I get to play in front of a big crowd and it's going to be almost silent – it will be really weird.

#### Which other teams are going to be big competition?

For us it's the United States, Japan, Great Britain and even Canada. But all eight teams have worked hard and earned their qualification spot. It all just depends on what happens on the day.

## Who are some of the Aussie players to look out for?

Chris Bond and Ryley Batt. They're our big 3.5 players – the ones who score all the goals while we do all the hard work so they can score those goals. [laughs] Ryley's always good to watch. He's the best player in the world and has been for many years.

# What's the thing that you're most looking forward to about the Games?

I'm just excited to get over there and finally be able to call myself a Paralympian – hopefully, a gold medal-winning Paralympian, if everything goes to plan! ▲

# THINKING ABOUT TAKING UP WHEELCHAIR RUGBY?

Here are 10 things you need to know, according to four-time Paralympian legend and Suncoast Spinners coach, Ryan Scott

- 1. Wheelchair rugby was designed by a group of Canadian quadriplegics who wanted to play wheelchair basketball, but didn't have the upper body strength to shoot goals. They were just guys mucking around, throwing a ball into bins at the ends of a court, slamming into each other and having a great time. They called the game "Murder Ball" but because it was a pain to get the ball out of the bins after scoring they created try lines, and that's how it became wheelchair rugby.
- 2. The Suncoast Spinners is a wheelchair rugby team based at the USC Stadium, at the University of the Sunshine Coast.
- 3. We run a "reverse inclusion" program, which means that everyone's welcome. Obviously we want people with spinal cord injuries to play, but we're open to able-bodied players as well. It's a great opportunity for somebody with a disability to play sport with their friends and family members.
- 4. It doesn't matter if you have zero experience. We have people play who have never even pushed a wheelchair before! Just turn up and we'll take you through everything.
- 5. There's no commitment just turn up when you want.

- 6. The program's free, and we supply the chairs and all the equipment (including a hoist, if needed).
- 7. I have a coaching role at the Spinners, but it's very much a social program. We just want everyone to play some games, learn some skills and have fun!
- 8. Don't worry if you feel nervous at first: metal wheelchairs running into each other can sound intimidating. But once they get out on the court and take their first hit, most people usually think, "Oh, it's not as bad as I was expecting!"
- 9. We encourage everyone to give the game a try. There are three of us who play every week: myself, a Queensland representative, and Chris Bond, who's co-captain of the Australian team. His support worker has even started playing!
- 10. We normally play between 10am and 12pm on Saturdays during the school calendar year, but always check first on the Suncoast Spinners website or Facebook page.

To find out more or check that games are on, go to suncoastspinners.com.au or facebook.com/thespinners



# SATURDAYS 10AM - 12PM

USC STADIUM - 32 OLYMPIC WAY, SIPPY DOWNS+

+ SUBJECT TO STADIUM AVAILABILITY

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SUITABLE FOR PEOPLE OF ALL ABILITIES. AGES AND SKILL LEVELS





# Getting sweaty on the Jetty 2 Jetty

There's a brand new category at this year's race and elite wheelchair athlete Natasha Price has got her eye on the prize



This year's Jetty 2 Jetty Fun Run, on 18 July, is one for the history books. Not only is it the 35th anniversary of this beloved annual community event, but it's also the year a brand new race category will be introduced: the GKS Law Wheelchair 10km.

The course will follow the scenic Redcliffe Waterfront and run in conjunction with the GKS Law 10km run/walk. Starting the race will be a wave of elite wheelchair athletes, who will be competing for prize money donated by Spinal Life Australia.

One athlete who'll be racing in this new category and using it as a training run for the Sunshine Coast Marathon is Gold Coast resident, Natasha Price. We spoke to the elite wheelchair racer and international marathon winner in the lead-up to the Jetty 2 Jetty Fun Run.

I want to show people that disability doesn't mean inability.



# How did you get into professional wheelchair racing?

I made the leap to wheelchair racing about three years ago after initially just pushing around in my day chair for up to 20 kilometres at a time. Then I did my first marathon, and things have developed from there!

#### Tell us about your very first race?

I guess I'm a little bit crazy because it was the Gold Coast Marathon, a full 42-kilometre event. I'd only had my race chair for six weeks so I hadn't really had time to prepare much. On the day, my inexperience meant that I had a lot of problems and the wheelchair wasn't working correctly so it was like the brakes were on – it took me almost five hours to finish that race! I ended up with a flat tire and pulled my thumbnails off, but I was so proud of myself for crossing the finish line.

# What's a moment you're most proud of during your racing career?

Winning the Auckland Marathon in 2018 was a really big deal for me. Also being the 2020 and 2021 Queensland State Champion in the 100 metres, 200 metres and 400 metres, and just recently taking the podium for a third place in the 400 metres at the Australian Athletics Championships.

# What's your source of motivation?

I get motivation from knowing how far I've come and not wanting to go back to where I was four or five years ago, where I was unable to get out of bed. I want to keep driving forwards and show people that disability doesn't mean inability.

# What equipment do you use for your racing, and is it funded through the NDIS?

I use a racing wheelchair, helmet and specialised gloves, as well as gym equipment. While the chair

isn't funded through the NDIS, its maintenance is, along with the gloves and helmet, and also physiotherapy and exercise physiology.

# What other interests do you have outside of wheelchair racing, both professionally and otherwise?

Outside of wheelchair racing, I don't really have a lot of time – I'm very busy! I run my own business along with my coach, Adam Shepherd. We do inclusion and diversity training and accessibility consulting, so we spend a lot of time working on our passions.

# Why do you think it's important for people with disability to go out and give sport a go?

Because of the confidence, the sense of community and the sense of belonging it gives you, and just the people you meet and the friendships you make along the way... it changes your life.

# What would you say to somebody with disability who's considering racing, but doesn't feel confident?

I'd recommend contacting an organisation like Para Sports Qld where they can point you in the right direction and help you develop the skills and confidence you need in order to pursue your passions and your dreams.

# What are your plans for the future?

I just want to keep kicking goals. Whether that's from racing hopefully working towards the 2022 Commonwealth Games – or in my personal and professional development, I want to take the world by domination and just show what people with disabilities are capable of. A

The Jetty 2 Jetty Fun Run is on Sunday, July 18 from 5.30-10am, at Pelican Park, Clontarf. For more details, go to j2j.com.au

# Dear Diary

How my husband (with a C3 injury!) went from the Spinal Unit to working back at the mine site, all in record time...

When Keith Haley suffered spinal injuries after a serious mountain bike accident in late 2020, no one could have imagined that the general manager of a Central Queensland mine would be back at his job just four months later.

Keith had an incomplete injury, which meant his future was unknown. Thanks to his determination, discipline and superhuman effort, his recovery astounded all of the health professionals tasked to help Keith on his journey.

It was all captured in a searingly honest blog written by Keith's wife, Kayla (caring-bridge.org/visit/keithhaley/ journal). Somehow she managed to find time to capture all of the tears and triumphs while she supported Keith during his greatest challenge.

It's equal parts heartfelt and hilarious, uplifting and tough to read, and Keith and Kayla have been kind enough to allow us to reproduce excerpts from the blog (abridged and edited) here...

**66** Keith approaches every visit from the PT as if it's a year-end final exam. ??









## **KEITH'S STORY**

November 2, 2020 | Keith was in a mountain bike accident yesterday. He hit a bump, was thrown over his handlebars and knocked unconscious. His injuries include chipped C2 and C3 vertebrae, along with some issues with a few of the thoracic vertebrae. His spinal cord is swollen and he initially had no feeling in his body, but over the next 24 hours he has gradually regained some feelings.

**November 3** | Mobility is the number-one priority right now. This morning Keith was able to shrug his shoulders, curl the fingers on both hands and then reopen the fingers on one of those hands. These are all things he couldn't do or feel yesterday. They are all wins.

**November 7** | It was Keith's first time in a wheelchair and he experienced what he's calling his Marilyn Monroe moment, but I think it was more Sharon Stone in Basic Instinct. As I was pushing him out the front doors of the hospital a swirling wind lifted his gown and his commando state of dress became available for all to see. We laughed like loons.

**November 8** | The neuropathic pain was worse today. It radiates through his entire body and has the sensation of being stabbed by razor blades or walking barefoot over piles of broken glass. He doesn't want to take anything for it until he talks more to the neuro team. He's afraid if he relieves the pain, he will also reduce feeling. He'd rather feel pain than nothing at all.

**November 10** | It was a HUGE day today. Keith's legs took his weight and we said goodbye to the hoist! Keith will have to relearn how to walk, but I am confident he is going to get it. It was an extremely emotional moment and we all cried including the two Personal Trainers (PT).

Later, all three members of the neurology team gave Keith something to work on. The most critical, according to Tony, the Director of Neurosurgery, is thumb-to-finger touches. Fine motor skills like this will be the difference between

clumsy clubs and useful fingers in the future. It was great to see the neuro team so excited about Keith's progress. It was a good, good day.

**November 12** | The speed at which Keith has gained back some of his mobility this week has been incredible. I leave for 10 hours and when I come back, he's added 10 more tricks to his repertoire.

**November 13** | Keith approaches every visit from the PT as if it's a year-end final exam. He precedes each "exam" with an all-night cram session. He lies in bed, stares at the white ceiling tiles overhead and visualises each and every movement he's been asked to demonstrate. Each one is a puzzle that first must be broken apart into individual pieces and then put back together. It is mentally exhausting.

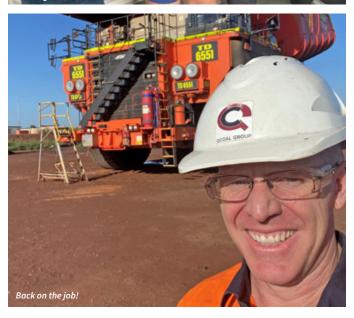
**November 16** | The journey Keith is on can be likened to the progression of an infant. Day one he couldn't move; days two and three he had to lean how to drink (he couldn't swallow); days four through six were all about getting the breathing regulated. Blessedly, he maintained his ability to reason, his ability to laugh and his strong work ethic. The other saving grace (or curse, depending on how you look at it) is that he retained his ability to talk! Everything else, Keith is having to relearn.

**November 17** | Keith has graduated to the gym for PT. During today's session, he worked on balance and coordination. As long as he doesn't try to talk at the same time, he does a pretty good job of walking. But he only travels in straight lines. It's like watching a game of Pac-Man.

November 18 | We had been warned and we knew it was coming: Today, Keith had a down day. Everything he accomplished yesterday was twice as hard today. He has had several big days with big gains and I think it's all finally caught up with him. >







**November 19** | Moving day! Keith has been relocated to the Spinal Injuries Unit (SIU)! This is what we have been wanting: intense rehab to get full mobility back.

**November 27** | Keith's walking is getting better and better. The fear that he is going to tip right over has abated. Therefore, it was time to start tweaking the walk. At the moment, he gets no points for style. If he's not reminded he turns into the Hunchback of Notre Dame, with a turkey neck and straight, unmoving arms. Today, his physio session was focused on breaking down and rebuilding a "natural" walk. He isn't quite ready for the Paris catwalk, but we undoubtedly made some improvement. In other news, he is finally 100% opioid-free!

**November 29** | In just 29 days, Keith is down six kilograms. This is probably the result of several things: loss of muscle tone, hospital food and a very strict, clean diet. Many factors influence spinal cord injury recovery and most of them cannot be controlled. Diet is one of the factors we can control, so Keith is focusing on the foods that are said to be beneficial to his recovery. He is deviating very little from a protein, vegetable, berry, nut and limited dairy-based diet.

November 30 | Today, Keith's OT Glenda announced, "Keith it's time to get you into a Back To Work Program. It's time to start working to the bigger goal". (This is a huge milestone, yay!). Glenda will continue to provide OT, but an outside not-for-profit organisation, Spinal Life Australia, facilitates the Back2Work program. Glenda started checking Keith's chart to verify she had all of the necessary details to pass on, but quickly stopped short. "You're a C3 ASIA D?". She was astounded. "Keith, in my entire career, I have never, EVER referred a C3 ASIA D to a Back2Work program!" Glenda had a career first today!

**December 3** | PT today was followed by OT. In the session Keith was given much more detail on the Back2Work program. One aspect of this is what I call CYA (Cover your A\*\*) assistance. For example, once Keith is released and is declared fit to drive, he can still run into trouble if he gets behind the wheel of a car and is involved in an accident (regardless of fault). Insurance could deny coverage and he could be subject to legal action unless he takes the necessary steps to close all of the loopholes that exist as a result of his injury. The Back2Work Program is going to be very helpful on many fronts.

**December 11** | Keith had a really good day. Why such a great day? It's simple... He had a great night's sleep!

**December 12** | We went to a party today. Keith walked from the parking garage to the venue. He stood for 45 minutes. He sat and chatted for another two hours and easily managed the walk back to the car. Not once did he trip, stumble, spill his drink or fall asleep on anyone. It was just about as normal as it could get.

**December 17** | Christmas is coming early for Keith this year. I am not sure he is going to get everything on his wish list, but he is definitely getting the big item: He will be released from the SIU tomorrow. He is coming home!

**December 18** | Keith is home! Saying goodbye and thank you to all his doctors, nurses, PTs, OTs and roommates took us to three separate buildings on the PA campus, and he covered 5,000 steps. Needless to say, he was wiped out by the end. There was no celebrating his release when we got home. He went straight to bed.

**December 27** | Keith was released from the SIU just over a week ago. Since then it has been a vicious cycle of "Boom and Bust": too much too quickly, followed by paying the price.

**February 12, 2021** | Now that Keith is home, life has returned to normal – or rather, a new type of normal. Some weeks feel like we are going absolutely nowhere. But that's not entirely true. Keith is improving each week. The gains are just much smaller. I won't lie, after the consistent big improvements in the first couple of months, this phase of the recovery is frustrating.

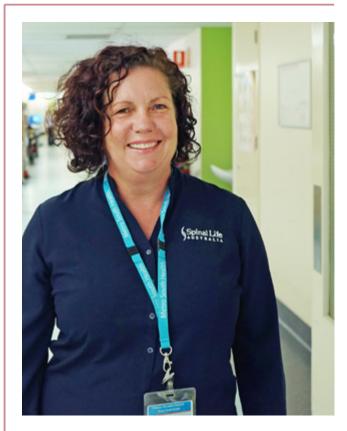
March 17 | This is a public service announcement: If you live in the Brisbane area, stay off the roads! After countless hours, an occupational therapist, a driving instructor, an optometrist, a GP and finally a Transport and Main Roads visit, Keith has finally received a full release to operate a vehicle once again. You have been warned!

But let's not stop there: he also put in a four-day work week at the mine this week. This involved flights, drives, and... work! He survived, even if he is moving a little slow tonight.

It's been quite the journey and it isn't over yet, but look how far he has come! 

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Visit spinal.com.au/back2work for more information



## **MEET TANIA**

Tania Goossen, Spinal Life's Senior Vocational Rehabilitation Counsellor, supported Keith through the Back2Work program within the Princess Alexandra Hospital's Spinal Injuries Unit.

On the day he made his first trip back to the mine in March, Keith sent the following message to Tania:

"I am doing great. Running on huge spikes of excitement and adrenaline. I'm loving my job, and I'm already fixing problems and teaching leadership. It feels so good, but it was hard to leave today. It felt like walking out of an excellent movie with 30 minutes left".

It's an extraordinary result following an extraordinary recovery.

"This is the guts of why I do what I do," says Tania, "and why Back2Work is so important."

# Love to drive?

# Total Ability helps people with disability get behind the wheel again

Learning to drive with hand controls after sustaining a spinal injury had a hugely positive impact on Paul Crake's outlook on life. It helped him regain his freedom and independence, and was the catalyst to him forming his own business: Total Ability. For more than 10 years Paul has dedicated himself to giving others that same opportunity by providing the very best in driving aids and accessibility products.

The leading global brand in hand controls is Fadiel Italiana.

Total Ability became the exclusive distributor of Fadiel Italiana products in Australia after Paul used one of their products and was blown away by not only their performance, but also the company's commitment to continuous product research and development.

"They were the first to introduce the Satellite Accelerator to enable driving with two hands on the wheel, the first to use Bluetooth, the first to use new strong and lightweight metals... The list goes on," he explains.

**66** There will be a hand control for every level of disability now. 99

Earlier this year, Paul introduced the latest advanced product from Fadiel Italiana.

The Ergonomic Radial Hand Control is an option for someone with limited hand dexterity to drive independently and safely, without needing more complex, highlevel hand control models. Elegant and Scan here Scan here of the guide compact, it's also very customisable to individual needs and preferences.

"This will complete Total Ability's range of hand controls in Australia," says Paul. "There will be a hand control for every level of disability now."

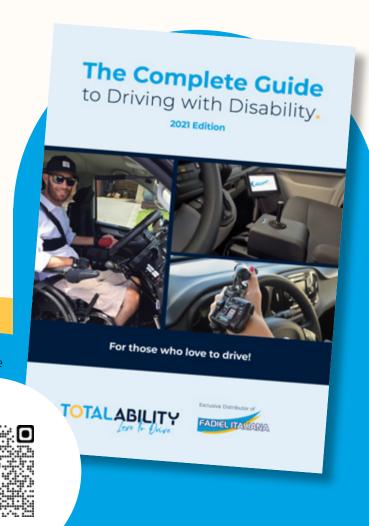
But there's still work to be done when it comes to helping people with disability to drive.

"Whether you are self-funded or going through a funding body like the NDIS, negotiating the approval process and paperwork is a challenge," says Paul.

That's why Total Ability has launched The Complete Guide to Driving with Disability, a step-by-step guide that makes the whole process easier.

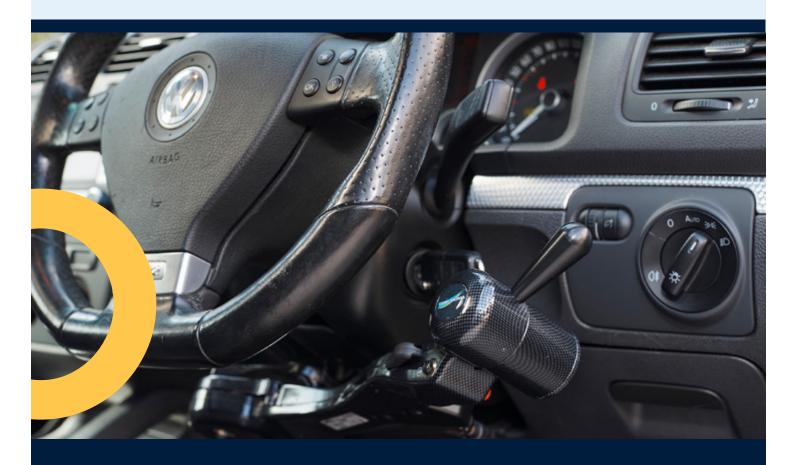
"Our aim is to get this guide to as many people as possible, including Occupational Therapists and potential drivers out there who never thought they could drive," says Paul.

Visit www.totalability.com.au to download the free guide, or inspire others with your own 'Love to Drive' story.



# Ergonomic Radial Hand Control.

**By Fadiel Italiana** 











totalability.com.au

1300 858 410

# Good morning, Sunshine!

A new accessibility review of the Sunshine Coast shows that there's much more to this beautiful part of the world than just beaches

Everybody loves a holiday or day out in Queensland's beautiful Sunshine Coast region. So if you're lucky enough to visit as part of your job, you've really hit the jackpot. Spinal Life Australia Advocacy Officer, Lachy Chapman recently found himself in exactly that position, when he was asked to create the *Sunshine Coast Accessible Tourism Review* (released April 2021).

The brief? To review some of the tourism offerings in the Sunshine Coast region (in this case, mostly in the hinterland region), and then provide feedback about their accessibility.

The goal is for this feedback to be used by the local Council, tourism operators and others to help make changes that will make the Sunshine Coast region an even more accessible destination in the future. It's a win-win: not just for people wanting to enjoy an accessible holiday, but also for local businesses who might not currently recognise the economic potential associated with accessible tourism.

We asked Lachy to list some of his eye-opening and hugely helpful findings here:

# LACHY'S TOP 5 ACCESSIBLE THINGS TO SEE AND DO ON THE SUNSHINE COAST RIGHT NOW

#### 1. Australia Zoo

Located in Beerwah, about an hour north of Brisbane, everybody knows of Steve Irwin's extraordinary legacy. The award-winning zoo

is enormous and you'll need one or two days to fully experience it. The good news is, they've clearly gone to a lot of effort to make everything as accessible as possible, all while preserving the natural landscape. It's relatively easy to get around in a wheelchair as there are very few steep hills, but there's a safari shuttle if you want help accessing the zoo's more remote areas. The famous Crocoseum arena features a lift to the upper level, plus accessible seating and big screens for people with vision impairment. We also experienced animal encounters with meerkats, koalas and giraffes, all of which were accessible to me in my manual wheelchair. It's obvious that a lot of thoughtful planning has taken place in order to make the zoo as inclusive as possible. australiazoo.com.au

#### 2. Montville

This charming little town surrounded by rainforest and perched on the Blackall Range is about 90 minutes from Brisbane. It's a fantastic place to visit, with an old-fashioned vibe and lots of arts and crafts galleries, fudge and sweet shops, and cafes for high tea.

Don't miss the beautiful Russell Family Park – it's a lovely place for families, with a large children's park and several areas where you can enjoy a barbecue or picnic, and it's almost completely wheelchair-accessible, with pathways winding through the trees and around a large lagoon. There are still improvements to be made in Montville, but it's far more accessible than I had imagined, especially considering the natural terrain and 'vintage' style of the town.

#### 3. Queensland Air Museum

Australia's largest heritage air museum is located in Caloundra, and is an absolute must, even for people who don't consider themselves to be aviation enthusiasts. You'll need at least two hours to fully appreciate everything on show here, including a real F-111 and more than 80 other aircraft. This fantastic museum boasts good accessibility features, and the whole thing seems even more impressive when you learn it's a not-for-profit, community-owned museum run entirely by volunteers. qam.com.au

#### 4. Sea Life Sunshine Coast

Located in Mooloolaba, this award-winning aquarium is a delightful, family-friendly experience. Fascinating exhibits include a colony of the smallest species of

penguin and an 80-metre-long ocean tunnel where huge rays and grey nurse sharks swim all around you. There's designated accessible seating at the must-see seal presentation, and at the interactive Tidal Touchpool you can actually touch marine creatures. Although this is inaccessible to wheelchair users, staff placed some of the sea stars and sea urchins into a container and brought the exhibit to me, which was very thoughtful and inclusive, and I'm sure children with a disability would be delighted by this hands-on experience. *visitsealife. com/sunshine-coast* 

# **5. Mary Cairncross Scenic Reserve Rainforest Discovery Centre**

Cairncross Scenic Reserve is a truly special spot in the Sunshine Coast hinterland. The gateway to this precious 55-hectare reserve – one of the last remaining pockets of the subtropical rainforest that once covered the Blackall Range – is the Rainforest Discovery Centre. It's a new building with very good accessibility, and thanks to the well thought-out design I was able to partake in most of its multi-sensory, interactive displays and activities. There's lift access to the upper level, where you can take in the breathtaking views from fixed binoculars. They even have some at just the right height for a wheelchair user – this is very rare to see and I was delighted to be able to enjoy them with my son. mary-cairncross.sunshinecoast.qld.gov.au >

Overlooking the Glass House Mountains, the Mary

# LACHY'S TOP 5 CHANGES TO MAKE THINGS ON THE SUNSHINE COAST MORE ACCESSIBLE

#### 1. Eumundi Markets

The historic town of Eumundi is famous for its artisan markets, where you'll find all sorts of locally made and grown products, food and drink stalls, seating areas and local musical talent. Set among eritage-Listed fig trees, most of the market is shaded so

stalls, seating areas and local musical talent. Set among Heritage-Listed fig trees, most of the market is shaded so it's pleasant even on a hot day. The south corner of the original market area has a good accessible bathroom, wide pathways between vendors and good-quality ramps to access the different levels. But as you travel north towards Caplick Park and across Napier Road the stalls are closer together and cluttered, and the pathways become narrow – if you're using a mobility device, it's tight. The path to the Pavilion Markets, across Memorial Drive, is dangerously steep, making this section completely inaccessible. These areas need addressing to make the markets truly accessible. eumundimarkets.com.au

#### 2. Alexandra Headland beach

The great beach at the family-friendly coastal town of Alexandra Headland was the only one reviewed for this report, but we give very similar feedback

at nearly every beach we visit: there's room for improvement when it comes to accessible beach matting, beach wheelchairs and providing surf lifesavers with quality training so that they have a better understanding of the needs of people with a disability. At Alexandra Headland, the council has invested in beach matting at the patrolled beach, but it wasn't out when I visited. When I asked why, the surf lifesavers said there's no need for it, as two different kinds of beach wheelchairs are now available. This perfectly highlights why education is so important. Beach wheelchairs are fantastic, but they don't negate the need for beach matting: without it, you're still completely dependent on others to get down to the beach. And the matting isn't just for wheelchair users: it also helps the elderly and anyone else who struggles to walk safely across soft sand. The purpose of beach matting is to make the beach truly accessible to everyone.

# 3. Mary Cairncross Rainforest Walk

I've already sung the praises of the Mary Cairncross Rainforest Discovery Centre [previous page], and was looking forward to getting out onto the Rainforest

Walk. There are several options, depending on your level of ability, including the 1.3km wheelchair-friendly Pademelon Loop which has no steep hills and is step-free.

This is a beautiful walk, with tree ferns, towering native fig trees, regular sightings of native birds and pademelons, and volunteer guides to answer questions and point out interesting things you wouldn't normally notice in the forest. Unfortunately, the 1.7km Rainforest Loop is not wheelchair-friendly, with a small section that features three or four small sets of stairs. Making this walk 100% wheelchair-friendly is definitely on my list of things to change.

#### 4. Maleny

Famous for its rolling hills and breathtaking views, Maleny is a quaint and eclectic town in the Blackall Range, about 30km southwest of

Caloundra. But for wheelchair users, Maleny is a difficult place to navigate. The main shopping and dining precinct is located on a very steep hill, and many shopfronts have step entrances. Some cafés and shops are accessible via narrow laneways or quaint staircases, which fit with the style of the town but make accessibility in a mobility device very difficult, if not impossible. And everywhere other than this small shopping and dining precinct can be difficult to access thanks to a lack of connecting footpaths and curb ramps. Improving accessibility to this area as a whole should be a priority of the council.

## 5. Skydiving

I *loved* my skydiving adventure with 1300Skydive.
From my physical assessment prior to the jump to the big day itself, the entire team were amazing and extremely accommodating. Skydiving was an

incredible, breathtaking experience and I had a big grin on my face the entire time. We landed on the beach at Currimundi Lake, where extra staff were on hand to help lower me to the ground, and a beach wheelchair helped me off the sand. My partner met me there with our car, as the small bus that transports skydivers back to the base is not accessible for wheelchair users. This is one thing that could be remedied, but the main thing is the need to dispel the misconception that people with a C-spine injury can't participate like I did. It's simply not always the case. We need to work together and educate operators to help make this amazing experience available for more thrill-seekers with mobility impairments. 1300skydive.com.au

Lachy's review was funded by a grant from the Sunshine Coast Regional Council. You can read his full report at **spinal.com.au** or visit **accessibleaustralia.com.au** to check out reviews of the Sunshine Coast region and share your own experiences.

# Guarding skin integrity



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PROSHIELD\* PLU

# **PROSHIELD PLUS**

Skin Protectant



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Moisturises, conditions and protects skin.<sup>8,9</sup>



Helps protect skin from breaking down due to incontinence.<sup>5,6,10,11</sup>







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# **FUTURE-PROOFING OUR HOMES**

At Spinal Life Australia we work hard as advocates for a wide range of issues. It can be a pretty tough job, but we had a moment to celebrate earlier this year, when we helped to influence a significant decision that will shape housing for generations to come of Australians.

On 30 April, a majority of Australia's building ministers agreed to include mandatory minimum accessibility standards in the 2022 National Construction Code (NCC).

That might sound like a bit of a mouthful, but what it means is they agreed to the Silver level of the Livable Housing Design Guidelines (LHDG), which includes seven accessible design features.

Some of these simple but crucial features include a safe, continuous and step-free path of travel from the street entrance and/or parking area to a level dwelling entrance; at least one, level, step-free entrance; wider internal doors and corridors; and a loo on the ground or entry level that provides easy access.

There was fierce opposition from the building industry regarding this decision, so it was a big win!

Our mission was aided by some recent studies, which show how accessible features are already being incorporated in new homes as standard, and how it's actually relatively simple and inexpensive to include many of these features – as little as one per cent of the building cost, compared to almost 20 times the cost to retrofit.

Any short-term costs are far outweighed by the long-term value of accessible features – including the fact that elderly people will be able stay in their homes longer as they age, and how people with mobility limitations will have their quality of life improved. And when you consider the fact that within the next 40 years it's anticipated almost six million people are likely to have a mobility limitation, these new accessibility standards cannot come soon enough (for the record, they will come into effect in September 2022).

Including the seven Silver-level features as standard in all new homes is a huge achievement, but we won't stop until, ultimately, all 16 features in the Platinum-level become standard!

Visit **spinal.com.au/service/advocacy** to find out more about our advocacy campaigns

# The results are in

One of our big advocacy jobs at Spinal Life Australia is raising awareness about the late effects of polio, and promoting better support, services and funding.

To help in our planning and future efforts we recently surveyed polio survivors about a range of key issues. The feedback was invaluable.

#### WHAT YOU TOLD US

37.5% of respondents said their number-one priority is to continue to live independently, and successfully manage things like fatigue/pain/loss of mobility

70.83% of respondents said GPs are the most important health professionals when it comes to raising awareness of the late effects of polio

told us they've shared our information booklet with their GP/s, which is a great result! >



# **WANT TO GET MORE INVOLVED?**

- Share our info booklet Late Effects of Polio:
   A Guide to Management for Medical Professionals with your GP and health professionals
- Ask your GP to complete a professional development course, called 'What's polio got to do with general practice in Australia in 2021?'. It's found here: thinkgp.com.au/education/polio2020
- Being admitted to hospital or undergoing a general anaesthetic? Read our booklet *Anaesthesia & Surgery:* A guide for people with a history of polio.
- Call 13 HEALTH for advice about connecting with a Rehabilitation Specialist at a Queensland Health hospital near you. They can help assist your GP to provide you with more appropriate care.
- If you're a polio survivor, keep a Medical Alert card on hand so health professionals have access to key information if they need it.



# WHY WE CAN LOOK FORWARD TO MAJOR GOVERNMENT PROJECTS BEING INCLUSIVE

A new, independent advisory body has been established and it has one major goal: to make transport and major infrastructure projects accessible for all Queenslanders.

The Queensland Accessible Transport Advisory Council (QATAC) will provide strategic access and inclusion advice to the Minister for Transport and Main Roads, relating to transport and major projects across the state.

Two big drivers behind the formation of QATAC are the prospect of hosting the Olympics in Queensland in the future, and the need to move forward from mistakes of the past.

These mistakes include the New Generation Rollingstock (NGR) train project, where trains were procured that failed to comply with disability legislation. The resulting Commission of Inquiry led to a report containing 24 recommendations... and the Government accepted every single one.

That Commission of Inquiry was headed by retired District Court Judge, Michael Forde, so it seems perfect that he has now been appointed the inaugural Chair of QATAC.

The council includes seven members with expertise in achieving inclusive outcomes for people with disability. John Mayo, Spinal Life's Chief Advisor – Government, has been appointed QATAC Deputy Chair.

The advisory council will ensure that, when it comes to future major infrastructure projects in Queensland, people with a disability will have the opportunity to be represented in a formal capacity, and representatives will be consulted right from the start, providing muchneeded first-hand experience.

QATAC will be available for consultation to the broader Queensland government, delivery partners and local governments, on major infrastructure works such as the Sunshine Coast Mass Transit Project and special projects such as the Olympics.



# CATCH UP WITH YOUR COMMUNITY

Our Peer Support catch-ups are held across Queensland and Western Australia, guided by the latest advice from health authorities in response to COVID-19. Keep an eye on Facebook and our website for updates on upcoming events, including online opportunities. 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: Bill Peacock on 0403 686 998.

Combined with Post Polio group.

**BRISBANE**: Ross Duncan on 0475 077 080. **BUNDABERG**: Pat Allison on 4153 1005. **CAIRNS**: Sam James on 1300 774 625. Combined with Post Polio group.

FRASER COAST: Sam James on 1300 774 625.
IPSWICH: Eric Rushton on 0403 191 698.
MACKAY: Ross Duncan on 0475 077 080.
MORETON BAY: Ross Duncan on 0475 077 080.
ROCKHAMPTON: Robynne Clifton on 0473 576 107

or Anne Guthrie on 0407 116 035.

TOOWOOMBA: Wendy Adams on 0422 799 580.

Combined with Post Polio group.

WESTERN AUSTRALIA: Aileen Ward on 0420 985 734.

# 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.

**TOWNSVILLE**: Eric Collins on 4729 0275.

## Transverse Myelitis Group

Contact Jodi Gallon on 0451 235 860

Join our community today at **spinal.com.au/membership** or call 1300 774 625 to find out more.

# A Handy Hospital Checklist



Spinal Life Registered Nurse, Deb Dent shares her tips on what to pack if you have to go to hospital

#### **EMERGENCY TRIPS**

An emergency visit to hospital means you won't have the luxury of packing everything you might need. But if you have a catheter it's wise to always have a bag packed and ready to grab at a moment's notice, containing the following:

<u>Suprapubic</u> catheter
☐ Catheter change pack
Catheter
☐ Drainage bag
Antiseptic - blue chlorhexidine
60ml syringe
Sodium chloride
Indwelling catheter
☐ Catheter change pack
☐ Catheter
☐ Drainage bag
Antiseptic – blue chlorhexidine
Lignocaine numbing gel

#### **PLANNED TRIPS**

When you have time to plan, prepare and pack, don't forget these key items:

Plus... don't forget to talk to the hospital prior to your admission if you require a pressure-relieving mattress; a hoist to transfer; assistance relating to hygiene care; and advice regarding bowel therapy.





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#### **Less Mess:**

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## **Speed and Discretion:**

Quick preparation with no unnecessary delay – start catheterising as soon as you break the water sachet and wet the length of the catheter.





# - Gyl Stacey

# 1. What are some of the things the Board's been up to since the last issue of The Advocate?

With our primary focus on the practical things that affect our members' day-to-day lives, we'll be working with universities and others on things like pain management and research focusing on functional improvements. To help guide our efforts, we're excited to welcome two new Alternate Directors, Dr Dinesh Palipana and Rebecca Tweedy. Dinesh, who is also Deputy Chair of the Research Committee, was 2021 Queensland Australian of the Year and has particular expertise in spinal research, as well as extensive connections across government and health. Rebecca is a physiotherapist who specialises in chronic spinal conditions and complex musculoskeletal conditions. She understands the challenges faced by young people with spinal injuries particularly well as her son, Conor, broke his neck in a school rugby match three years ago. He's made great strides in his recovery and rehabilitation, not least because of the positive support he's received. Rebecca will help guide our efforts in advocating for and supporting people in Conor's position. With the appointment of these two highly motivated individuals as Alternate Directors, these are exciting times!

# 2. What does being an advocate for people living with a disability mean to you?

We've been working to reshape Spinal Life's Board and its organisation so that we're best able to deal with a changing economic, social and technological landscape. Core to this has been our advocacy, which has renewed energy and focus, working on behalf of both individuals and the wider community. At the same time, we've adopted a more strategic approach, working with other organisations on interests we share and the things that matter to our members.

# 3. What's going on when it comes to innovation and technology at Spinal Life Australia?

We've put new systems in place to manage the back office and improve things like rostering for personal support workers. The Accessible Australia app is also being further developed to provide useful information about accessible accommodation and facilities across Australia. More hands-on, practical innovation can be found in the Healthy Living Centre (HLC) in Cairns, where the accessible gym has equipment that can be used by pretty much everyone, with little or no assistance. There's also smart technology in each apartment, with an iPad available to control TV, blinds, air conditioning and more. All equipment and IT was designed from the ground-up for, and by, people with a wide range of mobility impairments.

# 4. This version of The Advocate focuses on inspirational people with disability in sport. Who inspires you?

It's not, and never has been, just one person. I speak personally now, not as the chair of the board but as Gyl, a woman who became paraplegic at age 15 and has led a productive and fulfilling life ever since. I won a flying scholarship in California because my friend saw an advert and said, "Why not you?" I learned to sail, dive, climb mountains and get out in the wilderness because other friends thought it would be fun and, again asked, "What's stopping you?" I've had a good career as a technologist, manager and executive, because of positive people around me who did not see the barriers, but instead saw the opportunities. So who has inspired me to live my best life? My friends and family: the people who encouraged me all the way, saw my capabilities and not just my spinal cord injury. For me, it was never about heroes.

# Out of the bunker

Russell Spencer's back on the green thanks to an NDIS-funded golf buggy

When Russell Spencer had a spinal stroke in 2018, one of the hardest things he had to face was the idea that he might never play golf again.

But, happily, the Gladstone resident is back on the green, doing what he loves most. And it's all thanks to the NDIS -Russell's believed to be the first person in Australia to receive NDIS funding for a golf buggy and trailer.

Russell's passion for golf first started around 40 years ago, when a work colleague invited him to a round.

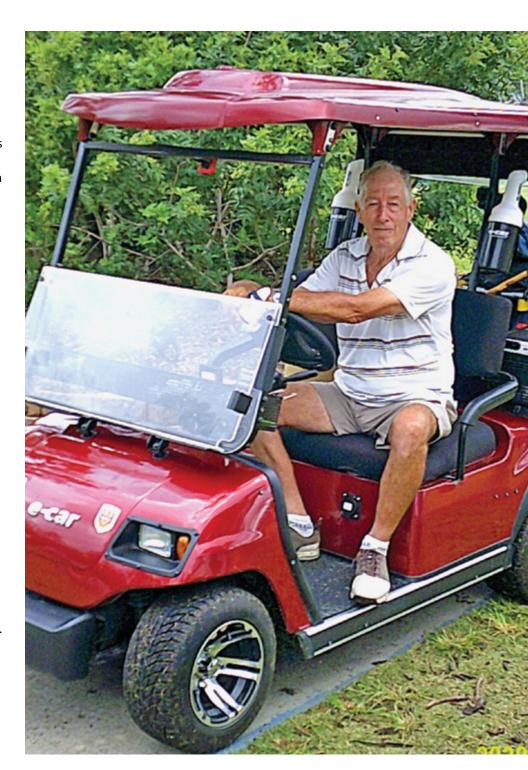
"Of course I was terrible at first, but I instantly fell in love with the game, the challenges, the camaraderie and the fun you have," he reflects.

After his stroke Russell was told he might not be able to walk again, but fortunately he soon began to experience some movement in his legs, ankles and toes.

He slowly progressed with the help of his physiotherapist and was finally discharged after spending 100 days in hospital. By this time, he was using a wheelie walker and could stand and walk unaided for short distances. However he was still uncertain if he'd ever be able to return to the golf course.

But then one day his brother, also an avid golfer, asked Russell if he'd like to join him on a round.

"It was great to just get out on the course in the buggy," says Russell.



Realising a spinal stroke had done nothing to diminish his love for the game, he bought a putter and a ball, and got to work.

"I was able to develop techniques to suit my limitations, such as my balance," he explains. "By the middle of June 2019, I was playing my first full 18 holes."

The only issue was the amount of ground players have to cover on the golf course during a typical round of golf: on average, around eight to 10 kilometres.

"There's just no way I can manage that distance," says Russell. "I can walk about 400 metres on a treadmill, but free-walking I can only walk about 200 or 250 metres, so I was flat out walking to one hole."

A golf buggy was the only option, but when you play golf three or four times a week, the hire costs quickly put this out of Russell's financial reach.

Without a buggy, Russell was simply unable to continue with the game that he loves – and so he decided to explore the possibility of purchasing a golf buggy as part of his NDIS plan.

"Because I'm limited in what I can do, golf is a big part of my life - without it, I'd just be sitting at home all the time," he says.

"The NDIS is all about supporting people with disabilities to pursue

their activities as much as possible, including sport and recreation, so I thought I'd give it a try," he says.

Russell's request to purchase a golf buggy from his NDIS funding was denied twice initially, both in his plan and a subsequent review, before he applied to have his case heard at the Administrative Appeals Tribunal (AAT).

During this time Spinal Life's Rockhampton team - Client Service Officer Kerrin-Lea Smith and Occupational Therapist Margaret Henry - supported Russell with advocacy and by sharing their expertise and advice.

After nine months of endless meetings, reports, a personal impact statement and documentation from not only Margaret but also Russell's GP and physiotherapist, his request was finally approved.

He received his golf buggy and trailer in October 2020, with funding for maintenance, insurance and registration included.

"Spinal Life were absolutely brilliant," says Russell. "I can never thank Kerrin and Margaret enough for the support they gave me, doing up reports and attending teleconferences with the AAT. They went far above and beyond anything I expected."

"I've shared my story to encourage people to keep trying. You never know what you can achieve, so please don't give up." A



#### **NEED HELP FROM AN OT?**

Spinal Life's occupational therapists are available across Queensland to assist with personalised assessments and advice for mobility, seating and assistive technology solutions, plus home and workplace modifications, and more.

Visit spinal.com.au/alliedhealth for details.

# "It feels like we're on a holiday somewhere really nice"

Why staying in a self-contained unit overlooking the Cairns esplanade beats more time in hospital



Sheryn Logan will never forget the fateful Sunday last year when, without any warning, she lost all feeling in her legs.

She was alone at her home in Speewah, Kuranda, about a 50-minute drive from Cairns, just pottering around and doing a few chores, when she suddenly "felt a bit weird".

"I called my husband to make sure he was coming straight home from work, but then my legs just went from underneath me – I couldn't feel them," recalls Sheryn. "It was very scary, but luckily I had the phone in my hand and was able to ring 000."

Sheryn was taken to the Cairns Hospital where it was revealed she'd had a spinal stroke: a blood clot in the spine, cutting off blood to the nerves. "They don't know what caused it, it's just one of those things that happens," explains Sheryn. "It's very rare, apparently, and left me with a T12 injury."

She spent two months in the Cairns Hospital before being transferred to the PA Spinal Injuries Unit in Brisbane for a further five months. It was during that time Sheryn started working with Spinal Life Australia.

It was her Support Coordinator, Alice, who – as well as doing everything from ordering equipment to looking after her NDIS account – suggested that Sheryn forget about going back to the Cairns Hospital, and head to Spinal Life Australia's Healthy Living Centre (HLC) in Cairns instead.

And that's exactly what she did.



"My husband and I have been here for about two months," says Sheryn. "It's been so good; so much better than going back into hospital again. We're staying in a spacious two-bedroom unit, with a kitchen set up so that I can do the cooking from my wheelchair, a great bathroom and there's even a café downstairs.

"We're right on the Esplanade and we've got the waterfront just out the front. Every morning we sit on our balcony with a coffee and watch the sun rise, or we head down and go for a walk along the Esplanade. Brad pushes me in my chair and it's just lovely.

"To me, being at the Healthy Living Centre feels like we're on a holiday somewhere really nice.

"The best thing of all is that we don't have to worry about hospital visiting hours. I've got lots of friends and family – my three children all live in Cairns – so we've hardly ever been on our own since we've been here! It's been a big help to have them around to support me."

But it's not just her friends and family who have helped smooth Sheryn's journey – she also sings the praises of her support team: "Everyone here at the Centre has been fantastic and looked after me so well".

She has two sessions a week with her physio, Julie; one's in the hydropool, which is a big hit with Sheryn who loves being in the water, while the other involves strengthening exercises in the gym.

"I'm in a wheelchair and have no feeling from just below my stomach and bottom, but I can actually stand up," says Sheryn. "I can't feel anything, so I really have to watch my feet because I don't know where they're going to go, but I am sort of walking. When I was in the PA I tried to walk with a wheelie walker, but didn't have any control over it. But Julie's helped me and I can now use one, so I am making progress. I've been told it takes about four years to really know what you'll be able to do and not do after an injury like this. In the meantime, these physio sessions are so important."

Sheryn's occupational therapist, Georgia, is another key member of the team. She's been helping Sheryn with everything from trialling smooth drive on her manual wheelchair to getting everything organised so that Sheryn will be able to drive again.

But helping Sheryn get ready to move out of the Healthy Living Centre and into a new home is one of Georgia's biggest roles.

"With all that's happened we've decided to move from Kuranda and live in Cairns, so we can be closer to everything," says Sheryn. "We've done a house swap with my son and his partner! They've moved up to our place in Kuranda and we're moving in to their home in White Rock."

Georgia is working with Sheryn and Brad to help make their new address more accessible. They've been going out to the house to determine what modifications are going to be needed, and Georgia has organised for builders to come in and give quotes. Then it's time to start the NDIS approval process.

"We've only got about another three weeks here at the HLC before we move to the new place, and the home modifications are going to take about eight months," says Sheryn. "So we're going to be roughing it a bit at first!"

The beauty of working closely with personal support workers in the HLC, and really getting to know them and form close bonds, is that they're the same team Sheryn will be working with when she moves into her new home.

And while that might be happening a little faster than some might expect, Sheryn is keen to make the move and get back to "normal" life as much as possible, because she's been working with Georgia and Tania from Spinal Life's Back2Work program, to help achieve another major goal: rejoining the workforce.

"I work in an office for a food company, taking orders and doing invoicing, that sort of thing, and am heading back to do three hours a day, four days a week – I'm really looking forward to it," says Sheryn.

"I'd just like to say thank you to the doctors, nurses, physios and OTs at the PA Brisbane and Cairns Hospitals, and of course to Spinal Life Australia for giving me the opportunity to stay at the Heathy Living Centre. After seven months in hospital, you really don't feel like going back again! To be able to come here instead of going back to hospital was wonderful. I'm so grateful. When I first saw it, I just said to Brad: it's like five stars for a person with a disability!" A

Visit spinalhealthyliving.com.au to find out more

# The latest

Information, inspiration and inclusivity

#### THE MUST-SEE EVENT OF 2021

Mark this amazing event on your calendar now. Taking place from 15 to 18 September 2021, the Undercover Artist Festival 2021 is a game-changing new arts and disability festival that's not to be missed.

Promising bold and daring performances from international, national and local artists, the festival is an Australian first. That's because it will headline only artists with disability.

They will break the rules, push artistic boundaries and, quite simply, entertain. Expect performances and workshops in everything from theatre, dance and comedy to circus, music, cabaret and poetry.

The Undercover Artist Festival is partnering with Brisbane Festival to bring this exciting four-day disability-led performing arts festival to Queensland. Don't miss it!

For bookings or more information, go to: undercoverartistfest.com







# **EXCELLENT FUN AT THE EXPO**

The Disability Service Provider and Participant Connection Expo 2021 is an opportunity to connect and talk with NDIS service providers in Australia. It was held at the Brisbane Convention and Exhibition Centre earlier this year, and the Spinal Life team – including Peer Support – was there to meet with people, discuss their unique needs and help them find the best services.

As part of the expo we also ran a competition with an incredible prize. Congratulations to Cindy Malcolm, who will be heading to Cairns to stay for five nights in a two-bedroom unit at our incredible Healthy Living Centre. She's also won a \$500 Flight Centre gift voucher to help get them to this

beautiful part of the world, and a \$50 gift voucher to spend at Guyala Café. It serves delicious food and coffee inside the HLC on Smith Street, just a few metres from Cairns' famous Esplanade.

And if you didn't get to speak to members from Peer Support at the expo, never fear: our groups hold regular catch-ups across Queensland and Western Australia. They connect people who have lived experience with physical disability, so that they can share their experiences. They're a great way for people with spinal cord damage or the late effects of polio to stay informed and connected with their local community. Refer to page 24 for contact details.

# VR CONNECTS PEOPLE WITH SPINAL CORD INJURIES WITH NATURE

A world-first study has shown the benefits of virtual reality (VR) for people with spinal cord injuries, allowing them to 'get back to nature'.

The study was led by Dr Ali Lakhani from The Hopkins Centre, one of Spinal Life Australia's most significant partners. The research took place in Brisbane's Princess Alexandra Hospital, with the help of Spinal Injuries Unit Leisure Therapists and Spinal Life's Peer Support team.

Dr Lakhani says the idea of the study stemmed from the fact that patients who are in hospital following a spinal cord injury have limited access to recreational activities.

"This can lead to poor emotional health from the acute stage of injury until transition to the community, and potentially adversely affect quality of life in the longer term," he explains.

The study explored how VR could be used to let patients experience 'natural' environments – and how in turn this impacted their psycho-emotional health.

The results were encouraging, to say the least. After each VR session, levels of happiness, relaxation and feeling good were significantly higher in participants. In the short-term, there was a definite beneficial impact on their psychoemotional health.

"These findings have important clinical implications," says Dr Lakhani. "There is potential for simulated natural environments delivered via VR to be incorporated into traditional rehabilitation settings. For example, physiotherapy or occupational therapy programs could deliver therapeutic exercises in a virtual natural setting – perhaps resulting in functional gain while improving psycho-emotional health."

The project will be used as evidence for VR-delivered recreational programs to be considered for implementation across health and hospital services.

"This research is also important as it was informed by the lived experience of people with spinal cord injuries and allied health professionals," says Dr Lakhani.

It has also formed the basis for future studies that will explore the impact of other recreational interventions, including visual art and meditation, on the health and wellbeing of people receiving rehabilitation in hospital and health services.

The study received funding support from The Hopkins Centre, Menzies Health Institute, Spinal Life Australia and Griffith University.



# **HOT BLOG:**

# The Life Quadriplegic

Continuing our rundown of the best blogs written by people with spinal cord injuries, this issue takes us to the UK...

**THE BLOG** | The Life Quadrapelgic (quadlifeblog.com)

**WHO RUNS IT** Alex, a 30-year-old quadriplegic powerchair user who lives in Lincolnshire, England, with his parents and "two hyperactive cocker spaniels named Millie and Lola". He's been living with disabilities since 1995 when he sustained a head injury in a car crash. Limited movement in his arms and legs means he needs to use a powerchair to get around... but it didn't stop him from graduating from university in 2012 with a BSc in Interdisciplinary Science and, later, a Masters in Global Environmental Change.

why we Love IT | Whether it's tech, travel, health or popular culture, Alex has the gift of being able to take any subject matter and make it super-interesting and engaging. From high-concept topics like "Artificial Intelligence: How Robots Could Help The Disabled" to everyday things like "5 Problems with Disabled Toilets", you just want to read every post!

# **Q&A WITH ALEX**

#### When did you start The Life Quadriplegic?

In 2015. It was originally called "Where There's a Wheel There's a Way" but that seemed a bit cumbersome, so I changed the name a couple of years ago.

### What inspired you to start it?

After I finished university I didn't know what I wanted to do. People had told me I was good at writing so I thought I'd give blogging a go. I hope that after reading my posts other disabled people might learn something, or be inspired to try activities or go to places that I talk about.

#### How often do you post?

I try to post once a week, but I'm a procrastinator so sometimes I don't publish for a month or more! And, thanks to the pandemic, I obviously haven't been able to go out much – and it would get boring if I just wrote about me sat on my computer all day! I also post on facebook.com/ AlexSquireBlog, twitter.com/AlexSquire22 and instagram.com/ alexsquire22





#### What sort of things do you write about?

Mostly about anything interesting I've been doing, as well as accessibility reviews of the places I visit. For example, the wheelchair access of places when I go abroad. I also write about more general disability-related things and some of my other interests, like chess, science, PC games, books, movies and technology. It's varied!

# If you could interview anyone for your blog, who would it be?

Tim Curry [legendary actor from *The Rocky Horror Picture Show*]. I'd talk to him about how he coped after his stroke in 2012 and how he's adapted to being a wheelchair user. He's kept quite a low profile since his stroke, so it would be interesting to find out more about his recovery and how he's doing now.

# What sort of advice would you give to anyone else starting a blog?

Try and write regularly. Maybe say to yourself: "I am going to publish a post every Monday" and then try to get into a habit and hold yourself to that.

# What's the best thing about doing your blog?

Being able to help people, whether it's by providing them information, entertaining them or showing them what's possible in life. Helping others is one of the most worthwhile things you can do, and blogging helps me do that in some small way.

Know of a great blog you'd like to recommend? Maybe you write one yourself? We'd love to hear from you at **theadvocate@spinal.com.au** and maybe feature you in a coming issue!

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<sup>..</sup> Larson et al. 2003\_Microbial flora of hands of homemakers (PM-10554) .. CPIC\_Market Survey\_IC user survey\_2016 (PM-06287)

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