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Cover photo of Jaimen Hudson courtesy Leighton De Barros, Sea Dog TV International

FROM THE CEO

Have your voice heard in 2021



Welcome to our new-look magazine, a collection of profiles, news and information that is relevant to you.

As you'd expect, the COVID-19 pandemic took up much of our focus in 2020, and many of our plans were put on the back burner while we worked to ensure the health and wellbeing of our customers, employees and community.

While we continued our advocacy efforts during this time, we're now participating in – and leading – more and more campaigns on key issues that impact your daily lives.

Earlier this year we joined the Building Better Homes campaign, a coalition of peak bodies and agencies seeking mandatory accessibility standards within the National Construction Code. If successful, it will result in hundreds of thousands of Australians having access to appropriate housing.

We're also part of the Assistive Technology for All alliance, which

includes advocates from both the aged care and disability sectors, and aims to address the current inequities between funding systems for people over 65 years who cannot access the National Disability Insurance (NDIS).

Another one of our key goals is to raise awareness of the devastating symptoms that polio survivors can experience later in life, so that health professionals, including GPs, can increase their knowledge and the support they provide.

Our accessible tourism work is also continuing, with our Advocacy Officers conducting a series of regional audits which has so far included Cairns, Mackay, Moreton Bay and the Sunshine Coast. The feedback they gather is provided directly to operators and businesses, and of course their reviews are added to our Accessible Australia app.

You can read about all these campaigns and more in this issue. I encourage you to become involved, whether it's writing to your local MP on a topic that's affecting you, or leaving a review on our app, to share more about the places you visit and help others navigate their communities.

Until next time, I hope you enjoy

MARK TOWNEND

Do you have a story to share?

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





ILSREHAB.COM.AU













Don't worry, be appy

If you haven't signed up to Spinal Life's Accessible Australia app yet... why not?!

This free, web-based app lets you "know before you go," so in just moments you can check the accessibility of places all around Australia.

It's an absolute must if you're planning an outing or a getaway - or just wanting a sense of confidence and freedom as you go about your everyday life.

You'll find reviews ranging from charming, personal messages to helpful lists, all written by the very people who use the app.

It's a living, growing, ever-changing resource, so we urge you to leave reviews of the places that you visit as well. Your tips and feedback will help us create the best accessibility resource in the country.

To give you a little taste, here are five of the top beaches currently featured on the Accessible Australia app. We hope to read your beach reviews soon!

Four Mile Beach, Port Douglas, QLD

According to reviewer Tim McCallum (who was using a power chair when he visited), this is "beach access done right". Four Mile Beach offers accessible parking, ramps to the sand and a mat to give wheelchair users direct access

to hard sand. It prompted Tim to write: "Congratulations and thank you Port Douglas Shire Mayor and team, as well as Port Douglas Water Sports for helping create such inclusive facilities for those with mobility challenges. Had a great day with my family and being able to build sandcastles with my son (priceless). Forgot the boardshorts, though. Didn't think the access would be so good!"

Fingal Beach, Fingal Bay, NSW

This beach has an access mat down to the water's edge, two different beach wheelchairs on-site hoist (BYO sling), great cafe, accessible bathroom and parking - and friendly, helpful surf life savers.



Burleigh Heads, Gold Coast, QLD

Three different beach wheelchairs are available for free use at this beach, where matting is provided every Saturday during the patrol season - and there's an accessible bathroom within the Surf Life Saving Club (SLSC).



Mt Martha Beach, Mt Martha, VIC

This beach has two floating beach wheelchairs and matting that extends right to the waterline (phone the SLSC for details) There's also parking available and excellent accessible facilities within the SLSC.



Ngarkal Beach, North Coogee, WA

Beach mats are provided here between October and Easter, and two different beach wheelchairs are available for free use. There are also accessible bathrooms, parking and access ramps and pathways.



Want to "know before you go"? Head to accessibleaustralia. com.au and follow the prompts. You'll find all sorts of businesses, services, locations and activities on this webbased app – but please keep adding your reviews!

*All accessible features are subject to weather conditions, tide times, resources, availability and bookings.









Jaimen Hudson's aerial footage of whales, dolphins and the Esperance coastline is breathtaking and has been seen by an astonishing 250 million people across the planet.

An uplifting story that promotes an understanding and respect for people living with disability, captures magnificent wildlife up-close and lets us travel to stunning locations? This is the film we all need right now!

Not bad for a guy born and bred in a little town in Western Australia with just 14,000 people. And even more astonishing when you discover that Jaimen does it all from a wheelchair.

Jaimen has always been passionate about the outdoors and, in particular, the ocean. His parents operated a diving academy from before he was born, and Jaimen learnt how to scuba dive at the tender age of 10. From then on if he wasn't diving, he was surfing, skateboarding or riding dirt bikes, until he sustained quadriplegia in a motorbike accident in 2008.

But just a few years later Jaimen had discovered his new passion: drone photography and videography. It's taken him down a new path, but one that still ensures he's in his happy place: near his beloved ocean.

Since then, as well as creating his incredible art (which he does while running two other businesses), Jaimen's also been named a WA Young Achiever, a finalist for Young Australian of the Year, and become a husband and a father.

And now he's the star of a 90-minute documentary film called *Jaimen Hudson:* From Sky to Sea, which tells the story of Jaimen's quest to get back in the water again, and go free diving with whales.

An uplifting story that promotes an understanding and respect for people living with disability, captures magnificent wildlife up-close *and* lets us travel to stunning locations at a time when most of the world is still in lockdown? This is the film we all need right now!

On the eve of the film's release in his home town, we spoke to Jaimen about this inspiring film and his extraordinary life...

The film's locations are stunning. Why Esperance and Exmouth?

Esperance is my home town and it's where we did most of the filming, but a lot of the good diving here is deep and it would have been far too great a risk to take me down to those depths. Plus, I've been very lucky to dive here a lot already, so I wanted to do something I'd never done before. That's where the idea for the film's grand finale came about: to travel north and free dive in the shallower waters off Exmouth.

What were the risks?

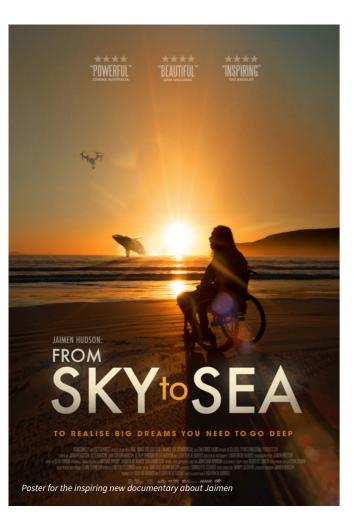
I'm like a lead weight, really. If you throw me in a pool, I wait on the bottom >











until you come and get me. We had to ensure I had decent buoyancy and that water wasn't going to enter my lungs, because I don't have my diaphragm assisting me to cough anything up. The main concern was if a big wave copped us over the head all of a sudden. Luckily, it didn't happen!

But it must have been tough to go into the water with that in mind?

If I'm honest with you, that was not my greatest concern. It was being with these wild animals. Trying to dive with a 40-tonne humpback whale on migration with its young, my main thought was: "Hopefully they don't squish me, because I'm not going to be able to move out of the way!"

Did you have any moments when you felt like you connected with the animals?

Absolutely. When we swam with a whale shark, even the dive masters who have worked out there for five years said it seemed like it was swimming in slow motion, as if it knew I couldn't swim fast. The humpback whales also swam slowly past us, and it felt like they looked me dead in the eye – it was this connection like nothing I can explain. I really do feel as if they knew I wasn't a threat and were just trying to put on a good show or welcome me to the ocean.

Your photography is exquisite. How did you get into drone photography?

About six years after my accident, a guy came to town,

wanting to go to Lake Hellier, the beautiful pink lake about 130 kilometres from Esperance. But it's extremely isolated and you can only get there by boat or helicopter. It takes five hours and a lot of fuel to get there by boat, so it's out of the question for the average person. But this guy *had* to go. It turned out he worked for the world's biggest manufacturer of drones, and needed footage for a soon-to-be-released model. When he returned he gave me some footage, and I was just blown away by the cool perspective it gave you. This was in the early days before anybody had drones, so I'd never seen anything like it before.

And that was it for you?

Yep, I started researching them immediately. Because of my reduced hand function I didn't know if I'd be able to operate a drone, but eventually we decided to buy one and if I couldn't fly it, we'd just sell it. But there were no problems operating it and I was hooked right away. I was out all the time, looking for wildlife. I was lucky to have a couple of my videos become quite popular online, and I guess the rest is history. It's still primarily a hobby, but I've been lucky that I can make a living from it as well.

Where do you love to film that you'd recommend people visit in Esperance?

Definitely The Great Ocean Drive, a 40-kilometre loop near the town centre. It's close to my heart because it includes a stretch of coastline where I've filmed the majority of my videos featuring dolphins surfing and whales interacting. Lucky Bay and Duke of Orleans Bay are also magnificent – you're pretty hard-pushed to find a bad beach down here!

So, what's next?

As well as continuing to shoot drone footage and running our businesses (Esperance Diving and Fishing, and Esperance Island Cruises), we've got an idea for a mini series featuring different islands of Western Australia. We'll start here in Esperance and work our way up the coast, maybe all the way to Christmas Island. The plan is to get me back in the water and tell the story about all these magnificent locations: ones with great wildlife, unique history and beautiful scenery both above and below the water.

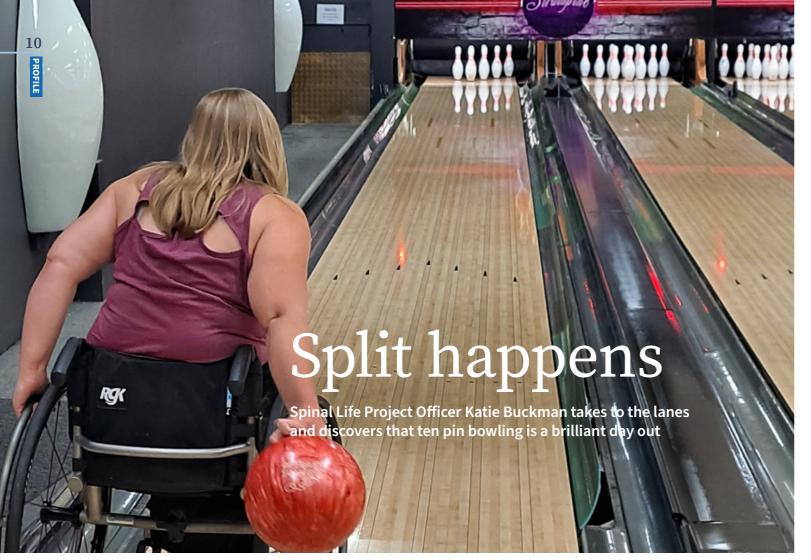
Once the world gets back to normal, is there anywhere in particular that you'd love to shoot?

I'd love to go to Tonga. The humpback whales are a bit more placid so you can spend longer interacting with them, and the water clarity looks amazing. But if COVID has taught me one thing it's just how *truly* magnificent Australia is, so I'd love to spend more time here, exploring, filming and sharing it with everyone.

Jaimen Hudson: From Sky to Sea is available for global 'cinema-on-demand' and virtual screenings via

Fan-Force.com

All images courtesy Sea Dog TV International and Jaimen Hudson.





Katie Buckman had a strikingly good time recently, and it was all thanks to her job as a Project Officer for Spinal Life, working on the Accessible Australia app.

This invaluable – and free – web-based app aims to give people detailed information about the accessibility of places all over Australia, so that they can explore the country with freedom and confidence.

A major part of Katie's job is to gather and input data from places such as local councils, tourism organisations and accommodation venues.

She also visits venues herself, to leave helpful, personal reviews for others.

So after working with Ten Pin Bowling Australia, Katie just had to go and check out the Strathpine Hyperbowl and knock down a few pins!

It was only Katie's second time in a bowling alley since sustaining

paraplegia in a 2009 accident. Her first visit was five years ago – and on that trip she didn't even pick up a ball.

This time around, however, Katie was with her children, aged four and two, and eager to enjoy a fun day out with them at their local bowling alley.

You can get as much assistance and advice as you need from Ten Pin Bowling Australia, but according to Katie, when it comes to bowling using a wheelchair, the best way is to just figure it out for yourself.

"It was the first time I'd bowled in 12 or 13 years, and the first time ever in a wheelchair, but I found it quite instinctive and natural," she says. "It just required a bit of trial and error."

Katie experimented with all sorts of different techniques. "When people bowl they normally face the pins straight on and position themselves right in the middle of the lane," she explains. "But I found it worked a lot better for me if I went right to the edge of the lane.

"I tried to bowl with no brakes on, but it felt a bit unsafe because your whole body kind of gets thrown forward. I also tried both brakes on, but that just stopped me in my tracks and I couldn't get any power behind the ball – I was lucky to get it down the lane," she laughs.

It was the first time I'd bowled in 12 or 13 years. > >

"Finally I tried one brake on and one brake off, and it all fell into place. I held onto my chair with one arm to give me stability, and then I could swing back my other arm, which was holding the ball. With just one brake on, the chair would swing a bit and give me some momentum, so I could get a bit more power behind the ball."

If you need a bit of extra help there are also ball ramps. "Bowling balls are quite heavy, so this is a safe and simple

option, especially if you don't have good balance or strength," says Katie. "You put the ball at the top of the ramp and simply push it down onto the lane. It's a great option for people who have quadriplegia but can use their hand or arm to push the ball."

A ramp is also ideal for children, and Katie's kids loved using one during their bowling adventure.

"I also really recommend using bumpers," says Katie. "They cover the gutters so your ball stays on the lane. I think if you went bowling regularly and perfected your technique you wouldn't need bumpers after a while. But this was my first time, so they were a lifesaver."

So is ten pin bowling something Katie would do again? "Definitely," she says. "When you get put in a chair and have to do something for the first time, you're not sure whether you're going to be able to do it. But now that I know I can manage it, I'd love to make bowling a regular family outing with my children and husband."



TEN PIN BOWLING TIPS



- Contact the bowling alley before you go so that they can put you in the most accessible lane
- Wear comfortable clothing something a bit looser so it doesn't limit your arm movement
- · Make sure you select the right size ball
- Use bumpers if you're a beginner
- Be patient! Give yourself a few goes to test out different methods and find the best one for you



Visit **accessibleaustralia.com.au** to find a ten pin bowling centre near you, and help others by leaving a review.

JOCELYN FINDS

Cairns stays easy

WITH CENTRE SUPPORT



Adelaide Paralympian Jocelyn Neumeuller has found her 'home away from home' in Cairns, where she goes to visit her twin sister, Simone.

"Simone told me about the Spinal Life Healthy Living Centre and how it's been designed especially for people with spinal cord injuries," says Jocelyn. "That was a really big attraction for me."

In 2012, a rare autoimmune disease left Jocelyn with partial lower-limb paralysis, and she turned to sport to help in her recovery. Wheelchair basketball and sailing were favourite activities, but towards the end of 2015 Jocelyn took up canoeing. She quickly excelled, and in early 2016 won gold in the national championships. Later that year she also qualified for the Rio 2016 Paralympic Games – and even placed fifth!

It's no wonder the athlete – who has completed a Bachelor of Medical Science at Flinders University and is now studying law and legal practice– is such a fan of the Healthy Living Centre.

"It's great to have so many services available, and so close by," says Jocelyn. "I can just go downstairs and everything's there."





Jocelyn took up swimming following a sporting injury – and it turns out she's good at that, too! So far she's competed in state swimming events and eagerly awaits the national titles, which are still on hold due to COVID-19.

In the meantime, she's stayed at the Healthy Living Centre twice during the past 12 months, with her faithful assistance dog Coco always by her side: "Being able to engage with the OTs, physios and exercise physiologists while I recover from surgery is giving me a headstart for when I get back home". There's a fantastic accessible gym ("probably the best I've seen") and a first-class hydrotherapy pool.

"Whether I'm at home or out and about, I like to try and be as independent as I can, and not rely on others to do everything for me," says Jocelyn. "The Centre is probably the closest I will ever get to being at home, with ceiling hoists and equipment and all the accessibility features.

"It's also so close to the city if I want to go out and explore – I can head along the Cairns Esplanade into the city at least once every day."

Visit spinalhealthyliving.com.au to find out more.

Happy 1st birthday...

TO THE HEALTHY LIVING CENTRE!



Regional Manager – Qld North, Margaret McDonald, looks back over the past 12 months at the Spinal Life Healthy Living Centre in Cairns. The Centre recently celebrated one year since opening in February 2020 – and what a year it's been.

What has been the biggest challenge since the Centre opened in Feb 2020? Our biggest challenge was the same as everyone else in 2020 – COVID-19!

We opened this beautiful centre and then COVID happened. Over the past 12 months, this has meant that while we've welcomed guests through our doors from all over Australia, the numbers have been severely impacted by border restrictions and people being unable to travel.

Even when the restrictions were at their highest, we were fortunate to still be able to offer many of our services as they were deemed as being essential. We continued to build our connections in the community and welcome locals into the Centre.

What are you most proud of?

I am incredibly proud of the team at the Healthy Living Centre. Without

them, it would just be a fancy building.

They're not only highly skilled, they're also strongly people-focused and committed to getting the best outcomes for people in the best possible way. I see examples of this every day: whether they're making sure accommodation guests are settled in and connecting to their Wi-Fi, supporting reluctant first-timers in the hydrotherapy pool or welcoming people for an event in our community rooms.

What's the feedback been like from Centre guests – and what are the most popular services?

All of our services are popular!
From the beginning we knew the hydrotherapy pool would be a hit – it's so accessible and relaxing to do exercise in the warm water with our friendly staff. The gym also has great equipment that people just don't have access to anywhere else.

Our accommodation absolutely blows people's minds – its accessibility and location are way beyond most people's expectations. Even though we've only been open for just over 12 months, we've already had quite a few repeat visitors.

Why is the Centre so important to the Cairns community?

For many years people in Cairns who had spinal cord damage didn't have access to these services and needed to travel to Townsville or Brisbane. Now, people can come home sooner and get the specialist services they need for life-long rehabilitation.

I recently showed Cr Bob Manning, Mayor of Cairns Regional Council, around the Centre and he was excited to see such a range of specialised services available to people in Far North Queensland. It also plays a small, but significant, part of the Cairns tourism scene, providing accessible accommodation for people who otherwise may not be able to holiday in the region.

I love showing people around the Centre. Almost without exception locals will say that they watched it being built. It's in such a great location, right beside the Esplanade, so lots of people drive past and have been excited to see inside and hear about the services we offer.

What are you looking forward to over the next 12 months?

We have big plans for the Centre! I'd like to build on our connections in the community and work closely with operators of accessible tourism attractions to grow Cairns' profile as one Australia's most accessible destinations.

I want to continue to be responsive to the needs of our local community, and deliver more specialist services. Our recently launched Wellness Series is a great step in this direction – special events featuring guest speakers who can share their expertise on topics that matter most to our community.

In a nutshell, the team and I are looking forward to welcoming more people – whether they're here for the first time or coming back for another visit.





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What are some of the things the Board's been up to

since the last issue of The Advocate?

January got off to a busy start for the Board. Part of our meetings always involve discussing financial and compliance activities, which are necessary as part of managing the organisation. We also agreed on personal development plans for all Board Directors, as part of having a professional and qualified Board to represent our members.

On a more interesting note, we discussed the issues our members who are over 65 are facing due to the disparity in funding compared with those eligible for the NDIS (read more on page 23). It's an issue the Board sees as important and so we have committed funding for an advocacy campaign to help support national efforts.

We also approved a new Research Committee, to be led by Board Director Professor Phillip Morris who has more than 40 years' experience in this field. The Committee will report directly to the Board and focus on clinical research with strong member engagement and links to research institutes.

2. What are the most important things you've achieved during this time?

Sometimes, the most important things are not always the most obvious – they're the things that our members tell us are important to them. Two of these priorities are tourism and transport. Spinal Life has a very active group of Advocacy Officers who have achieved some great outcomes. They have been travelling throughout the state researching accessibility in Far North Queensland, the Moreton Bay, Mackay and Sunshine Coast regions, with reports and recommendations being prepared for local councils, tourist operators and businesses.

We also recently conducted a Maxi Taxi trial at our Woolloongabba site which included member participation,



to make sure that the new fleet of vehicles are accessible for wheelchair users.

3. What are the biggest challenges facing the Board over the next three months?

With more than 10,000 unique shifts to fill each fortnight, our Personal Support and Home Care Services team are always busy, including our frontline Personal Support Workers (PSWs).

Like most similar organisations, we have issues around staff turnover to manage and will be continuing to look at this over the next three months. Some of this work will involve exploring how to increase the number of hours we can offer our PSWs, as well as bringing on additional team members to fill vacancies where there are gaps. We're also focused on engagement and supporting our PSWs in their daily roles, like giving them more access to online training and opportunities to meet with our CEO directly.

4. And the things you're most excited about?

There are a few things on the horizon, but in the short term it's the development of a new Rehab and Fitness Centre at our Woolloongabba site. Given the success of the Healthy Living Centre in Cairns and the demand for specialist rehabilitation, we anticipate similar demand in and around Brisbane. More details will be revealed in the next Advocate.

5. What's the one thing you'd love members to become more involved with between now and the next issue?

As mentioned previously, we're establishing a Research Committee. We'd like our members to be involved to help bring their lived experience and expertise to discussions and make sure our research is prioritised according to what's most important. Watch out for information on how to apply coming soon.



Last year, two Spinal Life Advocacy Officers were sent on a mission to explore Queensland's scenic Moreton Bay Region. Hey, it's a tough job, but someone's got to do it.

Dane Cross and Lachy Chapman headed to this beautiful part of the world to help create the Moreton Bay Region Accessible Tourism Review.

We spoke to Dane about how he helped create this important

What was your role in putting the Review together?

To gather accessibility information about the region and give recommendations that will help everyone in the tourism industry work together to truly make the Moreton Bay Region an accessible tourism destination.

Prior to COVID-19, the value of the accessible tourism market in Australia was greater than that of the inbound Chinese market 99

The biggest benefit of us getting out there was the subtle (and not-so-subtle) advocacy that we were able to do along the way. Having one-on-one interactions with operators and stakeholders went a long way in helping to raise awareness of the accessible tourism market.

What specific places did you cover?

The Moreton Bay Region has such a diverse range of offerings and attractions, it was challenging to cover them all.

We divided the region into four manageable 'sub-regions': Bribie Island, Redcliffe Peninsula, Southern Inland Areas and Northern Inland Areas. We then identified each of their key attractions and tourism operators, and set about visiting them. Lachy covered Bribie Island and I took care of the rest.

We spent a combined total of six days within the region and visited more than 40 places - everything from adventurous four-wheel-drive tours on Bribie Island, to wine tasting in a hinterland vineyard. There's a lot to do in the Moreton Bay Region!

What recommendations did you include in the Review?

Some of our recommendations were specific to the local tourism industry – such as encouraging all operators to have an up-to-date listing on the Australian Tourism Data

Warehouse. This information is then used to populate Spinal Life's Accessible Australia app, so it's vital it's accurate.

However many recommendations relate to all businesses, not just ones focused on tourism. For example, the need for disability awareness training to be undertaken by all staff, and refreshed and reviewed regularly. And for physical access barriers to be removed so that *all* people, regardless of ability, can gain equitable and dignified access to a facility or attraction.

What's the current state of accessible tourism, in general?

As we all know, the tourism industry has been decimated by COVID-19. Many operators are suffering and searching for ways to maintain revenue. I truly believe that the accessible tourism market has huge potential to fill a great portion of the void left by the absence of international travellers.

To put it into perspective, prior to COVID-19, accessible tourism domestically in Australia was estimated to be worth as much as AU\$8 billion per annum to the industry. A further \$2.1 billion came from overseas. That makes its value greater than that of the inbound Chinese market... and that's from an industry not traditionally geared to cater for, or market to, travellers with disability. Imagine if this market was able to realise its full potential!

There are opportunities everywhere, both within the Moreton Bay Region and across Australia. We are encouraging operators to improve their understanding of the opportunities created by accessible tourism and how to improve their offerings to this market.

And the Moreton Bay Region, in particular?

Overall, it offers plenty to the traveller with disability. With many new operators realising the economic potential of the accessible tourism market every year, the region has the potential to become the destination of choice for travellers with disability.

And with international borders remaining closed to travellers, tourism operators have increased incentive to consider the recommendations in the Moreton Bay Region Accessible Tourism Review and to view the accessible tourism market for what it is: an opportunity! >

Dane and Lachy's review was generously funded by a grant from Moreton Bay Regional Council. Visit accessibleaustralia. **com.au** to check out reviews of the Moreton Bay region and share your own experiences.



Dane's top five "don't-miss" places to visit in the Moreton **Bay Region**

Dane and Lachy created a series of accessible itineraries, offering suggestions for what to see, do and discover in the region.

According to Dane, while it's obvious that the region has made a significant effort to cater for travellers with disability, there's still a lot of work that could be done to improve accessibility and entice travellers with disability. That said, there are some significant and noteworthy locations deserving of specific mention.

Here are five attractions that both Dane and Lachy enjoyed.

BEACHES

A couple of beach access points deserve a specific mention: Woorim Beach on Bribie Island (via accessible beach matting), and the newly installed ramp and matting at Sutton's Beach in Redcliffe. Their presence means these beautiful beaches are accessible.











WALKING TRAILS IN D'AGUILAR NATIONAL PARK

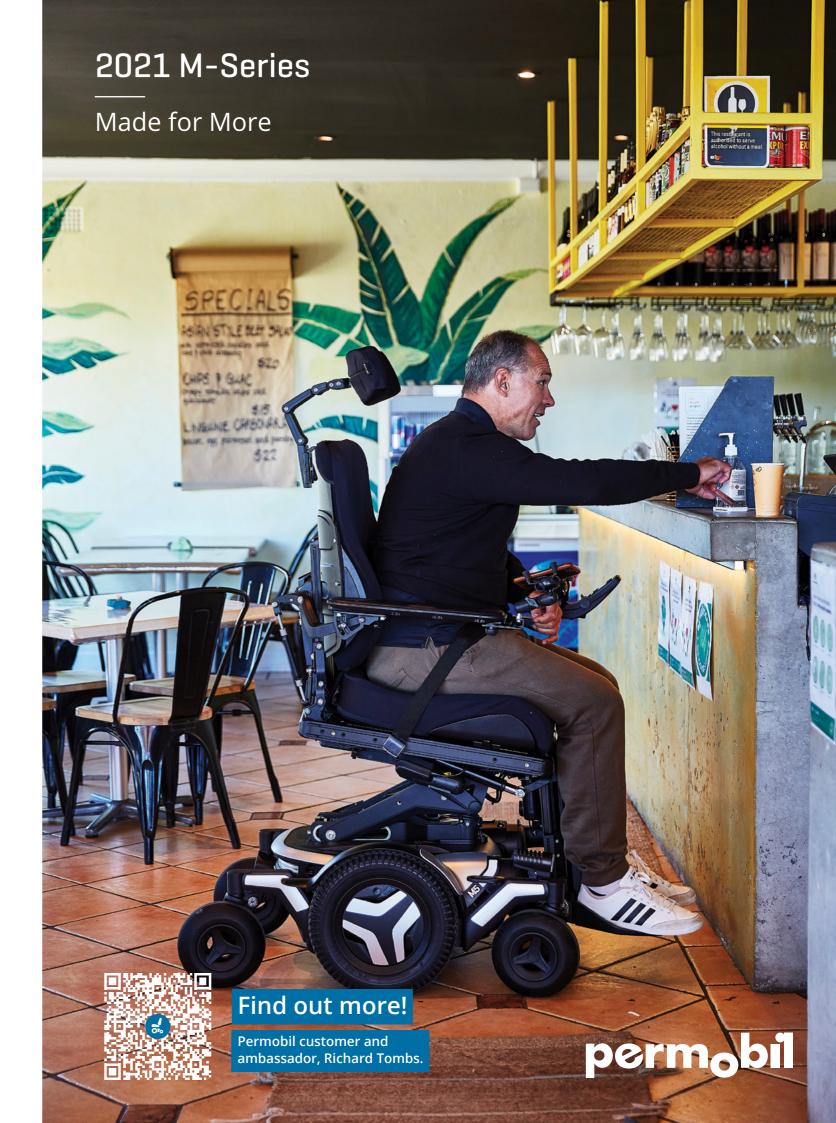
Boasting some 36,000 hectares, D'Aguilar National Park is a stunning region north-west of Brisbane. There are brilliant accessible trails in the South D'Aguilar section at the southern end of the park, with panoramic views from both Jolly's Lookout and Westridge Outlook. In the North D'Aguilar section don't miss Piccabeen Walk, which begins opposite the Gantry Day Use Area, a popular picnic spot.

THE CABOOLTURE HISTORICAL VILLAGE

The Caboolture Historical Village earns its place on this list thanks to its attitude towards access and inclusion. The Village's ability to modify decadesold buildings to provide access, along with its provision of accessible amenities and assistive equipment (wheelchairs and walkers) creates a welcoming and inclusive environment for travellers with disability.

G'DAY 4X4 **ADVENTURE TOURS**

G'day 4x4 Adventure Tours on Bribie Island make it possible for travellers with disability to experience their services. While their vehicle isn't defined as an accessible vehicle, their inclusive attitude makes G'day 4x4 Adventure Tours on Bribie Island a welcoming attraction. A





From being diagnosed with polio as a child to surviving an incendiary bomb during World War Two, Margaret Culling has been through it all – and now she's struggling with a medical condition many doctors are unaware even exists.

Margaret contracted polio in London in August 1939, when she was just five years old. Days later, the Second World War was declared.

She was placed in isolation for three months and put in an iron lung to stimulate her breathing, before being transferred to a countryside hospital as the war began to intensify.

It was there an incendiary bomb was dropped in the outside courtyard – right beside the ward where Margaret was sheltering with other children.

"In the morning there was glass everywhere and the nurses' quarters had been bombed, but luckily everyone survived," Margaret recalls. "I can still remember the nurses' stockings hanging in the trees where they had been blown thanks to the bomb."

Margaret spent more than three years in the hospital. When she left, she was faced with another challenge: starting school – at the age of *nine*.

"Polio had affected my whole left side and I just couldn't do the same things as other people," she says. "I had callipers for both legs that I had to wear at night while I slept, and a calliper for one leg that I used during the day with a walking stick."

Nonetheless, she flourished.

"I was put in the baby class and after a couple of months I was pushed up to the next one, and up and up until I got to my normal class," she remembers.

Three years later, Margaret moved with her family to South Africa. Once again she didn't let anything hold her back, learning how to ride horses, play tennis, swim and ride a bike.

She began working in an office when she was 16, and quickly

In the morning there was glass everywhere and the nurses' quarters had been bombed, but luckily everyone survived

moved up into a management role. Soon after, she met her future husband John, and the pair married and went on to have four sons.

It wasn't until many years later – decades after she was first diagnosed – that Margaret first began to experience the late effects of polio.

Up until that point, she had been perfectly fine: "I was working, helping my husband mix concrete and lay pavers," she says. And then, something started to feel wrong.

Margaret says she can pinpoint the day when it all started: "I was walking home, and all of a sudden it was like a brick wall came down in front of me and I couldn't move," she says.

"I tried to walk, and it was like I was pushing through something heavy. To get home took me forever, and when I got inside I collapsed in a chair.

"I didn't mention anything to my husband because I thought it was my imagination. Then, after about a week I said, 'something's happened to me'."

Margaret and her family moved to Australia in 1991, still with no answers to her worsening condition.

It was here that, finally, Margaret found the answers she was searching for – albeit in a very unlikely place!

On a chance visit to Albany Creek Shopping Centre she spotted a noticeboard near the post office.

"I'll never forget it," she says. "There was a green flyer with a phone number and a message that said: 'Have you ever had polio?'. I knew something was wrong, and so I called."

On the other end of the phone was the Spinal Life team, who provided Margaret with information and resources. They also encouraged her to see a specialist at the Prince Charles Hospital, who diagnosed her with post-polio syndrome, a condition that occurs due to the late effects of polio.

"I was a very active person, and I was teaching craft and used to sew every day of my life," says Margaret. "Now, I have issues with heat and pain, I'm very sensitive to anaesthetics and can't do what I used to do at all. Post-polio syndrome has also put me into a wheelchair."

One of the biggest challenges Margaret has found is that many health professionals, particularly general practitioners (GPs) and dentists, are unaware that the effects of polio can return later in life.

"They say, 'We didn't learn anything about polio when we were at university, that was something from long ago," says Margaret.

"They don't understand how you feel and put a lot down to old age. We all know we're getting old, but there are certain things that have nothing to do with that."

While sadly she lost John three years ago, Margaret's grateful for the support of her sons and their families, including the 11 grandchildren and 16 great-grandchildren who brighten her days. And, as The Advocate goes to print, she's excitedly awaiting news about the arrival of great-grandchild number 17!

Visit **spinal.com.au/polio** to learn more.

CALLING ALL GPS

We urge you to complete an online course that helps to identify the late effects of polio and support survivors.

It's been developed with leading Queensland experts and is accredited by the Royal Australian College of General Practitioners (RACGP). It's available for free on ThinkGP, a professional development website for GPs, and only takes around one hour to complete.

If you're not a doctor but think your local GP could benefit from this course, please share this link: www.thinkgp.com.au/education/polio2020. Or you can request a copy of the information booklet we've put together especially for GPs – simply email members@spinal.com.au or call 1300 774 625.

Everyone deserves the right to a safe and accessible home.

That's why we're continuing our fight for accessible housing and have joined the chorus of voices in the Building Better Homes campaign – a coalition of peak bodies and agencies who all want to see change happen.

The campaign recently gathered more than 15,000 signatures in a petition sent to Building Ministers from across Australia, ahead of a meeting scheduled for 30 April. At this meeting, a critical vote is set to be conducted: whether to include mandatory minimum accessibility standards for housing in the National Construction Code (NCC).

According to Spinal Life Chief Advisor – Government, John Mayo, nearly three-quarters of Australians with mobility impairment are unable to find housing that meets their needs.

This astonishing number includes people with disability, older Australians, people with a medical condition or chronic illness and those recovering from injury.

"There are so many flow-on effects of accessible housing," explains John. "When you have a safe, accessible, comfortable place to live, it greatly benefits your health and your ability to be independent. It minimises how much assistance you need in your daily life because it's so much easier to do things. This leads to increased opportunities to participate in the community and the workforce.

"Having more accessible housing options is also important for our ageing population, as it will allow them to live independently for longer."

Overseen by the Australian Building Codes Board (ABCB),

the NCC's mission is to provide "the minimum necessary requirements for safety and health; amenity and accessibility, and sustainability in the design, construction, performance and liveability of new buildings".

The possible inclusion of mandatory accessibility requirements for housing in the NCC stems from a review undertaken by the ABCB in 2017, following extensive advocacy from the disability and aged care sectors, including Spinal Life. A

Visit buildingbetterhomes.org.au to find out more.

OUR RECOMMENDATIONS

We're calling for a minimum Gold level to be introduced in the NCC, as per the Liveable Housing **Australia Design Guidelines. This includes:**

- · A safe, continuous and step-free path of travel from the street or parking area into the home
- · Wider dimensions for internal doorways and corridors, as well as between fixed benches in the kitchen and laundry
- · Access to a toilet on the ground or entry level, as well as a space that could be used as a bedroom
- · Having a bathroom with a hobless shower recess and reinforced walls, in case grab rails need to be installed later
- · Ensuring light switches and powerpoints are within easy reach, as well as doors and tap hardware that can be used independently









Aged Care recommendations remove over 65s inequity

The lives of older Australians with disability are set to improve, if recommendations from the Royal Commission into Aged Care Quality and Safety are put in place.

The Royal Commissioners' final report was tabled in Parliament on 1 March, and includes a recommendation that relates to anyone who is receiving aged care and also living with disability.



In most cases right now, funding provided to people aged over 65 with a disability is simply not enough

It says that they should receive supports and outcomes equivalent to those available under the National Disability Insurance Scheme (NDIS) – which currently only covers people who are under the age of 65.

"In most cases right now, funding provided to people aged over 65 with a disability is simply not enough," says Spinal Life Chief Executive Officer Mark Townend. "It considers only a person's age and not their specialised needs, including equipment, assistive technology and personal care."

For people aged over 65, the funding that's provided is nowhere near the level of the NDIS.

"This means many people are either going without muchneeded equipment, such as wheelchairs and other mobility aids, or they're forced to purchase these items themselves, on their own limited incomes, and may not be able to afford what's best for their health and wellbeing," says Mark.

"We also know many of our members are relying on loved ones to help. They don't have enough funding for personal support workers, which would enable them to be more independent and create less strain on partners and families."

The report recommended implementing changes by 1 July

2024, however Spinal Life is calling for these inequities to be addressed as soon as possible.

People with disability who are not eligible for the NDIS may receive funding from the Commonwealth Continuity of Support Program, My Aged Care or state-based aids and equipment programs.

Bribie Island Spinal Life member and advocate Bill Peacock, who is living with the late effects of polio and a spinal cord injury and has My Aged Care funding, urges the Commonwealth Government to implement the recommendations.

"When the NDIS came in, I was already over 65. I was very fearful of what my future held because I knew I was going to need more support," says Bill.

"With the prices of equipment and supports, I was greatly concerned about having enough funding to access what I need to let me live an independent, enjoyable life."

According to Bill, these recommendations will go a long way to make the funding systems far more workable.

The Royal Commissioners' report, titled Care, Dignity and Respect, includes 148 wide-ran ging recommendations, calling for a fundamental reform of the aged care system.

The report also recommends that both the Disability Discrimination Commissioner and the Age Discrimination Commissioner be required to report annually to Parliament to ensure equivalent access is being met.

Spinal Life is part of the Assistive Technology for All alliance, which includes advocates from both the aged care and disability sectors, who made the recommendations to the Royal Commission as part of a detailed submission.

For Bill and so many others aged over 65 and living with disability, the changes can't come soon enough.

Visit **spinal.com.au** to find out more on our advocacy campaigns.



When Cairns resident Lynn Barnes undertook major renovations to her home recently, both style and function were her inspiration.

With some clever design and thoughtful changes, Lynn's been able to not only increase the aesthetic appeal of her home, but also her own independence within it.

One of the main makeover areas was Lynn's bathroom. She faced several accessibility challenges in this room, including difficulty reaching the taps, insufficient space for wheelchair circulation, and needing to reduce the number of transfers.

"I wanted to make it as easy as possible so I can continue living here as I get older," she explains.

As part of the upgrade, the shower and bathtub were removed and an accessible shower area was installed, along with a toilet and hose beside the shower. Add in taps with levers, an accessible vanity with drawers and a towel grabrail, and the makeover was complete.

To achieve her bathroom goals, Lynn worked with Spinal Life Occupational Therapist Lucy Burke. Lucy completed assessments to apply for funding through the National Disability Insurance Scheme (NDIS), and to ensure the modifications would suit Lynn's personal needs.

With the NDIS requesting further information about how the modifications would improve safety and function for Lynn, they were only approved after two applications. All in all, the process took almost two years.

Lucy's tips for anyone applying for NDIS funding for home modifications are to include clear descriptions of the house in question, plus any accessibility issues – and be sure the descriptions are all accompanied by photos, as well as measurements to show circulation space.

Information about your daily routine and how the proposed modifications will improve your safety, function and the cost of personal care – and contribute to your independence – are also vital.

"We provided a clear drawing of Lynn's house, including doorway measurements, circulation space and the heights of appliances, and why these were not appropriate to her situation," says Lucy.

"While it's been a challenging and lengthy process, it was fantastic to see the modifications completed with the support of local builders."

And how does the bathroom owner herself feel about the makeover?

"I had input into everything, which was great," says Lynn. "I'm really happy with it." [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.

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Under pressure

Deb Dent, a Spinal Life registered nurse and expert in supporting people with spinal cord damage, shares her tips on preventing pressure sores.





Pressure ulcer points

In supine position. In side-lying position.

Pressure injuries are open wounds caused by continuous pressure or friction on a localised area. Although anyone can experience a pressure injury, people with a spinal cord injury are at greater risk.

Generally speaking, once you have a pressure injury the only way to treat it is to remove the pressure or friction. Depending on the location of the injury, this can mean sitting or lying down for days, which is something we all want to avoid.

If pressure injuries aren't treated quickly and appropriately, they can lead to hospitalisation, multiple surgeries and potentially devastating complications. Thankfully there are things you can do to help minimise the risks:

HOW TO PREVENT PRESSURE INJURIES

1. Check your skin regularly

Ask your partner or carer to check and double check areas. Ideally, you would do a full body skin check twice a day (morning and bedtime). Look for skin colour changes (redness or darkening), blisters, bruises, cracked, scraped or dry skin. Make sure you pay close attention to at-risk areas like your lower back, tailbone, heels, buttocks, hips, elbows, knees, ankles, feet and the back of your head. Make sure you check your nails as well – a cut along the nail bed or an ingrown nail can lead to an injury which can easily become infected.

2. Move more

Pressure relief is about moving or lifting yourself to remove the pressure on certain areas and promote blood circulation. If using a wheelchair, try and do some pressure relief movements every 15 to 30 minutes for at least 30 to 90 seconds. Do these movements whether it's in the car, at work, at the gym, at a bar and at home.

3. Invest in wheelchair cushions

A good wheelchair cushion can make a world of difference. There are a lot of cushion and mattress options that reduce pressure and promote circulation – speak with your occupational therapist to find what's best for you. Once you've made your choice, be sure to regularly wash your cushions and keep them inflated.

4. Establish an exercise routine

A good exercise routine will not only reduce your pressure injury risks but will make you feel good too. An ongoing exercise regimen will promote skin integrity, improve cardiovascular health and prevent fatigue and de-conditioning.

5. Eat well

You may be surprised to hear that what you eat can increase or decrease your pressure injury risks. Ensuring your nutritional intake has a healthy balance of calories, protein and micronutrients (zinc, vitamin C, vitamin A and vitamin E) will go a long way in improving your health and reducing your pressure injury risks. Make sure you talk to a qualified dietician before making changes to your diet.

Visit **spinal.com.au** for more information, including the stages of pressure injuries.



Photo by Oscar Nord on Unsplash

Did you know you can include important medical information on your phone's lock screen, to help emergency services if it's ever needed?

This means that first responders can access your critical medical information including allergies and medical conditions, as well as your emergency contacts, without needing your passcode.

It only takes a few minutes to set up and could make all the difference.

How it works

For iPhone users, you can update your personal profile in the Health app which has a Medical ID section. To make these details available from the lock screen, turn on 'Show When Locked'.

For Android users, there are a few different ways to set this up depending on what phone you have. If you have a Samsung phone, you can add it to your profile using the Contacts app – and check it's all working by swiping up on the lock screen and tapping 'Emergency Call'. Google Pixel phones use the Google app for the same purpose.

For all other Android phones, you'll need to tap 'Settings' and look for the 'About phone – Emergency Information' or 'Users and Accounts – Emergency Information'. You can also swipe up on the lock screen and tap on the 'Emergency' or 'Emergency Call' button to set up the details from there.

If the above instructions don't work for your current make or model, a quick Google will help answer your questions! **A**

Know a great health tip that you'd like to share? We'd love to hear from you at **theadvocate@spinal.com.au** – and may feature it in our next issue!





THE BLOG | myc5life.com

who runs it | Brisbane-based Lindsay Nott, who has 27 years' experience living with a spinal cord injury and wanted to share it with the broader community. He's an advocate for disability awareness and speaks at numerous engagements, as well as volunteering as a peer support mentor for people who are newly injured and their families. That's when he's not working, travelling... and writing a blog!

WHY WE LOVE IT | We love the site's clean and contemporary design, great photos and snappy, fun videos. We're also a big fan of the interesting mix of stories and adventure-filled experiences, and Lindsay's positive approach to everything.

AS HE SAYS | "My injury hasn't stopped me from making the most out of this beautiful life."

Q&A WITH LINDSAY

When did you start myc5life.com?

"It was launched in July 2020, but I'd been thinking about it ever since 2018. A friend was helping me out, but when COVID-19 hit I was able to *really* get things going. I even reached out to an organisation, Klyp, which is now helping me run the site.

What inspired you to start it?

"Six months after I left hospital I wanted to go travelling on a ski trip, but back then we had very few resources – not even the internet. So I basically just picked the brains of my physio and another gentleman who had travelled! Now that I have travel experience I wanted to share my knowledge with other people who might be scared to go on holiday for the first time, so they can see that it *can* be done."

Did you have any writing experience before you started your blog?

"No, I basically 'word bomb' and then piece it all together later! I do a lot of research and tend to write the way I talk."

How often do you post?

"At the moment, not as often as I want, but now that I'm more comfortable with the process, my goal is to post more regularly. I also share everything across Instagram (@myc5life), Facebook (facebook.com/myc5life) and YouTube (youtube.com/lindsaynott).

What's the best thing about doing your blog?

"Getting feedback and hearing from people who say they love what I'm doing. I've even had health professionals tell me they're using my site as an educational tool and inspiration for their clients. It's opened up lots more opportunities for me."

What's your most popular post so far?

"It's a toss up between 'An intro to flying with a disability' and 'Sun's up, surf's up'. One is about the realities of travelling on a plane and answers all the 'How do you do it?' questions. The other marks a big milestone for me: hopping into a pool for the first time since my accident – 25 years later!"

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

"Don't be afraid – just go for it. It's amazing how much you can touch someone's life – you might think it's just little, random stuff that you're talking about, but it can really make an impact."

Know of a great blog you'd like to recommend? Do you write one yourself and would love to share it with readers of The Advocate? We'd love to hear from you at **theadvocate@spinal.com.au** – and maybe cover your site in a coming issue!

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LIGHT WHEELCHAIR:

STRONG FRIENDSHIP



When Steve Fell needed a new wheelchair, he knew exactly who to call: his mate Dion Reweti from Wicked Wheelchairs.

The two first met around 20 years ago, when they were teammates in the Brisbane Wheelchair Basketball League.

Over the years their friendship has gone from strength to strength, with the added bonus that Dion has been able to share his expertise and knowledge to help Steve choose wheelchair models to meet his needs and active lifestyle.

Early on in their friendship they discovered they were both born in New Zealand, just one year apart. But it wasn't until 2014 that they realised their connection went even deeper. A family funeral was the unlikely setting for the revelation that Steve's long-time friend and wheelchair supplier was also... his cousin!

"I just thought, the world is so small," smiles Steve.

Steve is a New Zealand Defence Force veteran who represented the Land of the Long White Cloud at two Invictus Games - Toronto in 2017 and Sydney in 2018 competing in wheelchair tennis and basketball, as well as swimming.

"The Invictus Games weren't about winning for me, it was about camaraderie and participation," he reflects. "My fondest memories come from the connection that I was able to make with athletes and veterans from abroad."

Steve's continued to lead an active lifestyle, taking part in a variety of community and therapeutic activities, such as deep-water aqua aerobics classes and wheelchair tennis.

He says he couldn't do them without the support of the National Disability Insurance Scheme (NDIS), and last year used his NDIS funding to receive a brand-new wheelchair from - where else? - Wicked Wheelchairs.

Steve loves his Panthera X Carbon Fibre wheelchair, which is set to help make his life easier as he gets older, thanks to its transport weight of just 2.1kg and a total weight of 4.4kg.

"My wife always struggled to put my old chair in the boot of the car, so this will make her life easier too," says Steve.

"It's the lightest chair I've ever had - this has been a game changer for me."

Visit wickedwheelchairs.com.au for more details and to see the latest range.



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The latest

Information, inspiration and inclusivity



COME AND SEE US AT THIS MUST-VISIT EXPO

The Disability Service Provider and Participant Connection Expo 2021.

Phew! The name may be a mouthful, but the concept is simple: this is an expo dedicated to increasing connections between disability service providers, participants, carers and guardians.

Over two huge days you'll be able to find and connect with up to 200 service providers – including Spinal Life – all in one place.

To connect with this many service providers you'd usually have to schedule appointments in multiple locations - or make multiple phone calls. This is a great opportunity to save time and stress, and really connect.

The Disability Service Provider and Participant Connection Expo 2021 will be held on Friday 30 April and Saturday 1 May at the Brisbane Convention and Exhibition Centre, and is free to attend.

The event will also be held at the Perth Convention and Exhibition Centre on Friday 11 and Saturday 12 June, with Spinal Life hosting a stand.

Plus, come and visit us at either event to find out how you can win a trip to the Spinal Life Healthy Living Centre in Cairns!

Visit auscommunities.com/disability-service-providerand-participant-connection-expo-2021 to find out more.



Photo by Conrad Masset on Unsplash.

HELP OUR COMMUNITY – AND THE ENVIRONMENT

Do you or your friends and family have piles of empty cans and bottles mounting up? The easiest thing is to put them in the recycling bin for your weekly pick up. But if you're able to make a trip to a Containers for Change refund point you can raise money for our community and help the environment, all at the same time.

It's easy: when you drop off your containers, please use our scheme ID: C10271823. For every eligible

container you return, 10 cents will go towards helping our Peer Support program, ensuring we can provide one-on-one support for someone newly injured.

We hope you can help (geddit?!).

There are different types of Containers for Change refund points, so visit containersforchange.com.au to check the one that's right for you.



"My dream is to go to the college of my choice without having to worry about someone coming to tie my shoes every day.

At 16 years old, I am able to completely dress myself, but my parents still have to tie my shoes.

As a teenager who is striving to become totally self-sufficient, I find this extremely frustrating, and at times, embarrassing.

Bill Bowerman said it best, "If you have a body you are an athlete." I believe everyone, no matter what their physical, economic, or social circumstances may be, deserves to call themselves an athlete, and deserves to have a sense of freedom and independence."

This is an excerpt from a letter that Matthew Walzer posted online to Nike in 2012.

At the time he was 16 years old and looking ahead to university life. But while Matthew had overcame many of the physical obstacles presented by his cerebral palsy, tying his own shoelaces remained a challenge.

So he asked Nike for help.

His letter went viral and Nike were, understandably, moved and inspired. They got to work.

They collaborated with the teen visionary, sent him prototypes and listened to all his feedback. Then, in 2015, they launched the FlyEase – sneakers with no laces. Matthew's reaction was joyous: "Your talented team of designers has thoughtfully created a shoe that, for the first time in my life, I can put on myself. When I put the shoes on every morning, they give the greatest sense of independence and accomplishment I have ever felt in my life."

33

But the innovation didn't stop there, and in February this year Nike unveiled its latest design: the Go FlyEase.

These sneakers are not just lace-free; they're completely hands-free. The heel hinges, so your foot can slip right in. As you step down, the mechanism locks the shoe back in place. They're a marvel of engineering but, importantly, once on, just look like a super-cool sneaker.

This accessible and empowering shoe line is a game changer for countless people with physical challenges. And the inspiration for it all? A letter from a 16-year-old.

The Nike Go FlyEase is available on **nike.com**. Follow Matthew on instagram.com/matthewwalzer or visit matthewwalzer.com to check out his new website.



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Peer Support in your community

Our Peer Support Groups connect people with lived experience with physical disability to share their experiences, advocate for inclusive communities, hear from special guest speakers and talk about the issues that matter.

Our groups hold regular catch-ups across Queensland and Western Australia including for people with spinal cord damage or the late effects or polio. They're a great way to stay informed and connected with your local community.

Visit **spinal.com.au/peer-support** to find a contact in your region.

Spinal Life's Brisbane Peer Support Group and Board Director Michelle Wilson (below right) recently heard a presentation from Brisbane City Council's Connected Communities Project Coordinators.











JOIN US!

Our Peer Support Facebook group is a safe, welcoming and private online community to ask questions and share information. Just search for 'Peer Support - Spinal Life Australia' on Facebook and request to join!

ABOUT OUR SERVICES

At Spinal Life Australia, we support people with spinal cord damage to live an accessible, equitable and empowered life









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