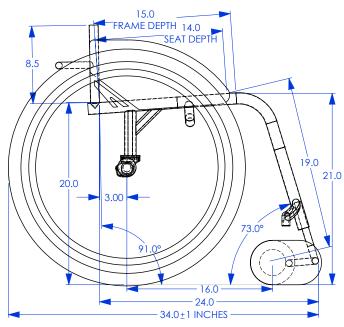




TiFit by TiLite is the art of building the ergonomics of the wheelchair around you, the rider. How you sit and fit in the chair is the greatest predictor of comfort and independence, and, over the long-term, will impact the likelihood of secondary injuries.

The difference between a TiFit chair and all other chairs is that a TiFit chair is tailored specifically to the person: Every chair is a made-to-measure, optimally fitted, wheeled prosthetic. The more you understand TiFit, the more you will realise that no other manufacturer does what we do at TiLite.



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Editor

Rachel Toune

Design and Production Manager Stephen Lawrence

Advertising Coordinator Samantha James

Publishing and Printing VRC Printing

Contact The Advocate: theadvocate@spinal.com.au PO Box 5651, West End QLD 4101 1300 774 625

spinal.com.au 🐠

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Stock images used are sourced from @iStock.com Cover photo of Bevan Kearsley by Stephen Lawrence.



In this issue of The Advocate, we are sharing more about our latest advocacy campaigns to create a more accessible, inclusive Australia for everyone.

One of our key priorities is accessible housing, to ensure all levels of government are aware of the many challenges faced by people with a disability, beginning with finding accommodation that is both suitable and affordable.

With the Australian Building Codes Board conducting a review into the inclusion of minimum accessibility requirements for housing in the National Construction Code, now is the time to make our voices heard.

We will be sharing more on how you can become involved in our campaign soon, including template letters and emails to send to your local MP to raise awareness of the issue.

Our recent Spinal Cord Injury Awareness Week campaign (7-13 September) also encouraged local businesses and tourism operators to focus on improving their services, especially as they begin to recover from the COVID-19 pandemic.

With the key message of 'Accessibility equals opportunity,' the Awareness Week shared stories from our community and tips on how businesses can remove physical barriers as well as make their accessibility information more accurate and more easily available.

We are continuing to explore ways to improve access and inclusion in regional tourism, which includes visiting

operators to conduct audits in Mackay, Townsville, Moreton Bay and Bribie Island, building on similar work which took place in Cairns late last year.

These audits will contribute to our upcoming Accessible Australia app, which will be launched soon for users to share photos and reviews of destinations you visit, from hotels, restaurants and cafés, bathrooms, parks, beaches and more.

In other news, we are continuing to respond to the COVID-19 pandemic, in line with the latest advice from government and health authorities.

I'd like to acknowledge the efforts of all our team, including our Personal Support Workers and Allied Health team, who have been working so hard to continue delivering essential services.

As always, we welcome your feedback as we strive to continuously improve – simply fill in the online form at spinal.com.au/feedback or email feedback@spinal.com.au.

Mark Townend Chief Executive Officer

CORRECTION:

In the Winter 2020 issue of The Advocate, member Joy Hay was incorrectly quoted with reference to researcher and writer Kerry Highley, who is not a polio survivor as published. We sincerely apologise to Joy for the error.









From growing up on a cattle station in Collinsville to now managing a large property at the back of Woodford, Jimmy Hammond has always loved life on the land.

Jimmy recently shared his experiences as part of our Spinal Cord Injury Awareness Week campaign, speaking about the importance of accessibility, particularly in smaller rural communities.

He said there were many challenges that he didn't know existed before he sustained his own spinal cord injury in 2009.

"I actually knew someone who had an injury before I had mine, so I knew what it was but I didn't know the major impacts it has on your life and how you get from A to B," he said.

"I come from a world where I grew up on properties, riding horses and motorbikes chasing cows, and this was a whole world unknown to me."

Jimmy and his wife Katie moved to their current property in 2016 which spans 41.5 acres, seeking to return to the farm lifestyle while raising three children.

With horses, cows, dogs and a cat, and the many daily jobs that come with having a farm, Jimmy has been working to make things easier for both himself and Katie, who also has a spinal cord injury and is part of our Peer Support team.

He has concreted a path from the house to the shed, worked out how to best access his tractor and now has a chair lift to get on and off his horse.

"It's about figuring out the best way to do things – everything works differently for everyone else, so what may work for someone may not work for the next person," he said.

Jimmy Hammond

- Grew up in Collinsville and was raised on a cattle station
- Moved to Adelaide before returning to the land after he turned 18, working as a jackaroo
- > Maintains a property spanning 41.5 acres where he lives with wife Katie and three children, as well as horses, cows, dogs and a cat
 - > Established his own business in 2019 conducting wheelchair maintenance and repairs
 - > Loves the driving aspect of his business, travelling around South East Queensland and finding new sights to see.

You can visit us on Facebook to watch Jimmy's video and read more about our Spinal Cord Injury Awareness Week campaign on Page 6.

Businesses encouraged to improve accessib



ility amid COVID-19 recovery efforts

Perth community advocate Karen Harvey recently took part in our Spinal Cord Injury Awareness Week campaign, encouraging local businesses to explore how they can become more accessible and inclusive for everyone, including people who use wheelchairs and mobility aids.

The message for this year's Awareness Week (7-13 September) was 'Accessibility equals opportunity', sharing stories from our members on what accessibility means to them and ways local businesses can make a real difference in their communities.

The campaign also aimed to raise awareness that it's more than just being able to physically access venues and services – it's about ensuring all venues and services provide comprehensive, accurate accessibility information that can be found quickly and easily.

As a Spinal Life Peer Support Officer working to improve inclusion in her region, Karen said even a simple catchup with friends meant planning the location in advance, to check there were no stairs to enter the building, along with things like bathroom availability and accessibility of seating areas.

She said sometimes the most challenging part was uneven or steep footpaths, which made it difficult to reach the venue in the first place.

"These physical barriers just put a stop to the thought of going somewhere," she said.

"It is disheartening to want to do something or go somewhere and these barriers dictate whether you go out or not – it's plain sad really."

Karen said she frequently returned to businesses that were accessible and encouraged others to visit these venues as well.

"I am always on the look-out for places that are accessible, so I can visit again with confidence," she said. Karen (pictured) was joined in our campaign by Gold Coast member Carol Taylor, who said accessibility was one of the biggest challenges she faced.

As a lawyer, artist, fashion designer, wife and mother, Carol said she had experienced exclusion and disappointment when visiting places such as restaurants and cafés, hotels, concert venues, beaches and even medical services.

Carol said she also conducted extensive research before going anywhere for the first time.

"If there was one message that I wanted to share for Spinal Cord Injury Awareness Week, it is that we need to

Tips for businesses

Below are some tips on how you can improve your services, as part of the Queensland Government's All Abilities campaign:

- Have a lower section of the reception desk to make it easy for people using wheelchairs to talk with staff when entering your office
- > Check the access to your building make sure there is a clear path to the entry, the door and hallway are wide enough for a wheelchair, there is enough circulation space in waiting rooms for a person using a mobility aid to easily turn around
- Ensure there is an accessible bathroom in your building
- Staff are trained to respectfully ask if a person may need some extra assistance.

Priorities for tourism operators

According to findings from Tourism Research Australia, the most significant priorities for travellers with a disability included:

- > Deals and offers for those travelling with a carer
- More information for accessible and inclusive travel including specific disabilities on review sites
- Accreditation or recognition of businesses that do a great job for travellers with disabilities
- Specialist planning tools so they could map out their entire journey

Visit spinal.com.au/awarenessweek/business for tips.

embrace universal design from the beginning – people with disabilities do not want to be an afterthought."

With the accessible tourism market in Australia estimated to be worth \$8 billion, and ongoing restrictions on air travel and border closures due to COVID-19, we are advocating for tourism operators in particular to focus on improving their services and making more people with disability aware of their accessible tourism offerings.

Our aim is to improve accessibility and inclusion in regional tourism, including conducting local audits in Mackay, Townsville, Moreton Bay and Bribie Island to provide feedback to operators and the industry.

Visit us on Facebook for the latest campaign updates and how you can become more involved.



For the past three years, the Australian Building Codes Board has been conducting a review into the inclusion of minimum accessibility requirements for housing in the National Construction Code (NCC).

This process has culminated in a Regulation Impact Statement (RIS), which was released for public consultation before final recommendations are made to the Australian Government.

We recently made a submission in response to this consultation, sharing feedback gathered through an online survey of our customers.

Chief Advisor - Government, John Mayo, said Spinal Life recommended including a minimum Gold level in the NCC, as defined by Livable Housing Australia Design Guidelines. He said it was critical that this issue was addressed for social and economic reasons, and to reduce the discrimination being faced by many Australians.

"This is an opportunity for the Australian Government to support all Australians who need accessible housing and give them a fair go," he said.

"By introducing legislation that mandates accessible housing, we will move forward as a nation and create a more inclusive community for all Australians."

John said questions had been raised in the RIS about the economic benefits of introducing legislation into the NCC. He said many of the flow-on effects of accessible housing were not considered, such as increased employment and productivity, and the need for paid and unpaid personal care.

"Our survey responses showed a clear connection between inaccessible housing and employment, including preventing people from taking a job, reduced hours and productivity at work, and losing or giving up employment," he said.

"It's not just about people with a disability – having more accessible housing options will also greatly benefit seniors,



people with medical conditions and young families who wish to have grandparents visit and provide support as well."

John said previous efforts at achieving accessible housing had focused on self-regulation within the industry, which had proved to be unsuccessful.

"That's why regulation is critical, to ensure that everyone can work together with one common goal, which should cover not only private homes and social housing, but tourism operators as well."

In 2017, the Australian Building Codes Board was directed by the Building Ministers' Forum and the Council of Australian Governments to undertake a regulatory impact analysis on changing the NCC to include accessibility in housing.

The first stage of this process involved an Options Paper, which was released in 2018 to outline the proposal in more detail, with the opportunity to share feedback on this document and a series of forums held across the country to discuss the issue.

Our Advocacy team also provided feedback on the Options Paper and took part in the Brisbane forum, providing our expertise as well as first-hand insights from our community.

Researchers Andrew Dalton and Emeritus Professor Rob Carter also prepared a comprehensive economic analysis for The Melbourne Disability Institute, University of Melbourne and the Summer Foundation, which also helped inform our submission.

The Dalton Carter economic report recommended further assessment be undertaken into introducing minimum Silver or Gold levels of accessible housing, in combination with a subsidy program to increase accessible rental housing.

To read our submission and find out how you can take part in our advocacy efforts, visit spinal.com.au/accessiblehousing or visit consultation.abcb.gov.au to find out more.



Your feedback

We surveyed our members asking what it is like 'living with a disability in inaccessible housing'.

Among the results, the survey found a connection between inaccessible housing and employment, with 100% of the respondents impacted in some way.

Has a lack of accessible housing ever:

Prevented you taking a job?	30%	
Reduced your hours of work?	28.33%	
Reduced your productivity at work?	25%	
Led to losing or giving up a job?	16.67%	

This further highlights the many economic benefits of introducing regulation on minimum accessibility standards for housing into the National Construction Code.

What is Accessible Housing?

Economic Development Queensland has three Principles which define accessible housing:

Principle one: Equitable use

The dwelling provides an easy and convenient living environment for all levels of mobility and health in a potential occupant.

Principle two: Flexibility in use

The dwelling provides for potential changes in the mobility and health of the occupant.

Principle three: Simple and intuitive use. The layout of the dwelling and its fixtures are easy to understand, regardless of an occupant's experience, knowledge, language skills or concentration level.

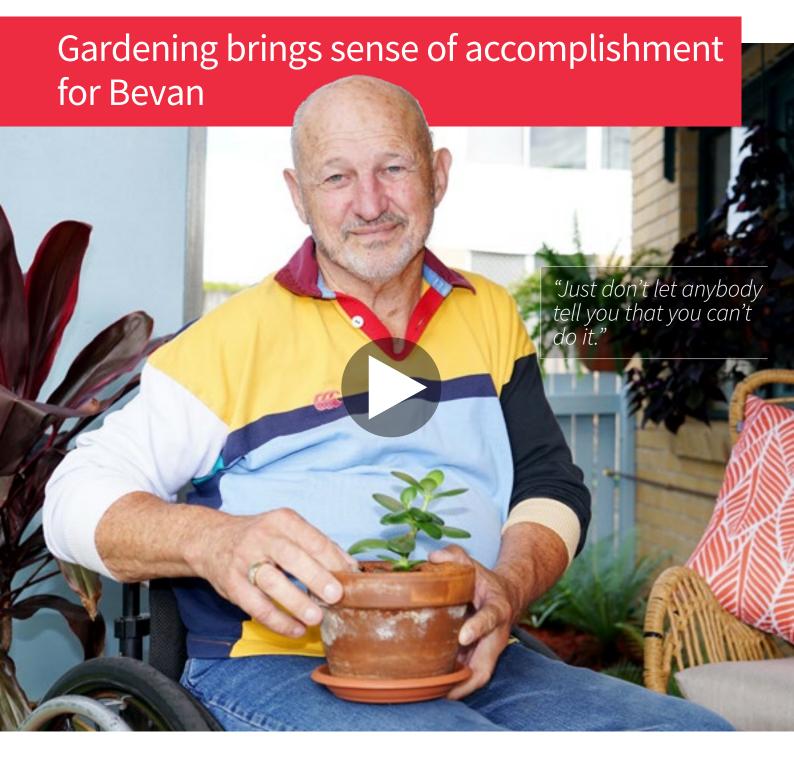
Make your voice heard

Join our campaign and have your say on this issue.

We are working to highlight accessible housing at all levels of government, so you can ask your local elected representatives to advocate for mandating minimum levels of accessible housing into the National Construction Code.

Visit spinal.com.au/accessiblehousing to download a template letter or email to send to your local MP to raise awareness of the issue.

You can also download a template for a letter to send to Australia's 10 largest housing construction companies asking them to consider leading by example when it comes to provision of accessible housing.



When visiting Bevan Kearsley at home, his natural talent and love of gardening is clear.

Since moving from Toowoomba to Brisbane two years ago, Bevan has created an oasis within his unit complex, progressively adding an array of hanging plants to the fences and making over the gardens with colourful foliage and greenery.

He said he could see the gardens needed attention when he first moved in and was always thinking about what he could create next.

"I enjoy the planning and seeing it grow from these little things – the more you plant, the more oxygen you get," he said.

"When you get out into the garden and look at the plants, it's relaxing, especially if you've had a busy day and want to unwind." Bevan has used hanging pots at various heights that are easily accessible for him and made a stand to rest the plants on whenever he needs to take them down.

As part of his gardening transformation, he put his carpentry skills to work and built a deck for the front of his unit, where he can "sit and watch the world go by."

"It's a floating deck so it's not attached to the building, which means it basically just sits on top of the ground," he said.

"I had to plan it in a way that I could start from the end and work back so I didn't have to climb over anything.

"It's just a nice place to sit and relax – it's quite enjoyable to look back and see what you've achieved, and that's what I've always loved about being a tradie."

Bevan said growing up, he had always been interested in joining the building trade, leaving school on a Friday when he was 14 years old and beginning his apprenticeship the next Monday.

When building houses, he was also tasked with landscaping on several occasions and that's where he grew his love of gardening, which was first inspired by his parents and grandmother.

"I spent most of my apprenticeship out in the bush and that's where you learn to do all aspects of the building trade and not just one part," he said.

"I learned landscaping, plumbing, painting, carpentry, plastering – the only thing I didn't learn was electrical."

Following his injury, he started a small business selling building supplies, and since retirement is still using his carpentry skills to build wooden lifting blocks that assist people with spinal cord damage during transfers.

Bevan encouraged others to try gardening and said there were many online resources to help get started.

"It's a hobby that is good for your mental health," he said.

"I've learned a bit over the years but if you know nothing about it and want to get started, just Google it or there's gardening programs on YouTube that show you how to do things.

"Just don't let anybody tell you that you can't do it."

Tips from our community

- Explore raised garden beds to access your gardens at a more manageable height. There are plenty of ready-made options available for purchase, or you can make your own from wood, tubs, old tyres – or even styrofoam boxes from your local fruit shop, sitting on a few milk crates!
- Stackable pots, vertical gardens or planters on stands are also a good option and can be found at many discount stores as well as larger retailers.
- Look into self-watering garden beds or watering systems with timers – or technology like the 'WaterMe Wireless Irrigation Controller' system, which allows you to control your irrigation system with your phone, tablet or computer.
- Use quarter turn garden taps which have a lever that makes it easier for anyone with dexterity challenges.

For more tips, visit the Peer Support Facebook group (search for Peer Support Spinal Life Australia on Facebook to join). You can also search for past posts for more great gardening ideas.





Vehicle Mobility Solutions

- Accessible Vehicle Hire (Short/Long Term)
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- Steering Spinner Grips and Controls
- Personnel Transfer Aids
- Wheelchair Loading Hoists
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CARING



Artistic passion gives Andrew ne



wfound purpose

For Andrew Evans, art is more than just a hobby – it's a chance to express his sense of humour and his creativity, it's a welcome distraction from chronic nerve pain, it's shared time with his daughters, and so much more.

After sustaining quadriplegia in 2001, Andrew returned to his life-long passion for art, switching to mouth drawing when he could no longer use his hands.

He was inspired to begin drawing again after receiving a postcard in the mail from the Mouth and Foot Painting Artists association.

One of his neighbours, who was a retired builder, made him a wheelchair accessible easel that he still uses today.

"I basically picked up where I left off drawing with my hands," he said.

"I've just had to learn to hold my breath when I'm doing really fine things like drawing a line or a circle."

Andrew prefers to use a pacer (a mechanical pencil) when drawing on paper, clicking the button with his tongue whenever more lead is needed, and continues to experiment with oil and acrylic paints.

He has also learned the art of digital drawing, which involved trialling and testing several different apps and devices to see what worked best for his individual needs.

"I've got an iPad with an Apple Pencil and the Procreate app and that's brilliant to do all the digital drawings."

Andrew's work can be found across Pinterest, Instagram and YouTube, under the moniker 'Smart Mouth Art' – a mixture of lighthearted cartoons and line drawings filled with intricate details.

Along with exploring his creativity, Andrew also uses art as a welcome distraction from chronic nerve pain, combining his drawing with listening to music.

He has experienced chronic pain after his spinal cord injury was aggravated further when he was injured on a bus in 2012, which fractured his C5 vertebrae.

"The biggest thing I've learned about chronic pain is that distraction is key, so I'm always keeping my mind busy – I'm constantly learning or listening to a podcast or audio book, or drawing," he said.

Andrew has the support of his wife Melissah, as well as his two daughters, Jorjah, 11, and Isabellah, 8, who are both creative and love drawing with their Dad.

One of Andrew's latest business ventures involves being part of a 'print on demand' website, with his images available on everything from t-shirts to towels, while he also has an online gift shop selling printed coffee mugs.

He is furthering his creative skills by spending his weekends learning to use a computer-controlled cutting machine, called a Computer Numerical Control (CNC) router, which is used to carve designs into wood. Andrew has been doing this by visiting a local tree lopping company, who have been teaching him with the use of their own machine. Andrew has used his NDIS community participation funding to make this happen.

"They have been showing me how it works on their huge CNC machine in their workshop, so eventually when I get mine I'll be a step ahead," he said.

Andrew has published a series of timelapses on his YouTube channel, showing his digital drawings coming to life, and is also looking at other ways to share what he's learned over the years, including low-cost modifications and technology he uses at home.

Andrew regularly liaises with Spinal Life's NDIS Supports Coordinators to help implement his NDIS plan, and has also been assisted by our Occupational Therapists, particularly with pressure area mapping and trialling multiple wheelchair cushions. He has also received individual advocacy assistance from our Advocacy team.

Visit spinal.com.au or call 1300 774 625 to find out how we can support you.



James back on the bike thanks to



Since he was three years old, James Powell has had a passion for riding bikes – and for fixing things.

The Caboolture resident has drawn on his skills as an aviation engineer to modify his motorbike, designing his own 'landing gear' system to allow him to stop safely and keep his balance. Following his spinal cord injury in 2009, James initially returned to riding on a quad bike, but faced restrictions and

red tape when he sought to have the vehicle fully registered. "I realised if I was able to modify a normal motorbike, then all the restrictions could be removed," he said.

James purchased an automatic motorbike, a Honda 2016 Africa Twin, which needed to be modified to suit riding on dirt tracks (often for hundreds of kilometres), as well as commuting to and from work.

aviation ingenuity

"The biggest challenge was stopping – I couldn't make the system run automatically because if I'm in an off-road environment doing slow maneuvering or locking up the wheel into a corner, I didn't want the landing gear coming down automatically" he said.

James researched many different options, but found existing systems would not be reliable or durable enough for long days riding out in the bush.

With many years' experience in the aviation industry as a technical support engineer, James saw a connection between the modifications he needed and the movements and linkages that occur within an aircraft when landing.

He set about installing stabiliser wheels on each side of his bike and built a landing gear system that raises the wheels and lowers them slowly when he is ready to stop, just like an aircraft.

"I have a button on the handlebars and the landing gear goes down when I press it," he said.

"I can even keep the stabiliser wheels part-way down so I can stop faster if there's an emergency situation.

"It keeps me in an upright position when I stop and also means the bike is stable enough to transfer onto."

James has also undertaken further modifications to the bike, including adding wheelchair storage on the back, and an Airhawk motorcycle cushion to prevent pressure areas.

The modifications took James eight months in total, which included designing, constructing and trialling several prototypes, engineering certification, registration, doctor approvals and occupational therapy assessments, as well as completing riding courses to obtain his licence.

He has now been using the bike for three years and particularly enjoys spending time exploring new places in the bush, usually with a group of riders who share his interests – including his dad who is a fellow riding enthusiast.

"These are normally big days – the biggest was about 700 kilometres of dirt trails," he said.

"I find that riding gets me out of my chair, provides normality, helps with pain, clears the head and soothes the soul."

He has also shared his knowledge with others wishing to get back onto their bikes, along with speaking to a variety of audiences about returning to riding following his spinal cord injury.

James was part-way through his apprenticeship in aviation engineering when he sustained his spinal cord injury and was able complete his studies while supporting different areas of the business within the office, including reviewing reoccurring issues and reliability.

In his current role as a technical support engineer, he is responsible for managing any issues with the aircraft, from defects and repairs that arise to scheduled maintenance and replacement of parts periodically.

Aside from riding, James enjoys spending time with wife Megan and son Taylor, 7, and daughter Ava, 5.

"I was really worried before having kids as to how I would cope – how I could lift them, teach them to ride a bike, things like that," he said.

"The truth is, they adapt and you both find a way."

James has also won six titles in body building prior to becoming a father and had been planning to compete again prior to COVID-19, which has put his ambitions on hold for now.

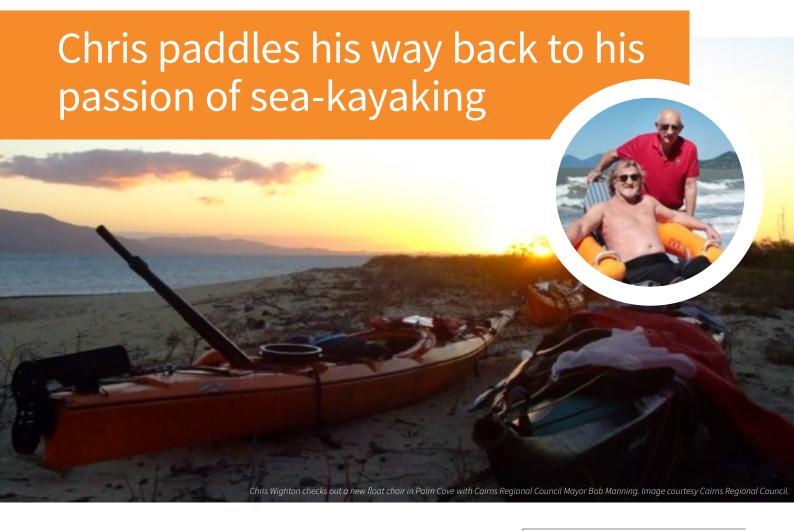
He has been supported by Spinal Life's Occupational Therapists with his equipment prescriptions, along with assistance from our Advocacy team during his bid to have his quad bike fully registered.

When asked for his advice to others with injuries, James said it was about finding a different way to do things. "Don't listen to the naysayers, if you want to do something,

just do it."

Visit spinal.com.au or call 1300 774 625 to find out how we can support you.





Chris Wighton has a simple method for getting back in a kayak after you fall out.

"First you panic for a bit, then you build up your strength and get back in again," he said.

"And you can always call on your friends for some help."

That attitude is also what helped the Cairns member get back on the open ocean and rekindle his love of seakayaking after sustaining a spinal cord injury in 2012.

"Before my accident I was a serious sea-kayaker, sometimes taking trips that would last for weeks," he said.

"After my injury I thought my days on the ocean were over – I even went as far as to sell my kayak."

While Chris tried to hang up his paddle for good, his kayaking friends weren't content with letting him off the hook.

"I thought I was done, but my friends were determined to get me back into it," Chris said.

"With their help, I managed to slowly regain my confidence, practice transferring in and out of the craft and was eventually able to get back to the open ocean once again.

"Getting back on the water after everything that had happened was just wonderful – I felt so elated."

In 2014, two years after his injury, Chris and his kayaking friends set off on a two-week ocean journey from Palm Island to Hinchinbrook Island, via Orpheus Island.

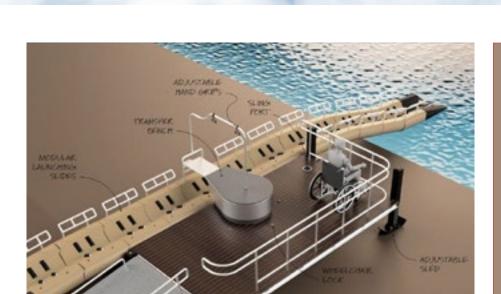
"That trip was about spreading awareness of mental health, as well as showing what is possible for people with a disability," he said.

"I'm getting older now and my days of being at sea for weeks at a time may be "Getting back on the water after everything that had happened was just wonderful – I felt so elated"

over, but I still love every chance I get to get back on the water.

"Feeling at one with everything around you, being at the mercy of whatever the sea has in store and even the quiet repetition of it all – it's just like nothing else out there."

You can learn more about Chris' journey with spinal cord damage and getting back to the water by watching his TEDx Talk Legless and all at sea on the Great Barrier Reef, available to watch on YouTube.



Kayak platform design project asks students to consider accessibility

We recently initiated a new project designed to encourage Industrial Design students to include greater consideration of accessibility in their designs.

In the project, thirteen teams of Queensland University of Technology (QUT) students competed to design an accessible watercraft launch and recovery system which would allow people with a physical disability to go kayaking in lakes and dams.

The entries were judged by representatives from Spinal Life and Seqwater, with Seqwater providing a \$2,000 prize to the winning team.

The winning design was the "Adaptic Land Launcher", which uses a launching slide with railings in combination with a transfer bench and adjustable hand grips to allow kayakers with a disability to transfer to and from their mobility device to their watercraft.

Executive Manager – Member Services Ross Duncan said he was very impressed with the entries, especially as social distancing restrictions meant online collaboration was the students' only option.

"A key goal of this competition was to get the students to start thinking more about accessibility and the needs of people with a physical disability, and how it can be incorporated into the design process," Ross said.

"As many Spinal Life members would be the ones to benefit from a project like this, we wanted to include them in the judging process, and they were very impressed with how well disability was considered in the entries.

"As these talented students move towards professional careers, we hope they continue to innovate as they help shape the future of design and infrastructure in our communities."

QUT Creative Industries Facility senior lecturer Andrew Scott said the winning design will be further refined for potential development and testing and he hoped to eventually see the final product in waterways around Queensland.

"All the students involved definitely rose to the challenge," Andrew said.

Visit spinal.com.au/our-advocacy-work for more information on our advocacy work.

Tips on getting involved in watercraft sports

"A key goal of this competition was to get the students to start thinking more about accessibility and the needs of people with a physical disability"



As we work to strengthen our organisaton and our community, we are focused on continuing to improve the services we deliver.

Guided by survey feedback from our customers, we've established the FOCUX (Focussing On Customer and User EXperience) Project.

This project includes a range of key initiatives that will deliver significant and immediate benefits for our employees and customers as well as informing future service improvements.

For example, we are undergoing some changes to the structure of our Personal Support and Home Care Services and upgrading technology and systems to ensure our employees have the latest tools to support them to perform their roles effectively.

We are also increasing training and coaching for our Personal Support Workers to build their existing skills and knowledge, as well as improving the rostering and communication processes.

As we make these changes, we'll be following up with customers through satisfaction surveys to fine-tune our service improvements.

We also have a dedicated Feedback and Compliance Manager to manage and respond to feedback, and we encourage you to fill in the online form at spinal.com.au/feedback or email feedback@spinal.com.au.

As COVID-19 restrictions ease throughout Queensland and Western Australia, we hope you are continuing to look after your health and wellbeing.

Don't forget, if you would like to reach out to someone who has their own lived experiences with physical disability, our Peer Support team is available to support you in person, over email or phone, or in our private Facebook community.

You're also welcome to get in touch with me directly at chair@spinal.com.au if you would like to share any feedback.

Gyl Stacey Chair

Annual General Meeting goes virtual

For the first time, Spinal Life Australia's Annual General Meeting (AGM) will be held as a virtual meeting, making this important event more accessible than ever for our community.

The AGM will be held on Thursday 26 November at 10am, with the opportunity for our members to watch, listen and submit online questions.

In planning for this year's AGM, the Board has reviewed the health and safety of our customers, employees and other stakeholders and considered the current uncertainty surrounding the COVID-19 pandemic.

At the meeting, we will present a summary of the organisation's activities and financial results for the 12-month period ended 30 June 2020.

In late October we will be sharing further details on how to access the virtual meeting and voting instructions, plus uploading our official Notice of Meeting, 2019-20 Annual Report and Financial Report.

All AGM voting will be conducted online in accordance with the requirements of the Constitution of Spinal Life Australia and all relevant legislation.

If you are unable to vote online or would like some assistance in attending the virtual meeting, please contact 1300 774 625 or members@spinal.com.au. Visit spinal.com.au/agm2020 to find out more.



Looking to the future

The Board is excited to announce that Spinal Life's new strategic direction has been finalised, which will help us to achieve our mission of supporting accessible, equitable and empowered lives.

Our new strategic direction will guide our activities and set clear goals, so we continue to be a strong, financially sustainable organisation, following our successful transition to the NDIS, expansion of our services and opening of the Healthy Living Centre in early 2020.

You can hear more at our upcoming Annual General Meeting, or read the next issue of The Advocate for the full story.

Changes to membership fee

To help keep our members connected to peer support, advocacy and other important services, the Board has made the decision to remove the membership fee for the 2020-21 financial year.

This fee has been waived for new members as well as existing members, who have automatically had their membership extended as of 1 July 2020.

At the 2020 Annual General Meeting later this year, the Board and voting members will decide on if this change should be made permanent.

If you know anyone who would benefit from becoming part of the Spinal Life Australia community, they can now become a member for free by applying at spinal.com.au/membership or calling 1300 774 625.

What our Board Directors say:



Gyl Stacey ^{Chair}

"We've seen many great changes and unforeseen challenges for our organisation over recent times, and this new strategic direction ensures we have a clear focus on how we can continue to achieve our mission and continue to deliver efficient, customer-aligned services into the future.

"As Chair of the Board, I'm looking forward to sharing more on our plans and continuing to engage with our members, working together to create positive outcomes and strengthen our organisation for years to come."



Mark Dillman Deputy Chair

"I have served on the Board of Spinal Life for over 12 years and have enjoyed contributing to the development of the previous Strategic Roadmap that has resulted in the organisation almost tripling in size.

"We have recently revisited the strategic direction of Spinal Life and I am excited to see how changes that have been made will continue to enhance our service offering, our ability to influence government at all levels, and the impact this will have on improving the wider community for the benefit of our members."



Phillip Morris Board Director

"Joining the Board in 2018 has provided me with an opportunity to contribute to the organisation's growth. It has been rewarding to be part of the development of our new strategic direction and to ensure the "lived-experience" voice is heard on the Board.

"As a researcher for many years, and with my own personal experience with spinal cord damage, I have been keen to see Spinal Life expand its participation in the research space and look forward to this growing in future."



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Surprise apnoea diagnosis makes a world of difference for Vicki



It took Vicki Field years to realise it wasn't normal to feel tired all the time.

"I just always felt like sleeping – it was rare to see me without dark rings under my eyes," the Brisbane member said.

"Being tired became my new normal but after several years of it, I could tell something was wrong and decided to see a professional."

Vicki's doctor recommended she undergo a sleep study at the Sleep Disorders Clinic at Princess Alexandra Hospital.

From there, Vicki (pictured right) discovered she had sleep apnoea, a disorder that disrupts regular sleep patterns by obstructing breathing.

"The sleep clinic staff told me that apnoea can be a common occurrence in people with quadriplegia," she said. "I was shocked – as someone with a C6 level spinal cord injury and experience working in Allied Health, I thought I had a fair idea of the potential health impact of spinal injury, but apnoea is something I never even considered."

To help regulate her breathing, Vicki now uses a CPAP (Continuous Positive Airway Pressure) machine, a device that delivers constant air pressure to keep her airways open during sleep.

She noticed the difference immediately.

"My apnoea was just a mild case but using the machine still makes a world of difference," she said.

"It's admittedly a bit odd to sleep with a mask on at first but it's absolutely worth it to get a proper night's sleep." Vicki said she's sure she's not the only person with spinal cord damage to not be aware of their apnoea risk.

"During a conversation with (Spinal Life Peer Support Officer) Col Mackereth, he mentioned how he was constantly tired and I advised he should follow my lead and get tested for apnoea," she said.

"Turns out he had a particularly severe case and he had no idea either that he was at extra risk as a person with quadriplegia.

"If you are constantly tired, or have a partner who has noticed you snoring, breathing irregularly or gasping for air during the night, I recommend bringing it up with your doctor, especially if you have a spinal cord injury. It's made such a difference; I only wish I got tested sooner!" Research from the Institute for Breathing And Sleep (IBAS) in Victoria, published in 2019, found more than 80 per cent of people with quadriplegia due to spinal cord injury have sleep apnoea, with many not aware they have it and don't know it can be treated.

You can read the research at ibas.org. au/blog/read/77/do-you-have-spinal-cord-injury-tired-get-treated or connect with others on our private Peer Support Facebook group.



Pain explained – identifying and managing chronic pain



Sustaining a spinal cord injury can often result in an especially unfortunate side effect – chronic pain.

Spinal Life Community Nurse Specialist Deb Dent said recent studies have shown up to 80% of people with a spinal cord injury have reported a form of neuropathic pain as a result.

"Pain can vary greatly in terms of severity and variation from person to person, but it's very likely that someone with a spinal cord injury has experienced some form of ongoing pain as a result of their injury," Deb said.

"This pain is often chronic, meaning it continues for many months, even years.

"It can be a frustrating and continual battle however, there are constantly new developments and improvements in pain management techniques."

Deb said neuropathic pain occurs when transmissions from the body through the spinal cord are misunderstood by the brain and result in feelings of pain from the site of the injury and below.

"It's not just soreness – neuropathic pain can manifest itself as feelings of burning, electricity, coldness, pins and needles, itchiness or sometimes like a tight band is wrapped around the problem area,"

Deb said the best strategy for dealing with pain was to consult a GP and follow their advice.

"It can be often hard to distinguish

between neuropathic pain (caused by nerve responses) and musculoskeletal pain (pain affecting bones, muscles and tendons) and causes can vary greatly," she said.

"Because of this, treatment can be complex and may involve a combination of drugs, therapy and even psychological treatments."

"There are constantly new developments and improvements in pain management techniques"

Deb said there were many ways of treating pain, including medication such as anti-seizure drugs and antidepressants, physiotherapy and fitness routines and other self-management strategies.

"I've worked with many people with spinal cord injuries on developing comprehensive self-management strategies, which looks at behaviours and coping strategies for flare-ups and bad episodes," Deb said.

"These strategies can involve regular physio or physical routines to increase fitness, as well as mental techniques to help someone distract themselves from pain or relax and reduce the level of stress they're feeling."

"Living with chronic pain can be extremely frustrating and often overwhelming, but with the right strategies and treatments in place, it is possible to keep your pain levels managed and keep living your life."

Contact us on 1300 774 625 or enquiries@ spinal.com.au for more information on physiotherapy, exercise physiology and community nursing services to assist with pain management.

Deb sees some familiar faces in new role as Nurse Specialist



Deb Dent wants to help people "find their new normal" as she joins the Spinal Life Allied Health team as our newest Community Nurse Specialist.

Having previously spent six years as a nurse at the Spinal Injuries Unit at Princess Alexandra Hospital, Deb (pictured) knows just how challenging maintaining health and wellbeing can be for people with spinal cord injuries.

"There aren't many types of injuries that are as complex as injuries to the spinal cord." she said.

"You're not just dealing with the medical complications, there are also many psychosocial and mental challenges to overcome.

"Working with Spinal Life clients, my aim is to provide a holistic nursing service that works with people with spinal cord damage to achieve their specific health goals and help them find their new normal."

Deb will be working alongside our other Community Nurse Specialist Elle Saint to provide nursing services to clients in the greater Brisbane region.

"Funnily enough, Elle and I started at the Spinal Injuries Unit on exactly the same day!" Deb said.

"It's great to be working with her again, she's a fabulous and dedicated clinician.

"Having spent so many years at the Unit, I'm expecting to see many familiar faces in my new role.

"In fact, as soon as I walked into the door during my first client visit at Spinal Life, the first thing I heard was 'hey, I know you' – it was someone I had previously helped at the Unit!

"It already feels like home."

Community Nursing Services

With the addition of Deb Dent to the Spinal Life team, we have greater capacity to provide comprehensive community nursing services to people with spinal cord damage in south-east Queensland.

In addition to routine services such as catheter changes and wound dressing, our team is happy to discuss any health concerns or queries you have around current or future issues.

"We take a holistic approach to health assessment, meaning we encourage clients to talk freely with us about issues that are concerning them," Deb said.

"For example, if you have a routine catheter change booked but are concerned about developing wounds or pressure sores, we have the flexibility to discuss that as well during the visit."

Our team have years of specialist experience treating patients with spinal cord damage and can support with:

- > Catheter changes
- > Wound dressings
- Bladder and bowel assessment
- Management plans (including continence care and bladder and bowel regimes)
- Carer training (including wound dressing and bowel management)
- > Pressure area care and assessment
- > Basic equipment checks
- > Consumables planning and advice
- > Tracheostomy changes
- › Autonomic dysreflexia reviews
- Respiratory management
- > NDIS reviews for continence and wounds, and more.

Contact us on 1300 774 625 or enquiries@ spinal.com.au for more information.

Personal support worker role a privilege for Suzanne



Cairns Personal Support Worker Suzanne Elliott firmly believes "experience is life", which has led her on many different career paths over the years.

From being a high school English and Drama teacher to running a banana farm packing shed, Suzanne has now been part of the Spinal Life team for almost eight years and is passionate about her role.

She applied to become a Personal Support Worker because she wanted to make a difference, and said it was a privilege to be part of her client's lives and watch them achieve their goals.

"I have sat in the back seat of the vehicle while my client was receiving driving lessons and now I sit alongside them in the passenger seat as they drive wherever they want to go – work, shopping and lunch," she said.

"I have witnessed a client discover in a hydrotherapy session that they can walk in water, after 36 years using a chair, and see their dad watch with tears in his eyes.

"I have seen a client run their own business for many years, while raising a young family and always managing to have a good time.

"I have observed a client start their hydrotherapy sessions with flotation devices and complete a lap of backstroke and then working with true grit and determination over a period of time to complete a one-kilometre swim without any flotation device," she said. "Each milestone, like reaching 20 laps, was celebrated with an ice cream – these were good days."

Suzanne said in addition to supporting people to be independent and reach their own goals, her role was all about being flexible, paying attention to detail and focusing on safety and teamwork.

Having lived in Cairns for 30 years, Suzanne said it had been exciting to hear about plans for the Spinal Life Healthy Living Centre in the region, and to watch the building come to life.

"Upon completion of the Centre, I think it is simply first class," she said.

"The accommodation is not only highly functional, but also elegant and beautiful.

"The rehab areas, particularly the gym, offer a facility that meets the needs of the client – not to mention the superb location."

"I have witnessed a client discover that they can walk in water"

In her spare time, Suzanne can be found four-wheel driving and "chasing waterfalls", exploring the beauty of the Cairns region.

Visit spinal.com.au to find out more about our Personal Support and Home Care Services, along with the Personal Support Worker role.

If you would like to learn more about the Healthy Living Centre, visit spinalhealthyliving.com.au or call 1300 774 625 to speak with our team.



Healthy Living Centre brings together community



Our Spinal Life Healthy Living Centre is growing as a community hub for Cairns locals, who have been making the most of the gym, hydrotherapy pool and specialist services.

Spinal Life members are using the Centre as a base to stay connected and catch up with each other, with brunch held on the second Sunday of the month at the Guyala Café.

Remedial yoga has also become a favourite each week, led by experienced yoga instructor Julie Cooper, with participants enjoying lunch at the café afterwards.

For visitors to the region, the Centre has allowed them to enjoy the sights of Far North Queensland while being able to access dedicated facilities to support them during their stay.

Recent guests have taken the opportunity to trial equipment with the assistance of our Occupational Therapists, with power chairs available at the ILS showroom located in the Centre.

Another guest is combining a holiday visit with trialling mattresses, thanks to the specialist equipment available at the Centre.

The Centre has also hosted tours for like-minded community organisations to explore opportunities to partner and connect, including the Cairns Rotary and Sunrise Rotary Clubs, who were excited to see the facilities and hear more about the services.

The Healthy Living Centre features seven self-contained units for short-term, transitional or holiday accommodation, specialist personal support and therapy services, and access to our Active Gym and Active Hydro Pool for ongoing rehabilitation.

Visit spinalhealthyliving.com.au or call 1300 774 625 to find out more.







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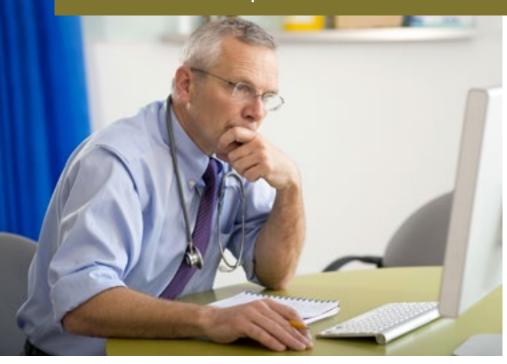
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Australian-first polio education module launched for GPs



We've been working to raise awareness about the late effects of polio, as part of an education campaign that was developed in consultation with members.

This campaign focused on health professionals, aimed at increasing their knowledge and supporting them to better diagnose and treat polio survivors.

Online training module for GPs launched

Our members previously shared how important it was for them to be able to access care and support from knowledgeable and experienced GPs and allied health professionals.

That's why a key activity in our campaign was to create an online training module for GPs, to promote increased knowledge and improved management strategies for patients.

We worked closely with leading providers of medical advice for polio survivors in Queensland to develop Australia's first comprehensive online education module for GPs about the late effects of polio.

As the module was accredited by the Royal Australian College of General Practitioners (RACGP), we were able to provide the training through ThinkGP, an online platform for GPs to access professional development courses.

The one-hour module is called 'What's polio got to do with general practice in Australia in 2020?' and aims to educate GPs on the late effects of polio and how to identify and support patients who may be experiencing symptoms.

With the module being promoted to tens of thousands of health professionals, we are seeing more and more GPs accessing this module to create better outcomes for polio survivors in future.

Resources you can access

We are continuing to provide members with copies of our 'Late effects of polio:

A guide to management for medical professionals' that you can give to your local GP to share more about the late effects of polio with them.

This guide has been recognised as an Accepted Clinical Resource by the RACGP – another Australian first



Late effects of polio

We also have copies of a Medical Alert card for polio survivors to keep on hand, to assist in providing key information to health professionals when needed.

When visiting the GP, please encourage them to complete the online course and provide a copy of the brochure.

Visit spinal.com.au/polio to find out more.



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Registered NDIS Provider

Matt is all smiles after landing his first paid job with help from Back2Work



For his first ever paid job, Matt Coulcher wanted work that was meaningful and useful.

With a bit of help from Spinal Life's Back2Work program, Matt's goals have come true after landing a job at Makeables, an Assisted Workmanship Service in Rocklea.

Matt met Back2Work's Senior Vocational Rehabilitation Counsellor Tania Goossen while he was a patient in the Spinal Injuries Unit at Princess Alexandra Hospital.

Tania worked with Matt to explore what he wanted out of a job and helped him to connect with Makeables to find meaningful work which would also accommodate his disability.

In Matt's new role, he assists with the assembly, production, labelling and finishing work of grocery items and more for large businesses such as Aldi.

Matt said finding work after sustaining a spinal cord injury had helped boost his confidence and put a smile on his face.

"I felt lucky to have a job, especially through COVID-19 – it makes me feel like I'm doing something important"

Matt said he was filled with pride when he first put on his uniform shirt.

"If you're thinking about finding work after a spinal cord injury, give it a try! It's a bit hard at first, but so worth it," he said.

Tania said it was a pleasure helping Matt to find his first paid job.

"He's really taken well to it – Matt's supervisor said he always gives it 100% and gives it with a smile," Tania said.

"Matt's a real social butterfly, so he's happy to be at a place where he can work with others."

"He has a good sense of humour too – when asked what his favourite day of the week was, Matt replied with 'payday!."

Back2Work is a pilot project by Spinal Life Australia in partnership with Princess Alexandra Hospital – Metro South Health and Griffith University.

The project is proudly supported by the Motor Accident Insurance Commission (MAIC).

Visit spinal.com.au/back2work for more information.

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Be part of our Welcome Wall at the Healthy Living Centre

The Healthy Living Centre is an important part of the Cairns community, dedicated to enhancing the health and wellbeing of people with spinal cord damage and other physical disabilities.

Thanks to the support of donors and supporters we have been able to make the Centre a reality – the first of its kind in Queensland and regional Australia, offering fully accessible facilities and specialist services and the opportunity to visit accessible tourist locations and experiences throughout the region.

Your support will ensure we can continue to deliver lifechanging programs and services closer to home for people living in and visiting Far North Queensland.

By making a tax-deductible donation of \$300 (and above), you can secure your place on the Welcome Wall in the beautiful Chapman Lounge. Depending on your gift - your name and/or a special message will be displayed on a Legacy Tile on the Welcome Wall.



Leave a gift in your Will

Leaving a gift in your Will is one of the most effective and important ways that you can help Spinal Life Australia. We value every gift, large or small, because we know the lasting impact your bequest will have on helping more people with spinal cord damage and other physical disabilities.

By leaving a bequest to Spinal Life, you will ensure the continued delivery of important services including the Peer Support program which provides one-on-one peer support and mentoring for people with spinal cord damage.

If you would like more information on bequests, or have your donation recognised on the Welcome Wall at the Healthy Living Centre, contact our Fundraising team on 1300 774 625 or fundraising@spinal.com.au.



Move to digital licence to benefit people with disability

We've been working with the Queensland Government on the rollout of a Digital Licence App trial to make identification and concession processes easier for people with a physical disability.

The Digital Licence App, which is being trialled in the Fraser Coast region, will allow Queenslanders to store their driver's licence, photo identification cards and other official authorisation on their smartphones.

Our Chief Advisor – Government John Mayo said Spinal Life and its members had been involved in the development of the Digital Licence App for more than a year, formerly known as the Digital Wallet project.

"One of the key issues that our members have found challenging is the requirement to constantly get documents from a doctor proving they have a disability every time they apply for a new scheme or service, or renew an existing one," he said.

"Thankfully the Queensland Government has been listening to us and advocacy efforts have progressively phased out the requirement for multiple doctor visits required to get paperwork to renew state disability concessions."

John said Spinal Life's recommendations around the Digital Licence App were to make someone's disability and concession information available in the one place which can be easily referenced for future applications.

"This project is an important step in our advocacy efforts to make 'proving' a permanent disability for government schemes a one-time thing," John said.

"The move to a digital licence will also benefit people with limited hand function as they can use their phone for identification, rather than having to remove a card from their wallet."

Visit qld.qov.au/transport/projects/ digital-licence for more information about the Digital Licence App.



Penalty increase for parking misuse a welcome deterrent

Oueensland drivers who misuse disability parking spaces are in for a shock, as the penalty for parking in these spaces without a permit has more than doubled from \$266 to \$533 from 31 August.

We have welcomed the new laws, which will provide more incentive for motorists to do the right thing and leave disability parking options for people who need them.

Disability parking has been a key advocacy issue for our members for many years, asking Queensland's Department of Transport and Main Roads to introduce further regulation.

Under the new laws, Queenslanders with permanent and temporary vision loss are now eligible to apply for a disability parking permit.

Currently in Queensland there are more than 198,200 disability parking scheme permits issued to individuals, as well as 9,700 permits issued to organisations supporting people with a disability.

"This project is the next step in our advocacy efforts to make 'proving' a permanent disability for government schemes a one-time thing"



More than 1000 submissions have been received by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, aiming to better understand the experiences of people with a disability.

The Royal Commission was first established in April 2019 and is examining how to prevent and better protect people with disability from experiencing violence, abuse, neglect and exploitation; best practice in reporting, investigating and responding to issues when they are raised; as well as promoting a more inclusive society.

Submissions are still welcome by phone, email, video or audio recording, or through the online form available on the Royal Commission's website.

The website also includes a guide with questions to assist with making a submission, which involves sharing more about your experiences and how the Royal Commission can help prevent this in future.

In April, the Royal Commission also released an issues paper on Emergency Planning and Response which explored the effects of the COVID-19 pandemic for people with disability.

The issues paper sought feedback from people with disability, their families, advocates and experts about their experiences, with responses covering a range of issues including accessibility of information, safeguarding and oversight practices, access to services and supports and the impacts of restrictions throughout the pandemic.

The Royal Commission's interim report is expected to be released by 30 October 2020, and a final report by 29 April 2022. To find out more, visit *disability.royalcommission.gov.au* or call 1800 517 199.

If you or anyone you know needs help, you can call services such as Lifeline (13 11 14), 1800 RESPECT (1800 737 732) or the National Disability Abuse and Neglect Hotline (1800 880 052).



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: Bill Simpson on 0412 729 843. Bundaberg: Pat Allison on 4153 1005.

Cairns: Jeanette Kretschmann on 1300 774 625.

Combined with Post Polio group.

Fraser Coast: Jeanette Kretschmann on 1300 774 625.

Ipswich: Eric Rushton on 0403 191 698. Mackay: Debra Reaves on 0487 021 735. Moreton Bay: Tom Dutton on 0448 949 910. 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 Louise Remilton on 0414 254 531

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

CALENDAR of important dates

10 October

World Mental Health Day

24 October

World Polio Day

3 December

International Day of People with Disability

About our services

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

Personal Support and Home Care Services

Our team provides reliable services seven days a week* including:

- Personal care at home and work
- > Specialist complex personal care
- > Domestic assistance around the home
- > Lifestyle support to attend appointments, activities, holidays and events
- > Transition support from hospital to home.
- * Seven-day service available in most locations. Contact us for more information.

Allied Health Services

Our dedicated professionals include physiotherapists, exercise physiologists, occupational therapists and registered nurses, who can assist with:

- Access to expertise and funding schemes
- > Mobility, seating and equipment solutions and prescriptions
- > Specialist personal advice and assessments
- > Workplace/home modification assessments and pressure mapping
- > Continence and wound assessment and management
- > General health assessments and respiratory support
- > Specialised physiotherapy
- > Hydrotherapy and exercise programs for home or gym (available at the Spinal Life Healthy Living Centre)

The team is offering telehealth appointments wherever possible in response to COVID-19. Services available in some areas only. Contact us for more information.

NDIS Supports Coordination

Our experienced team can help you navigate the NDIS and assist with planning and coordinating your supports.

Member Services

Our members can access a range of services including peer support, individual advocacy assistance, events and activities, and more. You can also help set our course and have an active voice in our organisation.

Our Peer Support team also regularly visits the Princess Alexandra Hospital's Spinal Injuries Unit to assist newly-injured patients and their families. Note: in-person visits are currently suspended due to COVID-19 and will restart soon.

Employment, study and workplace assistance

The Spinal Life Australia Back2Work® program supports patients in the Princess Alexandra Hospital's Spinal Injuries Unit to return to work or study, while our Allied Health team also provides detailed workplace assessments and equipment solutions.

Plus, we deliver disability awareness workshops to educate staff on inclusiveness, conducted by our Training Solutions facilitators.

Sharing your feedback

We value your feedback, as part of our commitment to continuous improvement. You can submit feedback and view our Feedback and Complaints Policy by visiting spinal.com.au/feedback.

Contact us today on 1300 774 625 or enquiries@spinal.com.au to find out how we can support you or follow us on Facebook and Twitter for the latest news and information.



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