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#### Home sweet home

Welcome to the autumn issue of The Advocate, our first for 2022.

In this issue, which focuses on housing, we take a dive into the world of Specialist Disability Accommodation; chat to someone who's been through the process and is now happily living in his own SDA apartment, and get home tech advice from our newly appointed Assistive Technology Mentor.

We also share more about our ongoing advocacy efforts - this time in Rockingham, Western Australia and get health tips from our new Exercise Physiologist, Ernest Starowicz.

Ernest is part of the team at the new Healthy Living Centre Brisbane, which opened earlier this year. We're so excited to be able to reveal more about this new hub for therapy and rehab needs.

As well as the Exercise Physiologist, a Physiotherapist is also based in the Centre's state-of-the-art Fitness Hub. You can also visit our Occupational Therapist and Nurse, and – by the time this magazine is out – we'll be offering adaptive yoga, there'll be a visiting dietician, and the Assistive Technology Room will be open. The Back2Work team, Occupational Therapists, and

Assistive Technology Mentor will all work in this space, helping find personalised solutions for improving your everyday lives.

The beauty of the Healthy Living Centre Brisbane is that all of these services are under one roof, so you can come and visit them all in one day, from wherever you are.

It's a hugely exciting time, and we'll update you in future issues as we expand our partnerships and services at the Healthy Living Centre.

At a board level we continue to adapt, holding our Annual General Meeting virtually for the first time in November 2021. At this meeting, we farewelled a resigning Del Childs, while Bill Peacock and former Chair David Riley were recognised as Honorary Life Members for their exemplary service to, and support of, the organisation. Members also voted to elect Dr Dinesh Palipana OAM and Carol Taylor as Board Directors. With such accomplished professionals helping to guide the strategic direction of our organisation, I know we'll be able to achieve many more great things in 2022 and beyond watch this space!

Finally, I'd like to take this opportunity to acknowledge Dylan Alcott OAM who was recently announced as Australian of the Year 2022. As a fellow disability advocate, I have no doubt Dylan will use his position to further challenge perceptions and drive change at a national level, to benefit all people living with a disability.

Gyl Deny

**GYL STACEY** 

## Do you have a story to share?

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











#### **4 QUESTIONS WITH THE CEO**

## Mark Townend

#### What is the big focus for Spinal Life in 2022?

"Our number-one priority is to further enhance the customer experience. We will continue to improve our technology platforms and communication channels, so our members have better access to relevant information. A good example is this issue of *The Advocate*, which is all about accommodation."

## What do you hope to see change in the disability community this year?

"As this issue goes to print, we continue to actively advocate on several significant issues. In particular, we remain committed to the Disability Doesn't Discriminate campaign ahead of the federal election, and are lobbying for changes to legislation for motorised mobility devices."

## What are you most excited about for Spinal Life Australia this year?

"We recently started our Access and Inclusion Consulting

Service, and have already secured clients in local government, private enterprise and utility providers. The service aims to bridge the gap between consumers with a disability and businesses, community organisations and State and Local Governments, by helping these groups to comply with legislation and provide outcomes that are functional for the entire community. I'm very pleased at the growth of this endeavour and am excited to see where we can take it in the future."

## What do you think your biggest challenge will be in 2022?

"Unfortunately, it looks like it will continue to be COVID-19. So far in 2022, as State borders have opened, we have inevitably seen an increase in cases among staff and customers. I am very proud of the way staff have adapted to this challenge. They're so dedicated to ensuring disruption to customers is minimised and supports continue."



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Let's work together to take life back!

What Katie Did

A smart investment put Spinal Life Peer **Support Officer,** Katie Buckman on the property market - and into a beautiful family home



For Katie Buckman, her home in Dakabin – five minutes from North Lakes on the north side of Brisbane - truly is her sanctuary.

She moved in in 2011, two years after sustaining paraplegia (T12/L1) in a car accident, aged just 19.

"I got a payout from the accident and thought I should do something with it to help me for my future," she says. "I realised that building a completely accessible home was the best option for me."

Prior to the move Katie had been living at home with her parents, but their house was on two storeys.

"We did get funding for a hydro lift so that I could get upstairs," she explains, "but after a year of doing that it just got a bit old. My parents said, 'Why don't you look into buying a house and making it 100% accessible for you, so you don't have to deal with these obstacles all the time?"

So that's exactly what Katie did.

Her tailor-made home features wider doorways and corridors, an easy and obstacle-free entry, and an ensuite bathroom decked out with a roll-in shower and grab rails beside the toilet. There's convenient access space underneath the sink, and the mirror's at the right height so Katie can do her hair and makeup with ease.

"In the kitchen, I've got a gap under my stove so I can cook safely from that spot. I also have a kitchen bench that's at just the right height and allows me to park myself underneath it while I prepare meals. Part of the bench is this perfect lower height, while the other part is the standard height."

Just right, then, for one of the home's other occupants: Katie's husband, Callam. They've been together for 14 years, and married for nine.

"We were together for about six months before my accident," says Katie. "Afterwards, I told Callam that he didn't have to stick around, but his response was: 'I didn't go out with you because you could walk."

Callam is a coffee-machine technician and develops games on the side. "He builds them when he has a spare five minutes to himself, which is not very often!" says Katie. She herself works two days a week as a Peer Support Officer at Spinal Life Australia. They're also parents to a five-year-old girl and a three-year-old boy, so needless to say, their days are very full!

Katie's new role only started in November 2021 and thanks to restrictions imposed by COVID-19 things have yet to settle

Without a routine, things would definitely be chaotic ??

down to "normal". So far, however, things seem to be working out very well.

"Spinal Life is very flexible, so the hours I do with them work really well with my home life" she says. "I've never had this sort of freedom with other employers!"

With Callam leaving for work between 6.30am and 7am most days, the responsibility of the morning ritual falls almost entirely to Katie.

Her daughter just started prep this year, and has to be taken to school five days a week. Her son also goes to daycare on

the two days that Katie goes to work. While it's an undeniable juggling act, Katie has taken it all in her stride.

"I've been able to manage things quite well so far," she says, with typical understatement.

"As long as I have their lunches done the night before, it's pretty calm in the morning! I make sure I get up a bit earlier so I can have an hour with the kids to play games and do some activities before breakfast. Then it's time to brush our teeth, get dressed and so on. Without a routine, things would definitely be chaotic."

And just because Mummy's using a wheelchair, it doesn't mean her kids cut her any slack.

"While my daughter's pretty good and will dress herself and get ready for school, my son's like, 'Oh, let's play games!," laughs Katie. "In the mornings at the moment, Mummy's the monster, so there's lots of running away from Mummy! When I'm on my own and physically can't reach him, I rely on reverse psychology. There's a lot of, 'Okay, I'm leaving now' and heading towards the door – and then grabbing him as quickly as I can. He's getting better, but it's definitely a challenge some days – and I have to use my stern voice sometimes!"

Katie's son is three and even though he's walking, she has to be on guard the whole time. "He can trip over at any time. We might be in a shopping centre and he'll be walking in front of me and all of a sudden he'll stop. Or fall over. I have to quickly grab my wheels because I don't want >







to run over him – and if I hit him, I'll fall out of the chair as well!"

The children's learning-to-walk stage was also very interesting.

"They would use my chair as a walking or climbing aid, so I'd always have to look out for them and make sure their little fingers and toes didn't get trapped. They would crawl underneath my chair and I'd only realise where they were when I'd hear them giggling."

While Katie's son is perhaps still a little young to fully comprehend the importance of Katie's wheelchair, her daughter is very aware.

"One day Callam was mucking around and jumped in my wheelchair," says Katie. "And she just freaked out, saying, 'Get out of there, that's Mum's! You can't be in there!' She knows that the chair is my legs."

Katie has a Support Worker two days a week, sometimes three. "AJ's been with me for two and a half years now, so we're more friends than anything. I have a cleaner who comes once a week, but AJ will help out with little things – in the mornings she might chuck on a load of washing or clean up the kitchen from the night before if I haven't had the chance and am busy getting the kids ready for school. Or if there are a few toys lying around she'll pick them up for me – it will only take her two seconds, whereas it would take me 20 minutes."

AJ is also a big help when it comes to school drop offs and pick ups

"My daughter's prep class, because they're all so young, have to be physically taken into school every morning, and then personally collected at the end of the day," explains Katie.

"On the days that I'm working and don't have any help, I have to bundle both children into the car, buckle them in, get myself and my chair into the car, drive to the school, pull my chair out, put it together, get not just my daughter out but also my son (because I can't leave him in the car by himself!), take her into the school and drop her off, get my son back in the car, pack my chair up again, drive two minutes up the road, take my chair out and put it back together again, drop him off to daycare and then get back in the car, along with my packed-up chair, before I can finally head to work."

It's a process that takes Katie half an hour every morning. But when her Support Worker's with her, it's a different story.

"If AJ's with me, we'll all drive to school together, and then she'll just walk my daughter in to class. She's back in the car within two minutes."

Occasionally, Katie will rev up "Mummy's Motorbike". By adding a Klaxon Klick to the front of her wheelchair, Katie says the click-on power-assist attachment gives her chair great acceleration and "kind of turns it into a bit of a motorbike".

"Instead of all of us having to pile into the car, I can leave my son at home with AJ and cruise up to the school, daughter on my lap, and avoid all the school traffic," says Katie. "I think my daughter might be getting a bit too old for it the other day we rocked up to the school and she was like, 'Okay Mum, stop here, stop here!'"

As well as school drop offs and pick ups, AJ accompanies Katie to any appointments, and helps with the grocery shopping and other everyday tasks.

"When both of the kids were at home during the day we'd do a lot of other activities, like go to the park and take them to zoos and that type of thing," says Katie.

Now that the children are older, these fun outings are the domain of weekends, so Dad gets to join in a lot more.

There are still occasional trips to the zoo, but that's more of a once-a-year thing because it's such a big day out for everyone. SEA LIFE Sunshine Coast (formerly Underwater World) is a favourite and Katie's daughter has recently become hooked on fishing, so trips up the coast are on the cards fairly regularly.

"We aim to go out one day each weekend, even if it's just going to the park or going for a walk around the block," says Katie. "Lately we've been going down to Scarborough Beach quite a bit; letting the kids ride their bikes, kick a soccer ball and play a bit of cricket. We'll have a barbecue or, if we're near the water, get some fish and chips. We love to get out and do family things. And then we love to come home again at the end of the day and just hang out all together." A

To read more about Katie and the Peer Support team, visit spinal.com.au/service-types/peer-support







Keep hearing about SDA, but not quite sure what it is or if it relates to you? To find out more, we spoke to Alison Kidd, a Supports Coordinator who's worked at Spinal Life Australia for four years, and – along with the Supports Coordination team – helps participants of the NDIS navigate the confusing world of SDA. Those documents, forms and paperwork that have most people cowering in terror? The Supports Coordinators deal with them before they've even had breakfast. In short: they are definitely the team you want on your side when you're dealing with SDA!

#### So what is SDA?

SDA means Specialist Disability Accommodation. It might be a house or an apartment or a unit, and it's for people who have physical support needs, or behavioural or safety needs.

But it *only* refers to the building: as Alison puts it, "It's the actual 'bricks and mortar' – any other support that you may receive from people paid to help you live independently is funded in a separate way within your NDIS plan and is completely separate from SDA."

"The Federal government, via the NDIA, is supporting an increase in funding into SDA providers – usually property developers, or big organisations in conjunction with developers – in order to provide accessible housing. It's giving them a financial incentive in order to increase the number of accessible homes in the community."

Some of the features you can expect in an SDA home include wider doorways and hallways, lots of circulation space, and accessible kitchens and bathrooms. "Some places might also include things like home automation, ceiling hoist provision and around-the-clock onsite support,' says Alison, "and even things like height-adjustable bench tops, to accommodate a person living with a spinal cord injury who uses a wheelchair, as well as – for example – their partner who does not."

#### **How does SDA work?**

"To give you a simplified example of the journey through the SDA," says Alison, "if we had a participant with a housing problem, we would usually engage an SDA specialist and an Occupational Therapist, who would do a detailed assessment of the person's needs and their life situation. The relevant documents would then be submitted to the NDIS for approval for funding."

If the application is approved, the next big thing is finding out what type of accommodation the participant has been approved for (for example, apartment, duplex, house, shared home etc), and in what category. There are four different categories:

- 1. Improved Liveability (buildings require a 'reasonable' level of physical access)
- 2. Fully Accessible (must have good wheelchair accessibility)
- 3. High Physical Support (need a very high level of specialised design and physical access)
- 4. Robust

Whatever category and type of accommodation you're approved for will equate to a dollar amount per year. For example, you might be approved for \$30,000 for a fully accessible share house, so therefore you'd go and find a place that ticked all these boxes. The SDA provider running the house would then claim \$30,000 from the NDIS every year for the time you stay in that home.

That money reimburses them for the costs involved in building an accessible property, which have much higher building standards than a regular home, and have to be maintained to an incredibly high standard for the lifetime of the property.

#### Am I eligible?

## You may be eligible for SDA in your NDIS plan if:

- Your NDIS goals include housing
- You have very high support needs
- Mainstream housing, home modifications on an existing building, assistive technology, or being provided with SIL supports cannot meet your housing goals
- Even with appropriate home modifications and/ or assistive technologies, you still need a high level of in-home support from a paid worker with daily activities such as getting in and out of bed, getting dressed, moving around, preparing meals and accessing the community
- Your 'informal supports' (eg unpaid family or friends) can't meet your personal care needs
- You've spent a long time in a group home or residential aged care

But you still need to pay rent and utilities on top of this.

"The general rule is that rent contribution is 25% of income," explains Alison. "For people with the Disability Support Pension, it's capped at 25% of the pension, plus rent assistance. It's very complicated and there is more involved – but that's what we're here for!"

"There are a lot of SDA properties now – in places like the northern Gold Coast, around Ormeau, Pimpama and Coomera, and also North Lakes and the northern suburbs of Brisbane, as well as inner city and Gold Coast apartments; often anywhere where there's been a big housing development boom. But even so, the entire process to get SDA approval tends to take at least six to 12 months."

"It's not a perfect program, and a lot of the time there are disconnects with the people making the decisions and doing the approvals. For example, I support a participant who, for medical diagnoses reasons, requested a single-occupant dwelling in his submission. It would be unsuitable if he went into a share house, but they approved him for a three-person share house. We've requested and have been approved for a review. But the NDIS is just exhaustingly slow and the

review still hasn't taken place. So, we've negotiated a solution with another SDA provider who luckily agreed to rent him a different property for same money that he was approved for. He's going to pay the same rent, with a family member co-tenant paying the difference."

"For the people who have received approval and actually moved into SDA homes, the overwhelming feeling they seem to experience when it happens is relief. It's such a weight off their shoulders to have a permanent housing solution for the rest of their lives." A

#### Want to explore SDA options? Call us!

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## **CATCH UP WITH** YOUR COMMUNITY

Our Peer Support catch-ups are held across Queensland and Western Australia, guided by the latest advice from health authorities in response to COVID-19. Keep an eye on Facebook and our website for updates on upcoming events, including online opportunities. If you'd like to connect with our Peer Support, Post Polio or Transverse Myelitis Groups in your region, please use the contact details below.

#### Spinal Life Peer Support Groups

BRIBIE ISLAND: Bill Peacock on 0403 686 998.

Combined with Post Polio group.

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

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

or Anne Guthrie on 0407 116 035.

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: Sam James on 1300 774 625.

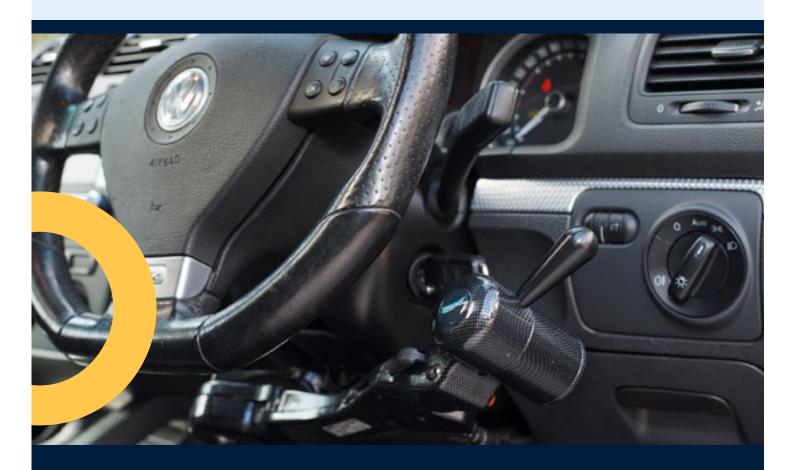
#### Transverse Myelitis Group

Contact Jodi Gallon on 0451 235 860

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

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**By Fadiel Italiana** 





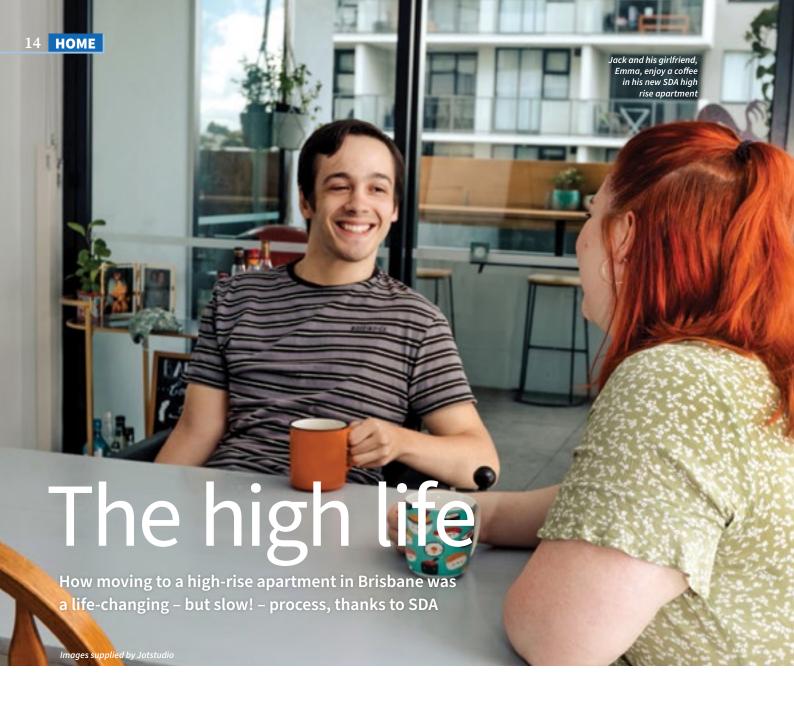






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Specialist Disability Accommodation (SDA) is helping people with disability to access housing and live independently. Jack Gillespie, 25, works for SDA Services and not only helps people with their applications, but has also been through the process himself. We asked him to share his experience.

#### My history

I was born with cerebral palsy, which is caused by brain damage that impairs the messages from the brain to the different parts of the body. For me, this means that I can't walk, and I use an electric wheelchair to mobilise.

I grew up in Buderim on the Sunshine Coast, with my parents, older sister, and our beautiful black labrador, Molly. For the last 15 years that I lived at home, my parents spent every second Saturday driving me down the coast to Brisbane, so I could play Powerchair football (basically wheelchair soccer – if you've never seen it, you're missing out). I've also been fortunate enough to play for Queensland and Australia.

I went to uni in 2014, straight out of school. I wanted to be a writer of some kind, so I did a Bachelor of Arts majoring in journalism and creative writing. While I was there I did an internship with the Sunshine Coast Daily, and later I wrote some freelance articles about disability and navigating the NDIS for a company called First2Care.

I got my first "proper" job, however, with a company called SDA Services.

The interesting thing is, I actually first went to them as a client.

In 2018, I, like most early 20-somethings do, decided it was finally time to leave the nest. Finding a place though, proved to be more difficult than I'd initially realised. Instead of excitedly picking out my first furniture and trying to figure out how to do my own laundry, I was realising that there were very few mainstream housing options that would allow me to live on my own. Then I heard about SDA.

Through some friends, who were looking for the same thing, I learned of an SDA Provider called Summer Housing that had purchased 10 apartments in a new building in Nundah and were having them built as High Physical Support apartments. I got in touch, was told I'd need to apply for SDA funding through the NDIS.

I went to SDA Services to help me with the application. It started with an interview, which was conducted by the company's founder, Greg Barry. In the process he learned about my background in writing, and ended up offering me a job. Now, I conduct those initial interviews myself. I actually started my job before I completed the SDA process!

66 The apartment itself is modern and well-designed. It was so great to be moving into my own place anyway, but the fact that it was brand new was a bonus. 9 9

#### My application

After meeting with Greg and making sure I had an SDA-related goal in my NDIS Plan, I then had to get a functional assessment from an Occupational Therapist (OT).

SDA Services referred me to an OT who did lots of SDA-specific reports. I was asked questions about my functional abilities, my support needs, my desired support arrangement, and basically anything else that could possibly relate to my need for housing. I also had to send videos of me doing things like opening and closing a fridge, and going in and out of the front door, to give them an idea of my movement in my wheelchair and what completing daily tasks look like for me.

This OT report was sent to SDA Services and used to create a larger housing report, which was submitted as my application for SDA. From the initial interview with Greg to the submission, I think it took around two months.

#### My agonising wait

After my application was submitted, all I could do was wait.

Back then, it typically took around six weeks to receive an outcome. So, I waited patiently, and at the end of those six weeks I didn't get a response.

I started to call the Agency. Frequently. And, long story short... I called them for six months.

Every time I rang them they assured me that my application was sitting on their desk and that they would be looking at it soon.

We would sometimes drive past the building on our way to soccer, excited to see how much progress had been made on the build. When the development was finished, I wanted to be excited, but the lack of response from the NDIS had me worried.

The thing is, Summer Housing had given me a conditional offer, which meant that I would only get the apartment on the condition that I was approved for SDA. They were basically holding the apartment for me, and if I didn't get SDA approval, they'd have to offer it to someone else. So, after six months had passed, they were forced to give me a two-week deadline.

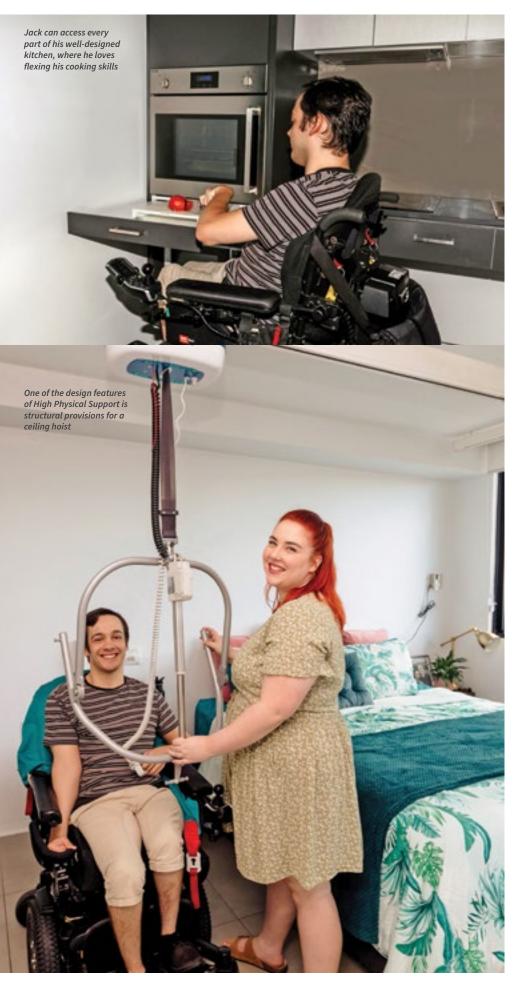
In desperation, I wrote a letter to my local member.

They opened up an inquiry that forced the NDIS to review my application. And it worked! About two weeks later, I received a phone call to tell me that I had been approved for SDA.

I realise now, as someone who works within this space, that my experience was an anomaly, and that most applicants will go through the process without needing to take these measures. However, this does illustrate the need for a good support system, who are prepared to help you fight for things when you feel like you're getting nowhere.

#### My apartment

I finally moved into my own place a few months later, in 2020. It's a brilliant apartment in Nundah, and only about a 15-minute drive to the Brisbane city centre. You can catch me on the weekends eating way too much at one of the million restaurants in the city.



One of the key benefits of living in SDA, is that they try to ensure they're centrally located to make it easy for residents to get around. My apartment is really well located - I'm 100 metres, if that, from the train station; Woollies is less than two minutes away; and there are lots of restaurants, cafés and a few pubs all close by. Like many SDA participants, I don't drive, so being so close to everything really helps me to maximise my independence.

My SDA funding goes to Summer Housing and I then pay rent on top of that. I also receive separate funding for Supported Independent Living (SIL), which covers the building's concierge: a 24-hour support service.

The concierge is there for incidental assistance. I still have core support workers, who usually come for at least two hours a day, but the concierge covers unexpected things or smaller tasks that take up to about 20 minutes. For example, I use them to get me out of bed each morning, when I drop things, or if I need a hand to cook or get food throughout the day. It's a great service and it means that someone is available 24/7 if I need them. Having this kind of on-site help is amazing, allowing me to receive support when I need it, while remaining independent throughout the day.

When you receive SDA funding, you get approved for a certain design category. As a wheelchair user who can't weightbear in order to transfer, I was approved for "High Physical Support," which is the highest level.

This design category decides things such as the layout of your home - so all my doors and walkways are widened to fit a wheelchair - plus automated technology, structural provisions for a ceiling hoist and things like that.

The apartment itself is modern and well-designed. It was so great to be moving into my own place anyway, but the fact that it was brand new was a bonus. There are two bedrooms, which has made it easier for me to work from home.

Most of the fixtures were already installed, including all the home automation that can be operated by an iPad; I just needed to provide furniture. I was given a say in certain design elements such as the location of the kitchen tap, which I asked them to move to the front of the sink so that I can reach it from my wheelchair. I also asked them to raise the bracket in the bathroom that holds the vanity, so that my knees can fit in under it a little more easily. These are the sorts of changes that seem small, but that make a huge difference to my day-to-day life. Being able to fill up my own drink bottle or cook for myself wasn't the sort of thing I was able to do before. I love being able to cook for myself, and have discovered that I make a mean beef massaman curry!

The building has 120 apartments – with 10 of them being SDA. The great thing is, a couple of my friends from soccer live in the other SDA units in the building, too. We found out about the development and applied around the same time, and were all approved. When I was living on the Sunshine Coast, I only really got to see them on soccer days, so living in SDA has really given me the opportunity to see many of my friends more frequently.

It's also allowed for my girlfriend, Emma, to move in with me, which wouldn't have been possible before – so I guess I can thank SDA for the fact that I've officially lost control of the TV remote.

#### My final words

I love living here. I love that I can access every area of my home. I can cook. I can get in and out at any time because we've got automated doors. I can work from home. I can ask for assistance from the concierge team at any point during the day. It's really boosted my independence and opened up so many opportunities.

It's also great to know that if one day I want to move, or I want to buy a home, SDA will help me to do this as well. For so long, the life-choices of people with disability have been limited by their housing options, but SDA is filling this gap in the market, and giving us more choice and control over where and how we want to live.

For more information and help about SDA funding, call 1300 774 625 or go to **info.spinal.com.au/sdaenquiry** 

## My advice

Jack's advice to anyone about to embark on the SDA process is:

- Find a Supports Coordinator who knows about SDA there are a lot of restrictions and limitations that are placed on participants, and it can be very difficult to get through to the NDIA. A Supports Coordinator can do that for you.
- Research and talk to a lot of different SDA providers to see what accommodation is available out there.
- You can start the process at any stage, whether you're starting from scratch and don't know of any providers, or if you want to apply for a specific place that you already know about. You can use your NDIS funding to access services that can help you through the process.





We're helping NDIA participants explore and pursue SDA and other home and living options to assist in life changing housing outcomes.



Founded in 2017, SDA Services has produced and provided over 600 SDA submissions to the NDIA, giving us a reputation nationwide as a premier Home and Living consultancy service. We have an extremely high knowledge of SDA and will work with you to assist you to understand the variety of home and living options available that best aligns with your wishes and needs. This informing, exploring and listening approach puts you in best control of how you want to live, where you want to live and who you want to live with.

We would be proud to be a part of your SDA journey. To arrange a no-obligation initial personal consultation to discuss your SDA eligibility and the SDA application process in further detail, or to request a brochure, please contact us directly on

(07) 3821 2699 or through our website www.sdaservices.com.au





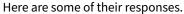
## Handy home hints

#### **Tips from our Peer Support Facebook group**



If there's a topic we're discussing here in The Advocate, we like to take it straight to the Brains Trust: members of our Peer Support Spinal Life Australia private Facebook group. They're people with lived experience who we trust to give us no-holdsbarred answers, intriguing insights and some truly helpful hints.

For this issue, we asked them to share their experiences and advice relating to the home – anything from the challenges they've faced when looking for suitable accommodation; to their favourite products, gadgets, tips and hacks.





"When you're in a position to buy and build, have a tick-off list. Choose land near nature (land or sea), positioned near transport systems, industry, retail, hospital, schools and entertainment. And go for a house design that maximises space and accessibility – high roof, open living, huge pantry, oh and complete thermal control. When my partner goes up north our security is like Fort Knox, so I have always felt safe and love alone time too!"

#### **Chelsey Phillips**

"There's a builder here in Toowoomba, Kev Morris, and all of his house designs are disability-friendly. He also did a unit complex on one of the golf courses here, and all the units have internal lifts and are disability-friendly. There should be more builders like him."

#### **Steve Hatherell**

"Don't believe what real estate agents say. And don't sign anything until you actually see the accommodation with your own eyes. Also, if you're struggling to open a jar, tap the lid two or three times onto a timber cutting board and it will be much easier to open."

#### **Greg Hayden**

"There are no specific websites for long-term accommodation. You have to develop an eye to overlook the photo tricks of elongating rooms. Google Maps/Earth will help you make a short list, as you can generally see things like driveways, how flat the land is, how far from amenities the property is etc. Door widths, corridors and kitchen benches are a big problem. Newer units have very narrow bathroom doors, but often have showers walls you can take out. And they have lifts, disability parking and will need fewer modifications. Never assume you can wheel around the neighbourhood. Do a test run. When moving, make sure you have someone at the other end to put the bed together and organise the space so you can move about and go to bed."

#### Kelly Parry A

Want to join the Peer Support Spinal Life private Facebook group and connect with other like-minded people? Sign up at facebook.com/groups/peersupportspinallifeaustralia

## Hey Alexa, please automate my home...

**Assistive technology and home** automation is providing a new lease on home life for many people with disability

There's been a revolution in smart home technology over the last few years. And while it originally might have been aimed at gadget-loving technophiles, it's proved to be truly life-changing for people with physical challenges.

So what does Assistive Technology (AT) encompass? And what does the future hold? We spoke to Jocelyn Stocker at Spinal Life's new Healthy Living Centre in Brisbane, to find out more.

### You're the AT guru at Spinal Life Australia - what does

"In my role as Assistive Technology Mentor, I provide impartial information and guidance about AT and/or home automation. I'm here to help people make informed decisions. It's not about recommending or prescribing, but rather guiding and supporting them to find the best AT solutions that suit them, and then connect them with suitable therapists, where required, who will be able to assist them even further."

#### When people come to you for advice about AT in their home, what are some of the steps you take them through?

"When you book a consultation with Spinal Life's Assistive Mentoring Service, you'll get unbiased information, guidance and support to help you to make informed, educated decisions on what the best options may be for you. We don't sell products, but we can recommend retailers who stock the product you might be searching for. We also consider product compatibility, to enable home automation to continue to evolve as your needs change. Plus we offer home installation, product education, set-up help, programming and trouble-shooting. This is a great part of the service – how many times have you bought a product only to find you need assistance to set it up or install it, or require another part to make it work?"

AT sounds inherently expensive. Can most people incorporate it into their lives somehow? Is it funded through the NDIS?



"Assistive Technology is basically anything that a person can use to perform everyday tasks that might otherwise be difficult or impossible. There are different categories of AT, so you can have something inexpensive but super-useful (like a jar opener or a modified eating utensil), right through to a high-tech item like voice-control software to control a computer instead of a keyboard. People with disabilities have traditionally been early adopters in the use of assistive technology and a large number of our members already use some form of AT. The great news is, because home automation is now being widely used in the mainstream community, the mass production of products means they're now more affordable than ever before. NDIS participants can also access funding for most of these types of products."

#### What are some technologies that you've heard about that excite you for the future?

"In recent years there's been an explosion in the home automation market, of products that can really enhance the lives of people living with disability, and help them gain back the independence to control their environment. The list of new software, innovative technologies and smart devices is expanding all the time, and what makes things really exciting is the affordability of products available on the mainstream market."

#### What's the one AT device that lots of people find super useful in their home?

"Most people with quadriplegia have a love/hate relationship with keys, particularly house keys. Holding a key at just the right angle and turning it at the same time can be complex for anybody with any hand dexterity issues. Home automation - adopting the use of a digital deadbolt - provides keyless entry (so there's no need for those pesky key safes any more), generally with the ability to store up to 40 pre-programmed pin access numbers." A

To arrange a time to speak with the Spinal Life Assistive Technology Mentor go to spinalhealthyliving.com.au/ brisbane/enquiry

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January was a big month for Spinal Life Australia. That's because we threw the doors open to the new Healthy Living Centre Brisbane.

Located at our headquarters in Woolloongabba, we're so proud of this rehabilitation and fitness centre, which has been specifically designed for people with spinal cord damage and other physical disabilities.

It's a one-stop hub where all your therapy and rehab needs can now be met in one convenient place.

Are you looking to gain more independence through increased movement? Do you want to improve your strength and flexibility? Are you hoping to manage and reduce pain? Or do you just want to stay fit and healthy? Our experienced team is on hand to support you, whatever your goals may be.

They include an Exercise Physiologist, Physiotherapist, Occupational Therapists, Nurse and an Assistive Technology Mentor, who all specialise in treating and supporting people with spinal cord damage and other physical disabilities.

As well as the onsite Driving Clinic and Assistive Technology Room, one of the highlights of the Centre is our fully accessible Fitness Hub.

This is where you can try out state-of-the-art HUR equipment, which has been designed to allow people to wheel in - no more pesky transfers! Another unique feature is that it uses air resistance rather than weights, and adjusts the resistance automatically.

It's a brilliant system that involves your personal training program being loaded onto a Smart Card. When the card is swiped in front of the machine, it automates your personal program, so you do exactly what your therapists have recommended, or you can do your own program. It also records the performance from each session, so monitoring and analysing your program is easy. HUR equipment's touch-screen capacity makes it perfect for anyone with limited hand function.

The Fitness Hub is also decked out with other fully adaptable gym equipment that's suitable for the majority of wheelchair users or those using other mobility devices. Strength-training equipment includes specialised cable machines that can be height-adjusted from the seated position, as well as an electrical stimulation bike and pilates trainer. For cardio fitness, there are things like a seated cross trainer, MOTOmed, ski machine, leg bike and adapted row machine. Other specialist equipment includes standing frames, tilt table, parallel bars, hoists, treadmills, gait aids and transfer equipment. Plus, we have a range of handles and gripping supports for use across most of our equipment.

The Fitness Hub can be accessed independently - with casual passes for \$16.50, or if you'd like to visit more regularly, there are options for three, six and 12 month memberships. We hope to welcome you there – and to the rest of the Healthy Living Centre Brisbane – soon!

To find out more about the Healthy Living Centre Brisbane, visit: **spinalhealthyliving.com.au/brisbane** 



Charmaine

**New Farm** 

T7/8 Incomplete Paraplegia



access to."

Mike

Mt Gravatt East

What do you like most about coming to the Healthy Living

machines is fantastic and it's so easy to use - it's programmed

so that it only allows you to do what the therapist wants you

to do, in line with your goals. It's an awesome thing to have

Final word? "It's a really well set-up place; obviously a lot

Centre? "The thing that really stood out was the state-of-

the-art equipment. The technology involved with the HUR

Incomplete Spinal Cord Injury with significant mobility impairment

#### What do you like most about coming to the Healthy Living

**Centre?** "The first thing that struck me was how bright it is and the layout – the way the machines are grouped together is very effective. The HUR equipment is cool. The way you can program your workout and it tells you what you're going to be doing next is fabulous and you don't waste any time. And although I've been working out regularly since I had my injury, I've never been able to remain in my chair – it's nifty. Having somewhere to make coffee is also a great bonus.'

Final word? "I like the idea of it being a one-stop kind of place. Whether you're going to the Centre to do yoga or to see the physio or for whatever reason, everything is there in the one place.'



Mark

Rocklea

Cerebral Palsy

Centre? "I like that it's so spacious, with no tight or awkward spaces and room to accommodate your wheelchair so you can reach the equipment a lot more easily. The cutting-edge technology means that the machines know what you're up to, and what you should and shouldn't be doing. I love that the equipment is all modified and most of it uses air pressure instead of weights."

What do you like most about coming to the Healthy Living

Final word? "It's just fantastic."



Lisa

of thought has gone into it. It's fantastic."

Inala

C5/6 Tetraplegia

What do you like most about coming to the Healthy Living **Centre?** "It's close to home, which means that it takes

less of both the care worker's time and my own time in the mornings. The tilt table has also been very good for my level of pain, which has definitely reduced. I also like how the Centre is well set up and spread out, the equipment is new and there's a calming atmosphere."

Final word? "I enjoy going to physio; I look forward to it, it's good for my mind and body. And I like that the Centre is associated with Spinal Life Australia - I like to keep all the services I need in the one spot."



Bevan

Greenslopes

T4/5 Paraplegia



Judy

Shailer Park

C4 Spinal Cord Injury

What do you like most about coming to the Healthy Living **Centre?** "It's only a couple of minutes down the road from

me, so it's pretty handy! There's always available parking too, which is great. It's quite accessible and easy to get around, with lots of wide-open spaces - it's not claustrophobic like a lot of gyms you go to, which are designed for people who are able to walk."

Final word? "There are a lot more machines for all the different muscles; some of them are a little different to what I'm normally used to, but they're really good and are a lot easier to use."

What do you like most about coming to the Healthy

**Living Centre?** "I like having equipment that is suitable for all levels of disability, and having practitioners who are really experienced in treating people with spinal cord injury, who get what you are saying. It is great for your health, overall wellbeing and physical ability; I'm already seeing improvements in my range of movement and strength more than I expected."

Final word? "I had my injury over 50 years ago and I've never seen a place like this. If you can get here and workout, I don't think you will regret it!"

## Rock Star

The results are in from Spinal Life's latest accessibility review: this time, it's all about Rockingham



Rockingham is a lovely spot about 45-minutes south of Perth. With 37 kilometres of beautiful coastline, protected bays and gorgeous beaches, it's no wonder it's well-known for its water activities.

Recently, Spinal Life Australia received a grant from the City of Rockingham to deliver a report called "Accessible Rockingham". It involved staff and volunteers with disabilities visiting 20 points of interest in order to highlight their accessible features and identify changes that could help improve the accessibility of the region. The aim was also to educate tourism operators and small businesses on steps they can take to make these changes happen.

We spoke to Spinal Life Community Advocacy Officer, Karen Harvey, who headed up this great project.

What was Rockingham's overall accessibility like when it came to points of interest and tourism offerings?

"Quite a few of the points of interest were accessible; the ones that weren't so accessible were water activities, such as water skiing and kayak tours."

How did tourism operators and small businesses react to your suggestions about becoming more accessible?

"The people I spoke to were very open to ideas and forthcoming with information."

#### What are some of the steps you've recommended they undertake?

"In the case of the kayak tours, for example, we recommended they tailor a shorter trip and encouraged them to consider taking off from a different site that's more accessible. Networking and meetings were also held to further discuss accessible kite surfing in the area, and we also recommended that all businesses and tour operators connect with locals to keep these important conversations going. The kayaking company are currently in the process of designing this new experience." >





## Karen's top 5 "don't-miss" places to visit in Rockingham

#### 1. Tandem sea kayaking

"While in Rockingham I was able to experience sea kayaking. It was my first time and I was very excited about it. The tours are normally six hours, and you hop in and out of the kayak on different islands. This was going to be impossible for me, but Jimmy, the tour guide and owner of Capricorn Sea Kayaking (capricornseakayaking.com.au), really went the extra mile to allow me to experience it. He tailored a one-hour sea kayaking experience just for me. The first step was for me to transfer myself into a two-person kayak. As a paraplegic I was able to do this myself directly from my chair, as I do have strong upper limb function. We then had a safety briefing and a practice on solid ground before launching our kayaks from the local boat ramp. My anticipation grew as I got to the water's edge. I was pushed out gently and then... I was away! I can recall saying: "Look, I'm doing it!" like a proud child riding their bike for the first time. It's moments like this that really enhance your quality of life and I'm grateful for such a fantastic experience. It's such great news that Jimmy is very open to creating tours like this so that other people with a mobility impairment, as well as older people and families with young children, will be able to experience this wonderful activity."

#### 2. Dolphin, penguin and sea lion cruise

"A great spot to visit from Rockingham is the Shoalwater Islands Marine Park, one of Western Australia's most important protected marine areas, encompassing more than 6,000 hectares. Perth Wildlife Encounters (dolphins. com.au) offers wildlife cruises that let you come face to face with this amazing local wildlife, including dolphins, sea lions and penguins. I was lucky enough to go on a one-hour boat cruise, travelling to Seal Island (which, in actual fact, is home to sea lions). This tour is available for people of all abilities and takes place aboard an accessible boat with a glass



viewing area. Getting *on* the boat was a little tricky on the day. It has a ramp that sits higher or lower depending on the tide, so it's easier to board when tides are high. The tide was low on the day I boarded, so even though I was able to access the boat, I couldn't do it independently – the angle of the ramp was just too steep. Once on board I was able to find a spot with maybe the best view on the boat. From there, as we approached Seal Island, I was able to watch sea lions in their natural surroundings and learn a little about them from the commentator. Later, we were lucky enough to see dolphins, who rode alongside the boat and dove in and out of its wake. It felt so lovely to be out on the water and have the wind in my hair, and seeing such incredible mammals was a special experience I will treasure for a long time."

#### 3. Penguin Island

"Also part of the Shoalwater Islands Marine Park, Penguin Island is a small island just 700 metres off the coast of Rockingham. To get there you take a five-minute ferry





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4. Point Peron

"I hadn't heard too much about Point Peron before I visited it for the Accessible Rockingham report, but this is a beautiful spot, also known as Cape Peron, just five minutes from the heart of Rockingham. Finding our way there was exciting: we travelled up a winding country-looking road until, to our surprise, we came across the most beautiful limestone coastline, with bush paths and an amazing lookout; a man-made structure from where you get an incredible panoramic view. For me the push up to the lookout was really steep, but with the assistance of my friend pushing we made it to the top. It was so worth it. I felt like I was on top of the world. It was a peaceful and beautiful experience as I sat at the edge of the viewing platform and took in so much natural beauty, as far as the eye could see."

#### 5. The Rockingham Beach experience

"I highly recommend that anyone coming to this part of the world visits the Rockingham Foreshore. My day there started with a trip to the jetty. You can wheel right out to the edge, plus there's a lower level that can be easily accessed by people using wheelchairs. On the day I visited the tide was quite high, so the water almost reached this lower level. The ocean was so close - if I could have jumped in, I would have. I sat there for a while, just enjoying the calming sensation you get from being so close to the water and nature. My next adventure was to experience the beautiful and accessible Rockingham Beach. Thanks to its north-facing position giving it protection from the winds, it's is famous for its calm waters. And with seasonal beach matting, two beach wheelchairs available for free at the nearby yacht club, and a concrete path down to the edge of the sand, people in wheelchairs can easily enjoy a day here. I used one of the beach wheelchairs to go into the ocean. It was a beautiful moment: the first time I'd felt seawater on my body in more than 20 years. Having

worked up an appetite after these incredible experiences, it was time to hit the fantastic cafés and restaurants on the Rockingham Beach Boardwalk, which runs along the Foreshore. There's parking directly out front or by the yacht club, and accessible toilets are not far away, in Churchill Park. The restaurants that line the very front of the foreshore offer picture-postcard views, awesome accessibility... and incredible food. Over the days of my visit I experienced some wonderful meals, but I would have to give five stars to Rústico Tapas and Wine Bar (rusticotapas.com.au) on the Boardwalk. We chose a five-course shared tapas degustation menu, and it was an amazing culinary experience.

The Accessible Rockingham project was generously funded by a grant from the City of Rockingham. You can visit **accessibleaustralia.com.au** to check out reviews of the Rockingham region and share your own experiences.







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No wonder we're told exercise is such a vital part of a healthy lifestyle!

If you're getting back into exercising after a considerable break, the key to doing so safely is to *take your time*. Build things up gradually, and be sure to change your routine frequently: patience and variety will help reduce the chance of injury and hopefully prolong the time you stick at your exercise program.

If you have any doubts or questions, seek the help of a health professional to guide you through the journey of getting started again.

Speaking of health professionals, we asked Ernest Starowicz, the Exercise Physiologist at our amazing new Healthy Living Centre in Woolloongabba, to share his expert advice about how to keep motivated when you're getting back into exercise. Here are his top tips:

#### 6 top tips for keeping motivated with your exercise program

- When it comes to exercise, the key is to do something you enjoy, so you're more likely to do that activity – and keep doing it.
- Start small and build up from there. Having smaller, realistic goals from the start is a gamechanger: you'll hit your goals sooner and be inspired to stick at your program.
- 3. If possible, have a workout buddy. Exercising with a friend will not only help keep you accountable, it will make things a lot more fun too!
- 4. Focus on yourself. Everybody's different, and everybody's working on their own plan to suit their own individual needs, circumstances and body. So never compete and never compare just concentrate on your own goals and your own improvement.
- 5. Keep track of your progress you can go old school and simply write down your daily exercise achievements, or download a fitness app, such as Google Fit or Samsung Health. This will not only help you easily monitor your progress, but also your diet. Plus you can set goals, get health and fitness tips, and even challenge family and friends who also have the app, which can be a great motivator.
- Keep at it! If you exercise consistently, your body will adapt and over time you'll definitely see results.

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# Getting to know...

#### Personal Support Worker, Khushi Sharma

Khushi Sharma, 22, has been a Personal Support Worker (PSW) at Spinal Life Australia for around a year. She lives in Western Australia after moving from India two years ago.

"I've always enjoyed being able to help other people, either through work or in a personal capacity," she says. "One of the things I enjoy most in life is meeting new people and hearing about their stories and countries of origin."

Meeting new people and helping them? Sounds like Khushi's found the perfect job for her! We wanted to find out a little more about this ambitious and caring young woman...

#### What three words describe you best?

"Honest, trustworthy, responsible."

#### What do you think are the main qualities somebody needs to be a good PSW?

"Being a good PSW requires honesty, responsibility and reliability. It's also important that you're able to use any feedback you receive to improve in the role, and be able to communicate well with anyone you work with. This includes the people whose homes you go into, and your colleagues."

#### What are the main responsibilities of a PSW? Can you describe an average day?

"An average day for me involves getting to my client's home on time and starting the tasks required. These can change from one client to the next, and can include assisting someone getting out of bed in the morning, assisting with showering or breakfast, or making someone a cup of tea before their day gets started. Sometimes the needs of my client might change, and this means I need to follow any instructions given to me by the Team Leader and checking if I'm unsure of anything that comes up. Being a PSW means taking responsibility for my own work but doing it to the high standard of the organisation and always following Spinal Life policies and procedures."



#### What's the most life-affirming moment you've ever had while on a job?

"Building relationships and understanding with clients. It takes nothing from you to put in a bit of effort to make someone's day better and bring them some happiness. This is not just how I am at work, but my belief in all parts of my life. Something that always makes me feel special is when a client thanks me. It can make a big difference to my life as well, if I know that I have done a good job. It makes me happy and in my culture that is what my name means. 'Khushi' means happy/happiness."

#### What's the one thing you wish people understood better about people with spinal cord injuries?

"I wish that the general population understood that people with spinal cord injuries have often had to rebuild their lives, and that there's a huge amount of strength and resilience involved in doing that. I find this very encouraging for myself as it's a different way of thinking about things – I honestly believe that I have grown as a person because of the privilege of working with people with spinal cord injuries."

#### How do you relax when you're not at work?

"Take my dog for walk, do exercise while listening to music, or chat with my family overseas."

#### What's the most important lesson working as a PSW has taught you?

"That almost everyone, no matter who they are, will have difficult days or have struggles in dealing with difficult situations in life. I have learned that the struggles or difficulties may look different, but we all experience the ups and downs of life." A

To nominate a Team Member to feature in a future issue, email: theadvocate@spinal.com.au

## The latest

Information, inspiration and inclusivity



#### YAY, US!

Can we just take a moment to give ourselves a little pat on the back? The finalists of the Australian Access Awards (accessibility.org.au/awards) were announced late last year, and Spinal Life Australia was selected in the category of Not-for-profit/Community Website of the Year! These awards celebrate organisations that have implemented accessibility in their digital campaigns or resources, so we want to say a huge congratulations to the talented Spinal Life team who work so hard on making our website helpful, informative and easy to use.

An initiative of the Centre for Accessibility Australia, the Awards are held every two years – this time around they were held in Fremantle and some of our WA team were lucky enough to attend, alongside parliamentary decision makers, industry innovators and community members. It was a fantastic event, with live music and appearances from accessibility experts.

#### **MORE GLORY!**

When it comes to awards, the latter half of 2021 was also an exciting time for our esteemed board member, Carol Taylor.

First up, in September, Carol - who is Principal Solicitor at Taylor Law and Conveyancing and has been living with quadriplegia for 20 years was named a 2021 Regional



Practitioner of the Year by the Queensland Law Society.

Then, in December, the National Awards for Disability Leadership acknowledged the work of seven outstanding disability leaders who have significantly contributed to advancing the status of disabled people. The seven categories included everything from Rights Activism to Innovation. And the winner of the Arts category? None other than our Carol! She's not only a top lawyer, but also an award-winning artist and the world's first quadriplegic fashion designer designing incredible adaptive clothing.

Congratulations, Carol - we're so proud of you, and so glad you're on the Spinal Life Board!



## **CHILLIN' WITH DYLAN**

Quotes from the greatest quad tennis player of all time, four-time Paralympic gold medallist, and our new Australian of the Year



Just as we were finishing this issue of *The Advocate*, Dylan Alcott, AO, was named Australian of the Year 2022, and we knew we had to make some room to honour this icon of Australian sport and utter legend.

When it comes to wheelchair tennis he's a champion over and over, with 23 Grand Slam titles to his name. He's also a four-time Paralympic gold medallist in two different sports, having become the youngest wheelchair basketball gold medalist in history at the 2008 Beijing Paralympics, at the age of 17.

He's done a "few" other things as well as play sport... such as getting a commerce degree, hosting a radio show and a live music TV show, being a motivational speaker and writing his autobiography. He's also done extensive charity work with Australians with disabilities, including work through his Dylan Alcott Foundation – which he lists as one of his greatest achievements.

Dylan's an extraordinary advocate for Australians with disabilities and we can't wait to see what he does next. We know he'll use his amazing platform to continue to shape change in so many people's lives. In the meantime,

here are some of his most memorable and inspiring quotes from over the years...

"Wow. I'm forever grateful. My purpose today and everyday is to change perceptions so people with disability can live the lives they deserve to live. I'll do my best to make you all proud as your Australian of the Year xx" **Twitter**, 2022, after being named Australian of the Year 2022

"My all-time favourite saying is, "For every one thing I can't do, there's 10,000 more that I can." **sourcekids.com.au,** 2018

"Just because you are disabled it's not a life sentence, your life's not over, there's still so many things you can do to get out there and live a happy and successful life." *abc.net.au*, 2017

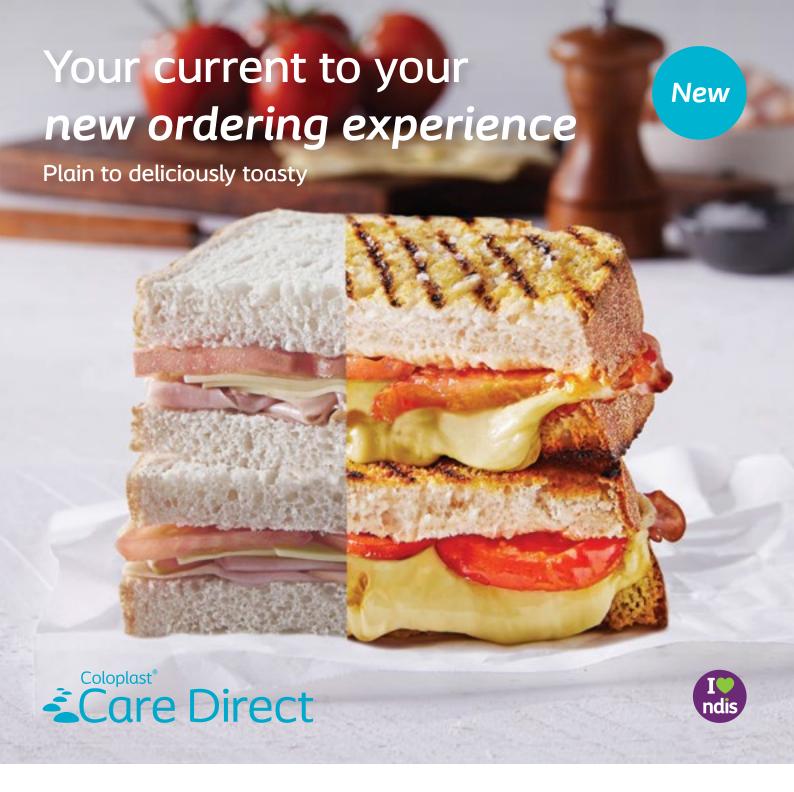
"Being a good tennis player is probably the 32nd priority of my life and I mean that. Being a good person is No. 1, a good family member, a good friend, a good partner to my partner Chantelle, and being a good advocate for my community to change perceptions for people like me so they can live the lives they deserve to live and get the opportunities that I've had. I'm so lucky." *foxsports.com.au*, 2021

"I can't stress enough the importance of putting yourself out there, on the line. You might get knocked down a few times, but on the sporting field – in a professional and personal sense – you make your own luck. You've got to buy a ticket to win the raffle." *intheblack.com*, 2016

"When I was getting bullied about my disability, if I could have turned on the radio and heard someone like me, or someone like Nas [Campanella] or put on the TV and see someone in a wheelchair – if I had have seen that, it would have changed my life instantly." *abc.net.au*, 2017

"Be confident and proud of who you are. Remain authentic to yourself and if one person gives you bad advice, go elsewhere." **sourcekids.com.au**, 2018

"It means so much to me this place [Melbourne Park] because of what Tennis Australia has done, the Australian Open but mostly the Australian public. Getting behind a disabled athlete in the way that everyone has, has just been life changing hopefully for a lot of people, and it's set the standard of how athletes with a disability should be treated. We are worthy, people want to watch, we do give a return on investment. I'm really excited about the next generation who are going to get the same opportunities." *foxsports.com.au*, 2021



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