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Cover image from Kintsugi (kintsugiclothing.com), photography by Merika Green.







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#### Farewell 2021, hello 2022

As I write this for the final Advocate of 2021, I cast my mind back to the significant challenges we've faced this year. Although it's been extremely difficult for everyone for the second year in a row – it's also been heartening to see how people help each other during periods of lockdowns and uncertainty.

Despite the challenges, 2021 has been productive and positive, and we've made great strides in a number of areas.

In particular, the investments we've made in new technology mean that it's now easier than ever to communicate with us. Wherever you are in the country, customers can speak with one of our community nurses via Telehealth video appointments. Meanwhile, our support staff can use CarelinkGo to see their roster in real time - and our clients can request shift changes via our new app, AccessSLA. Our website and social media channels have also undergone significant improvements - all focused on improving the experience for our customers. This magazine, too! We'll continue to work on all of these areas and more throughout 2022 as we evolve the ways in which we provide our services and communicate with

you. We've also been communicating with the public at large via our 'Take Life Back' adverts on TV and radio. Running since the middle of October, these ads are a first for Spinal Life Australia. They've been produced to create brand awareness, and tap into emotional stories that will connect with viewers, inspired by the positive 'Take Life Back' message.

One of the things I'm proudest of this year is the great work we've done in the field of Advocacy. Our 'Disability Doesn't Discriminate' campaign has generated 20,000 emails to Federal MPs, calling for change. Looking towards 2022, we'll stay true to our mission and be advocates for change on behalf of our members.

With the recruitment of our first Regional Operations Manager in Perth, our WA business is expanding more than ever before and we look forward to continuing to expand our presence and influence there.

Soon after this issue of *The Advocate* is printed, customers will be welcomed into the Healthy Living Centre Brisbane - a state-of-the-art rehabilitation and fitness centre at Woolloongabba, purpose-built for people with spinal cord damage. Stay tuned for more news on this exciting initiative.

In the meantime, on behalf of the board of directors of Spinal Life, I wish you and your loved ones a safe and happy Christmas, and all the very best for a positive, joyful New Year.

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 happened this year that positions Spinal Life Australia well for the future?

"Our Disability Doesn't Discriminate campaign (disabilitydoesntdiscriminate.com.au) was really special. It was our first truly national campaign and we made some great inroads and reached a lot of people. There's obviously still a long way to go to change the ridiculous legislation that affects so many Australians, but I'm so proud of our results so far, and looking forward to continuing to raise awareness of this important issue."

### What's the one thing that you're most excited about as 2021 draws to a close?

"Definitely our new Healthy Living Centre [HLC] in Brisbane. Based in Woolloongabba, right alongside our head office, it's another example of us improving services for customers, learning from our brilliant HLC in Cairns. It's been especially created for people with spinal cord damage, but will appeal to a broader audience.

It will mean our customers can enjoy superb gym facilities, as well as essential services from first-class physiotherapists, occupational therapists, social workers and more. It's going to be a real hub and we're all incredibly excited for the official opening, which is scheduled for early 2022."

### How are you intending to 'spread the word' about Spinal Life?

"In October this year we launched our campaign to increase brand awareness in the territories in which we operate. Starting with Far North Queensland and the Sunshine Coast, our 'Take Life Back' campaign aims to show to the community the ethos of our organisation and generate awareness in the broader community.

The responsive web app we developed – Accessible Australia – and our advocacy services also will help to build awareness of our brand in the community and our ability to continue to be financially successful."

#### What else is on the cards for 2022?

"We'll be hard at work on our precinct development for some time: our vision is to make Woolloongabba a real one-stop shop for our members. We can't wait for it to become a reality!

We'll also continue to work on improving corporate culture, and to introduce and embrace more technology in order to engage and support our staff and customers more deeply. And that's just the start – we look forward to sharing more with *Advocate* readers in the months ahead."



#### **Vehicle Mobility Solutions**

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CARING





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Spinal Life

Not so long ago, fashion-forward shopping options for people with a disability were limited, to say the least.

Approximately one in five Australians live with a disability, but even though they're one of the largest minority groups, historically they've been largely ignored by the fashion industry.

Adaptive fashion – clothes and accessories specifically designed to make dressing easier for people with disabilities or limited mobility – was out there, but the reality was often clinical, gender-neutral and one-size fits-all. And even then might still need altering.

Thankfully, the fashion landscape is changing. In the last few years there's been a noticeable rise in the availability of inclusive design and adaptive fashion: indeed, according to fashion platform Lyst, searches for adaptive fashion increased by an extraordinary 80 percent in 2019. It's unclear yet how the pandemic has affected things, but one thing is evident: savvy designers and some big-name brands are finally starting to respond.

That's because making stylish adaptive clothes is not simply the right thing to do, it also makes great business sense. Like maternity, active and plus-size clothing before it, adaptive fashion is a rapidly growing fashion niche and looks likely to be the "next big thing". The buying power of people with a disability is huge and largely untapped – but according to Coherent Market Insights, in just five years' time the global market for adaptive clothing is expected to hit nearly *US\$400 billion*.

It's no wonder some of the biggest names in the world [like Tommy Hilfiger; see feature on page 8] are catching on – and catching up. They understand how important it is to be inclusive.

Already, it means the days of purely practical adaptive choices are, happily, receding in our fashion rear-view mirror. Instead, brands are launching lines that give people with disabilities access to on-trend, mainstream clothes that meet their physical needs *and* their personal style.

Yes, they're accessible, functional, comfortable and safe, and made with the wearer's everyday challenges in mind. They embrace everything from magnetic fastenings and thoughtful closures, to pinch-free elasticated waistbands and tagless, seamless clothes in softer, less-irritating fabrics. Things like hidden pull loops and wider holes for the neck and arms make it easier to pull clothes on and off, and silhouettes are also different to accommodate people in wheelchairs – for example, pants are cut higher in the back and lower in the front for optimum coverage and sitting comfortably.

But, ultimately, personal style should be the key aspect that determines what we choose to wear. Which is why garments also need to be fashionable.

As we enter a new era in which modern, inclusive clothing is likely to take centre stage, it's not only going to be empowering for shoppers, but also play a vital role in improving how people with disabilities are perceived: stylish, independent members of society who are also bang on-trend.



#### ADAPTIVE CLOTHING IS THE FUTURE AND THESE **BRANDS ARE CHANGING THE GAME**

There are plenty of labels out there creating and selling clothes that make dressing easier. But an elite group of brands and designers is also dedicated to upping the style factor. Here are some of the coolest labels that truly value people with disabilities as fashion customers (and ship to Australia!).

#### **Billy Footwear**

Billy Footwear features unique FlipTop Technology – a zipper on top of the shoes that makes them easier to put on and take off. The label is named after cofounder Billy Price, who helped design the shoes after he became paralysed from the chest down after breaking his neck from a three-story fall, and sells cool shoes for everyone from toddlers up. billyfootwear.com

#### **Christina Stephens**

See our story on page 10.

#### **Elba London**

Elba ('able' spelt backwards) focuses on beautiful, frontfastening bras with a patented EZ magnetic closure, for people with limited mobility or difficulty dressing. As well as no fiddly fasteners, there are no itchy fabrics, with all bras made in soft, breathable fabrics. elbalondon.com

#### **FFORA**

FFORA (which stands for Fashion for All) specialises in stylish, wheelchair-attachable accessories — everything from wallets, bags and purses to accessible cup and wine glass holders. Wheelchair users are involved in advising, designing, promoting and all other aspects of the creation process. liveffora.com

#### GroundedClothing

See our story on page 14.

#### Intimately

Intimately sells beautiful inclusive ladies' lingerie, from companies including Elba London and Slick Chicks – but in February 2022 it's also set to launch its own line of lingerie. intimately.co

#### **IZ Adaptive**

IZ Adaptive sells stylish, adaptive wardrobe basics, mostly in black, white, grey and khaki, for wheelchair users and people living with limited mobility or dexterity. Founder

and designer, Izzy Camilleri is a pioneer in adaptive clothing, and the company not only seeks input for their designs from individuals with disabilities, but also features them as models and in their campaigns. izadaptive.com

#### JAM the label

Melbourne-based JAM [see main image] was cofounded by Molly Rogers and Emma Clegg, who are also full-time occupational therapists. In their previous lives as disability support workers, they met two young Aussies, Jack and Maddie: JAM the label is named after them. But JAM isn't about 'adaptive' clothing; it's an inclusive label. So while it was created with young people living with disability in mind, anyone can wear it. The aim is for all people to be able to get dressed more easily, by having access to fashion that's functional – and still on-trend. jamthelabel.com

#### Kintsugi

Our beautiful front cover image is from Kintsugi. This name draws on the Japanese art of repairing broken pottery with gold – the idea being that by embracing flaws and imperfections, you can create something even stronger and more beautiful. It perfectly reflects the brand's philosophy that all individualism is beautiful. The brand is all about being inclusive, rather than exclusive, and creates clothing that everyone can wear. kintsugiclothing.com

#### **Nike FlyEase**

We featured these cool hands-free shoes [above] in The Advocate a few issues ago. The lace-free, FlyEase closure system has an easy wraparound zipper with a hook-and-loop strap which allows a secure fit with one motion. It makes the shoes easy to open and close; easy to get in and out of; and adjustable so that they can accommodate different foot shapes and sizes. nike.com/flyease

#### **Slick Chicks**

As we all know, getting dressed isn't always as simple as putting your undies on one leg at a time. But Slick Chicks' undies are designed with side fasteners that make it easy for someone to put them on or take them off, whether they're sitting, standing or lying down. **slickchicksonline.com** 

#### **Tommy Hilfiger Adaptive**

See our story on page 8.

#### **Zeba Shoes**

Zeba Shoes come in a variety of modern styles and colours, and best of all the hands-free sneakers don't require tying or bending down to put on or take off. zebashoes.com



Everyone knows the fashion label Tommy Hilfiger, famous for its signature sporty-preppy look. But did you also know that the brand is leading the way when it comes to adaptive clothing?

It all started in 2016, when Tommy Hilfiger became the first mainstream fashion label to create adaptive clothing options for children. It was so popular that the line was expanded to include adult sizes as well, and Tommy Hilfiger Adaptive

> was launched in the United States in 2017. Today, it's available in Europe, Japan and – great news – Australia.

Designed to make dressing easier for people with disabilities, each piece features the same classic American cool-with-a-twist aesthetic as the iconic Tommy Hilfiger brand – but with innovative modifications like easy closures (zippers and buttons replaced by VELCRO® and magnetic buttons), modified hems and other seated-wear solutions.

As the first global lifestyle brand to modify its mainstream clothes to fit the needs of people with disabilities, Tommy

Hilfiger is a real pioneer when it comes to making clothing as user-friendly and inclusive as possible.

We can only hope other major brands will follow suit soon.

Getting dressed should be a joy – an experience that empowers you to look good and feel good in what you are wearing. Our adaptive collections have revolutionised everyday dressing for people with disabilities, giving them the independence and confidence to express their individuality through style.

Tommy Hilfiger, principal designer, Tommy Hilfiger Global



#### **Q&A WITH TOMMY HILFIGER**

#### Why is adaptive fashion so important to you?

As the father of autistic children, I have experienced first-hand the difficulties of getting dressed. Picking out your clothes for the day should be a joy, not a chore. Everyone deserves to feel good in their clothes and have independence.

#### **How did the Tommy Hilfiger Adaptive collection** get started?

It all began with a boy who wanted to wear jeans to school. He lives with muscular dystrophy, so buttons and zippers were challenging, and the legs wouldn't fit over his braces. The team and I heard how his mother stayed up late to add VELCRO® Brand closures down the inseams and raced to his school during her lunch break to help him go to the bathroom – all so he could wear jeans like his friends. It was a no-brainer; we needed to do something.

#### What are the challenges when designing an adaptive collection?

As the first designer brand to develop an adaptive line of clothing for both adults and kids, there was a steep learning curve and a whole lot of trial and error. We found there were a few useful features already available on the market, but quickly realised that to make a real difference; we would have to go further. Every disability presents a unique perspective. For example, when designing a piece for a wheelchair user, we need to consider where we place zips, buttons and pockets. We took a broad approach for the collection, creating innovations that would assist as many people in the community as possible. As time goes on, we hope to expand and provide style that is welcoming to everyone.

#### What is the philosophy that drives the collection?

I always wanted to build a global lifestyle brand that is for everyone. The Adaptive collections continue to build on that vision, empowering adults and kids with disabilities to express themselves through fashion. The future will only see us invest more into this collection.

#### What was the design inspiration behind the **Adaptive Collection?**

While Tommy Hilfiger Adaptive features modifications that make getting dressed less complicated, it is the same quality, design and aesthetic as our other collections. That's what makes it amazing. You would never know by looking at a piece that it's adaptive, and this kind of design equality was very important to me. That's what it's all about: levelling the playing field so that everyone can look equally cool and stylish.

#### What was the design process for creating the **Adaptive Collection?**

Tommy Hilfiger Adaptive starts with our classic, Americancool style. Each piece has the same design ethos and quality that we offer everyone else, but every innovation began with an individual need. We hosted extensive focus groups and gathered valuable feedback on the products. Our patent-pending magnetic zipper, for example, was originally designed for someone with a limb difference, as that was a significant issue. It quickly became clear that being able to zip and unzip a jacket with one hand was a feature that everyone could appreciate.

#### How well do you think the fashion industry has done with responding to calls to be more inclusive?

Over the course of our industry's history, we have seen the impact that inclusivity can have. Bringing side-lined marginalised groups into the spotlight breaks down barriers and preconceptions, creating the foundation for a more inclusive society. Big changes in any industry take time to be adopted by the mainstream. We've always seen ourselves as trailblazers, with our incredible teams focused on evolving consumer needs. As a global brand, we have a responsibility to cultivate change where we see it's needed most - and leading the way for adaptive fashion is something we're very proud of.

#### **How does Tommy Hilfiger Adaptive contribute to your** brand culture?

As a brand, we are constantly finding new ways to be more inclusive, diverse and democratic. Tommy Hilfiger Adaptive embodies these values. Whether it's through expanded curve sizing or more gender-neutral design, each season we'll continue further delivering on our promise to make fashion more comfortable, enjoyable and resonant for everyone.

Browse the new season Tommy Hilfiger Adaptive Collection at: au.tommy.com

# Crushing on Christina

Everyone's loving Christina Stephens, a Brisbane-based fashion label focused on inclusive fashion



Christina Stephens desginer and founder, Jessie Sadler

Finding great clothes that fit beautifully and look fantastic is a nightmare for many women – but factor in a wheelchair as well, and it's a whole new level of difficulty. Thankfully, a number of designers are helping to change the fashion landscape for people living with a disability. Here's a quick look at one of the leading lights, Australian adaptive fashion label, Christina Stephens.

#### **EVERYTHING YOU NEED TO KNOW ABOUT CHRISTINA STEPHENS**

#### So what is Christina Stephens?

It's a Brisbane-based fashion label focused on inclusivity, adaptability and sustainability - and designing great clothes that people love to wear. It's about giving women living with disabilities a choice, and helping empower them with greater confidence.

#### **Who is Christina Stephens?**

Christina Stephens is the name of a label, not a person. It was founded by Queensland designer and entrepreneur, Jessie Sadler. She wanted a label that sounded "designer-y" rather than functional or clinical. Her mum's name is Christine and her dad is called Stephen, so she combined the two names and... voilà!

#### How did it all begin?

About five years ago, Jessie's mum had a fall and badly damaged both her elbows. As a result she had limited movement and was unable to dress with ease. All the fashion options for women living with short or long-term physical challenges left Jessie and her mum seriously underwhelmed – it was an endless array of one-size-fits-all, unisex, functional apparel, and nothing for style-conscious women who want fashion that makes them look and feel good. Jessie got to work and, 18 months later, the Christina Stephens label was born.

#### What's the brand's aesthetic?

Think minimalism: clean lines, flattering cuts and colours, minimal trims, and basic pieces that can be worn and accessorised with ease. Clothes that are effortlessly stylish and easy to wear. With beautiful, high-quality adaptive fashion that's also on-trend and highly desirable, it means people no longer have to choose between style and comfort.

#### When did the label launch?

Jessie launched the business in March 2020 (yep, just when the world was going into pandemic panic). Nearly two years later and it's going strong. During that time, Christina Stephens has featured on runways at Brisbane Fashion Month, London Fashion Week and twice at Melbourne Fashion Week, been showcased numerous times in the media, released an extended size range and expanded its retail partnerships. Earlier this year, when online retail giant *The Iconic* launched a dedicated Adaptive Edit featuring more than 130 pieces from leading brands (including Tommy Hilfiger Adaptive), Christina Stephens was one of two Australian labels to be included.



# Guarding skin integrity



### **Smith**Nephew

### **PROSHIELD Foam & Spray**

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No-rinse foam suitable for incontinence and total body skin care.<sup>2-6</sup>



Formulated to help eliminate odour and breakdown dried stool.



#### **PROSHIELD PLUS**

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# Tailored tips

#### Inside advice for sartorial splendour, SCI style

When it comes to adaptive fashion, forget fashionistas and celebrated style gurus: you need advice from people who really know what they're talking about. That is, people with lived experience.

We asked members of the Peer Support Spinal Life private Facebook group to tell us their favourite brands and share their best tips and hacks when it comes to clothes that look good and meet the very specific needs of people with a SCI.

From shoes and shorts to workwear and wedding dresses or ponchos and pockets, here are some of their smart, stylish suggestions.

Want to join the Peer Support Spinal Life private Facebook group? Sign up at facebook.com/groups/peersupportspinallifeaustralia

"Johnny Bigg. I wear all of their gear. Great size selection and really nice fashion. In my opinion, anyway!"

**Tim McCallum** 

"I have shorts made with no seams in the back of them, it helps so much with pressure areas."

**Mark Farrell** 

"I buy shoes online from billyfootwear.com. They're great as the zip opening goes right the way round and I can get my toes flat, which can be difficult in other shoes."

**Helen Bonynge** 

I recommend fishing shirts, which are good for when you're still learning to regulate your temperature, and basketball shorts. Ponchos have also been a lifesaver for us. They go over your power chair without having to worry about putting arms in and out. They also allow air circulation to prevent overheating. Hubby has three on rotation. I even made our own - it's super-easy to do if you're handy with a sewing machine!" Jess JJ Hitchens

"Find an incredible tailor and get all your formal clothes (and even work clothes) tailored to fit you! And always get your jeans altered. The alterations are even claimable on NDIS."

**Kadie Maree** 

I bought Black Beauty woven pants from Bonds. They do have a back pocket, but no buttons etc. They seem to stay up and look a bit smarter. Nike Dri-fit are the best stretchy pants – they're super stretchy and great for home or the physio." Ben

"Maternity dresses, men's kaftans, robes/throbes and anything you can just throw on. The Adaptive Boyleg underwear from Modibodi is also great." Ana Bell

"When it comes to catheter bags, I use a clamp and don't have a leg bag at all. Or, if my dress is long enough, I just move the bag to the inner thigh." Louisa Meree Smart

I wear a lot of elastic-waisted chinos from Connor. I tend to go for cotton trousers because my butt slides around on the chair too much in synthetic pants!"

**Steve Edwards** 

l've worn shoes from The Athlete's Foot for years, but just bought my first pair of Dr Comfort shoes and they're very comfortable." **Norton Robin** 

Johnny Bigg for sure." **Col Mackereth** 

"Adapt clothes you like wearing. I like jeans and stretch pants, so I get the belt loops reinforced by a seamstress to take the strain off hoiking them up, and tie loops on the zip. I also buy high-waisted pants to avoid showing off my butt crack. Another tip: if undies are too hard, then don't bother wearing them!"

**Alison Beckwith** 

"Thermals from Kathmandu are the perfect weight, easy to put on, fast drying and as warm as." Jay Mee

# **Fancy pants**

When it comes to wheelchairfriendly long pants for men, there was lots of advice.

"It's shorts all year round for me! But when I do have to wear long pants I go for skinny leg stretch denim – they seem to work best for me." **Peter McDonnell** 

"Levi's 501 originals. I've never wore anything else in 42 years. They have high waists, come in all colours, and look bloody good in a wheelchair." **Arthur Noul** 

"I wear those cuffed chinos from Connors."

Steve Edwards

"RM Williams moleskin jeans." Col Pittorino

"Buy your favourite pants, jeans or trackies and get them altered. I do and it works perfectly. I'm in Perth and go to Megan Alterations in South Perth." **Douglas Milne** 

"I wear cargos that I get from Big W or sometimes even Aldi has them. They're great as my wallet sits on the side of my leg." **Mark Blowers** 

"I buy chinos, jeans, shorts, work/suit pants etc and have them modified." **Lindsay Nott** 

"After much trial and error I found that black chef pants with an elasticated waist work best for me. They're big and baggy, easy to adjust, and don't dig into your crotch. You can get them at Lowes." **Tony Leggett** 

"Levi 510s for me – they have a high waist, stretch and legs aren't too slim or too baggy. They fit the thighs just right for a wheelchair." **Bevan Kearsley** 

"I went to Big W and bought cargo pants, which I found to be surprisingly good. They have a stretchy waist and the leg holes are stretchy too. They're easy to get on and off, and warm too. I just cut a hole in the knee for the catheter." **Shem Ahhoy-Singer** 



# CATCH UP WITH YOUR COMMUNITY

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

#### Spinal Life Peer Support Groups

BRIBIE ISLAND: Bill Peacock on 0403 686 998.

Combined with Post Polio group.

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

FRASER COAST: Sam James on 1300 774 625.

IPSWICH: Eric Rushton on 0403 191 698.

MACKAY: Ross Duncan on 0475 077 080.

MORETON BAY: Ross Duncan on 0475 077 080.

ROCKHAMPTON: Robynne Clifton on 0473 576 107

or Anne Guthrie on 0407 116 035.

TOOWOOMBA: Wendy Adams on 0422 799 580.

Combined with Post Polio group.

WESTERN AUSTRALIA: Aileen Ward on 0420 985 734.

#### Post Polio Groups

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

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

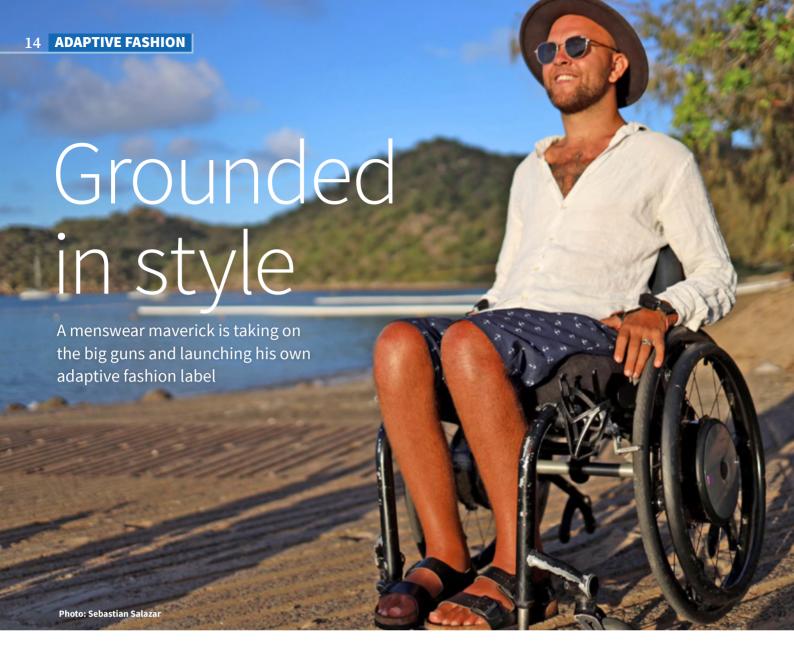
**SUNSHINE COAST**: Cathy Newman on 5447 6608.

TOWNSVILLE: Eric Collins on 4729 0275.

#### Transverse Myelitis Group

Contact Jodi Gallon on 0451 235 860

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



In 2013, Ben Everson was 19 years old and awaiting the results that would determine whether or not he would be able to pursue his dream profession as a paramedic.

But after jumping into the Murray River on a fun weekend away with friends, he needed to be *rescued* by paramedics instead.

"I actually heard my vertebrae snap," Ben says when recalling that fateful leap.

When his mates realised he was in trouble, they called an ambulance and Ben was taken by air to the hospital in nearby Murray Bridge. Suspecting a spinal cord injury, they quickly transferred him to the Royal Adelaide Hospital, where the final diagnosis was life-changing.

"I'm a high level quadriplegic," explains Ben. "I've broken my C5, but I'm classified as a C4-5 quadriplegic complete. I've got upper limb movement, but I don't have upper limb control. So I can bend my elbow with my bicep and I can raise my hand with my shoulder, but I don't have any finger dexterity and there's minimal movement throughout the arms, and complete paralysis from the chest down."

As he adjusted to his new reality, including spending 11 months in Adelaide's Hampstead Rehabilitation Centre, Ben quickly realised that the effects of his accident permeated just about every part of his life. Even clothes.

"All through hospital you're told, 'Go invest in trackies – you've got a leg bag now, so that's all you'll be wearing," says Ben. "So I was buying tracksuit after tracksuit. I did try to wear pants, but you have to buy them three or four sizes too big so that they fit over your bum. And then of course they're too long in the legs and just don't look good."

Growing up, Ben always enjoyed looking his best and wearing nice clothes. "That doesn't change after you break your neck," he explains. "I'm a young dude, wanting to look smart and go out with my mates, but still have functional clothing." He employed professional sewers to make adjustments to his clothes, "But because nobody designs clothes for the seated position, they still wouldn't be right, even after I'd spent all that money on the clothes and alterations".

Ben had pretty much accepted that his future was going to involve a lot of ill-fitting clothes... until a life-changing

adventure in 2019, when he took off to travel the world for six months.

"I relied heavily on Support Workers," he says. "We had to problem-solve on many occasions, whether it was getting out of a train with a one-metre drop and no platform, or transferring from a bed that was literally on the floor, into my wheelchair. But I believe that there's a solution for absolutely everything."

The solution for his wardrobe woes came to Ben in a beachside epiphany while he was in Ibiza.

"I was chilling by the beach with my best mate, struggling to hide my leg bag in my swimmers, and I said, 'You know what? I'm going to create my own adaptive clothing label."

And that's exactly what he's done.

"I did market research and trialled anything and everything I could find (which was limited). My biggest surprise was these companies were still designing their pockets in the usual position, just below the hips, leaving no room to actually use them. Also, zips weren't long enough and clothes simply didn't have enough elastic in them."

Armed with some great practical advice from his friend Charlie, who helped create Australian-based clothing and lifestyle label, ortc Clothing Co, as well as another friend's bridal designer mum, Ben was able to navigate everything from cut and fabrics, to sourcing and dealing with a manufacturer. It was a steep learning curve, but it helped him work out exactly what was needed, and how to actually achieve it.

The result is a collection of smart casual clothing, launched under Ben's own label, GroundedClothing.

"I love nature and have always loved being outdoors, so that's definitely reflected in the name," says Ben. "But it's also about being connected to the earth in another way – if you're in a wheelchair you're literally connected to the earth: you're grounded."

Some of Ben's clever, simple solutions include placing pockets 12cm lower and making them large enough to fit wallets and phones. "They're the perfect size for your phone, so it will be secure and no longer fall out," he says. He's also added crucial extra strength by using double stitching on absolutely everything, and adding hooks on belts to help when pulling pants up. "Adaptive clothing isn't always for the individual, it's also to help all supports, family friends or workers," he explains.

The launch collection comprises key items for every man's wardrobe: shorts, pants, trackies, t-shirts, polo shirts and even bathers (an item he's never found online). Made predominantly from high-quality cotton – including 3% elastane to ensure there's some 'give' – they're available in a range of suitably earthy colours such as charcoal grey, khaki, navy blue and a dark forest green. Each piece is tag-free (everything from sizing to care instructions will be screen-printed on the reverse side), and has been deliberately designed to be as functional, stylish and "basic" as possible.

"I've contacted the NDIA and the clothes are all fundable as well," says Ben. "'Because GroundedClothing provides specialised clothing, it can be purchased using your lowrisk, low-cost assistive technology support budget, if you're self- or planner-managed. People will be able to buy pieces separately, but my future goal is to package everything together so that they can get everything they need, in one bundle, on their NDIS plan."

Speaking of the future, Ben plans to add button-up tops, socks, underwear, stain-resistant clothes, and maybe even team up with another designer to create clothing for women. And he's already in the process of designing shoes with his manufacturer.

"My plan is just to make good-quality, simple, stylish and comfortable items that people like," he says. "They're going to like the fact that the clothes will last longer, and that they're Australian-designed, so they're supporting local. But I think the thing they'll like most is that these clothes are designed by somebody with lived experience. Unlike other labels, I'm the designer and I'm the wearer. I know what adaptions I need to make my life better. And I'm hoping that all these solutions will help everyone else as well."

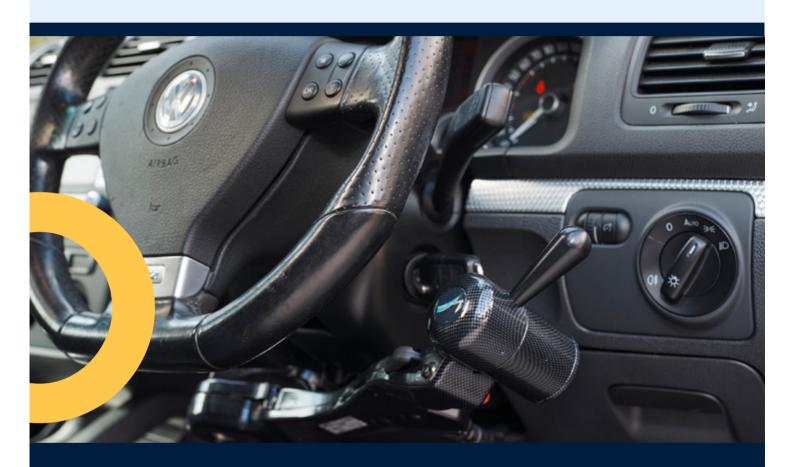
Not bad for someone who had zero interest in design before his accident.

"I wanted to be a paramedic," reflects Ben. "But what I really love is just helping people, and the instant reward you get from helping them. You definitely feel better when you do something for someone else. Designing adaptive clothing does that for me. Being able to give someone that little bit of help to give them an extra level of independence is an instant reward for me."

The launch collection from GroundedClothing will be released in early 2022. To check out the full range or if you'd like to preorder any items, go to: **groundedclothing.com.au** 

# Ergonomic Radial Hand Control.

**By Fadiel Italiana** 











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# Fashionable follows

Things to read, videos to watch and social media accounts to follow in the fashion world



Heidi Herkes, 41, is a lifestyle influencer and personal stylist from London. In 2014 she fell down some stairs, which left her instantly paralysed from the chest down and with very limited movement in her arms. Pre-accident, Heidi was a professional hair and makeup artist. Post-accident she decided to draw on her knowledge and experience and train as a personal stylist. "I never wanted my disability to define me,' she says. "I wanted people to still see the real Heidi and not just a woman in a wheelchair." Today, Heidi uses the power of style and fashion to empower other women and help them regain their self-confidence after they've been through tough times. If you're after some fabulous female fashion inspiration, follow Heidi at: instagram.com/heidiherkes/ and YouTube: Heidiherkes

#### **Runway of Dreams**

There was a spectacular event at New York Fashion Week in September: the Runway of Dreams 2021 Fashion Revolution. With the brilliant slogan, "Where there's a will, there's a runway," it featured more than 60 models of differing ages, ethnicities and disabilities, all sharing one runway and showcasing adaptive apparel and footwear from six major brands. The show (which you can watch on YouTube) is all thanks to Mindy Scheier. Once upon a time she was a stylist at Saks Fifth Avenue, but in 2014 she founded Runway of Dreams, a non-profit organisation working towards a future of inclusion, acceptance and opportunity in the fashion industry for people with disabilities. The aim is to make adaptive apparel as common as petite or plus size, and for people with disabilities to have access to fashion that excites and empowers them. runwayofdreams.org

#### **Adaptista**

"The market needs a high-end voice," says Maria O'Sullivan-Abeyratne. She's the CEO and founder of Adaptista, an adaptive fashion, beauty and lifestyle marketplace of carefully curated brands set to launch at the end of 2021. Word on the street is that while it will offer a range of



adaptive items at different price points, the overall feel will be significantly more elevated than most existing adaptive platforms. So if you're looking for something special to wear, this fashion-forward adaptive platform could be your new best friend. We can't wait for this new website to launch – in the meantime, you can check them out on Instagram and Twitter (@adaptista). adaptista.com

#### The Future is Now!

True Colors FASHION *The Future is Now!* is a series of videos about adaptive fashion empowered with technology. It features some of the world's leading tech companies and fashion brands, who came together to push the limits of fashion as we know it. The result is a range of incredible tech wearables, all worn by a diverse cast of models. The adaptive fashion on display goes far beyond standard prosthetic limbs and wheelchairs: it's human creativity and technology at its best, and the future is most definitely now! Launched in mid-2021, the fascinating and thought-provoking True Colors FASHION videos are all part of the True Colors Festival, a long-running international festival of performing arts that celebrates diversity and inclusion, and is still available on YouTube (youtube.com/c/truecolorsfestival).

#### Cur8able

"People with disabilities are not seen as fashion customers, despite the six *trillion* dollar combined buying power of these individuals. I started on a journey 30 years ago to try and change that." So says Stephanie Thomas, the founder of Cur8able. This inspiring, US-based fashion company specialises in styling people with disabilities, reporting disability fashion news and trends, and consulting brands interested in authentically engaging disabled shoppers. It's eye-opening, helpful and *über*-stylish. And the concept of using fashion styling as a tool to challenge negative perceptions of people with disabilities is just incredible.

#### cur8able.com

While you're checking out all of these amazing website and social media accounts, don't forget to follow us too! We're at facebook.com/spinallifeaustralia and twitter.com/



Our favourite accessible beaches for a summer holiday

Some of Australia's most fantastic beaches and beachside experiences are wheelchair accessible. So with summer on the way, we thought we'd compile a list of some of our favourites in Queensland and Western Australia.

We asked Dane Cross and Karen Harvey from Spinal Life Australia to inspire us with some of their favourite inclusive waterside locations and activities. Have a great summer!

#### City Beach, Perth, WA

Apparently, Perth has more sunny days than any other capital city in the world. How convenient then, that one of its favourite beaches is just a 15-minute drive from the CBD. The aptly named City Beach features a 500m-long stretch of white sandy beach and two purpose-built groynes which block large waves and provide beautiful calm waters for swimming. There are also excellent facilities, including barbecues, picnic tables and shaded playgrounds, as well as accessible bathrooms with both left-hand and right-hand transfer bars for the toilets, and a fold-down shower seat in the bathroom. Fantastic wheelchair-friendly restaurants look out over the beach and offer spectacular views of the sun setting into the Indian Ocean. You can park in one of the accessible spaces along the foreshore and head to one of these, or head down to the water. A concrete pathway allows wheelchairs to get right down to the sand, while beach matting runs from there down to the water's edge, right in front of the Surf Life Saving Club. A Sandcruiser beach wheelchair is available free of charge during beach patrol hours, subject to availability (for more information and bookings, go to: cambridge.wa.gov.au/beachaccess.)

#### **Rockingham Beach, Rockingham, WA**

There are some great beaches in the seaside town of Rockingham, about 45 minutes' drive south of Perth. One of the best is Rockingham Beach, situated in the busy foreshore area and surrounded by restaurants and parks. It's more accessible than many of the other beaches nearby, thanks to the availability of accessible parking and toilets, a lack of steep hills, dunes or challenging terrain, and connecting ramps and concrete paths which give easy access to the beach area. There's also beach matting, which provides safe and clear access across the sand to the water from October through to April each year, depending on weather conditions. A Beach Trekker wheelchair and a Hippocampe All-Terrain Wheelchair are also available for loan (for more information, visit: rockingham.wa.gov. au/community/people-with-disability/accessibleplaygrounds-beaches-and-facilities).

#### Yanchep Lagoon, Yanchep, WA

Head north along the coast from Perth for about 50 minutes and you'll arrive at Yanchep, a coastal resort town that's famed for its outstanding national park, and is the gateway to Lancelin, Cervantes, Jurien Bay and other must-see places along the Coral Coast. A hugely popular spot here is Yanchep Lagoon. It boasts calm, crystal-clear waters, with waves averaging just over a metre along the beach. The beautiful lagoon is famous for swimming, snorkelling, beach fishing and even abalone fishing (during the permissible and license season only). There are two accessible parking bays outside the Yanchep Surf Life Saving Club, as well as an accessible shower and toilet room. Concrete ramps take you down to the beach area, where wheelchair-friendly beach mats

ensure people with impaired mobility have access to the sand and surf. A Sandcruiser purpose-built beach wheelchair is available for hire at various times across the summer season, which runs from 1 November 2021 to 30 April 2022 (for more information and bookings, visit wanneroo.wa.gov.au/beachwheelchairs). A Beach Trekker wheelchair is also available at nearby Quinns Beach.

#### Mooloolaba, Sunshine Coast, Qld

Everyone loves a holiday on the Sunshine Coast, and it's pretty hard to top the beach at Mooloolaba, with its pure white sand, fantastic beachfront esplanade and alfresco restaurants, and relaxed holiday vibe all year round. Accessible beachfront apartments mean you can be just metres from the pure white sands of the beach – which in itself is accessible, thanks to the forward-thinking Mooloolaba Surf Life Saving Club. The summer season here runs from September until the end of April, and during this time beach matting and a beach wheelchair are available seven days a week, during patrolling hours. The Mobi-Chair Floating Beach Wheelchair is complimentary and can be loaned from the life savers or professional life guards at the patrol tower, while the beach matting will take you from here right to the water's edge (for more information, go to: **mooloolabasisc.com.au**). Other accessible attractions nearby include the SEA LIFE Sunshine Coast Aquarium (formerly Underwater World), where you can get face to face with a wondrous variety of sea creatures in the 80 metrelong Ocean Tunnel.

#### Redcliffe, Moreton Bay Region, Qld

About 40 minutes' drive north from Brisbane in the Moreton Bay Region lies the town of Redcliffe. Here you'll find some lovely accessible things to do, from discoing down Bee Gees Way to fishing off the jetty. From the Redcliffe Peninsula Surf Life Saving Club it's only about 400 metres to Sutton's Beach, a lovely patrolled swimming beach with views out to Moreton Island. Wide, accessible pathways lead to more than a kilometre of foreshore, accessible via beach matting and a Mobi-Chair Floating Beach Wheelchair and Sandcruiser beach wheelchair that are available from the Redcliffe Peninsula SLSC (to book a beach wheelchair, email admin@redcliffeslsc.com.au). There's also accessible parking, toilets, beach showers, picnic shelters, playgrounds and BBQs. You can savour modern Australian cuisine or simple fish and chips at the lovely Sutton Beach Pavilion, an Art Deco landmark that was built in 1937 and is located right on the beach. And just 20 metres from the Pavilion you'll find Settlement Cove Lagoon, a brilliant (and free) wheelchairaccessible manmade lagoon that's open all year round.

#### South Bank, Brisbane, Qld

Not every beach has to be located by the sea. The manmade Streets Beach in Brisbane is Australia's only inner-city beach. It's located at the city's most popular tourist destination, >

South Bank, which overlooks the Brisbane River and city centre, and is home to 17 hectares of lush parkland, al fresco restaurants and year-round events. Best of all, visitors of all abilities are welcome and pretty much everything is wheelchair accessible: things like picnic and BBQ areas, walking tracks, the Collective Markets (which are held every weekend) and, of course, Streets Beach. There's also plenty of accessible parking and a number of accessible bathrooms, plus a specially designed accessible bathroom that includes a shower, ceiling hoist (BYO sling with loop attachments) and a change table/shower trolley. The key can be collected from the South Bank Visitor Information and Booking Centre, which is also the place to go to hire a wheelchair, or a purpose-built pool wheelchair or beach wheelchair. South Bank is home to the world-class Queensland Cultural Centre, which includes Australia's largest gallery of modern art, GOMA. From the Wheel of Brisbane (thewheelofbrisbane. com.au) you can soar almost 60 metres high above South Bank and get sweeping 360-degree views of the city and river from one of two air-conditioned gondolas that have been specially designed to accommodate wheelchairs. As well as accessible restaurants and cafés in the parklands and nearby Grey Street, there are also stylish bars, like the rooftop Terrace bar at the Emporium Hotel with its with retractable glass ceiling, and fantastic accessible accommodation (not to mention a pool with an electric hoist) at the nearby Novotel Brisbane South Bank. There are lots of wheelchairaccessible public transport options, but the most scenic way to get to South Bank is undoubtedly a CityCat ferry. They're fully accessible for passengers who use a wheelchair, and have wide access gates and dedicated seating on board.

#### Surfers Paradise & Burleigh Heads, Gold Coast, Qld

Everyone knows the Gold Coast is one of Australia's most popular and iconic holiday destinations, but it's also great if you're after accessible fun in the sun. You can hire party pontoons and self-drive BBQ boats from various locations along the Coast, or book an accessible fishing charter and head out into deeper waters to cast a line and (hopefully) snag some dinner. At iFly in Surfers Paradise (iflyworld.com.au), meanwhile, you can experience the thrilling sport of indoor skydiving. It's safe, fun and accessible for people of any ability. Surfers Paradise also offers beach wheelchairs, accessible beach matting (rolled out every Sunday during patrol season) and a mobile hoist, as well as accessible change rooms and car parking at the Surfers Paradise Surf Life Saving Club (for more information and to book a beach wheelchair, email admin@surfersparadiseslsc.com.au). A little further south,

and the Burleigh Heads Mowbray Park Surf Life Saving Club also provides lots of accessible parking, an accessible bathroom facility within the SLSC, and accessible beach matting and two types of beach wheelchairs: the Hippocampe and the Mobi-Chair Floating Beach Wheelchair. They're available, free of charge, on Saturdays, Sundays and public holidays during patrol season (roughly September to March), subject to weather conditions and availability. The beach matting is rolled out on the same days (for more information, including bookings, visit burleighslsc.com.au).

#### Tangalooma, Moreton Island, Qld

Switch to island time and head to Moreton Island, the third-largest sand island in the world (known to the Ngugi people as Mulgumpin or Moorgumpin: the Place of Sandhills). Just a 75-minute ferry ride from Brisbane, this nature paradise is famous for its pristine beaches, rolling sand dunes, untouched national and marine parks, and the oldest lighthouse in Queensland. It's also home to the Tangalooma Wrecks, 15 sunken vessels that are now home to incredible marine life and a playground for divers. snorkellers and kayakers. There's limited but fantastic accessible accommodation on the island at Tangalooma Island Resort. The rooms have lift/elevator access, wider doorways, flat-floor access to showers, and are larger than standard hotel rooms. They also feature great views over Moreton Bay and the Glasshouse Mountains. The wheelchair-friendly resort also has accessible toilets and ramp access to most facilities, including restaurant and dining areas. There are kookaburra feeding sessions at the Eco Centre every afternoon, and visitors have the chance to hand-feed wild bottlenose dolphins that visit the shores of Tangalooma at dusk. The resort not only has wheelchairs for hire, but also a beach/sand wheelchair that you can book (pending availability) for dolphin feeding or to access beach activities. Other accessible activities include heading out in a glass-bottom boat in search of dolphins, dugongs, turtles, stingrays, endless species of fish and even the Resort's resident shark, and going whale-watching from June to October. As these magnificent creatures make their way up the coast along the "Humpback Highway" you can take a trip on Australia's largest whale-watching vessel – if you're really lucky, you might even be able to see them from the land. A

Got some more suggestions about brilliant accessible spots in Australia? Please share your tips on our Accessible Australia app: accessibleaustralia.com.au

# The Disability Gateway is here.



The Disability Gateway is here. It's helping connect people with disability, as well as their families, friends and carers, to the information and services they need.

Visit disabilitygateway.gov.au or call 1800 643 787

Monday to Friday, 8am to 8pm AEST/AEDT





# The ultimate selfie

#### How to be a great self-advocate

Ever since Spinal Life Australia began, way back in 1960, our aim has been to advocate for - and with - people with disability, in order to achieve better outcomes and create long-term changes in the community. Last year alone, we provided almost 8,000 hours of advocacy.

#### So what is a self-advocate?

It's simply someone who speaks up for, and represents themselves. Everyone has the potential to be a selfadvocate, but there are certain things you should do in order to be as effective as possible. It's a process that involves research, outreach, follow-up and, most importantly, dedication and persistence.

Our mission is to support people become better advocates for themselves, by helping them understand what it's all about, and how to do it professionally and effectively. As part of this process we developed a self-advocacy resource called *Taking Action*. If you'd like a copy, email members@spinal.com.au. Also, let us know if you're interested in participating in a "How to be a better selfadvocate" workshop. They're available to interested members and members of the wider community who are keen to become a better advocate for change in their local communities.

In the meantime, here are some tips from *Taking Action*:

#### 20 TIPS TO BECOMING AN EFFECTIVE SELF-ADVOCATE

- 1. Clarify the issue and what you'd like to change.
- 2. Become as informed as possible about the topic or subject matter.
- 3. Know what changes need to be made, as well as why you need them.
- 4. Understand your rights and responsibilities.
- 5. Be willing to ask questions when something is unclear.
- 6. Seek to understand the issue from the other person's point of view.
- 7. Learn how to link and partner with others who may be interested in the same issues or can support you through the process.
- 8. Be clear, concise and organised, and always follow up.

- 9. Be patient but determined.
- 10. Be willing and eager to learn about others and yourself!
- 11. Be direct, but courteous and respectful at all times.
- 12. Remember to state the reason and purpose for your action/complaint. Remember to give your name and be specific.
- 13. Be clear about your audience, and craft your communications accordingly. For example, you could be dealing with a government department, your local Councillor or member of State/Commonwealth parliament, a hospital and/or doctor, a business or agency providing services in your community, an airline or even a carer/social worker.
- 14. Start at the top. Get the name and contact details of a person in charge (eg. chair of the board, manager, general manager, owner, supervisor, mayor) and avoid having to explain your problem to people who are in no position to help or change a situation. Also, avoid reaching out to everyone - if you do, no one will take responsibility.
- 15. Keep any emails short and to the point four to five paragraphs is usually plenty. People often won't read a long email. Make sure it's clear, concise and appropriate before you send it!
- 16. Keep a record of all correspondence. If you make a phone call, make a note of the conversation, date and the name of the person you spoke to.
- 17. Don't let too much time elapse between each of your calls, letters or emails.
- 18. Don't be rude, make personal insults or accusations. They won't get you anywhere.
- 19. Don't be afraid to take your complaint or issue to the next level if you get negative feedback from the business or public official. Remember, there are laws in place that protect the rights of individuals with disabilities.
- 20. Remember that social media is a great tool to get your message out there.

Need help with your advocacy efforts? Don't hesitate to contact our team at members@spinal.com.au or call 1300 774 625.

# GIGANTEX

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Since it opened almost two years ago, people have been raving about Spinal Life Australia's Healthy Living Centre in Cairns. It's not just the incredible facilities, but also the people. The good news? Its urban sister will open soon, with the official unveiling of another HLC in Brisbane, with many of the same facilities, scheduled for early 2022.

For anyone with a spinal cord injury, the importance of rehabilitation – in all its forms – and the benefits it can bring cannot be overstated. It is, quite simply, essential.

That's why we've developed this new Centre, conveniently located in Woolloongabba, just a short drive from the Brisbane CBD. It's been specifically designed to help people with spinal cord injuries with their rehabilitation, and to maintain lifelong health and wellness. In the process, it will benefit many other people with different physical disabilities too.

Whether you're at the early stages of your rehab journey or just wanting to stay healthy and maintain function as you age, our expert team is here to support and work with you. As well as Spinal Life staff we'll have visiting therapists and guests, to ensure you can address all aspects of your health and wellbeing. You'll be able to get expert help from professionals including:

- Physiotherapists
- Exercise Physiologists
- Allied Health Assistants
- Occupational Therapists
- Nurses
- Social Workers
- Dietician Eat Smart Nutrition
- Pain Management Practitioner

With state-of-the-art equipment, the facilities are second to none. Skilled therapists will help you work with the latest accessible fitness and rehabilitation equipment, including a tilt table, FES machine, ski ergometer, MOTOmed, cross trainer and much more.

We've also incorporated a tech room so you can try the latest in-home automation, equipment and devices that will provide even greater independence at home and work. You can work with our Assistive Technology Mentor, who not only has invaluable lived experience, but also accredited training from the NDIA on Assistive Technology (AT). As well as scripting and trialling, our AT service also includes installation – so your equipment won't still be sitting in its box 12 months later!

Visitors can look forward to monthly driving assessment clinics, wheelchair yoga and, for the first time, we'll be providing much-needed lymphedema therapy.

The Centre will be open seven days a week from 6.30am-8pm, with appointments available from Monday to Saturday, and unsupervised access to the equipment after hours to paid members. Savour a cup of coffee after your visit, or relax knowing your family and friends can enjoy a brew while you work!

To stay in the loop about the HLC Brisbane go to: **info.spinal.com.au/hlc-brisbane** 





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To find out more about GentleCath™ Glide and order your FREE sample, call our Customer Care team on **1800 335 276** or visit **www.yourconvatec.com.au** 

# No sweat!

# How to stay cool in the summer when you have a spinal cord injury



Summer in Australia can turn anyone into a hot mess. But summer in Australia if you have a spinal cord injury can be especially challenging, because you're more susceptible to overheating.

In an able-bodied person with a nervous system that functions normally, the average internal body temperature is around 37°C.

If this temperature begins to rise, the body sends a signal to the brain to say the body is overheating. The brain then sends a signal back to the body, telling it to cool itself (by, for example, sweating). The entire process is called thermoregulation and it all takes place via the spinal cord.

So when the spinal cord is damaged and this communication between the brain and body is lost, there can be serious problems.

Because the body no longer receives the appropriate signals to start regulating its temperature, there's a very real risk of overheating, heat stroke and all of the associated side effects, such as delirium, dehydration, confusion, nausea, vomiting and abdominal cramps. And if the internal body temperature rises as high as 42°C, there's also the threat of damage to the brain, heart, kidneys and muscles, and even death.

Generally speaking, the higher the injury, the more likely it is that a person will have issues with heat (and also cold). The completeness of a spinal cord injury can also affect thermoregulation: the more severe it is, the greater the interference is likely to be between the brain and body.

If you do overheat, you can go from feeling a little uncomfortable to having a fullon heat stroke quite quickly, so being able to regulate your temperature is vital. If you haven't tried them already, here are a few strategies that could offer relief.

In the meantime, stay cool, people!

#### **TOP TIPS**

#### Hydrate

Drink plenty of water and stay hydrated.

#### **Shelter**

Avoid extreme temperatures, don't stay out too long in hot weather and stay in the shade as much as possible. Try to enjoy the outdoors early in the morning or late in the afternoon/evening.

#### **Dress**

When you're outdoors on a sunny day, wear loose, breathable and light (both in weight and colour) clothing. And don't forget a hat!

#### Wrap

Keep things like ice vests, wet towels or gel packs in the freezer and then drape them around your neck when you need to cool down. Other options include cooling bands and ice neck wraps (fabric that you fill with ice cubes) – just be sure to check the skin after you apply any sort of wrap: ice can burn!

#### Mist

Create 'artificial sweat' by misting yourself with a spray bottle filled with cold water (keep it in the fridge if possible). Misting works best when humidity is low, as evaporation rates will be higher. When humidity is high (hello, Queensland), the water just sits on your skin and doesn't actually cool you. If that's the case, make the most of any natural breezes or get in front of a fan.

#### Chill

Seek shade, stay indoors, be prepared with sun safe protection, take breaks in air conditioning to help keep your body temperature steady.

Visit **spinal.com.au** for more information and health tips.



"Top Knot Pigeons", ink/nail enamel on canvas Photo courtesy Montville Art Gallery

# Nailed it

Brisbane artist, Nicole Condon is famous for her beautiful art, created using nail varnish. Now she's getting a hand from Spinal Life Back2Work as she recovers from a spinal injury

A horror movie action figure is on display in the home of Brisbane artist, Nicole Condon.

It's of Ash Williams from the Evil Dead franchise and he's missing his hand (he cut it off himself with a chainsaw in Evil Dead 2: Dead by Dawn, but the less said about that, the better).

It's something that has real significance for Nicole, who is renowned for her bright and incredibly detailed works depicting Australian landscapes and birdlife – and her unique method of painting, using nail enamel on canvas.

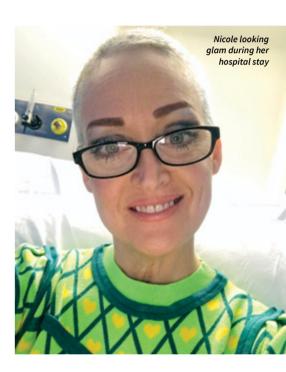
"There's a moment in the film when Ash cries out, 'Give me back my hand!' – and that's what I feel like yelling," she explains.

So how did she become such a talented artist... and what happened to her hand?

Born in Brisbane, Nicole's family moved to Townsville in North Queensland when she was just five. "I think that's where I got my love of the rainforest and birds, because we used to spend a lot of time in nature, trekking through the rainforest and camping," she says.

During her high school years, Nicole won the art prize on numerous occasions. After finishing school and moving back to Brisbane, she studied graphic design at a commercial art college, and won the Best Folio Award when she graduated. She then commenced a career as an illustrator for various advertising agencies. "It meant I could draw pretty pictures for a living," she says.

But at home she was also working on her own fine art style, using unusual media such as polymer clay, aka Fimo.





"Gouldian Finches", ink/nail enamel on canvas
Photo courtesy Montville Art Gallery

"They were like 3D paintings, done in modelling clay," explains Nicole. "They were ridiculously detailed and each work could take months."

Nicole put on her first exhibition, at McWhirters Art Space in Fortitude Valley, and with some brilliant PR from her brother, got on TV and was on the front page of the local paper, holding up one of her pictures. "And I sold out on opening day," she says.

With such an auspicious start, Nicole decided to take the plunge and become a full-time professional artist. Working from home, she continued to do a lot of freelance commercial stuff and her polymer clay art... and also started experimenting in nail enamel.

Nicole's nail polish collection was vast – and no longer being used, following the birth of her son [Elvis, now 19]. "I used to have beautiful long natural nails, but they disappeared after I had Elvis," she explains. "My husband is in the glass business and we always had offcuts lying around. It occurred to me that I could paint nail polish onto the glass and it would keep its sheen. It worked beautifully, I had another exhibition a little while later, and that was the beginning of the nail polish thing."

Nicole's work ended up being shown and sold in two galleries, including the Montville Art Gallery (montvilleartgallery.com.au), where her pieces would sell out as quickly as the gallery could hang them.

Her art was also being featured in a luxury sleepwear range, Pure Dreamwear (**puredreamwear.com**). "The company empowers and supports Cambodian women who have been sex trafficked," says Nicole. "By giving them training and employment opportunities, they're also giving them real hope and a future."

Things were going brilliantly, but then came the fateful day that would eventually inspire Nicole to quote an 80s horror movie character.

On 1 July 2021, with depleted electrolytes and low blood pressure after a terrible bout of gastro, Nicole fainted in the shower. >

"I was perfectly healthy before that," she says. "I'm not some old lady who slipped in the shower and broke her hip!"

The paramedics took her to the QEII Jubilee Hospital, where the staff treated her gastro with antibiotics – but couldn't seem to find a reason for the fact that she couldn't walk or move her arms.

"I remember them saying, 'It's a mystery,'" recalls Nicole. "That's the last thing you want to hear from a doctor!"

After about three days, Nicole was transferred to the Princess Alexandra (PA) Hospital. "They did various scans and found out that not only did I have a C5/6 fracture, but I'd also had a stroke," she says.

She stayed in the PA Hospital for seven weeks, and was then moved to the Spinal Injuries Unit (SIU). "I was probably only in there for about three weeks, but it seemed like longer because I met so many amazing people and it became like my second home," she says. Which is lucky, because she couldn't even have Chris, her husband of nearly 30 years, with her because of lockdown rules.

"But the PA hospital was amazing," raves Nicole.
"Every nurse and every doctor: they were absolutely freaking wonderful."

Nicole discovered that she also has central cord syndrome. It means her hands and arms are impaired more than her lower body which, as a fine artist, has a significant impact on her ability to produce her work. Because there's not a lot of room for error in her style of painting, it requires high levels of fine motor control and confidence. And after her accident, Nicole was lacking in both.

Which is why Tania Goossen from Spinal Life's Back2Work program was so keen to meet with her.

"I saw Tania at the very end of my stay in the SIU, and I remember saying, 'I don't know how you're going to be able to help me,'" recalls Nicole.

Tania has similar memories. "Nicole admits she really wasn't sure when she'd have the courage to try painting again – whether it was weeks, months or even years down the track," she says. "I reinforced with her that an artist is not defined by their physical ability – it's part of your identity, who you are, and how you express yourself in lots of different ways. You're an artist in your mind first."

The goal was to work with Nicole and find strategies that would help her find her way back to feeling like she was an artist again.

"I made a few minor, practical suggestions – for example, using rubber bands on the nail polish bottles, to help guide her finger placement while painting," says Tania. "This also helps her open the bottles independently – for really sticky bottles, she uses a silicone grip over the top as well."

After three visits and lots of discussion, Nicole felt it was time to have a go.

"She was terrified – but opened the nail polish bottle by herself, and painted a few sections," says Tania. "This was enough for the first attempt, but with a little encouragement, at our next meeting she felt ready to do a bit more. She painted a number of sections and used lots of tricks to texturise her work – from using dots of contrasting coloured enamel, to using a bamboo skewer to give the suggestion



of a feather. She even painted one of the bird's eyes – a crucial part of her work, as eyes are a really focal point and need to be spot-on to connect with the viewer. She smashed it – and surprised both of us with how well she could do her work. It was slower than she'd have liked, but she was actually doing it."

But the difference between then and now is something Nicole is still struggling with.

"I know I need to just put the work in and dedicate time every day to practice my art," she says, "but practising something that I was so good at seems kind of... sucky."

She's also still processing her entire experience and trying to come to terms with what she calls imposter syndrome.

"I had a pretty severe accident, but even when I was in the PA, I felt like a bit of an intruder, because I was able to walk. A C6 or above means you're technically a quadriplegic, but when I explain this to some people, they're like, 'What? How can you be a quadriplegic, you're walking around – just get on with it!' And that's the hard part. They don't understand how different I feel. Although I may look the same, I'm not the same. I am almost 'normal' in every way possible, except my right hand, which is my livelihood. I can dance on my deck, I can dress up and go to a Halloween party, but I can't paint.

"I feel like a different person since this accident. And the only people who can actually understand it are others who have been through something similar. I talked to one of my friends from the PA yesterday and said to him, 'I have this weird feeling where I feel like I'm living in a dream'. He agreed and said, 'Yeah, I feel like I'm waiting to wake up'.

I don't know why, but there's this weird feeling when you have a spinal injury, like you're living in a fog and everything's sort of happening behind glass. It's almost like nothing really matters."

But she knows it does, and still feels hopeful about her future.

"I definitely have faith and my painting gets better every time – I just need to practice more!" she says. "Tania has been my cheerleader, and thanks to her encouragement, when I did sit down to paint, I amazed myself that I could kind of do it. She seems to really love my art and has really invested herself in my recovery. She has stuck in there and helped me in all sorts of ways, and her support has been the one I've enjoyed the most. I feel like we've become besties!"

Nicole's recovery is still very much a work in progress, but she's building her confidence every day. Her hand function is slowly improving, and the Spinal Life Back2Work team is quietly confident that while her work may take a little longer in the early days of her recovery, she will continue to deliver her amazing and beautiful artwork, and her career (that she's worked so hard for) will continue to blossom.

In short, she'll nail it. A

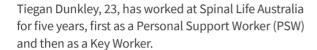
For more information about Spinal Life's Back2Work program, go to: **spinal.com.au/back2work** 

"Red Tailed Cockatoos, Glasshouse Mountains", ink/nail enamel on canvas
Photo courtesy Montville Art Gallery



# Getting to know...

#### **KEY WORKER, TIEGAN DUNKLEY**



"I genuinely feel like I am the luckiest person in the world to be able to do what I do and support our clients in the way that I do,' she says. "If I were to be offered any other role within the organisation, I would politely decline. What I do now is what brings me so much happiness."

It's an amazing take from Tiegan, so we thought we'd find out a little more about this inspirational Spinal Life team member.

#### What three words describe you best?

"Confident, dependable, positive."

### Have you always been a Key Worker, or did you start off in another role?

"I started as a Personal Support Worker in September 2016, and then moved into my current role as Key Worker in Service Establishment in September 2020.

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

"A positive, go-getter attitude, as well as being reliable, dependable and always on time. Being adaptable is also important. As support workers it's crucial that we make everyone feel comfortable and able to request things are done in their preferred way. This won't always be the way *you* like or the way you think is best, but so long as it is appropriate and safe we can do it."

#### What are the main responsibilities of a Key Worker?

"As a Key Worker in Service Establishment, I attend meetings with clients prior to them discharging from the Spinal Injuries Unit (SIU), making a plan based on what their life is going to look like once they get back home. Some clients will have weekend passes before they're discharged, to trial being out



of hospital – this gives us a chance to work together and get familiar with their routine. Once they do return home, I help them get things organised and start training the team to make sure their personal care runs smoothly. I am with the client and PSW for all shifts until everyone is confident, and stay connected so that the PSWs are supported. Outside of training PSWs, I also help fill shifts, assist with admin tasks from our Woolloongabba office, and of late, have even been helping out recruitment!"

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

"That just because somebody is in a wheelchair, doesn't mean they have an intellectual disability. People with spinal cord injuries are just like the rest of us – walking or sitting, we are the same and deserve to be treated equally."

### What's the most important advice you'd give anyone thinking of becoming a Key Worker?

"You need the ability to adapt to different environments, and think quickly on your feet while keeping a calm and level head. And you need to have good people skills and be passionate about caring for others."

#### What are the best and worst things about your job?

"The hardest part is not being able to do more for the people I work with – I can't change what has happened and at times I find myself wishing that I could. Life can be unfair. I love being able to do everything that I can do, to the absolute best of my ability, and help people live the best life that they can."

#### What's the most important lesson being a Key Worker/ PSW has taught you?

To nominate a Personal Support Worker to feature in a future issue, email: **theadvocate@spinal.com.au** 

# The latest

Information, inspiration and inclusivity

#### **D-DAY**

Happy International Day of People with Disability (IDPwD)!

Celebrated internationally, this United Nations-sanctioned day takes place on December 3. It aims to increase public understanding and acceptance of people with disability, and to celebrate their achievements and contributions.

Importantly, it's also a time for people with disability to raise awareness about the issues and barriers they still face. Some 4.4 million Australians live with disability, and this is not only one of the largest marginalised communities, but also one of the least represented and most excluded. This is a time to remind people that dismantling ableism is everyone's responsibility.

Every year the IDPwD chooses Ambassadors to help promote the achievements and contributions of people with disability and champion inclusion. And we're pleased to announce that this year, two of the Ambassadors are members of Spinal Life Australia!

The first is Board representative and Deputy Chair of the Spinal Life Australia Research Committee, Dr Dinesh Palipana

OAM. Dinesh has particular expertise in spinal research, as well as extensive connections across government and health – and he's also the 2021 Queensland Australian of the Year.

The second Ambassador is para-swimmer world record holder and gold medallist, Rachael Watson. She set a Paralympic record and won gold in the 50m freestyle at Rio in 2016 before doing it all again at the delayed 2020 Tokyo Olympics, winning back-to-back gold in the same event. When she's not breaking world records, Rachael is dedicated to improving health outcomes for people with disability and raising awareness of the importance of inclusion.

The International Day of People with Disability is a special day, and an opportunity to make positive changes – now we just need to make it a year-round reality, rather than being about one day.

For more information, go to: idpwd.com.au



# **MARATHON MAN**

Spinal Life member, Mark Blowers from Perth tells us about his "latest crazy adventure"... competing in the virtual London Marathon





On 3 October I took part in the virtual 2021 Virgin Money London Marathon, along with almost 25,000 other people from more than 100 countries across the world.

It ran alongside the  $41^{st}$  edition of the London Marathon, which is not only one of the biggest races in the world, but also the world's biggest annual one-day fundraising event – in 2019 it raised £66.4 million for charity (that's more than AU\$122.7m).

I was honoured to be doing my race for the Invictus Games Foundation. For those who don't know, the Invictus Games Foundation supports wounded, injured and sick veterans around the world, including here in Australia.

Thanks to COVID, in 2020 the London Marathon was held virtually for the first time. This year, the race was run on the streets of London *and* also virtually. The virtual race gives people the chance to compete from wherever they live in the world.

For me, that place is Perth, and I did the race around the Perth riverfront circuit. Considering I ended up not getting

a chance to train after being in hospital for the last year, I found it fun to be out of hospital in the fresh air and the weather was perfect.

The last 10 kilometres were the hardest as my arms and shoulders were so sore, but I wasn't going to give up!

My wonderful support worker, Keshi, biked alongside me the whole way, keeping me motivated and providing the tunes – either on her phone or singing (sometimes even both!).

The whole 26.2 miles (just over 42 kilometres) ended up taking us eight hours and 29 minutes. Hopefully next year I'll be able to get to the gym before the race and do some training, and finish the Marathon in an even faster time.

Best of all, I'll get the chance to actually fly to the UK to do the race in London, which is incredibly exciting. Watch this space!

Do you have an interesting story to tell? Email us at **theadvocate@spinal.com.au** and you could be featured in a future issue!





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