

**FEATURE:**

# ACCESSIBLE ADVENTURES

Explore Victoria's parks this summer PG08


**ALSO IN THIS ISSUE**

**HOW DION FOUND HIS PATH** PG12

**HOW IS SCI PORTRAYED IN  
THE MEDIA?** PG10

**INDEPENDENT ASSESSMENTS UPDATE** PG06

**AND MORE**



*News, events and resources  
for people living with complex  
disability and their friends*

**ADDRESS.**

416 Heidelberg Road  
Fairfield Victoria 3078

**www.aqavic.org.au**

**p.** 03 9489 0777

**p.** 1800 999 128

**f.** 03 9482 4371

**e.** admin@aqavic.org.au

**POSTAL ADDRESS.**

PO Box 219  
Fairfield Victoria 3078

**BOARD OF DIRECTORS**

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**BRAND, COMMUNICATIONS &  
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Ian Baker

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We love contributions from our community! If you have an experience you would like to share, or a story you would like to tell, please get in touch.

*Not a confident writer?*

*No worries* - we can help shape or edit your story.

Below are the upcoming contribution deadlines:

1st February

1st April

For further information:

**p.** 03 9489 0777

**e.** info@aqavic.org.au

# Celebrating our achievements

In November, we celebrated our community's achievements over the past 12 months with an online Celebration Event.

It was fantastic to be able to capture and share all the great work we have done together... and there was a lot.

AQA CEO Peter Trethewey spoke about the investment made in our staff capability and capacity. We have invested in a digital transformation to streamline our services. In the new year, all staff will have access to the Hub, which will greatly improve the coordination of our workforce.

"I'm really pleased to say we have a team that has proved we can respond to what is unfolding in front of us each day, and maintain momentum in progressing our strategy, and do so understanding that AQA exists to resource people to live well. We acknowledge the contribution of all our people," said Peter.

Annie Lillywhite, Executive Manager of Services, shared with us some service highlights, and announced recipients of our milestone awards, which included 5, 10, 15, 20, 25 and believe it or not Martha Best for receiving her 30-year milestone award. Annie spoke about the growth of our service suite, bolstered by our community engagement approach.

"Our Allied Health and Support Coordination teams are extremely proud to have supported a number of clients in achieving significant goals. Our peer-led services team has continued to evolve, with online webinars and personal development courses with increased accessibility," said Annie.

As Practice Leader, I talked about the valuable work our volunteers have supported us with. I announced the recipients of our Volunteer Awards, Community Awards, and the Nigel Steele award. Richard Balsillie, our volunteer video journalist, who has helped us tell our story over many years, won the Nigel Steele award.

Finally, Larnie Ball, Practice Leader of Coaching and Development, talked about our Living Well project. The project focuses on building the capacity of individuals with SCI or other complex disabilities. Covid has disrupted parts of the project, but we were able to hold a Skills for Independence course, as well as Wheelchair Skills development courses.

As you can see, our mission of building an inclusive community, where people have access to the resources they need to meet the challenges of change, and live fully, was on full display.



NAZIM ERDEM  
NEWSLINK EDITOR



# Victorian adventures and exercise physiology

## COMMUNITY NETWORKS UPDATE

Georgina Fiorentino

COMMUNITY ENGAGEMENT AND NETWORK COORDINATOR



Kirsty McRae, an exercise physiologist, presented to the Melbourne Network in October.

In October, the Melbourne Network hosted Kirsty McRae, our guest Senior Exercise Physiologist from STEPS Neurological Therapy Services. Kirsty has extensive experience delivering rehabilitation to people with neurological conditions, including traumatic brain injury, stroke and Parkinson's disease, to name a few. During the session Kirsty explained what exercise physiology (EP) is all about, and how

the discipline fits in with physiotherapy and occupational therapy. We heard about the benefits of EP for people living with SCI and learned some basic strength and conditioning programs. You can watch the recording of the session on YouTube [here](#).

In November, our guest presenter Christian Brackley, from the Northern Networks, invited regional members to his showcase of the beautiful Victorian towns of Echuca, Moama, and surrounding areas. Christian revealed why the towns are popular destinations for visitors, with lots of exciting attractions and activities to do throughout the whole year. In December, one of our Gippsland Network residents showcased the beautiful town of Traralgon, along with other nearby towns. If you are interested in showcasing your regional town, let us know and we will support you.

Also in November, the Melbourne Network meeting

Members from across Victoria heard about the attractions of Echuca and Moama from a member of the Northern Networks.

hosted guest speaker John Kenwright, the Accessibility & Inclusion Coordinator at Parks Victoria. John described all the achievements made to date from Parks Victoria's Disability Action Plan. In recent years, Parks Victoria has undertaken significant work to provide parks that are more accessible and inclusive for all Victorians. In order to achieve this, Parks Victoria develops a Disability Action Plan every four years, with the next plan starting in 2022. John revealed the many activities and experiences that visitors can access within the different parks in Victoria, including bushwalking, camping, canoeing, picnicking, sailing, fishing, beach and marine park activities, and visiting historical sites. For more information, visit the Parks Victoria [all-abilities access webpage](#).

Larnie and Dave Ball from the AQA's Coaching Development Team also joined in the meeting, and spoke about the future possibilities of conducting Wheelchair Skills Training in some of the parks within regional Victoria. The video recording of the presentation can be viewed on YouTube [here](#).

Our online network meetings will continue into 2022, along with the reintroduction of face-to-face meetings for all our networks. Look out for a range of events and activities in our events calendar in the next NewsLink issue.

Lastly, from the AQA Community and Networks team, we wish you and your families Seasons Greetings. We hope you safely enjoy your freedom this summer, and explore some of Victoria's accessible parks.

## AFTER NEARLY A DECADE, I'M RETIRING FROM INTERNATIONAL RUGBY

**Josh Hose**

PEER SUPPORT & VOLUNTEER COORDINATOR

It seems like only months ago that I was telling you about my adventures in Tokyo – wait, I was! You can read about them in the October issue.

In that article, I also touched on my spinal cord injury back in 2005, and how I could vividly recall the first time I watched wheelchair rugby, and how I was immediately hooked.



But today I'm sharing the news of my retirement from the sport of rugby with you all. Yes, after nearly a decade of the sport, 152 games played in the green and gold, I will roll away from international wheelchair rugby.

Now there are many memories: representing our country, travelling the world, winning medals. But the one I will hold most dear is those family and friends, and the wider community, that gave me so much support. In particular the Hosey Heroes. I'll forever remember their cheers and chants, at both London and the Rio Paralympics. Sadly they didn't attend the Tokyo Games this year.. thanks COVID!

Why step away, you may ask? Don't let my youthful complexion fool you friends. I'm old, and more to the point, at 35 years of age, job opportunities and other commitments take priority.

In July, I was promoted in my role at AQA, and I started full-time hours, which fills me with excitement to help continue the growth of the Peer Support program.



## A WELL-DESERVED VOLUNTEER LUNCH

**Nazim Erdem**

PRACTICE LEADER

Over the past 18 months, our volunteers have mostly provided peer support online or over the phone. This took some getting used to because it was a new way of providing a valuable service, especially if you haven't met, or don't have a relationship with, the person on the other side. Our volunteers met the challenge, adapted, and excelled.

We challenged ourselves because we knew the importance of this, especially in Covid lockdown. Peers needed support, not only around their disability and motivation, but also the added issues with mental health brought on with isolation.

Without this continued contact, peers would have suffered and felt more isolated. Thankfully we were able to provide some relief and understanding.

After the restrictions were eased, we thought it was about time we got together and shared a meal at Degani in Thornbury. Sometimes, you just can't beat meeting face-to-face, as you can see from the picture. It was so pleasing to have a chat and share stories in person again.

We're so thankful for our volunteers' perseverance, their skills, and their generosity. We are all looking forward to a big 2022 where we can mentor (and hang out!) face-to-face.

## INDEPENDENT ASSESSMENTS: PARLIAMENTARY REPORT TELLS NDIA TO DO BETTER

Dan Nathan



In October, after almost a year of inquiry, the Joint Standing Committee on the NDIS released its final report on a proposal to introduce compulsory independent assessment for NDIS participants.

In its report, the Australian parliamentary committee identified a flawed policy development process at the NDIA, the agency which administers the NDIS, in which a proposal with weak evidence and insufficient community input was allowed to progress to the point of announcement.

The report went further, saying that at the NDIA, there were systemic insufficiencies of transparency and consultation.

Under the independent assessments proposal, all new participants would have their functional capacity assessed by government-contracted health professionals who would have no prior relationship with the participant. Independent assessment would also be compulsory for existing participants when their plans were reviewed.

A broad coalition of organisations and community groups campaigned against the proposal, and Minister for the NDIS Linda Reynolds announced in July that she had decided not to proceed with it.

The parliamentary inquiry into the proposal received 400 community submissions, among them one from AQA.

Our submission highlighted the lack of evidence cited in support of the independent assessments proposal, and the absence of effective consultation in its development. We recommended that the NDIA make independent assessment voluntary, not compulsory. We also urged the NDIA to engage more meaningfully with the disability community when considering changes likely to affect it.

The Joint Standing Committee's report addressed all our points of concern, and there was a strong resonance between the report's recommendations and our own.

In describing the problems with the policy process that produced the independent assessment proposal, the report emphasizes deficiencies in transparency, in community and expert consultation, in supporting evidence, and in due diligence with respect to testing for the reliability or validity of the proposed tools.

In making the case that inadequate community consultation was a systemic issue at the agency, the report noted that the term "co-design" was not used in any of the three NDIS Corporate Plans that preceded the plan released this year. It said co-design principles should be at the heart of any major change to the NDIS, and should be written into the NDIS Act.

On transparency, the report said the committee had asked the NDIA to share financial data underpinning its fears about financial sustainability, but the NDIA had not done so.

AQA's submission to the inquiry was coordinated by Michael Moriarty, a researcher at AQA with a background in disability policy development and evaluation.

Michael said he saw the committee's report as a significant point of leverage for demanding accountability from the NDIA into the future, especially when concerning principles of co-design and transparency. Additionally, he said the campaign against compulsory independent assessment offered important lessons.

"The sector-wide advocacy effort we saw in response to independent assessments was a real success story," he said. "It was loud, but it was also well reasoned.

"Don't give up lightly! They looked like they weren't going to budge - until they did."

### CONCERN ABOUT NEW NDIA POWER

In late October, the Federal Government introduced the Participant Service Guarantee Bill to the Parliament. The legislation sets standards and timeframes for certain NDIS processes, like plan reviews and approvals. But, the bill also gives the CEO of the NDIA the power to change a participant's plan without their consent.

Defending concerns from disability advocates about this new power, the Government has said it would only be used for the benefit of the participant.

Some disability advocates remain unconvinced.

The National president of the Australian Lawyers Alliance, Graham Droppert SC, has said the proposed legislation included "unnecessary and concerning expansion of the CEO's powers."

For more information, and the opportunity to take action, visit: [www.everyaustraliancounts.com.au](http://www.everyaustraliancounts.com.au)

# Discovering the Power in Me participants find connection and motivation



LEFT: Karen fights off self-doubt. MIDDLE: Daily affirmations were an important part of the course. RIGHT: Ian tries his hand at adaptive sailing.

In November, AQA held an online motivational and goal setting course called Discovering the Power in Me (DPM). Specifically developed for people who've experienced traumatic injury, DPM aims to build hope, resiliency, and self-efficacy. Hear from two participants, Karen and Ian, about what brought them to the course, and what they thought of it.

## Karen

Karen James has been living with a T12 spinal cord injury for 46 years. She signed up for DPM because a couple of years ago her life was turned upside down: a pressure sore that put her in hospital for eight and a half months.

After decades of living independently, Karen returned home and needed full-time care. In the year and a half since leaving hospital, Karen's been working hard to rebuild her independence.

"I want my independence back. I really want it," says Karen.

"But the path to that independence has challenged me to my limits, psychologically and physically."

Karen says that DPM has reminded her to stay positive in the face of those challenges.

"I need to keep telling myself: I am resilient, I am gaining independence. The evidence is there - look at what I've done - I just need to keep going," says Karen.

Driving again was a primary goal for Karen during DPM, and she says that returning to that positivity helped her achieve it.

"When I wasn't hitting the mark on some of the car transfers I was practising, I made a point of remembering the part I did well. In the past, I'd get easily frustrated, and feel hopeless.

"I've got to keep reinforcing that habit. I've got to be kind with myself."

In mid-November, Karen got behind the wheel for the first time in two years.

## Ian

In late 2019, Ian Douglas was six days into a three month road trip with his wife when an oncoming B-double truck spilled into their lane, and they lost control. The accident left Ian with a incomplete C4 spinal cord injury.

Two years later, Ian has use of both hands, and can walk for short distances. Late last year, he returned to his work as a psychologist, part-time, but he retired in October.

"There are things I want to do," says Ian.

"I want to do more adaptive sailing, do some of the travelling my wife and I had been planning, and I'd love to become a Peer Mentor.

Ian says his modified van is almost ready, which will help with his independence.

Overall, Ian says he thought DPM was a great course, but there were parts that didn't gel with him.

"I'm not a great fan of affirmations," says Ian.

"I'm more interested in goal-setting, and thinking through the steps involved - I would have liked a bit more of that.

"I went into DPM thinking: things happen, and regardless of your background, it can be hard to get over them," says Ian.

"I found it really valuable to have other people there that were going through the same thing, experiencing the same thoughts, realising that what's happening to you is normal."



# Exploring accessibility in Victoria's parks

Hear from the filmmaker behind a new video series showcasing accessibility information for some of Victoria's top parks. Then, get a sense of the full range of accessibility initiatives underway at Parks Victoria, from their Accessibility and Inclusion Coordinator.

## MORE INFORMATION, MORE CONFIDENCE

In a recent initiative, Parks Victoria has produced a video series offering viewers on-the-ground accessibility information at Victoria's parks. The project was born out of the understanding that, for many people with a disability, not knowing what to expect can be a major barrier to exploring somewhere new.

The video series, filmed and produced by accessibility advocate Ryan Smith, a wheelchair user himself, aims to inspire people with a disability to get into nature by equipping them with the knowledge they need.

"Videos are a great way to communicate physical access, because 'accessibility' means different things to different people," says Ryan.

"With video, you can virtually visit a place and decide if the access will work for you in real life. It's a great format too because you can re-watch, slow down and share it easily."

What started as passion projects – documenting his adventures while traveling and recording the accessibility on various overseas trips – has turned into a career for Ryan.

In the 10-part video series for Parks Victoria, he showcases all-abilities walks at:

- Wilsons Promontory National Park
- Port Campbell National Park
- Cape Schanck Lighthouse Reserve
- Grampians National Park
- Dandenong Ranges National Park
- Werribee Park and the Victoria State Rose Garden
- Serendip Sanctuary
- Karkarook Park
- Albert Park



LEFT: Parks Victoria installed an electric hoist on the Patterson River Launching Way, near Frankston, in 2018. All photos courtesy of Parks Vic.

"I worked with staff from Parks Victoria to make videos that people with reduced mobility would find useful. Some of the questions I ask myself before I travel – like what's the surface like, where are the toilets, how's the parking – I wanted to answer in this video series," Ryan said.

The series features a diverse group of visitors, demonstrating the varying experiences of people with reduced mobility. It also showcases access at some of Victoria's most iconic places, such as Albert Park Lake, the Twelve Apostles in Port Campbell and the Grampians National Park.

*"With video, you can virtually visit a place and decide if the access will work for you."*

"About 18% of Australians have a disability and, as the population ages, this proportion increases," says Ryan.

"It's important we provide tailored advice about access, so we can empower people with disabilities to turn their planning to visitation, and their visitation into positive experiences. Put simply, information provides confidence."

To watch the video series, and find out more about accessible parks around Victoria, visit this [Parks Victoria web page](#).

## ON A MISSION FOR INCLUSION

**John Kenwright**

ACCESSIBILITY AND INCLUSION COORDINATOR, PARKS VICTORIA

For many years, Parks Victoria has been working to improve access to nature for diverse visitors. The project you've just heard about from Ryan, of compiling comprehensive park access information, is just one of the ways we've been working to make Victoria's parks more accessible and inclusive for everyone.

Parks Victoria's initiatives undertaken to date include the introduction of park adaptive equipment for visitors to hire in parks, such as TrailRider all-terrain wheelchairs and the provision of TrailRider volunteers. These enable visitors with low mobility to explore the many spectacular park trails that are not accessible with conventional wheelchairs.

A range of beach wheelchairs have also been introduced in some of Parks Victoria's coastal parks for visitors to access beautiful beaches. Plans are underway to further improve access to more beaches in Parks Victoria's coastal parks in the next few years.

A range of accessible visitor accommodation is provided at Tidal River, on Wilsons Promontory, and accommodation equipment is also available to make visitors' stays more comfortable, such as a portable hoist, shower commode chair and height adjustable seating. Additional accessible visitor accommodation is planned for Tidal River and for other park locations, such as Cape Conran Coastal Park.

Implementation of universal design for new visitor facilities in parks has been a high priority for Parks Victoria to improve access for more diverse visitors.

Work undertaken has included creating more accessible picnic areas, campgrounds, viewing areas, children's playscapes, and more all-abilities trails. Improving access to Parks Victoria's jetties and other waterway infrastructure has also been undertaken.

Parks Victoria is planning its priorities for its new Disability Action Plan 2022-25, and recently held a series of public consultations with people with disability and their advocates, to enable them to have their say. Parks Victoria received valuable feedback and this will help shape Parks Victoria's actions for its new Disability Action Plan 2022-25, due to be released early next year.

# Between invisible and inspiring

Senior physiotherapist Leanne Rees shares some of her findings from her academic research on how spinal cord injury is portrayed by the mass media.



The tragic victim and the superhero are the most common representations of SCI in the media.

If you're reading this story it's likely you know a lot about spinal cord injury. The reality is though, most people don't. What do these people understand about spinal cord injury and how is this influenced by mass media?

Last year, as part of my PhD looking at mass media portrayal of spinal cord injury, I spoke to people with spinal cord injury and asked, "how does mass media portray spinal cord injury and what is the impact on your life?" The results were interesting.

## One or the other

People told me mass media portrays spinal cord injury in a way that describes them as one or the other. You're either "suffering or a superhero", "invisible or inspiring", or "really stuffed or heroic".

People felt this was inaccurate and created a misunderstanding about what spinal cord injury is and what it means to live with a spinal cord injury.

One participant, Aaron, said: "It does turn your life upside down, but the misery and the sorrow photos I don't think are accurate, because I'm happy."

## Work hard and be determined

I was told that mass media stories often credit rehabilitation outcomes to hard work and determination, with little recognition for the type of spinal cord injury, if it was complete or incomplete, or how recent the person's injury was.

This suggested that spinal cord injury is something that can be overcome.

There was no question, everyone works hard, but as

another participant, Luke, said the problem is "people think you just have to work hard to walk again".

## Walk again or become a Paralympic athlete

People I spoke to suggested that potential quality of life when living with a spinal cord injury is overlooked in mass media.

People said mass media place too much value on ability to walk again or becoming a Paralympic athlete, rather than understanding that quality of life is also valued through things like family, work, travel or study. As Sam said, "not everyone with a spinal cord injury has to do sport".

## There is more to spinal cord injury than not being able to walk

People told me that other health and life domains impacted by a spinal cord injury are overshadowed.

Everyone agreed that maximising potential movement after a spinal cord injury was important, however, other issues

related to spinal cord injury, such as bowel, bladder and sexual function, health and relationships, were not recognised, but are just as important.

## Interactions can be uncomfortable

As a result of mass media portrayal of spinal cord injury, people I spoke to described experiencing unreasonable expectations and assumptions from others.

For Ruth, the impact of this is that "we all have assumptions made about us, the point is with somebody like me, they're generally fairly negative, they're not positive assumptions".

"People think you just have to work hard to walk again."



Leanne's interview subjects said they wanted to see realistic representations of SCI in the media.

This also led to uncomfortable interactions and remarks. Luke described people asking him "why aren't you trying to walk?", and Andrew said sometimes people think "if you give up the hope of walking then you've quit".

### **It's not what's present in mass media, but what's absent**

People I spoke to understood why mass media portrays spinal cord injury in this way: it's what draws people to a story. However the problem is, there are no stories in between.

Although this is improving, even when people with spinal cord injury are present, quite often it is with images that aren't very genuine.

People said they would like to be seen in mass media as members of our community – business owners, workers, dads, mums, and mates. Currently these stories and images are absent.

For Maria, this was important because: "It would be great if [we] are portrayed as active members of the community because that's how I would like to feel."

### **What's next?**

By understanding how news stories in mass media are made, we can help make things better. The next step in my research is to speak to journalists and the people they get their information from, to find out what they do and what their experiences are.

I'm fortunate to have a group of people with spinal cord injury working with me. Together we hope to show that using the right language and images are important if we want to shift current expectations and assumptions.

Media Diversity Australia have released a resource to help



Even when people with spinal cord injury are represented, they're often not genuine, says Leanne.

media professionals improve media portrayals of disability, find it on their [website here](#).

Attitude Foundation also advocates for improved media portrayals and have a podcast called Reframed. Reframed critiques TV shows and movies that have included characters with disability, [listen on their website here](#).

We are all engaged in media, one way or another. This research will raise awareness of how spinal cord injury is understood by society, in a way that has never been looked at before.

**Author note:** Leanne Rees is a PhD Candidate at La Trobe University and Senior Physiotherapist with the Victorian Spinal Cord Service at Austin Health.

# Stepping stones for reimagining a life

Long-haul truck driver Dion Woodward found himself unemployed and unable to walk after a tumour developed on his spinal column. Engaging with a range of AQA resources transformed his independence and ultimately, he says, his outlook on life.

Dan Nathan



Dion's transfer and wheelchair skills leapt forward during his time on the Skills For Independence course.

Until mid-2020, Dion Woodward was a long-haul trucker. When he got time off he liked to ride his motorbike, or to go out four-wheel driving and camping.

Then came some bladder and bowel issues. Dion was prescribed medication that helped, but he had to quit his trucking job.

And then he collapsed. And again. "It was like someone just flicked the off switch, and my legs would stop working," he says.

Scans showed that a tumour had been developing on his spinal column. It was slowly crushing his spinal cord.

"I was in shock. It was a very dark time," shares Dion.

"I was in lockdown, I wasn't working, and I was slowly losing control of my body. I knew it was bad, but it still hadn't really sunk in."

Over a two week period, his lower-body function deteriorated rapidly. By the time he got to hospital, Dion was using a wheelchair.

Surgeons removed as much of the tumour as they could,

but the damage was done: an incomplete T8-10 spinal cord injury.

Dion says that small, early improvements in his physical recovery put him in a fairly positive mindset. Three days out of surgery, he could stand with assistance. On the fourth, he could move a metre, with a speciality walking aide.

But after he was discharged from the neuro rehab ward at Monash Health, where he was the only patient with a spinal cord injury, that optimism evaporated.

"I got home, and it was overwhelming," he reports. "It just hit me - I had to do it all myself."

A doctor Dion had met at the hospital had told him about

AQA. Dion got in touch while he was still in rehab, and he was paired with an AQA Peer Mentor. A month after returning home, Dion engaged with AQA's

Support Coordination team. They helped him to sort out his NDIS plan, and within a month his first support worker arrived at his home.

Just six weeks after Dion had left rehab, he completed Discovering the Power in Me (DPM), a motivational and goal setting course run by AQA.

*"I feel part of a community. I've learnt so much from everyone I've met, and been so inspired by them."*



Dr Gillian Hilton, Evaluation and Engagement Lead with AQA's Living Well Project, tips her hat to Dion's mastery of the backwheel balance.

"DPM helped me return to the positivity I'd found when I took those first few steps in rehab," says Dion.

"Yes, my life's changed, and I've got to do things differently, but it's not the end of the world. I don't class myself as anything different to anyone else."

He says the experience was also quite raw for him.

"It was the first time I'd properly met other people with a spinal cord injury, and heard their stories. It was the first time I realised just how under-prepared I was when I left rehab. It was confronting."

Over the past year, Dion has engaged with many of the resources AQA offers. He has continued to work with his Peer Mentor, has joined the Community Network that AQA facilitates near him in Mornington, has attended webinars hosted by AQA networks across the state, has developed his capacity to use a wheelchair at AQA training days, and has completed a five-day residential course on building independence and capacity, delivered as part of AQA's Living Well project.

"From what I've heard, going through rehab at the Royal Talbot, or the Alfred, is a more structured experience. They give you a base of skills and knowledge, and a sense of community, to help with your re-integration," says Dion.

"Monash Health isn't set up for that. But I found that base at AQA.

"Every interaction I've had with AQA, even if it's just a phone call, I've come away with more knowledge. For me,

that knowledge has meant more confidence.

"I feel part of a community. I've learnt so much from everyone I've met, and been so inspired by them."

Alongside developing knowledge, connections and skills, Dion has thrown himself into exercise. For most of this year, he has been doing two sessions weekly with an exercise physiologist, and two more with a physio. The results have impressed him. When he left rehab, he could move a few meters, with assistance, and his doctors weren't confident he'd regain much more function than that. He can now walk 100m with a walker, sometimes twice a day.

"I'm very lucky in that sense, having an incomplete injury. Plus, I'm now fitter than I was before my injury," he says.

Dion says he has started to feel as though his physical recovery may have reached a plateau. That has prompted him to think about his next chapter, which will be about getting back to work.

"I'm not pushing myself, it might just be one day a week at first. And it doesn't need to be ideal - just a start."

So, what might be ideal? Since his injury, Dion says he's become passionate about helping people with disabilities.

"The people I've met in the disability community over the last year have been really inspiring," says Dion.

"So many interesting minds. I want to keep learning about what people go through, and how they deal with it.

"And I want to give back."

*"The flipside of this injury has been that it's made me slow down and appreciate things"*



Regardless of what work he finds, Dion says he's committed to a better work-life balance than he had as a trucker.

"The flipside of this injury has been that it's made me slow down and appreciate things," he reveals.

"I want to socialise more. I want to have lunch at a cafe when I feel like it. I want to start doing some sightseeing - I've never been to the State Library, or the Museum."

Doctors have told Dion that the tumor in his spine will keep growing, and will eventually deprive him of all lower-body function. He says he has lost function since leaving rehab.

So he says he's not wasting any time. Now that Covid-19 related travel restrictions have been lifted, he's desperate to get back behind the wheel.

"The independence of being able to get in the car and go anywhere I want, not needing to have a carer with me, that'll be huge," he says.

"I won't be able to drive my turbo Subaru Forester - it's too old to get funding, and it's manual. But I might keep it as a project car, I love tinkering. And I can still do most of the work, I just need to find a carer who's into cars, and they can help me with the bits I can't do."

In the meantime, he has his sights set on something more boisterous.

"Social nights of wheelchair rugby at the Royal Talbot are coming back," Dion notes. "I can't wait."

### THE LIVING WELL PROJECT & SKILLS FOR INDEPENDENCE COURSE 5 PARTICIPANT SPACES REMAINING

AQA's Living Well Project delivers peer-led services and activities to help build the capacity and independence of people living with disabilities.

This February, after multiple Covid-19 delays, the Project will be delivering its second Skills for Independence course.

The Skills for Independence course is a tailor-made program aimed at boosting the confidence of people with spinal cord injuries or similar physical disability, no matter what their goals are.

Skills for Independence is a comprehensive program that looks at a variety of topics most important to you. A choice of topics includes: wheelchair skills and transfer, planning for holidays and staying away from home, promoting verbal independence, healthy living, activity and exercise, goal setting, pain and fatigue, dressing, body image and intimacy.

Developed and led by people with lived experience, this residential course will be held at the hotel Citadines on Bourke, Melbourne. Arrangements can be made if you require day or overnight personal care support during your stay and participation on the course - please let us know in advance.

Across 5 days, the program will equip you with the skills and knowledge needed to improve your health, further your independence and share life experiences, hints and tips with others.



#### PROGRAM DETAILS:

**February 28th - March 4, 2022:**  
5 Days/4 Nights: \$TBC

*The Skills For Independence course is funded typically through your NDIS funding under your Core and Capacity Building Supports. For those not on the NDIS, or unable to access insurance, a limited number of subsidised places are available.*

If you'd like to be involved, please get in contact with our team.

p. 03 9489 0777

e. [community@aqavic.org.au](mailto:community@aqavic.org.au)

# Managing self-advocacy and burnout

Fighting for equality can be exhausting. Grant Maynard, a disability advocate, shares some of the techniques he's developed for effective wins and mental health management.



Grant, front centre, after speaking at the launch of Richmond Football Club's Diversity and Inclusion Plan.

Whether advocacy is a passion of yours or not, if you have a disability, you're an advocate. Constantly fighting for equality can be exhausting, so how can you stay focused and not burn out?

When you think of burnout, you generally think of work. Just like any job, self-advocacy can result in burnout, often far too frequently, but why? Recognised or not, the advocacy process can be just as time-consuming as any job. Being so personal, it often places the advocate into a position of vulnerability. This means it often isn't given time, nor the respect deserved from ourselves or others.

In the past few issues of NewsLink, we've heard various stories: equal access to tickets, vehicle modifications, updates to housing and NDIS access for over 65s. When dealing with such personal aspects surrounding equal rights and access, how do you effectively advocate and remain mentally healthy?

On paper, it sounds simple: "self-advocacy": the action of representing oneself or one's views or interests.

Isn't it just a simple matter of gathering the facts and the confidence to express your concerns?

However, as a friend and fellow advocate recently wrote:

"I'm wondering what the statistics are on how long 'lived experience' advocates last at a systemic level. Seriously contemplating shifting my focus to a more peer work level. Anyone got experience and/or advice?"

It's a valid question, one that unfortunately doesn't have a clear answer. Some issues have been fought for decades or longer. Where some have started to see change, others like public transport don't yet have an endpoint. A recent mind-

blowing change meant a global pandemic made flexible work possible worldwide, an issue fought for years, yet changed overnight. When looking at these examples, it's no surprise the toll this can take.

So what can be done, and how can you sustainably approach self-advocacy?

- **Research:** Despite the title's suggestion, self-advocacy doesn't mean everything has to come down to you. You can research, talk to others, review similar issues or talk to other advocates or services to develop a plan. Not everything needs to be re-invented.
- **Plan for roadblocks:** I've only ever had a handful of instant "yes" responses. So, expect many more negative responses along with comments about cost, we're working on it, we'll see, and often the pass-the-buck response.
- **Passion over Anger:** When experiencing roadblocks, it's easy to get angry. I always loved the line in MIKA's song Grace Kelly, "Getting angry doesn't solve anything". If you find yourself at that point, hit save and re-review later. Sometimes a bit of space, and rewording "this helps you" over "you did this wrong", can make a big difference.
- **Take a break:** Due to its personal nature, it can be hard to take time off. Unlike a typical job, you tend not to leave things behind at 5 pm. Be it a week, a month or a year, depending on the situation. Scheduling time into a calendar as you would a meeting can also help put your health first.
- **Be creative:** I often say "When is the problem, not the problem". This helps me think outside the box when encountering roadblocks. It could be that the person can't visualise the issue or maybe it's the wrong contact. Other approaches may be switching from personal to broad examples. Including other disabilities, parents with prams or the average punter can help give context.

At the end of the day, if you burn out and drop the issue, you'll probably find that it carries its own mental toll. Burnout and disability aren't a great combo so the more proactive you can be in ensuring you tackle advocacy in a sustainable and balanced manner the more effective you'll be. These are just some of the approaches I've developed, hopefully, they've given you some insights into new and different ways in managing self-advocacy while looking after your mental health.

**Author note:** Grant Maynard lives with a complex disability from birth. He works in design and communications, is a public speaker, a disability advisor for Yarra City Council, and consulted in the development of Richmond Football Club's Diversity and Inclusion plan.

# Calling SOS for my pressure sore

When his legs started to spasm violently, Wayne Bradshaw knew something was wrong. He describes how the Austin's Spinal Outreach Service (SOS) helped him recover from a pressure wound, at home.

## Wayne Bradshaw

INFORMATION OFFICER AT AQA

I have always loved jumping on my shower seat at home to have a wash. I have a fold down model fixed inside my glass double shower. After my accident, it all seemed quite daunting, wondering how I was going to get myself safely onto the Perspex top to have a wash. I slowly gained the strength and confidence to perform this task and just loved washing myself this way.



The scene of the crime.

I showered this way for 28 years without ever hurting myself but I had recently noticed that a small hexagon bolt was beginning to protrude a little onto the surface of the seat. I thought I must bring my builder son around to drill a hole and countersink the bolt before it becomes a problem but till then I decided to place a flannel over the bolt until it was repaired.

This solved the problem until one morning the face washer moved and I slid straight onto the bolt. I knew I was in trouble. How did I know this, you ask? Well, my legs started to spasm violently. I was actually kicking the wall in front of me.

I showered then dried myself, but before jumping back onto my bed to dress, I asked my partner, Michelle, to have a look. She said, "Wayne, you are in trouble as there is a 15mm by 15mm hole in your bum". I didn't really know what to do, so I rang Naz Erdem, a colleague at AQA, and told him the situation. He said that I had to go to the Austin Hospital Emergency Department and admit myself.

I arranged for a taxi to pick me up the following morning. Believing I was going to be admitted to hospital for a period of time, I packed a bag to take with me. I headed to the hospital and after waiting in the Emergency Department for a little while, I was looked at by a young doctor who proceeded to tell me the wound was nice and clean and that I should go back home.

I just did not know what to think, so I questioned him and he told me that Ben from the Austin's Spinal Outreach



Wayne demonstrates a pressure relief technique.

Service (SOS) team would give me a ring the next day. I just thought that I would end up on 13 West because all the pressure wounds were dealt with there. I had never been there myself, but I have heard stories about the ward. Ben rang two days later, and told me he'd had to go into isolation after possible COVID-19 exposure at the footy.

Ben asked for some photos to be sent, which Michelle took care of. After viewing the photos he had a list of wound care products that I needed to order. I asked Ben rather than sending me the list, to send it straight

through to Independence Australia as I have an account set up using my NDIS funds, to which he kindly obliged.

I spent one week in bed waiting for Ben to come out of isolation, so that he could observe the wound for himself. When he came by, he said the wound was very clean and not too severe. He dressed the wound and told me nurses

from Bolton Clarke (Home Help Nursing service) would be out every second day to redress the wound on my bum.

I was lucky as the Olympics had just started so there was something to watch. I had the creature comforts of home so I could do all my own showering and care routine - which was great. My son Ben countersunk the bolt, so showering was finally safe. The Bolton Clarke nurses would ring every second day letting me know they were on their way. I continued to do the right thing in regards to keeping off my butt, so after seven weeks I was right to get back up and back into life.

I have to say a huge THANK YOU to Ben who planned my care, and to my nurses, as they were all fantastic in their care and the way they treated me. I also had visits from Kristy and Claire - OT's from the Austin's SOS team - to have a look at my equipment, which resulted in a new Nexus Cushion and a gel shower pad to keep the pressure off my aging bum.

*One morning the face washer moved and I slid straight onto the bolt: I knew I was in trouble.*

## WHAT IS THE SPINAL OUTREACH SERVICE?

### Benjamin Clegg

SPINAL OUTREACH SERVICE NURSE

*Learn a little more about the Austin's Spinal Outreach Service from Benjamin Clegg, the SOS nurse who helped Wayne deal with his pressure wound.*

The Spinal Outreach Service (previously - Spinal Outreach Risk Reduction Team) has operated for over 20 years as part of the Victorian Spinal Cord Service (VSCS) based at Austin Health.

The team consists of Nursing, Physio, Occupational therapy and Social Work with extensive experience in spinal cord injury. The team's role is to help manage and assist with a wide range of spinal cord related issues. Ideally preventing hospital admission, but also facilitating this process when required.

A large portion of our work involves advice around pressure injury management and prevention, as this is a prevalent complication of spinal cord injury. Another focus of our work is assisting people with the challenges of aging with spinal cord injury, and many of the clients we work with are decades post their initial injury. We work with clients as well as their care team, and private therapists.

The service is available to previous clients of the VSCS, and covers all of metropolitan Melbourne. For those outside metropolitan Melbourne we still do offer advice via phone or telehealth. For more details about the service and to enquire about referrals please see the Austin Health web page and contact details listed.



#### Webpage.

<https://www.austin.org.au/spinal-community-services/>

#### Phone.

(03) 9496 5351

#### Email.

[SOS@austin.org.au](mailto:SOS@austin.org.au)

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# Blast From The Past: Driving and communication devices

Naz Erdem

I have a question for you all. What would you do if you were driving and had a breakdown? I'm assuming your answer would be to grab your mobile phone and call a friend, or roadside assistance.

Imagine you didn't have your mobile phone with you, you were alone, and you broke down on a rarely used highway or back road. You would hope someone would come past so you can flag them down to get assistance. Otherwise you'd be alone and helpless, at least for a few hours. It would be a lot worse if it was a super-hot or freezing day.

*But how did people cope  
before the invention  
of mobile phones?*

Mobile phones are a necessity these days to keep connected. The world is at your fingertips, be it navigating the world-wide-web, checking emails, and of course making phone calls to whoever you want.

But how did people cope before the invention of mobile phones? Well, there was a thing called a CB radio (short for citizen band radio). A CB radio was a must-have for any drivers with disabilities. Some of you out there may have heard of a CB radio, but the younger guys would be scratching their heads wondering what it is. It was a way to communicate with the outside world.

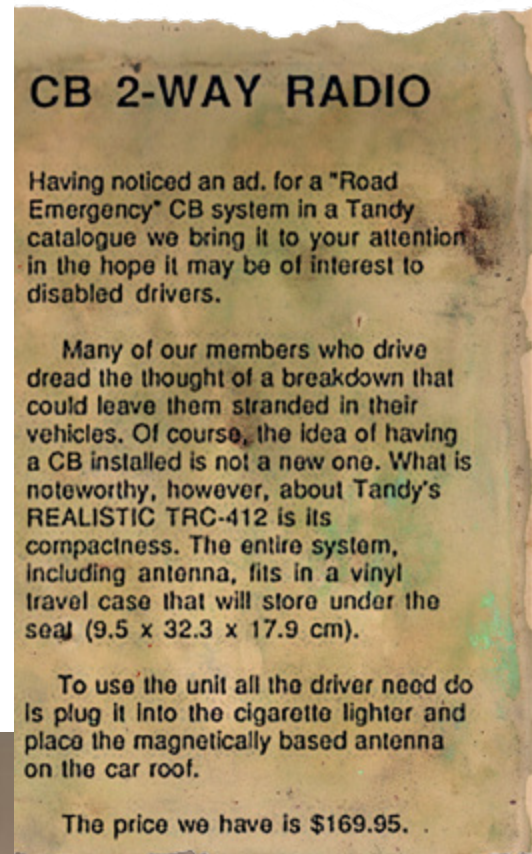
We have gone back into our NewsLink archives to see what was all the rage with CB radios.

Back in our August 1987 NewsLink edition, we wrote an article about how drivers with disabilities could have the luxury of communicating with others during an emergency through the wonders of modern technology. Yes, it was modern technology at the time.

Even though at the time it was considered modern, cutting-edge technology, available to the general public, it had its shortfalls. For one, you could only communicate with others that also had a CB radio, and you physically needed to select a transmission channel that others were using. And you could only talk one at a time, by pressing down and holding the button.

At the time, there were not that many CB radio users other than the vast trucking community. The article boasts about the compactness of the CB radio and how it fits into a travel case.

It may seem funny how things were back then. Technology has definitely come a long way.



The original article from Newslink 1987, and an old CB Radio

## CLASSIFIEDS

### EQUIPMENT FOR SALE

#### RT300 IFES CYCLE

Restorative Therapies RT300 IFES Cycle (Leg/Core 12 channels); It's a clinician IFES which means you have more control over settings and logging in; In very good condition; Pick up location is Euroa.

**Price** \$20,000

**Phone** 0409 636 989 (Emily) (10/21)

#### GLIDE CENTRO MID WHEEL DRIVE POWERCHAIR

In excellent condition; Purchased in 2019 for \$17000 - Receipt attached; Rarely went outside and was used in the aged facility; Many additional extras.

**Price** Reasonable Offer Accepted

**Phone** 0436 010 284 (Val) (02/21)

#### QUICKIE - SPORTS WHEELCHAIR WITH ROHO CUSHION

Cushion size 100cm - High profile; One Quickie cushion - 70x80cm x 6cm; Front wheels 570mm; Four New tyres 25-590mm; Two sets of Mobility Plus wheels 25mmx 590mm. The support chair also has an 16 inch Height Profile ROHO Cushion, which is in a very good condition. It also has a Jay Cushion that accompanies the chair, which is a bit smaller than the ROHO Cushion: This is all included at the bargain price.

**Price** \$600

**Phone** 0424 710 446 (Michael) (12/21)

#### EASYLIFT LIFTBOY II

Manufactured in Germany and tested to all Australian specifications and approvals; Virtually brand new - Used for 1 week only; Suitable for indoor and outdoor use - fully waterproof; 240V plug in - no hard wiring or hydraulics required; Suitable for a max. lift height of 830mm, or any required height in between, maximum lift weight of 300kg, user and attendant capable; The unit was \$12,000 brand new.

**Price** \$5,000

**Phone** 0438 008 584 (Gerard) (06/19#a)

#### ROHO MATTRESS CUSHION INSERTS

3 available @ \$300 each; Size 86cm x 49cm x 8.5cm; 10x18 cells; Purchased 2019 - As new condition; Pumps to inflate included; Perfect pressure relief for all areas of body for those who spend lot of time on the bed

**Price** \$300 each

**Phone** 0408 024 351 (Wendy) (09/21#a)

#### APOLLO RESIDENTIAL HYDRAULIC LIFT

The lift is a few years old but has never been installed or used; It was fabricated to travel 2850 floor to floor but that can be increased by the addition of material from the manufacturer; All of the dimensions, weights and load carrying capacities etc are detailed in one of the attached photos.

**Price** \$5,500

**Phone** 0414 593 790 (Mal) (05/20#a)

#### STANDING FRAME - MANUAL LIFT

As new condition; Comes with tools; Straps; Extra tray; Instruction booklets.

**Price** \$2,000

**Phone** 0414 428 882 (Lissa) (08/21#a)

#### RAZ - TILTING SHOWER COMMODE

With Headrest; In good condition; They sell for \$3,900 - \$5,000 new.

**Price** \$800

**Phone** 0432 566 930 (Selina) (03/21#a)

### CARS FOR SALE

#### 2017 MERCEDES BENZ VALANTE 116 BLUETEC

04/2022 Registration; Auto; 2.1L Turbo Diesel; 24,000 kms; RWC Supplied; Service History; Flint Grey Metallic; Meticulously looked after and fitted with a long list of factory options and safety options and most importantly a Fiorella Wheelchair Lift with seatbelt and 4 Q'strains secure retractors in 2017 by Mobility Plus in Fairfield (VIC)

**Price** \$51,000 ONO (Excludes Govt Charges)

**Phone** 0419 884 106 (Lou) (07/21#a)

#### CHRYSLER VOYAGER VAN - LX 6 SP AUTOMATIC 4D WAGON

Low kms; Auto; 2.8 L Turbo Diesel; Incredible power; Extremely economical; Over \$200,000 spent on this vehicle to make it arguably the most exclusive car in Australia; Self-drive fully computerised with electronic operation; Many features.

**Price** P.O.A.

**Phone** 0450 920 834 (Ken) (04/21#a)

### FREEBIES

#### CONTINENCE EQUIPMENT

Free to a good home; 8 Boxes of UltraFlex Clear 32mm & 40 Careline 500ml Short Tube Leg Bags.

**Phone** 0426 274 401 (David) (10/21#a)

#### 2 X HOSPITAL KING SINGLE BEDS

Two Hospital King Single beds to give away for free; Collect from Melton West. One has two functions and the other has three; The one with three functions also has a foot piece at the end of the bed for hanging, perhaps the machine for a pressure mattress; There are also good quality mattresses for both beds if required. **Email Maree: maree.jongkryg@sov.net.au**

#### FEMALE CATHETERS

Female InLine Releen 2-way Foley CH 20 catheters; 5-10ml balloon (for urethral and suprapubic use) 2 boxes (5 catheters in each) Expiry: 2022-12

**Phone** 0467 039 699 (Young) (07/21#a)

#### WHEELCHAIR MANUAL

Mobility Plus Manual Wheelchair; 16' x 17'; 24 Inch wheels; Can use for Lawn Bowls; Pick up from Mansfield or ring and arrange somewhere to meet.

**Phone** 0477 011 153 (Kevin) (09/20#a)

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or contact us on **03 9489 0777** or [info@aqavic.org.au](mailto:info@aqavic.org.au)



## SPINAL INJURY INFO & SUPPORT ONLINE

Like us on facebook for news, information, photos and more.

[facebook.com/AQASpinalSupport](https://www.facebook.com/AQASpinalSupport)



MARK HANSON  
B.OccThy (Hons)

# LIFE IS COMPLEX. WE GET THAT. CAN WE HELP?

AQA has expanded its **Support Coordination & Occupational Therapy** team. We have immediate capacity to accept new participants.

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Our Community Engagement Coordinator, Mark Hanson, is available to answer any of your questions.

**Contact Mark Hanson:**  
p. (03) 9489 0777

Or submit an online Service Inquiry at:  
<https://www.aqavic.org.au/contact>