

BULLETIN



Thanking OUR MSWA VOLUNTEERS



NATIONAL VOLUNTEER WEEK 15 - 21 MAY



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MSWA

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If you would like to comment on anything you read in this *Bulletin* please email bulletin@mswa.org.au or write to **MSWA, Locked Bag 2, Bentley DC WA 6983**
For general feedback or complaints please contact Davina Sawyer 6454 3173 or feedback@mswa.org.au

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The Editorial Working Group welcomes unsolicited submissions.

All articles are subject to a reviewing process. The views expressed are those of the authors and do not necessarily reflect the view of MSWA's staff, advisors, directors or officers.

NURSING SUPPORT

Our Neurological Liaison Nurses are usually the first point of contact after the neurologist's diagnosis.

COMMUNITY NURSE: 9365 4888

MONDAY TO FRIDAY (8.00AM - 4.00PM)

CLIENT ENGAGEMENT DEPARTMENT

Our experienced teams will provide you with personalised support throughout your service journey with MSWA. From helping you to access funding, to working with you to get the most from your selected services, our trained staff are here to help.

FOR MORE INFORMATION, PLEASE CONTACT 9365 4888.

OUR SERVICES INCLUDE:

COUNSELLING, PEER SUPPORT AND HEALTH EDUCATION

COMMUNITY SUPPORT

DIETETICS

OCCUPATIONAL THERAPY

OUTREACH

PHYSIOTHERAPY

SOCIAL WELFARE

SPEECH PATHOLOGY

OUTREACH AT MSWA

If you live in Perth, Rockingham, Bunbury or Albany and are interested in a trial to experience the Outreach community, get in touch with **SENIOR COMMUNITY OUTREACH COORDINATOR MELISSA COOMBS** VIA OUTREACH@MSWA.ORG.AU

EMPLOYMENT SUPPORT

The MSWA Employment Support Service is the only specialist employment service for people living with multiple sclerosis and other neurological conditions in Western Australia. Our Team can help you to stay in your current job or find employment in the open labour market.

LEIGH MCCAFFREY, EMPLOYMENT SUPPORT SERVICES

MANAGER: 1300 865 209

FOR MORE INFORMATION ON THE SERVICES MSWA OFFERS, PLEASE VISIT MSWA.ORG.AU

WELCOME

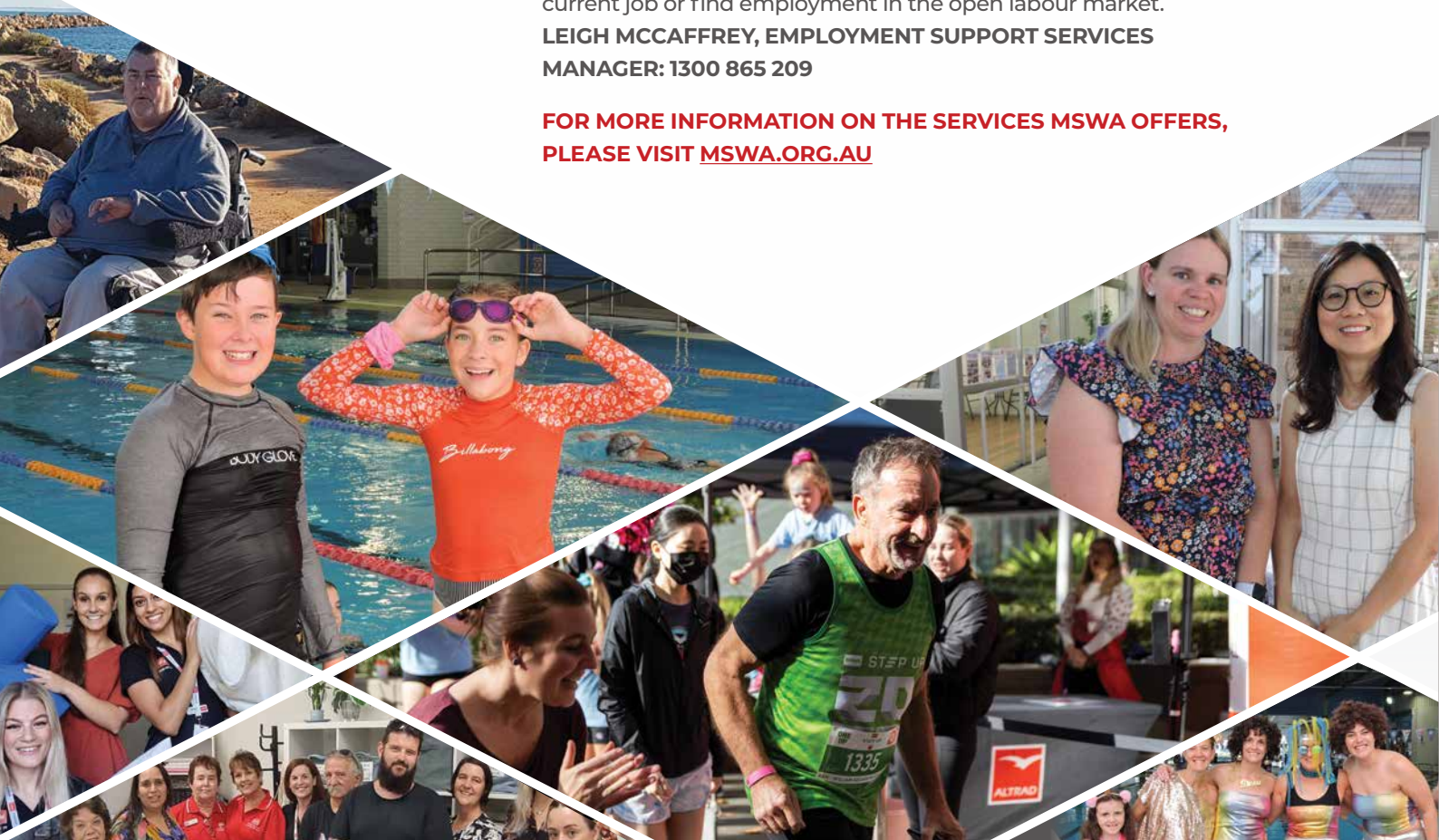
Welcome to the Autumn 2023 edition of *Bulletin*. We hope you enjoy the news, stories and service information we have brought to you in this edition.

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WOULD YOU PREFER TO RECEIVE *BULLETIN* ONLINE?

Help us to reduce our environmental impact by going digital!

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FROM OUR CEO

What a start to the year this has been. So much has happened, with many achievements under our belt already – and yet we still have so much more we want to do. I have a sense from talking to others that we are all trying to ‘cram’ in what we couldn’t do during the COVID-19 response, in both our personal and professional lives, which is unintentionally exhausting!

The privilege of working at an organisation like MSWA is that we are all so passionate about our Purpose and helping the community we exist to support, though this does translate to wanting to do more for people, all as soon as possible. Hence our reflection that we need to stop, take a breath and slow down to make sure we prioritise the right things that will make a truly positive impact.



It is good to reflect on what has been done and the difference it makes.

On the fundraising front, our community has continued to support us, including:

- / Rottneest solo swimmer Jamie Warnock, who raised \$3,735 in honour of his mum.
- / The Pharmacy 777 team and over 25 individuals who hit the pavement for MSWA in the HBF Run for a Reason on Sunday, May 21.
- / The Brown family, who donated an entire collection of craft supplies to MSWA Rockingham Outreach, resulting in what we now call ‘Julie’s Corner’.
- See page 11.
- / Our Albany Swim, which the local community supported so wonderfully to raise almost \$20,000 for MSWA (see the photos on page 24).
- / Our Albany Ride just gone on May 6 – see the wrap up on page 25.
- / Everyone who bought tickets in our lotteries, specifically the latest Mega Home Lottery – we are so proud to have held the final draw with our Clients and team at Margaret Doody House Respite. What a wonderful opportunity to show where the money raised goes, and highlight the difference your ticket makes.

If you haven’t yet had a chance to get involved with MSWA this year, why not sign up to Step Up for MSWA on Sunday, 25 June? Take on the challenge of climbing Perth’s tallest building alongside myself, the executive and our MSWA staff team, as we welcome new sponsors Commonwealth Bank. Details on page 36.

All these funds contribute to services for those who don’t or can’t get enough funding, to our research contributions in a search for a cure or better treatments, and the costs to build our Respite, High-Support Accommodation and Service Centres. We can’t say “thank you” enough for all the support we receive to help us do this.

Just as vital is the dedication of our volunteers. Your commitment to make a difference for our Clients is inspiring to us all; regardless of whether you work directly to support our Clients, behind the scenes in our kitchens and gardens, or at our events. Every role makes a positive, lasting impact and as we reflect on National Volunteer Week 2023, we hope you feel appreciated and valued - because you are!

In April, we celebrated the first anniversary of our Albany Service Centre and High-Support Accommodation. It is a lovely facility, but the most valuable aspect is the team and the Clients who bring it heart, as shown in the pictures on page 26 and our back cover.



The unveiling of Julie's Corner at MSWA Rockingham.

In terms of improving our services, we have selected our Advisory and Client Co-Design Committee and held our first meeting in early May with our amazing group of Client volunteers. We can’t wait to see what comes out of these meetings in terms of new and better ways of supporting our Clients and the community. See page 7 for more information.

Most importantly on services, it is the hard work of every care support worker, their support teams and our rostering team, who are core to MSWA achieving its Purpose. I never cease to be amazed by the difference they make.

It is worth talking about the very difficult challenge these teams, our support staff and our Clients have faced as we transition our Client Management Systems. This has not been easy, and projects of this kind never are, but it has made difficult times more difficult as we have bedded it down.

To those of you impacted as a result of rostering and billing challenges, please accept my sincere apologies. Most of all, thanks for your kindness to our staff as we have worked through this.

Lastly and very importantly, we have made good progress on our company structure change. We value the feedback received from you on the proposed Constitution and structure change via our email channel so far and encourage you to continue sending through any comments or questions to boardsecretariat@mswa.oru.au. If you wish to know more, please go to our website via mswa.org.au/member-information where you can find a summary of the proposed changes and the reasoning for them, the draft Constitution and some frequently asked questions.

As the leaves turn brown, the weather cools and we move into the next few months after our deep breath, I wish you good health and happiness and ask you to keep being open with us about where we can do better.

**MELANIE KIELY
CHIEF EXECUTIVE OFFICER**



Jamie Warnock.



Our Early Bird winners.



Some of our 2023 Albany Riders.

MEMBER & CLIENT SERVICES

Welcome to the Autumn Edition of our Member & Client Services Bulletin. I hope you are all keeping well and enjoying the cooler weather. Where has the year gone?

You may be aware of, or have been involved in, our Aged Care Accreditation Audit which took place in February. I am pleased to advise that we have met all Accreditation Standards, an achievement which speaks to the high calibre team I am proud to work with at MSWA.

Another piece of exciting news is the Client Advisory and Co-Design Committee, which held its first meeting in early May. The Committee provides an opportunity for members of the community, MSWA Clients and their carers to collaborate and input into MSWA's Client Services and service delivery designs. We value all feedback; this is a forum to facilitate that, with the intention of enhancing our Client experience and impact. We look forward to the positive outcomes in the following months.

In the last *Bulletin* issue, I mentioned the launch of our new Client Management System. As with any IT transformation, there are challenges that we need to work through and we thank you for your patience as we settle into the new system. We continue to look at system optimisation, with new features continually added, all of which will enhance our efficiencies and ultimately improve our services to you.

In March, our generous supporters from the 2022 Dinner Auction were given a tour of the refurbished Wilson gym, an opportunity to see first-hand where their money was used and to hear from Clients on the difference it has made. The addition of the new gym space has allowed us to add new equipment, expand our services, and create a dedicated assessment room. Our MSWA Wilson Clients have been thrilled to try out the new equipment and different exercises.

In April, we celebrated our Albany hub's first birthday with a community event. The day was filled with activities for all ages, with Clients and visitors given the opportunity to tour both the Service Centre and High-Support Accommodation. Staff members were onsite to showcase the services that we offer, both to Clients, families and external stakeholders.

Our MSWA teams are always looking at ways to enhance our service offerings to you. In this edition of *Bulletin*, learn about the new Supported Lying Service offered by the Occupational Therapy department on page 14,



Physiotherapy Manager James Beckett demonstrates the use of MSWA Wilson's new equipment during the supporter tour.

and how our Speech Pathology team is assisting Clients to re-discover their voice using the Lee Silverman Voice Treatment, see page 20.

I'd also like to take this opportunity to acknowledge the tireless work of our volunteers. Though we appreciate them every day for the difference they make here at MSWA, it was wonderful to have the opportunity to stop and reflect on their contributions during National Volunteer Week (15 – 21 May). It is because of people like Joan Crossman (read her story on page 22) that we can give our Clients the best possible care here at MSWA. Thank you for your service.

As always, your feedback is important to us. If you have anything you would like to share, please contact us via feedback@mswa.org.au. Stay safe and thank you for supporting all that we do.

NICOLA WASHINGTON
CHIEF CLIENT
OPERATIONS OFFICER

INTRODUCING THE MSWA CLIENT ADVISORY AND CO-DESIGN COMMITTEE

MSWA has stepped into an exciting new chapter, where the overwhelming theme is to ensure our Clients are at the centre of all that we do.

A key initiative to achieve this goal was the creation of the MSWA Client Advisory and Co-design Committee, and we are proud to share that this Committee held its first meeting on 4 May.

This Committee will be a formal mechanism for MSWA Clients and their carers to provide input into MSWA's Client services, service delivery models and processes, including how we communicate with Clients.

We would like to extend our thanks to all who submitted an expression of interest; we are very grateful for your passion and commitment to increasing our impact and support for people with MS and other neurological conditions.

We were pleased to receive a strong response to this call out, and as such were oversubscribed for the core Committee. As a result, a decision was made to create a second Advisory Group to support the core Committee in a consultancy capacity.

The selection process was conducted with careful consideration to ensure diversity of voice and representation across our Client community, including supporters such as carers and family members.



We would like to take this opportunity to introduce the members of the Committee below:

Client Advisory and Co-design Committee

Gavin Harper

Ann Marie Linto

Irene Long

Karen Gillies

Kim Flanagan

Brooke Cuthbertson

Susan Hyde

Ellen-May Eaton

Allen Donald Roberts

Terry Compton

Wildaliz DeJesus Arocho

The Committee membership will be reviewed on a yearly basis to provide further opportunities for Clients and their supporters to engage.

Our first meeting identified key topics of importance for Clients and carers, which will form the basis of the agenda for future meetings.

We look forward to seeing the positive gains that can be made through collaboration with our Client community, and will keep everyone informed of the Committee's progress.

As always, all Clients are welcome to share feedback at any time via feedback@mswa.org.au

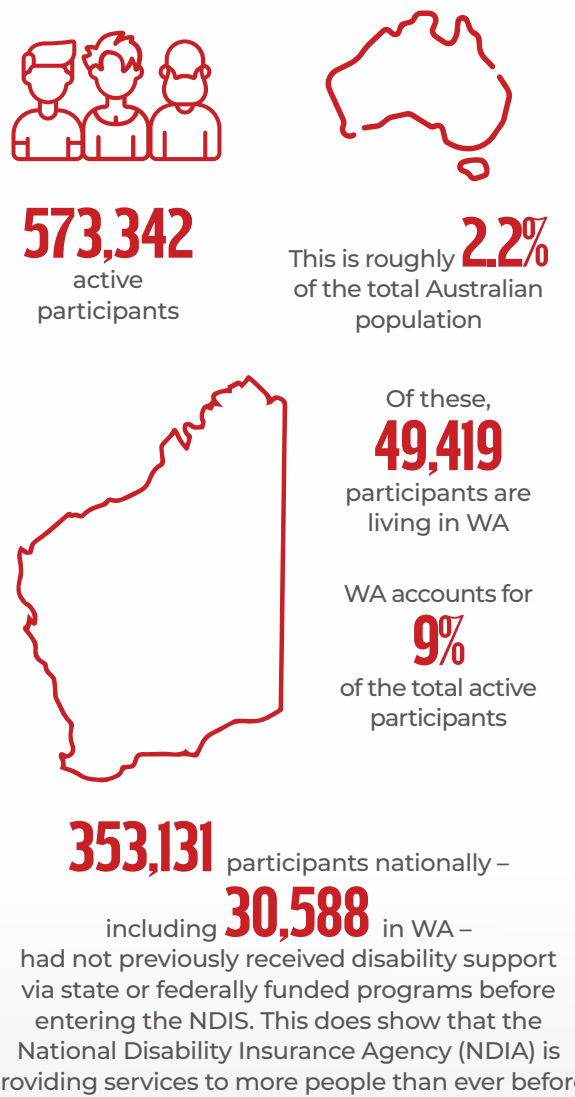
THE NDIS A DECADE ON: A LOOK AT THE NUMBERS

They say that Rome wasn't built in a day. In fact, according to the dates offered by ancient historians, it took roughly 1,229 years to build Rome from its foundation. And this example is not alone: the Great Wall of China was under construction for more than 2,000 years, while the leaning Tower of Pisa took 200 years to build – and that wasn't even straight. The reason for this trip down historical-construction-lane is to show that projects which are large and complex take some time to build. One example of a large and complex project we interact with each day is the National Disability Insurance Scheme (NDIS). The NDIS recently turned 10 years old, offering a good opportunity to dig into the numbers and see how far the construction has come.



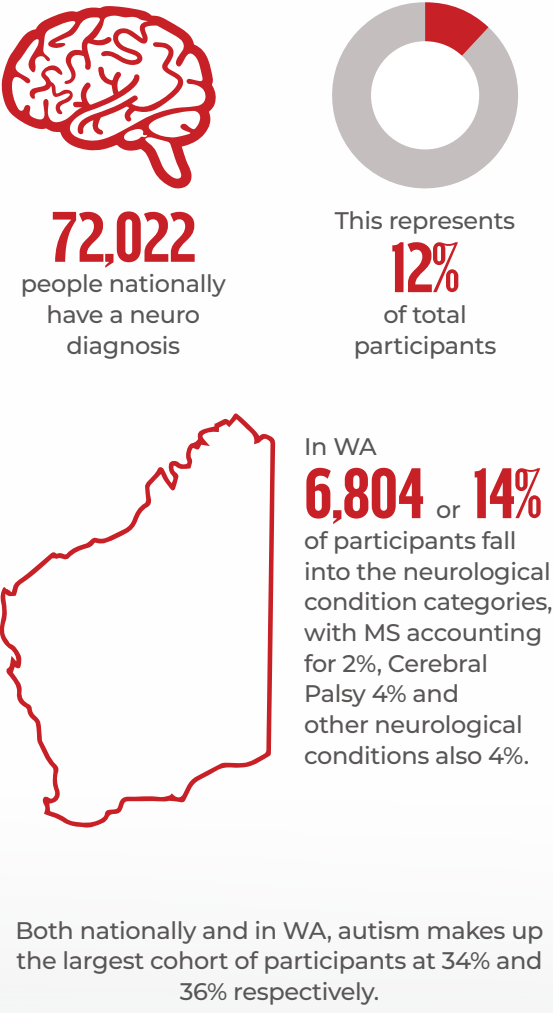
THE NUMBERS: AN OVERVIEW

At the end of 2022, the NDIS nationally reported:



THE NUMBERS: SPOTLIGHTING NEUROLOGICAL CONDITIONS

When we focus on those participants with neurological conditions, we see:



What does this mean?

In broad terms, the NDIA has been very successful in opening funding to more individuals across Australia than in the previous 'block-funding' era. While there is a lot of discussion around the impact of this growth, (see: *NDIS budget blowout and NDIS worker shortage Bulletin Summer 2022, Pg 14*) providing this many people with the opportunity to receive support based on their needs is a significant achievement within the first decade.

More people have funding for services than ever before. Who is going to provide services to them?

Since the NDIS was introduced, there has been an explosion of organisations providing services to people living with a disability. At the end of last year, 19,300 providers (2,851 in WA) had made at least one claim under NDIS funding. These providers cover everything from large organisations to sole traders. Interestingly however, only 9,660 of these providers nationally made a claim in the last quarter of 2022. This indicates some churn within providers across the NDIS.

One of the largest growth industries under the NDIA is the number of registered Plan Managers active within the community. In December 2022, over half of all participants nationally were using a Plan Manager for some or all of their plans (58%), while nearly half of all payments made under the NDIA were through a Plan Manager (49%).

Plan management is when a provider supports you to manage funding in your NDIS plan. These providers are known as 'Plan Managers'.

This shift towards Self-Managed/Plan Managed is not surprising. The NDIA was never going to be able to manage the plans of 500,000+ participants on an ongoing basis. However, the NDIA recently announced a review into Plan Managers to clearly establish the roles, functions, responsibilities and accountabilities of this service. If you are going down the Plan Manager route, please do your research.

So, what do all these numbers tell us?

One of the key takeaways for me is that the NDIS has become very big, very quickly. While this is great in terms of access to services, this type of growth does have the potential to deliver uneven results at times. I feel we can expect continued change over the next couple of years as the sector (both NDIA and providers) work to catch up with this increased demand.

That said, it is a remarkable result for the first ten years of something as big as the NDIS. There will come a time when the NDIS is a settled and structured scheme moving throughout the community, as seamlessly as previous large social initiatives (Medicare). But until then, I think we can look back on the first decade of the NDIS as an important and successful period in the history of support for the disability sector.

GEOFF HUTCHINSON
MANAGER CLIENT
ENGAGEMENT



DON'T BE AFRAID TO PUT YOUR TWO-PENN'ORTH IN

MSWA Client Nicolette Murphy is currently taking part in Edith Cowan University's Systematic Profiling in Neurological Conditions (SPIN) trials in Perth, and took the time to share her experience with our *Bulletin* readers.

For over a decade, Nicolette Murphy has been living with multiple sclerosis (MS) and has made it her mission to live her life to the fullest. Initially experiencing loss of fine motor skills in her hands and feet, making domestic activities difficult, Nicolette has faced numerous challenges since receiving her diagnosis. Despite these obstacles, she has approached life with courage and positivity. When she learned about Edith Cowan University's Systematic Profiling in Neurological Conditions (SPIN) trials in Perth, she knew she had to be a part of it.

Translating research into practice, this multidisciplinary team is identifying markers in individuals that will assist with developing and delivering targeted therapeutic interventions for stroke, Huntington's disease, Parkinson's disease and MS. Ultimately, these researchers aim to improve quality of life and outcomes by providing evidence-based information and application. Nicolette has been following the progress of the study and is thrilled to be actively engaged in the research.

Nicolette knows that her participation can help researchers develop new, or further existing, treatments for neurological conditions.

During various trials, Nicolette may undergo physical tests that evaluate her balance and coordination, as well as cognitive tests that require her to solve problems and puzzles. Nicolette finds the cognitive tests enjoyable, with one such example only requiring 11 minutes of her time, without a weekly commitment. Nicolette participates both on-campus and from home during the trials.

Nicolette values the excellent support provided by the researchers throughout each trial, as they are always available to answer her questions and offer reassurance. She encourages other participants to voice their opinions, as every consumer has a valuable perspective.

"Don't be afraid to stand up and put your two-penn'orth in," she said, "everybody's got a voice and it is always valid because we are the consumer."

At the end of each trial, Nicolette feels a sense of pride and accomplishment. She knows that her participation has contributed to a better understanding of MS and its progression, which has the potential to change the lives of those living with MS.



Nicolette using the blue light therapy glasses from the ENLightTIND Trials.

"My favourite part about participating in the trials is that it's all about me, for me and people like me," Nicolette said.

As the trials do vary, Nicolette recommends that those interested attend an initial conversation with researchers to determine which trials may be suitable for them. Nicolette also noted that her energy levels tend to drop after her participation.

For those interested in participating, keep an eye out for our *Vitality* newsletter, which will feature current research trials.

For the latest information on the research projects MSWA funds, please visit mswa.org.au/news-research/commitment-to-research

JULIE'S CORNER

A special legacy will forever live on at MSWA Rockingham, with a WA family generously donating their late wife and mother's curated collection of craft supplies to our Outreach Clients.

The donation was so large that our Facilities Team purpose-built a new shelving unit to store the sheer number of machines, papers, buttons, beads, glitter and just about every other item a crafter could ever dream of.

'Julie's Corner' now resides proudly at the centre, with Julie watching on from the top shelf to inspire our Rockingham crafters with their projects.

The new set-up was unveiled at a special morning tea in March, attended by Julie's husband Laurie and son Mitch.

"She was a really special lady. For her, craft was something she really enjoyed," Mitch Brown said.

"It's great to come to Rockingham to see how beautifully it is set up, but also just to hear the Clients talk about the things they will be able to do with it all."

"It's amazing, it's really what she would have wanted – to see people get that same enjoyment out of it is really special."

To honour Julie, our Rockingham Outreach Clients carefully decorated the letters spelling out 'Julie's Corner' using the gifted supplies.

"My dad has brought a photo of Julie to put up there which is really nice, and to see her name up on the wall, it means a lot," Mitch said.



"I think it is something that took my dad a while to come to terms with – what he was going to do with her things – but it is great to give it to someone who will get the same appreciation out of it."

"I would encourage others to think about giving a second life to the things their loved ones have left behind."

MSWA Client Teresa McCutcheon has attended Rockingham Outreach for close to a decade and had never heard of anything "quite so amazing" as this donation.

"It arrived in bits and bobs, and we thought we would get a few boxes," she said. "We would open them and think 'wow, that's amazing' and then more and more would turn up," Teresa said.

"A few of us are real keen crafters, so my craft stash envy is strong! Seeing Julie's picture on the wall, she was an ace in the 'stash' building game, and absolutely my idol that I aspire to."



"I just can't thank Laurie, and his sons Mitch and James enough, because I don't think they are ever going to get an inkling – we don't probably even have an inkling ourselves – of just how much it is going to mean to us going forward."

MSWA extends our sincere thanks to Laurie, Mitch and James for their kindness and generosity. We know our Client crafters will never take this blessing for granted.

HORST BEMMERL: REACHING NEW HEIGHTS



Climbing Cradle Mountain in 2021.

For Horst Bemmerl, there is always another mountain to climb.

Standing at the summit of Mount Kinabalu, Malaysia, an overwhelming 4095 metres above sea level, Horst reflected on the grueling two-day trek that led him to this new peak, conceding the climb was so much harder than he imagined.

With his wife Helen by his side, the pair were amongst the oldest in the group to tackle the gargantuan challenge, of which a third failed to achieve due to exhaustion and altitude sickness.

"I don't easily give up, but I told our guide I didn't think we could make it," Horst said, "he helped us break through the exhaustion and pain."

Despite having feet full of blisters following the enormous challenge, Horst was already thinking ahead to his next adventure; a 150km pilgrimage of the Camino de Santiago.

But there was a time when attempting these extreme challenges of physical and mental toughness seemed like an impossible dream.

In August 2007, a fit and active Horst was training for the City to Surf running event when something didn't feel right.

"I was jogging, and I was getting numbness in my neck and left hand, and I thought maybe I had pinched a nerve," Horst said.

After a third visit to a physiotherapist without any improvement, Horst was referred to a GP and soon found himself at Royal Perth Hospital.

"I went in and out for the next two or three days, not knowing what was going on," he said.

After arranging an MRI privately, Horst picked up his own results while on his lunch break from work.

"At the end of the report it said 'MS'," he said. "At first you are a little bit numb, wondering 'what does that mean?'"

"Being diagnosed with MS leaves you with the uncertainty of how it will progress."

"All the questions you ask are 'will this happen, will that happen?' and the answers are 'I don't know.'"

Horst's journey with MSWA started soon after his diagnosis, seeing a counsellor, Bev, who he credits for his tenure as one of the longest serving board members with MSWA.

"Our discussions gave me the motivation to apply to join the board when a position became vacant," he said.

"I was very fortunate in how I was progressing with the illness, and I thought I might be able to add value to the organisation that helps others with MS."

"For me, it is about contributing by creating a system that supports others who haven't been as fortunate as me."

After serving 12 years on the MSWA board, Horst was sworn in as the MSWA Board President in late 2022.

With Horst also holding a director position with Multiple Sclerosis Australia, a key focus is to work more closely with our state and national peers to achieve better outcomes for the people we support.

"It's the final piece of the puzzle," Horst said.

"Having been in executive positions most of my life, the one thing that was still lacking was coordination around the national body and the state bodies."

"The work we do is about helping people living with neurological conditions, but it is also about the research."

"A big part of what the national body does is research and advocacy, so it is making sure this gets done in a manner that is efficient and produces the best outcomes for people with MS."

For Horst, his MS diagnosis gave him the gift of perspective.

"I just wanted to get on with life and didn't want to let it stop me from doing things," he said.

"I think I did more as a result of getting MS, than I would have if I hadn't."

"There are many overseas trips I took that I said yes to because I didn't know how long I would be able to."

Exercise has continued to be a big part of Horst's life and has helped him along his MS journey.

"I always think keeping active – and I am very diligent about it – would help me," he said.

"So, I have done quite a lot of things in my time, like climbing Bluff Knoll, Cradle Mountain in Tasmania last year, and now Mt Kinabalu."

"We even climbed Mount Wellington in the snow – we just had sneakers on too. We weren't expecting to walk it, but the roads were closed because of all the snow, so we thought 'why not?'"

"I think each climb is an opportunity to squeeze the most out of life."



Hiking Yangtze Gorge in China, 2007.



Ocean Ride 2017.



Mt Kinabalu March 2023.

Looking ahead to the future, Horst said his ultimate hope was for people with MS and other neurological conditions to no longer need support due to a cure or even better treatments.

Until that time, his focus for MSWA is that the organisation provides the best support for people with neurological conditions, to live their lives the way they choose, in the best way possible.

"My perspective has always been about providing tools, resources and treatments so you can live as much a normal life as possible," he said.

"For me as a person, being able to be independent and living life to its fullest is so important."

When it comes to advice, Horst's is quite simple: focus on the positives.



Mt Kinabalu March 2023.

"Of course there are negatives, but what is the point of dwelling on them – you can't do anything about it, so focus on the positives," he said.

"That's what everybody needs: hope. Without hope you don't have anything."

LYING DOWN ON THE JOB:

SUPPORTED LYING WITH MSWA OCCUPATIONAL THERAPISTS

Gravity works every minute of every day.

Humans are instinctively driven to alter their posture to offset its relentless force.

Uncomfortable from sitting in an office chair too long? We adjust our backrest, take a stroll to the coffee machine and even participate in questionable 'office yoga'.

Ever woken up in the middle of the night and found yourself on a different side of the bed to where you started? Some repositioning is so subconscious, we even do it in our sleep!

The individuals with no mobility concerns are afforded the privilege of constant and autonomous postural variation to achieve optimal comfort, avoid pain and prevent injury.

However, for some individuals, regular or independent movement isn't always possible.

This is when gravity seizes its opportunity.

The bad news? Without intervention, these destructive body postures can become fixed and impact the musculoskeletal, neurological, respiratory and digestive systems. Additionally, altered postures can impact functional tasks such as toileting, dressing and communication, as well as affect sensory perception, self-image, learning, sleep and mood.

The good news? The body is a mobile structure, so whilst it is susceptible to distortion, with the correct positioning, it can be restored to its most neutral position or prevent destructive postures from worsening. Therefore, supporting the body in symmetrical lying (preferably on the back) is vital for those individuals who would otherwise be left to become static in destructive lying postures.

What is Supported Lying?

'Supported Lying' (often termed 24-hour positioning or sleep positioning) can be defined as postural care which is gentle and respectful in order to protect and restore a person's body shape against the forces of gravity.

If Clients are left unsupported over a period of time, it can lead to destructive body postures.

NEW
SERVICE
ALERT!



RACHEL KARSAKIS, CAITLIN ROSS AND SAM WARNE, MSWA OCCUPATIONAL THERAPIST SUPPORTED LYING CONSULTANTS

How can MSWA Occupational Therapists help?

Occupational therapists use a multi-disciplinary approach and consider a person's daily life across the **full 24 hours**. At MSWA, OTs follow their Clients through their journey and assist them in maintaining functional independence.

Clients can be supported in a great seating system with postural supports which consider alignment, pressure and function. However, the duration of time spent in bed far outweighs time spent in seating systems. It should be considered that if a Client has these supports in sitting, they may also benefit from supported lying.

This is a new service offered by the MSWA Occupational Therapy department.

Once referred, the Supported Lying OT team will:

- / Complete a review and assessment
- / Determine suitability for the service
- / Understand why/how a Client's postures impacts their body
- / Create customised intervention plans recommending equipment and positioning techniques
- / Provide comprehensive training and education for implementation of supported lying systems to family and support workers
- / Provide ongoing education, review and follow-up

Ask your MSWA Occupational Therapist today about how we can support you with supported lying. We look forward to assisting more of our Clients to combat the effects of gravity!

TAKING BACK TEMPERATURE CONTROL

Do you experience thermoregulatory dysfunction or difficulty regulating body temperature, especially in those hot summer or cool winter months?

This is a very common symptom in neurological conditions and we have developed a new group to help! The Thermoregulation Management Workshop will run quarterly, providing education around how your body responds to temperatures.

The workshop is specifically tailored to thermoregulation related to neurological conditions, the effects and impact of thermoregulation and strategies to help, delivered by our Occupational Therapists.

We also specifically discuss low-cost and mid-cost assistive technology which can aid with thermoregulation management. Additionally, we discuss NDIS funding, and other major funding streams, and how this can be used to access thermoregulation support.

This group is designed to be an interactive experience and we will have some assistive technology options available for you to trial/ experience on the day. We will also identify where you will need further support from your Occupational Therapist in securing funding.

Groups will be run in our Wilson and Butler facilities as well as via Telehealth sessions. **Our next thermoregulation group will take place in our Butler facility on 19 July 2023 from 9am – 12pm.**

Visit mswa.org.au/support-services/our-services/occupational-therapy for more information.



We are also looking to expand our small groups to cover additional topics, such as: low level assistive technology, sleep, cognitive strategies and pain management.

We also provide light morning refreshments and lots of laughter! We look forward to seeing you soon.

**SARAH COUTINHO
MSWA OCCUPATIONAL
THERAPIST**

KEY DETAILS:

- Date:** Wednesday, 19 July
- Time:** 9am – 12pm
- Location:** MSWA Butler 245 Butler Blvd, Butler
- RSVP:** If you are interested in attending one of our interactive groups, please call the Occupational Therapy contact line on **9365 4854** or email us on **ot.metro@mswa.org.au**. From there, one of our Occupational Therapy Assistants will get in contact and discuss further details.

LEARNING TO LIVE WITH YOUR INNER CRITIC

EVE PARSONS
MSWA COUNSELLOR



“Be nice to yourself... it's hard to be happy when someone is mean to you all the time” says coach Christine Arylo – and she's not wrong.

That ‘someone’ for many of us, is a part of our own psyche that we often call our “inner critic”.

Where does it come from? Possibly it developed as a response to serious life challenges in childhood or adulthood; but often our inner critic grew in reaction to other people criticising, bullying or excluding us. It also thrives in perfectionists, ‘Type A’ personalities and high achievers, who believe they have more to lose.

If the inner critic is extremely dominant in our mind, we may not even recognise it. It feels normal to be hard on ourselves all the time. For the rest of us, it is a part of our mind which comes in with harsh judgments, labels and scorn, and particularly when we are feeling low or like we’ve failed in some way. So, we are kicking ourselves when we are down!

Naming it creates a space between ‘me’ and ‘my inner critic’ (who is therefore NOT all of me). And with that space, comes room for observation, curiosity and dialogue.

If you have an inner critic, what do you think are its intentions for you? Is it trying to:

- / Help you be a better person?
- / Keep you motivated to aim high and achieve more?
- / Help you feel in control?
- / Lower your expectations of yourself, so you don’t end up disappointed?
- / Protect you from ‘stuffing up’ and getting criticised by others?

When we explore the purpose of our inner critic, we often find that it is trying to keep us safe and competent in a difficult, challenging world. The problem is, we hear those judgments and labels “you’re a loser”, “you’ve totally screwed up” and not surprisingly, we end up feeling anxious, sad, angry, ashamed, defeated, and depressed instead of grounded and motivated.

How do we tackle this dominating part of our mind? Paradoxically, not by fighting it, ignoring it or any other ways you might guess. Psychology research in the field of self-compassion has found that none of these approaches work.

Instead, we get to know our inner critic and say “thank you for trying to keep me safe” and “now you can have a break and take a back seat”. Then we work on our self-compassion, in particular, nurturing our internal compassionate self, who wants to help us grow and succeed through self-kindness, patience, understanding and warm encouragement.

The good news is that you can cultivate your compassionate self in an intentional, structured way. Slowly the inner critic becomes redundant and moves to the background, because you don’t need it any more. You’re getting on fine with the help of your compassionate self, and you’re a lot less stressed.

If you're interested in learning how to practise self-compassion, including how to handle your inner critic, you can sign up for the MSWA Introduction to Self-Compassion course, run by the Counselling Service. That's a shameless plug, yes, but I'm not going to give myself a hard time for it! Those interested can get in touch via email: Eve.parsons@mswa.org.au.

Kristin Neff (2021) *Self-Compassion: The Proven Power of Being Kind to Yourself*

WRITING YOUR WAY TO WELLNESS

GRACE VERITY
MSWA COUNSELLOR



Writing can be a wonderful tool for self-exploration (Schneider & Killick 2002). It can be a lifelong adventure!

Personal writing, rather than writing primarily for an audience, can be life-affirming, an aid to memories and a life raft in times of stormy seas. There can be enormous relief in finding words that match your experiences.

Author Julia Cameron teaches creativity through her book *The Artist's Way*. One of her tools is ‘morning pages’: three pages of longhand writing done every morning, soon after waking. It doesn’t matter what you write in those, as long as you do it without stopping, every morning.

“All the angry, whiny, petty stuff that you write down in the morning stands between you and your creativity... this stuff eddies through our subconscious and muddies our days. Get it on the page,” Cameron said.

References:

Julia Cameron 1994 *The Artist's Way*

Myra Schneider & John Killick 2002, *Writing for Self-Discovery*

David Spiegel 1999 ‘Healing Words: Emotional Expression and Disease Outcome’ JAMA

Visit mswa.org.au/support-services/our-services/counselling to explore our counselling services.

Cameron calls morning pages ‘brain drains’ and says they aren’t meant to be ‘art’ – it doesn’t matter if they are negative or fragmented or silly sounding... just do three pages of whatever crosses your mind.

“If you can’t think of anything to write, then write: ‘I can’t think of anything to write...’ until you have filled three pages. Do anything until you have filled three pages,” she said.

“Lawyers who use them swear they make them more effective in court. Dancers claim their balance improves – and not just emotionally.”

Cameron says this type of writing teaches the “logic brain to stand aside and let artist brain play.” She suggests a minimum of 12 weeks’ commitment.

**“The purpose of art is life; intensified, brilliant life”
Alain Arias-Misson**

“Typically it won’t be easy, but it can be rewarding to birth a more creative and playful life. Perhaps you will then find yourself fixing up an old guitar... writing a song or a letter or a poem... tying new fishing knots... opening up a difficult but important conversation in a new way... trying out things you haven’t before,” she said.

Research on the medical value of expressing emotion through writing about difficult life experiences shows improved health and wellbeing. If such outcomes were available through a new drug, “it is likely that it would be in widespread use” writes David Spiegel in the AMA journal JAMA.

From our commitment to writing as a way to nurture creativity, we can find ourselves living better: really living, in amongst all the challenges and surprises of our everyday life.

My Name Is.....

I acknowledge your suffering
react to your feelings with sorrow
I feel little or no sympathy
don't share emotional understanding
I'm not in the same emotional position
instead, I'm in a higher position

My name **is PITY.**

I recognise your suffering
react automatically to your feelings
I care about your suffering
have an involuntary affinity with you
I feel your feelings
and provide comfort and assurance

My name **is SYMPATHY.**

I actively attempt to experience your feelings
gain understanding through effort
I have experienced similar feelings myself
can put myself in your shoes
I share your feelings
and feel your suffering
My name **is EMPATHY.**

I understand your distress
want to relieve your suffering
I'm suffering alongside you
am deeply engaged
I strongly desire to alleviate your pain
and actively attempt to relieve your suffering
My name **is COMPASSION.**

Author: Peter Jones, MSWA Client
Penned September 2022

From the Author: I belong to an MS support group, have done for a couple of years. At our last get together the question arose about the difference between pity and empathy. I took it a little further and, after having done some research, added sympathy and compassion.

Above is a piece (I don't know that I could call it a poem) which explores the meaning and difference of the four emotions.

FINDING FREEDOM THROUGH SUPPORT

For 15 years, a task as simple as brushing her teeth or applying lipstick would leave MSWA Client Ellen-May Eaton in agony.

Severe facial pain, formally known as Trigeminal Neuralgia, has been described as 'the most excruciating pain known to humanity'* with the condition causing electric shock-like pain in the lower face and jaw.

It is this invisible but debilitating condition, caused by the irritation of the trigeminal nerve, that overshadowed Ellen-May's life until she underwent life-changing surgery 12 months ago.

"It is such a stabbing pain, it's like no other pain I have ever experienced," Ellen-May said.

"Even if you are lying down sometimes and you have got it, you think 'ok, can I breathe now or not?', because even that might make it flare up."

"Some people say if they get air conditioning on that side of the face, that will affect it, other times it happens out of nowhere, with no warning."

It was when Ellen-May was diagnosed with MS in 2009 that her MSWA Neurological Liaison Nurse helped to diagnose her Trigeminal Neuralgia, despite experiencing symptoms since 2007. Ellen-May initially believed these symptoms to be an extremely painful toothache that would come and go.

For years, Ellen-May managed her pain with painkiller medications, which initially worked well but became unsustainable over time, as the episodes increased in frequency and duration.

"I had to take more and more to dull the pain and that was all I was doing for such a long time," she said.

By chance, Ellen-May came across a Trigeminal Neuralgia support group which changed her outlook completely.

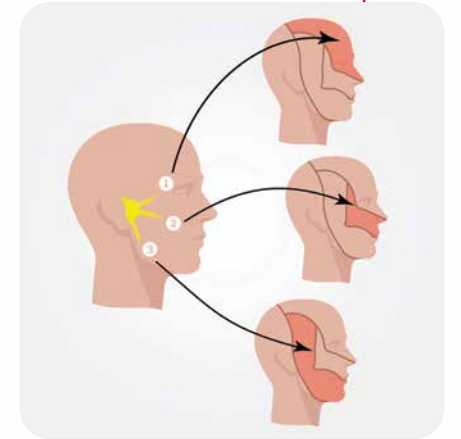
"I would have been lost without them," she said. "They have lived experience people and they demystify the language and the terminology because it is very specialised," Ellen-May said.

"I just found out so much information about all the other treatments and medications you can have, and the knowledge that you are not the only one who has it."

It was through this forum that Ellen-May found out about the various surgical procedures and names of specialists operating in this area. After further exploration, she then had the surgery called a 'rhizotomy', which she described as "freeing".

"I thought I was ok, coping with the painkillers and then not really making me groggy or drowsy, but I hadn't realised how much it affected me until I came off them," she said.

"It was freeing of my headspace too, because I was always anxious about 'oh, is it going to come back?'. I still have the memory of the pain, but it gets easier the longer the time is that I don't have it."



"The surgery has numbed my bottom lip, but that for me is far better than taking all the medications I was on. I'd rather put up with this any day!"

Ellen-May is now spreading the word far and wide in the hope of helping others experiencing facial pain, which can be common in people living with MS.

"Because it is a demyelination of the nerve, quite a few people with MS have it," she said.

"Absolutely go to the groups and find out about all the options and find out about the current thinking."

Ellen-May welcomes other Clients living with MS and facial pain wanting to talk through the experience to contact her at ellenmay@iinet.net.au.

The Trigeminal Neuralgia Support Group WA Inc meets quarterly in Perth and every 5 or 6 weeks in Midland. To find out more information, contact Julia McDonald (Perth) at juliamcdonald@ozemail.com.au or Julie Russell (Midland) at Julie.53@aussiebroadband.com.au.

*According to the American Association of Neurological Surgeons

LET'S GET LOUD

GEORGINA HETT
MSWA SENIOR SPEECH
PATHOLOGIST

Reduced speaking volume can be associated with a number of different neurological conditions. Having a quiet voice is often attributed to limitations in breath support, such as having shallower, weaker or less coordinated breathing.

However, alongside our breath, our brain and larynx (which houses our vocal cords) can also play an important part in creating and maintaining a stronger and more consistent speaking volume.

Therapy techniques, such as the Lee Silverman Voice Treatment (LSVT LOUD) can also be helpful.

LSVT LOUD primarily targets reduced speaking volume and was designed with people living with Parkinson's disease (PD) in mind.

People living with Parkinson's often find they experience a shift toward a quieter voice. This is among other communication changes that may include a hoarse/breathy vocal quality (due to changes within the larynx), mumbled speech and a less expressive, more monotone voice. These factors combined can negatively impact the effectiveness of a person's communication and how they feel about speaking with others.

Importantly, Parkinson's can also create difficulty in accurately judging the loudness of one's own speaking voice. People may feel they are speaking at the same volume as others, but in reality are much quieter.



Additionally, when receiving feedback to 'speak up', people can feel as though they are shouting or being too loud.

LSVT LOUD is a structured protocol of exercises that help people 'recalibrate' their voices, so they can practice and be better aware of how it feels to comfortably speak using a stronger voice, that is more in line with others in the conversation.

The LSVT LOUD protocol is standardised and well-supported by research. Initial treatment requires 16 sessions with a speech pathologist (in person or via telehealth) delivered over four weeks and requires a degree of home practice (approx 15 mins daily). This structure takes advantage of high intensity, high frequency practice, to bring about measurable change.

A series of core voice exercises are undertaken each session, accompanied by other tasks that practice short phrases, all the way through to conversational speech.

Content and topics are designed to be relevant to the individual's interests and daily life, making the activities more motivating.

Outside of research within the Parkinson's disease community, there are a number of smaller studies involving people living with Progressive Supranuclear Palsy (PSP), stroke and multiple sclerosis. These findings are a positive new direction for research into LSVT LOUD.

MSWA Speech Pathology has a number of clinicians certified in delivering LSVT LOUD treatment. Please feel free to contact MSWA Speech Pathology Speech.Pathology@mswa.org.au or 9365 4888 if you wish to know more about this treatment and how it could help you.

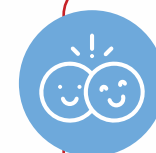
For more information on our services, visit mswa.org.au/support-services/our-services

WATER, LIFE, THE UNIVERSE AND EVERYTHING! - PART 3

ROCHELLE BROWN
MSWA NEUROLOGICAL LIAISON NURSE

GEMMA TOOVEY
MSWA DIETITIAN

For the third instalment of this series, we look at water's impact on your brain, mood and weight.



Drinking water improves your mood

Research has shown that by improving someone's water intake, their feelings of happiness increase. Further to this, when participants consumed five or more cups of water each day, their risk of anxiety decreased. To be in your best mental state, you need to look after your health and wellbeing, and that includes staying hydrated.



Staying hydrated keeps your brain in good working order

If you want to be at the top of your cognitive game, you need your brain to be hydrated. 'Cognition' is a term we use to describe the mental processes we use to learn, understand, remember, plan and problem solve.

If you fail to drink enough water, you will find your thinking becomes 'fuzzy', and you won't be able to focus, recall information, remember things or be able to solve problems.



Drinking water helps maintain a healthy weight.

Let's look into some scenarios where water intake can help with this goal:

1. You may be confusing hunger for thirst

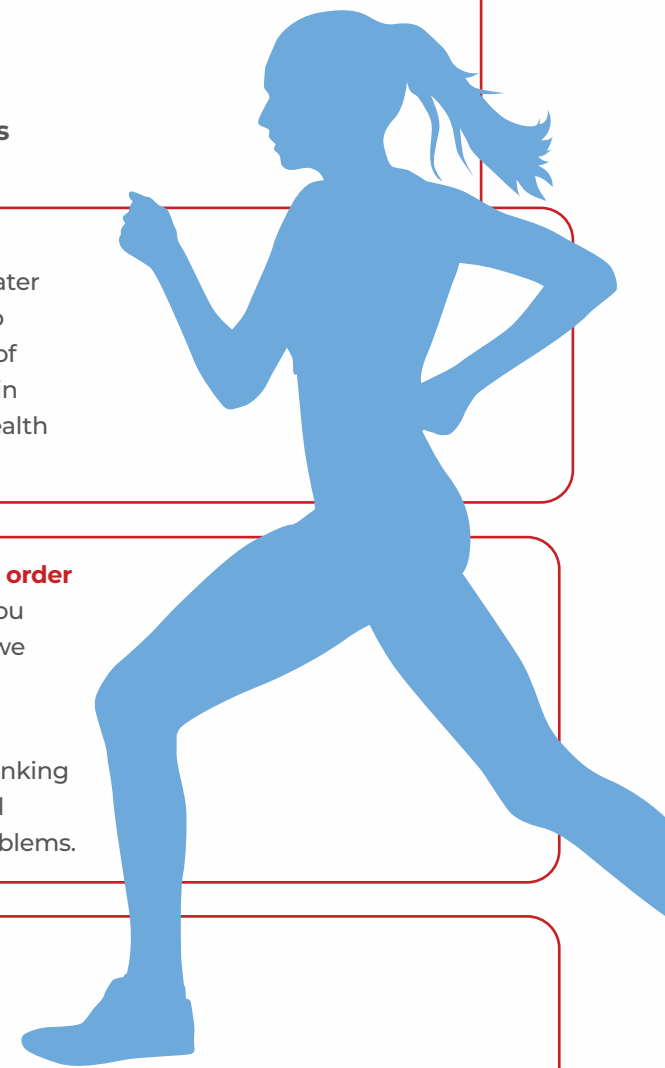
Although it sounds simple, a lot of people get this confused. Next time you open the fridge to get a snack, take a moment to ask yourself "am I hungry or thirsty?" or "when was the last time I had a drink?". If it was at least two hours since your last drink, try having a glass of water first, wait 15 minutes and check in again to see how you feel. If the sensation of hunger is still there, you must be hungry!

2. Your fluids are mainly sugar-sweetened/milk-based drinks

Switching to water will automatically reduce the number of calories you consume each day. If continued long term, this will result in weight loss. If you don't like the taste of water, our MSWA Dietitian Gemma provided some great ways to meet your fluid needs with tasty additions in our last *Bulletin*.

3. If you are drinking adequate amounts of water, you will have more energy

Water promotes blood circulation which helps oxygen enter your cells. If you are not drinking enough water, circulation will lag, and you will feel sluggish and tired. Meeting your fluid requirements can circulate oxygen, giving you a boost of energy. Having more energy means you are more likely to attend an exercise class or go for a walk, which will in turn support you to maintain a healthy weight.



In our next *Bulletin* we will be looking at the part water plays in relation to bladder health.

FINDING PURPOSE AND CONNECTION THROUGH VOLUNTEERING



"It's a win-win situation."

Giving back to the community is a way of life for MSWA volunteer of five years, Joan Crossman.

Dedicating her time as an MSWA Wilson Outreach activity assistant on Tuesdays, fundraising for the Cancer Council Relay For Life event and altering costumes for Ballroom Fit chair dancers in between; Joan is one busy lady.

"I really don't know how I ever had time to go to work!" Joan laughed.

It is this passion to give back which saw Joan nominated for the WA Volunteer of the Year Awards 2023.

Joan first came to MSWA Wilson Outreach supporting her late friend, Jenny, who lived with MS.

The pair made fond memories of visiting the centre, where Jenny was known for her love of puzzles.

"On Jenny's jigsaw puzzle it would have 'this is Jenny's, do not touch'," Joan recalled fondly.

"Her last puzzle I tried to finish for her, but only managed a couple of pieces. A friend in my village offered to help and two days later he had finished it."

"So, we had it framed and there it is up on the wall [in the Wilson Atrium] – how special is that?"

"At Jenny's memorial service, I was privileged to give one of the 'memories of Jenny' of all the times we spent here together at Outreach."

It is these special memories made within the walls of MSWA Wilson and connections forged over the years that convinced Joan to sign up as a volunteer in April 2017.

The determination and effort of MSWA's Clients inspires Joan each day and she finds great joy in their successes.

"The Clients put so much effort into what you and I might find simple," she said.

"When they do something well, it is such a thrill. It might be when we are doing our exercises, maybe they can lift a slightly heavier weight."

"The only rule is that they have to leave the group with a smile on their face, and they do, because they have given it their all."

"It's a win-win situation for me."

Joan's volunteering career started back in 1965, when she and her husband Rodger moved from New Zealand to Dowerin, in the West Australian wheatbelt.

It was here that Joan helped to revolutionise the volunteering system for the Dowerin Field Day Catering Committee, bringing about greater collaboration between community groups helping to cater for the major event.

"Cunderdin one year booked in so many volunteer hours, they ended up paying for the air-conditioning in their school from the catering profits," she said.

"It was a real 'everybody working together' attitude."

"For me, the meaning of team is 'Together Everyone Achieves Most'."

For Joan, this is the aspect of volunteering that most attracts her – the opportunity to be involved in the community, work together and give back.

"It helped me, because when we first came out to Australia, we didn't have any family here. Through volunteering I was able to make new bonds and connections," she said.

"We all age differently, but volunteering gives you a purpose and a belief, so you are not just sitting on the veranda whiling away the time."

From all of us here at MSWA, we thank you, Joan, for your ongoing dedication to our Clients.

NATIONAL VOLUNTEER WEEK 2023

National Volunteer Week is Australia's largest annual celebration of volunteering, taking place from 15 – 21 May 2023.

This was an important opportunity to reflect on the significant impact our MSWA volunteers have in our community. Their dedication of time and care makes it possible to do what we do best – support our Clients to live their best lives.

This year's national theme was 'The Change Makers', which could not be more fitting for the people actively 'being the difference' and stepping up to create a better tomorrow for our Clients.

Whether you are a long-time volunteer; like MSWA Wilson gardener, John Robertson, who has been with us over 25 years, or a one-day event-volunteer; like our MSWA Ocean Ride marshals keeping our participants safe on the roads, you are critical to our success in achieving our purpose. Thank you.

LOOKING FOR AN OPPORTUNITY TO VOLUNTEER?

We are on the search for volunteers to join our team on a regular basis, including:

Admin Assistants
City beach, Kelmscott, Vasse and Wilson



Kitchen Assistant
Beechboro



Gardener
Beechboro



If you or someone you know may be interested, contact Mala Padmanathan, People & Culture Officer - Talent & Diversity (Volunteering) at Mala.Padmanathan@mswa.org.au or fill out our online form at mswa.org.au/get-involved/volunteer

Looking for something with a little less commitment?

Step Up for MSWA - Powered by Commonwealth Bank has fun for one and all, even if you don't feel like climbing any stairs!

Come and join us at Central Park in the Perth CBD, as we cheer on and support our 2023 climbers.

With a range of volunteering positions available, on ground level and all the way up the building, there is something for everyone.

Job roles include helping set up and pack down the event, participant bib collection, new registrations, stair marshalling and experiencing the glory of the finish line; handing out medals and water to participants.

If this event sounds like the one for you, reach out on 6454 3131 or email events@mswa.org.au



ALBANY COMMUNITY OUT-SWIMS THE CLOCK FOR MSWA

2023 MSWA ALBANY SWIM

Swimmers of all ages and abilities came together in March to raise an astounding \$19,857 for people living with neurological conditions in the Great Southern, as part of the iconic MSWA Albany Swim.

The four teams brought high-energy to the challenge, arriving in a colourful display of costumes, with fun inflatables to help them in their pursuits.

An impressive 4,450 laps were completed at the Albany Leisure and Aquatic Centre over the eight-hour marathon relay, with Teen Marines clocking up the most laps at 1,330.

Teen Marines were also the highest fundraising team, amassing an incredible \$13,037, while Peter Oliver was recognised as the highest individual fundraiser with \$1,950.



RIDING FOR A REASON

2023 MSWA ALBANY RIDE

Albany's community spirit was on full display on May 6, as riders turned out in droves for the 2023 MSWA Albany Ride.

A total of 113 cyclists crossed the finish line on the day, proud to have achieved a personal challenge and having raised more than \$28,000 (and climbing!) for people living with neurological conditions in the process.

Of the ten teams, Southern Masters Cycling was the highest fundraising team with a total of \$5,875, followed closely by Worst Pace Scenario on \$4,275. Meanwhile, Tony Caramia was recognised as the highest individual fundraiser, amassing \$3,635 for the cause – astounding efforts all round.

MSWA Senior Events Coordinator Dannielle McConnell was proud to see the community come together for a worthy cause.

"Albany is such an incredible community, and this came through strongly during the MSWA Albany Ride," she said.

"Hearing the stories of the camaraderie that formed during the event and the great feedback after, it all made the cold morning worth it!"

There is still time to sponsor a rider with your donation, head to mswaalbanride.org.au/search before the end of May.

MSWA ALBANY CELEBRATES FIRST BIRTHDAY WITH A BANG!

MSWA Albany celebrated its first year of operations in Albany with a grand birthday celebration on Thursday, April 13, 2023.

The event, which was held at the MSWA Albany Centre, was attended by MSWA Clients, volunteers, staff, families and community leaders.

The event featured a range of exciting activities conducted by Clients and community members alike.

The event included live music, painting and guessing games, as well as balance, strength, and breath tests with the physio team.

Members of the executive team even jumped on the BBQ and cooked up a sausage sizzle for attendees.

Melanie Kiely, MSWA CEO, presented the first resident of the centre, David, with a certificate before sharing the duty of cutting the birthday cake.

"We are absolutely delighted to celebrate the Albany Centre's first birthday and express our sincere gratitude to all those who have supported us over the past year, including our valued Clients and residents, dedicated team members and volunteers, and the broader community," she said.

"The unwavering support we have received at MSWA events and fundraising initiatives is truly inspiring, and we remain humbled by the generosity of local businesses and supporters."

Happy first birthday MSWA Albany!



JAMIE WARNOCK: SHOOTING FOR THE MOON

For Jamie Warnock, taking on the open ocean in the Rottne Channel Swim was a daunting prospect, but it still pales in comparison to the challenges his mum faces day-to-day.

The channel swim is an expansive 19.7 kilometres out in the elements – but the sun, wind and waves were never going to stop Jamie from achieving his goal to make mum proud.

Although his mum was diagnosed with multiple sclerosis 10 years ago, things took a turn when Jamie was in his final year of high school.

"It started to affect her cognitive function and she developed early onset Alzheimer's," he said.

"Since then, it has been completely devastating to the family. She is now receiving 24/7 care and it has been a long, tough road trying to support her in the best way we can.

"MSWA helped to give us a road map – we were so lost and didn't know what to do, having direction was a life saver."

Having completed the swim as part of a team on two previous occasions, Jamie decided 2023 was the year to take a leap and do it solo for Team MSWA – raising an incredible \$3,735 in the process.

"The reason I took on the challenge is because MSWA has been instrumental in helping my mum," Jamie said.



"I have other family members who also have MS, so I have heard so much about the work you are doing and we have also experienced it first-hand."

It took five months of preparation and a qualifying swim to reach the big day, which wasn't without its challenges.

"The swell and wind got pretty hectic – I ended up getting flipped by a wave and swimming back to Perth at one point," Jamie said.

"It was gruelling, but I feel like with all the training I had done, that was the hard work, the swim itself was the payoff."

"It is a huge achievement, I am stoked I actually made it and got under my goal time of six hours."

Jamie's message to anyone wanting to join Team MSWA is simple: just go for it!

"It's a fantastic organisation helping so many people in WA," he said.



"It seems daunting to start with, but just set a goal. Even if you don't know if you can achieve it, shoot for the moon."

MSWA wants to extend a huge congratulations to Jamie for his amazing accomplishment and our sincere gratitude for being such a strong supporter of our cause.

ANNE AND DOUG'S ADVENTURES: YOUR ACCESSIBILITY TRAVEL GUIDE

Taking time out of your busy schedule to travel, explore new sights and unwind is an important experience everyone should have access to.

For those in our community with mobility and other accessibility issues, the process of finding suitable accommodation can be much more daunting, in what should be a stress-free experience.

Travelling is a passion for MSWA Client Doug Ward and his wife and carer Anne, who have made it their mission to get away as often as possible.

In fact, it was while on holiday in Lancelin, staying with a friend who also happened to be a doctor, that Doug's MS journey first began.

"We were in the pub, as you do, we were walking back and I was dragging my right leg as though I had been injured," Doug explained. "He (the doctor) said 'so what are we going to do about this?'"

After being referred for an MRI of his lower back, then entire spine, Doug was sent to a neurologist.

"We saw the neurologist and he said 'welcome to the MS Club,'" Doug said.

Years on, Doug is no longer receiving treatment for his progressive MS, as the medication he previously accessed is no longer available.

"So we decided, 'right, what we will do is get going while we can,'" Anne said.

In their travels, they have uncovered some incredible, fully accessible stays which can accommodate Doug in his electric wheelchair and their traveling hoist.

However, they have also come across providers who don't quite hit the mark.

"Sometimes 'wheelchair accessible' just means the ramp at the front door," Anne said.

"But my main tip is to ring. I don't book online; I just ring the places and say 'this is what I need', because sometimes even with photos on the website, you are not quite sure. It's a fair way to go to find out it is not going to work."

Doug and Anne's recommended checklist:

- ✓ **How wide are the doorways?**
- ✓ **Is the toilet located in the bathroom?**
- ✓ **How wide is the bathroom?**
- ✓ **Do you have a shower chair, and does it have a back?**
- ✓ **How high is the bed off the ground? (If you require a hoist)**
- ✓ **Are there ramps to enter the room?**
- ✓ **Are the other facilities in the accommodation (reception, restaurant, BBQ areas) wheelchair accessible?**

Anne said providing feedback was important to educate accommodation providers on what people living with mobility issues really need.

"Just a few weeks ago, we had spoken to someone about taller beds and the owner came by later that day to let us know he already had it on order," she said.

"They took action very quickly because they want to be the ones with the best accommodation."

"Everyone has always been really, really good with feedback and there have been places we haven't had to do it at all."

One such location is the Stirling Estate Chalets, owned and operated by Greg Norton. As a wheelchair user, Greg has a personal investment in making his accommodation inclusive.

"I knew what I was doing when it came to building accommodation for people in wheelchairs."

"I just don't do anything that is inaccessible, because I want to get access to it myself as well," Greg said. "That was my purpose, then it was just a matter of getting down, getting dirty and building it."

Greg encouraged all accommodation providers to "think outside the box" and ensure the entire building is accessible, not just the room.

"It's also about getting into the reception, the restaurants, bar areas or recreation areas," he said.

"It always seems in a wheelchair you have to manoeuvre around the whole building to find the one door which will let you in."

Greg said it is all about making sure all people can be included.

"There is always someone with some kind of disability in the family unit. Here, the whole family can come to this place and no one is at a loss to be able to access anything," he said.



Doug Ward on holiday in Dongara.



Stirling Estate Chalets.

"Everyone can do everything – head to the playground, see the animals around, they don't have to feel left behind because they can't get on the path."

Anne and Doug's Top Five WA Stays (in no particular order)

Friendship House Albany

There are two units at Emu Point and the one at the back is specifically made for people with wheelchairs and mobility problems. It is unbelievable, it has an overhead hoist, hospital bed and a bathroom bigger than some shops! Brilliant.



Nannup Tiger Cottages Nannup

Really rustic property at the back of Nannup. We went in winter and had the best 'stop' time. We did some reading, driving around and the owner used to bring us big drums of fruit and vegetables and would come past to make sure we had plenty of wood.



Stirling Estate Chalets Stirling Estate (5 minutes from Capel)

It is all off grid and it is the most beautiful place. Absolutely gorgeous. The chalets are big enough to sleep 10 people, but we just had the room we wanted. If you are in a wheelchair and wanted to have a celebration, there is heaps of room and a lovely outdoor area.



Jurien Bay Tourist Park Jurien Bay

It's only two to three minutes to the coffee shop, the beach and the IGA, so very accessible. You could lock your car up and not use it all week.

BIG4 Dongara Denison Beach Holiday Park Dongara

We have done Dongara several times, we love Dongara.



OUTREACH HAPPENINGS

If you live in Perth, Rockingham, Bunbury or Albany and are interested in a trial to experience the Outreach community, get in touch with Senior Community Outreach Coordinator Melissa Coombs via outreach@mswa.org.au

Outreach opening times		
Wilson	Mon, Tues, Wed + Thurs	8.30am – 2pm
Beechboro	Mon + Fri	8.30am – 1pm
Rockingham	Tues, Wed + Fri	8.30am – 1pm
Bunbury	Wednesday	9am – 12pm
Albany	Friday	9am – 12pm

Easter fun at Outreach

Our MSA Wilson Clients and staff came together to enjoy Easter celebrations in April, partaking in activities including Bunny Bowling, Eggs Ker-Plunk, Fishing the Carrot and Easter Pong – just to name a few!



Art Exhibition

MSWA Wilson Outreach transformed into an art gallery during the month of April, featuring the works of Client artists Nick Papadimitriou and Tony Villamagna.

Milestone Birthday Celebrations

There was not one, but two significant milestones celebrated at MSA Bunbury Outreach this quarter, with MSA Clients Judy Ann Whitfield turning 70 on 22 February, and Michael Kenny turning 80 on 16 March. A huge happy birthday to you both!



Jigsaw Table Donation

Kerry Reeves, Vickey Bartlett, and Lynda Whitton are enjoying a brand new jigsaw table, kindly custom made for MSA Bunbury Outreach by the Bunbury Men's Shed. Thank you!

Scaly visitors

Care Support Worker John Ryan brought his pet snakes along to MSA Bunbury Outreach for a special show and tell, sharing his passion for keeping exotic pets.



International Women's Day

MSWA Bunbury Outreach welcomed MSA CEO Melanie Kiely as a guest speaker in recognition of International Women's Day. It was an opportunity to reflect on this important date over a shared morning tea, as well as ask questions, share stories and make connections.

MSWA Wilson Outreach also celebrated the occasion with a visit from two talented henna tattoo artists, Care Support Worker Sakrina K C and Wilson Outreach student Pinky Kaloya. The artists were patient and attentive, ensuring that each Client got the perfect design for them.





ACCOMMODATION HAPPENINGS

Mega Home Lottery Grand Prize Draw

For the first time, the Mega Home Lottery grand prize draw was held at Margaret Doody House! MSWA Client Michael enjoyed the honour of telling our \$4 million dollar prize winner – also named Michael – the life-changing news. It was an emotional moment for everyone involved.



Cuddly baby animals

In May, Catherine from The Hygge Farm and her cuddly baby animals paid a visit to our Hamilton Hill residents for an interactive experience. Our residents enjoyed spending time with the different animals, and topped the day off with a hot pizza and quiche lunch.



A life-saving gift

Supported Accommodation Coordinator Stuart Jarvis and Care Support Worker Brenda Parsons have been rolling up their sleeves each fortnight to give a life-saving gift: a donation of blood, plasma or platelets at their local Lifeblood Donor Centre in Edgewater.

“For myself, caring and giving is just who I am. Back in 1992, my sister who was 13-months old had a liver transplant. She is now 32, so I often think about this and how things might have been different if donating blood wasn’t a thing,” Stuart said.

“I got into donating at Red Cross Life Blood because of Brenda encouraging me to finally get into it. I started going November 2022, I have since donated 10 times and will be doing a donation every fortnight from now on. I find this really rewarding knowing I am helping to save lives.”

Brenda has donated 22 times since the year 2000, motivated by “a sense of doing good and the thought of saving a life”.

The pair agree the downtime while donating is ‘relaxing’, with delicious food and drinks waiting for them at the end of each session as a reward.

“The staff are friendly and they do their best to make you feel comfortable,” Stuart said. “For anyone thinking of donating, both Brenda and I encourage you to do it – it honestly is the best feeling in the world.”



Happy Pants Friday

In February 2023, ‘Happy Pants Friday’ was encouraged by our Recreation Care Support Worker Susie Rowe. A fun day was had by all, with staff and Clients participating in wearing some very colourful garments. Pictured here is a group of respite and residential Clients and staff showing off their bright clothing, whilst playing Bingo!

Champion in our midst!

In March 2023, Paula Kennedy, Registered Nurse and Supported Accommodation Coordinator at Treendale Gardens competed in the Masters Athletics WA State Championships. Generally known for competing in throwing events, Paula also competed in some walking events and a sprint. Incredibly, Paula medalled in all eight events she entered, taking home two gold, three silver and three bronze medals. Paula said it was a great weekend of competition and fun. Outstanding!



THE 25 CLUB

Early bird winners Troy and Isobelle

For our young Mega Home Lottery ticket purchasers, lighting struck twice this year with both our Early Bird and Super Early winners instant millionaires at just 25 years of age.

Briana, a special needs education assistant, was at work when she was told she was the new owner of a \$1.3 million Mount Lawley Apartment.

Her initial thought was that someone had been trying to contact her because her dog had gotten out, but was floored by the real reason for the call.

"I thought no, this isn't real – I did not believe it," Briana said.

"I got the phone call at the start of lunchtime and less than 20 minutes later, everyone was running up to me from all sides of the school to congratulate me, asking if it was true."

Working each day with children with additional needs, Briana understands just how important MSWA's support is for Clients.

"My pop was also diagnosed with Parkinson's, so it all ties in," she said.

"I just like helping and supporting people where I can, but I also love being in it to win it – so it's a win-win all round."

For Briana, this good fortune has opened the door to so many more opportunities in life than she ever imagined.

"My job isn't great paying, but I really love it, so I had been battling it out. Now I have so many more opportunities and can keep doing a job that is so rewarding," she said.

It was also an exhilarating experience for MSWA Client and staff member, Tracey Hockey, who pushed the button to bring up Briana's winning ticket number.

"My heart was racing knowing that someone's life was going to be changed forever in a wonderful way," Tracey said.

Tracey even had the chance to give Briana a tour of her brand new apartment.

"Briana really has a wonderful calling to work with children. Listening to her tell her story of her vocation and how much she loves it was very heartwarming."

"Now that she has had this windfall, Briana will be able to keep on doing what she is called to be."

The impact was just as profound for our Early Bird winners Troy and Isobelle.

"When I received the call at work, it was just like any other day," Troy said.

"I had earlier been discussing with a colleague what it would be like to be mortgage-free and what life would be like."

"For us, this is so much more than just a house: this has laid the financial foundations for the rest of our lives and has set us up for success."



The MSWA team ready for the Grand Prize draw

Purchasing a ticket in the MSWA Mega Home Lottery was an easy decision for Troy and Isobelle, motivated by the difference MSWA makes in the community.

"For a number of years, we have prided ourselves with supporting such an amazing cause. To have it result in the Early Bird prize is more than we could have ever imagined," he said.

"Having seen MSWA provide services to a co-worker's husband and their family really showed us how much of a positive impact these funds can have towards support, research and care."

"Thanks, MSWA, for an amazing start to life!"

Setting up a future for my kids

Since 2016, Mike has bought three tickets in each Mega Home Lottery – one for each of his children.

The long-standing tradition turned into a \$4 million dollar windfall for the family man, who is now the proud owner of a \$3 million Mount Pleasant home with \$1 million cash in hand.

"I was at a client's house when Melanie and Michael rang," Mike said. "I didn't even have time to think about it until I was in the car, and then I am thinking 'oh, this can't be right.'"

"It's still surreal, dream-like – I'm overwhelmed in many ways, but so appreciative."



Lotteries team members Spencer and Laura.

"This is going to make such a difference to my kids, I will get a benefit out of it as well, but certainly for my children – that is my focus."

For Mike, buying tickets in the Mega Home Lottery was about supporting the cause, sharing that he would have "kept buying tickets even if I didn't win".

The tearful phone call was just as powerful on the caller's side, with MSWA Client Michael reflecting that giving the good news was "the next best thing to winning yourself".

"To be able to tell a fellow Michael he had won the grand prize, he was obviously totally moved by it," he said.

Michael encouraged supporters to "buy as many tickets as they can, as often as they can" with the funds put to good use at places like Margaret Doody House, one of MSWA's respite accommodation centres.

"It is state-of-the-art inside and they have all the equipment they need here... but it also has the cosy touches, like the fireplace, that really add to the respite air."

"They have thought of everything; no matter what your condition is."

"It's terrific to have a facility like this and a program like this that MSWA runs; it's just mindboggling and definitely worth every penny that people can give to support it."



Super Early Bird winner Briana (centre) with Tracey (left) and Melanie (right).



MSWA Chair Horst, Client Michael and CEO Melanie.



Tracey's message to our MSWA Mega Home Lottery supporters:

To those who purchased tickets, thank you from the bottom of my heart!

It is because of your generosity that MSWA can keep supporting more of us as needed. Life is challenging but knowing that we can come to MSWA for support is amazing.

It is so important to have safe places to go for respite, to grow, to enjoy the company of others and be supported.

MSWA can offer these safe places and support services because of amazing supporters of fundraising initiatives like the lottery.

STEP UP FOR MSWA

A CHALLENGE CAN CHANGE YOUR WORLD

At 62-years-young, Ken Thomas is throwing himself into the 2023 Step Up for MSWA not only as a personal challenge, but as an opportunity to support the organisation which has made a life-changing difference for his friends.

“I’m passionate about causes close to my heart, raising awareness and funds whilst I am still able,” says Ken.

“I have a young friend living with MS and a friend who had a stroke, so I am familiar with the work MSWA does in our community to help those with different neurological conditions.”

“My friend with MS said MSWA is the most wonderful organisation, and she is so grateful for the support they have given her.”

Powered this year by new sponsors Commonwealth Bank, the unique stair climbing challenge will take place on Sunday, 25 June at Perth’s tallest building, Central Park.

With four challenge levels, there is something to suit all fitness levels.

Taking part in the iconic event for the first time last year, Ken is going back-to-back with the aim of going bigger and better in 2023 – taking on the ‘Double-Up’ this time around.

“Sometimes we all need to challenge ourselves,” he said.

“A challenge can have many benefits. It can change your world and the world of others, be beneficial to our mental health, personal wellbeing, confidence and sense of fulfilment.”



“My aim is to recruit team members early this time, raising awareness and promoting the event itself to colleagues and friends.”

Ken recalled the buzz of event day in 2022 and eagerly anticipates what will be in store this year.

“As soon as we arrived, the atmosphere excited us even more than we already were,” says Ken.

“The volunteers were amazing and full of encouragement as we climbed.”

Over the past 15 years, the event has welcomed more than 12,200 climbers to raise \$2.3 million for MSWA.

Help us take it to even greater heights by signing up or sponsoring a stepper at stepupformswa.org.au.

**DANNIELLE MCCONNELL
MSWA SENIOR EVENT
COORDINATOR**

SUBMIT YOUR ARTICLE TO US

Do you have a story about living with a neurological condition in WA that other MSWA Clients might like to read? We invite you to share your experiences with our many *Bulletin* readers. Email your submission to bulletin@mswa.org.au for consideration by the Editorial Working Group.



SUGGESTIONS, COMPLAINTS AND COMPLIMENTS

We want to hear from you. Your feedback helps us to understand what is working well and where we can improve.

You can raise a concern or acknowledge the support an MSWA staff member has provided by:

- / Talking to the coordinator of your services
- / Telephoning the Complaints Liaison and Compliance Coordinator, Davina Sawyer, on 6454 3146
- / Emailing feedback@mswa.org.au
- / Writing to Quality and Compliance; Locked Bag 2, BENTLEY DC 6983

Please tell us:

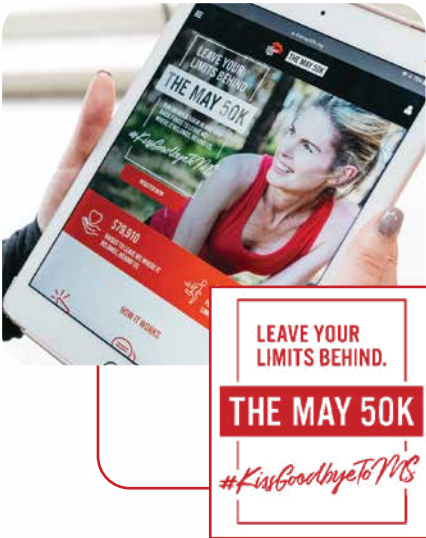
- / What happened
- / When it happened
- / Who was involved
- / What you would like to see occur as a result of sharing your feedback

All feedback is reviewed, and complaints investigated in a timely manner with the team responsible for the service.

Our goal is to achieve a positive outcome for all people involved and improve the quality of the care and services provided. You will be included in the process and the outcomes shared with you.

Please note, you have the right to have support from an advocate at any point in a complaint process. The Complaints Liaison and Compliance Coordinator can help you to access an advocacy service if you wish.

SAVE THE DATE!



THE MAY 50K

Organised by our friends over at MS Plus, The May 50k aims to raise funds to leave MS where it belongs – behind us.

Sign up for free to run, walk or move 50kms during the month of May and track your progress to achieve your fitness goals.

Share your commitment to the challenge and raise funds to support MS research.

Register your interest as an individual, team or workplace at www.themay50k.org.

MSWA STEP UP 25 JUNE, 2023

Set yourself a special challenge in 2023 by getting involved in our unique stair-climbing event.

Step Up for MSWA challenges you to climb 1,103 steps up Perth's tallest building – once, twice or even multiple times for the super steppers!

Registration is now open, head along to stepupformswa.org.au to join us on event day!

Interested in volunteering? Sign up now: stepupformswa.org.au/volunteer



WORLD MS DAY, 30 MAY

Join us as we recognise World MS Day across four MSWA locations!

First initiated by the MS International Federation (MSIF) and its members in 2009, World MS Day is a day to celebrate global solidarity and hope for the future.

The World MS Day 2023 theme is 'Connections', which aims to build community connection, self-connection and connections to quality care.

This year, MSWA Clients and staff will have the opportunity to join together for some art-filled fun – as well as a day of conversation and reflection on what 'connection' means to each of us.

If you haven't yet secured your spot, email communications@mswa.org.au



MS Readathon AUGUST, 2023

MS Readathon challenges kids to read as much as they can in August, where they have the chance to earn prizes, collect badges and complete challenges.

It makes reading fun and exciting!

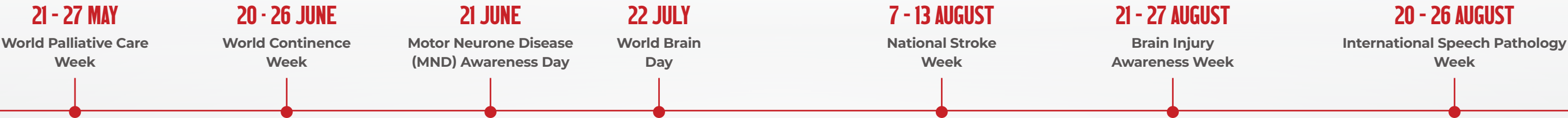
Register your interest for the 2023 readathon at msreadathon.org.au.

CLIENT FORUM, 6 JULY

Mark the date in your diaries for our annual Client Forum!

This free event is an opportunity for Clients and their carers to hear updates from neurological experts, WA based researchers and clinicians.

Planning is well underway, with official invitations to be sent to all Clients in the coming months.





Happy First Birthday **MSWA ALBANY**

