



WE KNOW NEURO

THE OFFICIAL MAGAZINE OF MSWA

Spring 2022
mswa.org.au

BULLETIN



INSIDE

- / Celebrating 50 years of MSWA
- / Our commitment to research
- / New technology taking the pressure off
- / Water, life, the universe and everything!

50
years
MAKING A
DIFFERENCE

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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

Our neurological liaison nurses are usually the first point of contact after the neurologist's diagnosis.

COMMUNITY NURSE: 9365 4888

PHYSIOTHERAPY

Our team provides treatment interventions to develop and maintain mobility and function.

JAMES BECKETT, MANAGER: 9365 4837 OR PHYSIO DEPARTMENT: 9365 4834

OCCUPATIONAL THERAPY

Occupational Therapists enable Clients to continue their work and other interests for as long as possible through advice, aids and equipment.

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SPEECH PATHOLOGY

Our Speech Pathologists assess, diagnose and create individualised treatment programs for Clients who experience swallowing and/or communication difficulties.

PAMELA WINDRAM, MANAGER: 6454 3140

DIETETICS

Dietitians are university-qualified nutrition experts who promote general health and disease prevention/management through dietary changes.

PAMELA WINDRAM, MANAGER: 6454 3140

COUNSELLING, PEER SUPPORT & HEALTH EDUCATION

Talking with a Counsellor creates a safe, respectful and confidential environment for you and those close to you to explore options, create change or gain understanding about your life.

TO MAKE AN APPOINTMENT PLEASE CALL: LISA PAPAS, MANAGER: 9365 4836 OR COUNSELLING DEPARTMENT: 9365 4811

SOCIAL WELFARE

Social Welfare Officers assist Clients and their families to access services and supports to remain living independently at home. They specialise in case management, advocacy and sourcing funding options.

KATH KNIGHTS, MANAGER: 9365 4835

COMMUNITY SUPPORT

We provide long-term and time limited in-home supports including assistance with personal care for people with MS, to help them remain in their homes. Care and supports are provided through a combination of funding from the Department of Communities - Disability Services, and our own fundraising efforts.
CUSTOMER SUPPORT TEAM, community.support@mswa.org.au

CUSTOMER ENGAGEMENT DEPARTMENT

Our experienced teams will provide you with personalised support right throughout your NDIS journey. From helping you to access the NDIS to working with you to get the most from your plan, our trained staff are here to help.

GEOFF HUTCHINSON, MANAGER CUSTOMER ENGAGEMENT: 9365 4879

CAMPS & RECREATION

MSWA provides separate recreation camps for Clients, carers, and families, primarily funded by Lotterywest, and for a nominal cost to participants. These camps provide a break from daily routines, and strengthen friendships and support networks.

MALA PADMANATHAN, COORDINATOR FOR CAMPS & RECREATION: 6454 3184

AGED CARE

MSWA delivers all levels of Home Care Packages to eligible people with a neurological condition who are over 65. Services are delivered by staff specifically trained in home care for older Australians who are living with a neurological condition.

JAY NARROO, AGED CARE COORDINATOR: 6154 5194

EMPLOYMENT SUPPORT

The MSWA Employment Support Service is the only specialist employment service for people living with multiple sclerosis in Western Australia and 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



Welcome to the spring 2022 edition of *Bulletin*. We hope you enjoy the news, stories and service information we have brought to you this quarter.

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FROM OUR CEO

I am writing this after an early morning walk with the dogs in this beautiful spring weather and I can't help feeling the hope and excitement that spring brings – the promise of new leaves, new flowers and new adventures. This is particularly poignant as we emerge from the COVID-19 pandemic.

At MSWA I think we are also starting to feel a little like this. It's been a tough few years for all our amazing staff and Clients, and it feels like things are starting to ease up a little – in time to celebrate our fiftieth anniversary! We have set our new strategy for the new year, one that is anchored in our purpose – *to be the difference – to empower people with neurological conditions to live their best lives.* The key to this is to put our Clients, and the community we exist to support, at the centre of every decision and action.



We have been undertaking roadshows with our teams around WA, talking about what this means and what we need to be better at:

/ Providing people with neurological conditions the services they want and need.

This means better listening, asking and maybe even an improved service model.

/ Attracting and retaining the best staff who are committed to our purpose.

Everyone is struggling to find staff, and harder still, to hold on to them. We need to be really good at this, and again truly listen to our staff to understand what we need to be better at.

/ A safety and quality culture that is core to everything we do.

This means investing in a team that is independent and works with the business to embed consistent best practices around safety (for Clients and staff) and quality services.

/ Partnerships and networks to drive greater impact.

We need to acknowledge that we can't and shouldn't be experts in everything. To provide better outcomes for our MSWA community we must form partnerships in research, services and advocating to government. We are very lucky to be part of a national network, the National Disability Services (NDS) and other bodies that allow us to collaborate for change and better outcomes. We need to build on this.

/ Financial stewardship for a sustainable future.

We want to make sure MSWA evolves and remains an impactful organisation for our community for the next 50 years. To do this, we must invest and use our funds wisely and efficiently. This includes setting aside any fundraising surpluses for future capital needs and to fund services of greatest need that aren't currently covered by government funding. We are in good financial health and we have the money to build our future homes, Services Centres and other developments, but we need to make sure we can keep doing this.

I look forward to working with the amazing team across MSWA as to how we achieve this, ensuring the culture we create along the way is centred on our purpose, with the people we support at the heart of all we do.

Lastly, I would like to say thank you to everyone who continues to support us and work with us. You are MSWA, and you make it possible to help now and in the future.

Good luck, thank you and happy spring!

MELANIE KIELY
CEO

MEMBER & CLIENT SERVICES

Welcome to the spring edition of our *Bulletin*. It is lovely to see the sun shining as we get away from the rain and grey skies.

Firstly, it is great to be able to see some return to normal from the COVID-19 pandemic. It feels good to think that we may be past the worst of it all, however we still need to take precautions to keep everyone safe. The article on page 16 by Jamie Puls provides a full update on how we are moving forward with COVID-19.

We have had a busy few months as we worked through our strategic planning, presenting this work to our teams across our sites through our strategy roadshow. The feedback has been very positive and we are looking forward to our next horizon. On that note, my last update mentioned we had commenced work to explore what our Clients need and want from us at MSWA. I am pleased to report that this has progressed well, and we have unearthed great insights from our Clients, carers and staff on how we can improve our service delivery. We are collaboratively working through the next steps to develop a new service model, supported by new systems and processes. I will keep you updated on this project as we progress through the new year.

Regarding systems and processes, we implemented our new Client Management System earlier this month. The new system will support us to deliver improved services and streamline our processes.

As with any system implementation, we are currently working through a bedding in period after going live and we will keep you posted on our progress.

Over the past few months Vanishree Chetti, Manager Clinical and Residential Services, and I have been visiting our residential facilities. It has been great to get around to meet our Clients in their homes receiving support from our teams. The passion from our teams to provide the best care clearly comes through. Another important piece of work on our radar is understanding what we can improve across our residential facilities.

We are looking forward to increasing our services at our Butler Services Centre. We now have the team relocated to our Butler Centre so we can increase the service delivery to our Clients, as we look at more options to provide service to the broader community north of Perth. If you are interested in what services are on offer at our Butler Centre, please contact 08 9365 4888 or visit our website: mswa.org.au/locations/butler

NDIS UPDATE

On page 8 you will find the NDIS pricing update from Geoff Hutchinson, as well as an update on the NDIS corporate plan for 2022-2026 on page 10.

We are still hoping to see some changes happening through the NDIA and it is encouraging to hear Australian Paralympic legend and disability advocate, Kurt Fearnley AO, has been appointed Chairman of the NDIA. We eagerly anticipate what comes next.

Finally, I would like to thank the entire MSWA community for an incredible 50 years. It is amazing to reflect on how far this great organisation has come over the decades, a testament to each person who has joined us along the journey.

As always, your feedback is important to us. If you have anything you would like to share, please contact us on feedback@mswa.org.au.

Stay safe and enjoy the springtime.

NICOLA WASHINGTON
CHIEF CLIENT
OPERATIONS OFFICER



A DECADE IN THE MAKING:

\$34 MILLION COMMITTED TO NEUROLOGICAL RESEARCH OVER THE LAST DECADE

Over the past decade MSWA has contributed over \$34 million to fund research into finding the cause, better treatments and a cure for MS and other neurological conditions.

We are excited and proud to announce that in the 2022/23 financial year, we are committing a further \$5 million to neurological research. This new contribution means MSWA has contributed over \$34 million to local, national and international research over a decade.

We believe that research provides hope for people living with a neurological condition and will ultimately improve the lives of our Clients and all people supported by MSWA.

Our understanding of MS and neurological conditions has improved significantly over the years. It's thanks to Western Australians supporting our fundraising initiatives and lotteries that we can continue to make these significant contributions.

"I am delighted to continue our funding of neurological research, including WA research projects, which we believe will lead to finding the cause, better treatments, and hopefully one day, a cure for many neurological conditions." MSWA CEO Melanie Kiely said of the announcement.

"We truly can't thank our supporters enough for continuing to trust us to support people with neurological conditions, and fund vital research not only here in Western Australia but nationally and internationally too."

For more information about MSWA's commitment to research and research projects we are currently funding visit our Commitment to Research page.



RESEARCHER IN FOCUS: PHD CANDIDATE REBECCA RUSSELL

MSWA funded PhD candidate, Rebecca Russell, who is part of Associate Prof. Lucinda Black's team at Curtin University, takes us through her contributions to the 'Elucidating diet in MS to improve disease outcomes'. MSWA's funding has been supporting this work for over six years.

1. Could you provide an overview of your current research project?

With the help of people with MS and MS health professionals, we are developing an evidence-based online nutrition education program to provide people with MS the information they need about diets, foods and changing eating habits.

The internet hosts a wealth of information, not all of which is correct. The influx of information can be overwhelming, confusing and conflicting, making it difficult for people to navigate and access information that aligns with the Australian Dietary Guidelines.

To make it easier and simpler for people with MS, we will provide clear advice on beneficial dietary changes and how to make healthy food choices. In addition, the program will help with selecting, planning, preparing, and cooking foods to create healthy meals.

The program and its effects on diet quality will be continually tested and updated in a study to improve the quality of life for people with MS. The findings from this study will then be used to develop a larger scale, randomised and controlled trial to gauge the impact.

2. What attracted you to the research around the impact of diet on MS?

As a chef, I have always had a strong connection to food, healthy diets and people. Over the years, I became fascinated by how people interact with food and how I can make a difference to people's lives. This encouraged me to do further studies in nutrition and get into research.

When I saw the chance to get involved in MS research, I searched the internet to find out what information was out there about diets and MS and was dismayed by how much conflicting advice there was.

I am passionate about helping people make healthy dietary changes that could benefit their symptom management and their overall health. I am privileged to have had so many people with MS share their stories with me through my research. This has inspired me to develop this nutrition education program, which will assist people with MS and their families, not just in WA, but across Australia.

3. What do you hope the outcome of this research will be?

I hope that this nutrition education program will help people with MS make healthy dietary changes that will be beneficial to their overall health, as well as their MS symptoms.

I also trust it will teach them how to sift through conflicting information and equip them with the knowledge and skills needed to manage symptoms such as fatigue, while selecting,

planning, preparing and cooking foods to create healthy meals. I am confident the program will be well suited to the needs of people with MS and that they will enjoy completing it.

4. What's next?

We have developed an online nutrition education program which includes a range of information, such as interactive graphics, expert videos featuring people with MS and MS health professionals, activities and engaging discussions around nutrition questions.

We are continuously fine-tuning and improving the program based on the helpful feedback we have received from people with MS on the first module.

My research team and I are at a very exciting stage where we are ready to test the program. Each module will take around one hour per week to complete.

To find out more please contact MSDietProject@curtin.edu.au



THE NDIS PRICE GUIDE AND YOU

The National Disability Insurance Agency (NDIA) recently released its NDIS Pricing Arrangements and Price Limits for the 2022 – 2023 financial year and, like so many things, there are some wins but also questions on how the new price limit will impact us over this period. We will try to highlight some of the key points below and what it means for you.

But first, some background. The NDIA sets price limits for disability services received by participants. These prices are outlined in the 'NDIS Pricing Arrangements' and are released annually or when the situation dictates (for example the COVID-19 response).

This helps the NDIA to control a market still in its infancy, supporting provider growth until the disability provider marketplace is established. So, what does this year's release mean for you?

The most significant change was a nine per cent price increase across a range of services, including personal care and social support, which took effect on 1 July 2022. The good news is that participants' plans will be automatically increased to account for these price limit changes, which means your funding won't be impacted.

This increase is designed to alleviate pressures providers are facing in supporting their workforce, in addition to covering compliance and pandemic preparations costs. It should be seen as a positive step in maintaining a capable workforce.

Despite this rise, the NDIA has decided not to increase the prices for most Allied Health and Support Coordination services. While the price update does suggest a 'further review' into these costs, the NDIA was clear in its determination that no change will be approved. While this means your plan will be unaffected, this decision will impact providers' ability to attract and retain their allied health workforce. The exception to this was Nursing Support which will be indexed by 2.94 per cent in line with the Wage Price Index and Consumer Price Index.

Another significant change was the NDIA's definition of 'short notice' cancellation. This was previously two days for shorter support services, up to five full days for others. This has now been set at a seven-day notice period requirement. On this point, it is important to recognise that a lack of sufficient notice is a concern for service providers and their ability to fill the service spot.

While MSWA will abide by this change, we do understand that at times a participant's condition may impact their ability to provide sufficient notice. We have, and will continue to review these occurrences as and when they arise.

Finally, the NDIS has sought to simplify the High-Intensity Support framework. This includes clarification of High-Intensity Support as services provided to a person who has support needs that require the skills described by the NDIS Commission as 'High-Intensity Daily Personal Activities'.

Overall, the latest price guide should not have a significant impact on your plan. Please keep in mind these guides are subject to change. If you have any questions, please reach out to your Client Liaison Coordinator for support.

GEOFF HUTCHINSON
MANAGER CUSTOMER
ENGAGEMENT

Other changes in the 2022 – 2023 NDIA Price Guide include:

- / Providers are now able to charge a Client for return travel when a cost has been incurred during a Core Support service. This brings core supports in line with existing rules for capacity-building supports.
- / Capacity building and training in Self-Management and Plan Management is now a Core Support. This means you have more flexibility in how you use these line items.
- / Locations which are not currently classified as 'remote' or 'very remote', but where it is not possible to travel from the location to another major city without crossing a remote area, are now classified as 'remote' for planning purposes. This shouldn't impact us in WA as the NDIS believes we are all 'remote'.
- / The Temporary Transformation Payment (TTP) has been reduced from 4.5 per cent to three per cent. MSWA has decided not to charge this cost to our Clients.



NDIS FIVE YEAR LOOK AHEAD

It's always great to have a plan. As kite flying enthusiast Benjamin Franklin once said, "by failing to prepare, you are preparing to fail".

It is pleasing the National Disability Insurance Agency (NDIA) not only has a plan for the next five years, but also went a step further to release it to the community, allowing us to look at where the NDIS (and its participants) will be heading.

The NDIA's corporate plan 2022 – 2026 celebrates the achievements of the NDIA over its first 10 years, while also highlighting its key focuses for the next period. Don't worry if you have better things to do in this spring weather than read through the 55-page document, because we've already had a look for you.

The first thing that jumps out is a commitment to co-design and consult with participants to ensure the NDIS meets the needs of the people it supports. This requirement has been discussed at length by participants and providers over the last couple of years and it seems that the NDIA has been listening.

"We understand that for the NDIS to succeed, it is critical that we listen and work with our participants, their families and carers and the disability community to make sure that each improvement is a step in the right direction and the NDIS is available for generations to come."

– NDIS Corporate Plan 2022-26, pg. 5

This reads as a strong commitment toward co-design; a goal supported by the recent naming of Australian Paralympian and disability advocate, Kurt Fearnley AO, as the new NDIA chair. With this focus, it appears the Agency has taken on feedback about the lack of consultation around the introduction of 'Independent Assessors' last year.



Having more people with lived experience in decision-making positions will only help improve the Scheme's effectiveness, so for the NDIA to place this so prominently is a good step.

But what is a Corporate Plan without some goals or 'aspirations' as the NDIA calls them. Within this plan, the NDIA has delivered five aspirations they will be working towards in this 5-year period. They are:

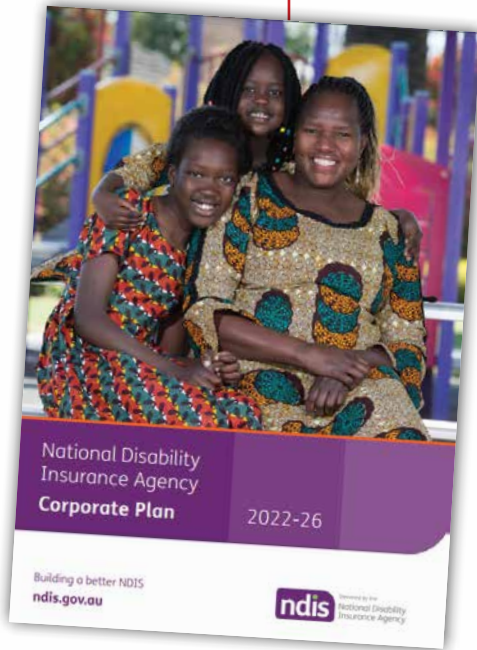
- 1. **A quality experience and improved outcomes for participants**
- 2. **A competitive market with innovative supports**
- 3. **A genuinely connected and engaged stakeholder sector**
- 4. **A high-performing NDIA**
- 5. **A financially sustainable NDIS**

All sounds pretty good, right? Providing a good experience for participants is the goal of everyone involved with the NDIA, and having a competitive marketplace that pushes providers to work harder and smarter is vital in achieving quality outcomes for Clients. And, while some may question the way the NDIA has tried to balance the budget, we can all agree that without a financially sustainable and high-performing NDIS, we're all in trouble.

If I was to provide a small critique however, it would be that a strategic vision should provide a panoramic view of 'where we are going' and a convincing rationale for why this makes good sense. While the list of aspirations is all positive, there are a lot of factors – including some of significance – that could impact the NDIA and the sector's ability to achieve these aspirations (for example a robust workforce). I worry that the NDIA hasn't convinced me as to how these concerns will be addressed.

Understandably, some questions won't or can't be answered in a high-level corporate plan. So, while I agree with the vision, there's a lot of work to be done to turn it into reality.

Overall, I think this is a positive document for the NDIA and those participants and providers who rely on its success. Furthermore, the news and information coming out of the NDIA in recent months hint at an agency which recognises that the more they understand the individual needs of its participants and the more they engage with its provider network, the more effective the NDIS will be for everyone.



This is important, as a final truth about 'planning' is that the more you know, the more effective your plans will be. The NDIA has been with us for over a decade and has learnt from supporting approximately 535,000 individuals to access personalised funding. The fact that we are all here 10 years later with an optimistic/realistic vision for the future shows just how far we've all come.

As John 'Hannibal' Smith from the 80's classic The A-Team used to say, "I love it when a plan comes together."

**GEOFF HUTCHINSON
MANAGER CUSTOMER
ENGAGEMENT**

JASMIN FRANKLIN: THE BIGGER PICTURE

"I'm grateful for every day that I'm alive. I'm blessed to wake up each day and open my eyes."

44-year-old Jasmin Franklin was born with a rare condition called Klippel-Feil Syndrome. Remarkably, the diagnosis took 40 years to be found. Jasmin is married with two teenage children. She's a passionate and award-winning classical portrait artist, illustrator and designer.

"I knew from the age of five that I wanted to be an artist," says Jasmin. "I was a very sick kid so it came to me very early on. I guess it's my happy place. It's the place I feel at most peace, doing something that I'm supposed to be doing. The years spent studying were difficult because of my health, but when you don't know what's wrong with you it's incredible how far you can push yourself."

Jasmin has learned to walk seven times. However, the symptoms that most affect her day-to-day life are respiratory. "I was born with compression of my rib cage – it's fused together so I can't take a proper breath." In addition, Jasmin only has one working lung, something which was missed on x-rays for 40 years.

"And I've got a fifth rib that's digging into that lung," she explains. "The fusion starts from the top of my head down to my ribcage. With Klippel-Feil Syndrome, it can continue down your body."

"It's a domino effect of finding out more about it as we go. Because it is so rare it's difficult for doctors to understand it."

"They can't tell me what's going to potentially happen in the future, or what my symptoms will graduate onto, or predict degeneration from the condition."

THE ROAD TO DIAGNOSIS

Jasmin navigated years of medical professionals being unable to find any underlying reason for her health troubles.

"I had so many doctors, and lots of misdiagnoses. When my second son was six months old, it got so bad that I couldn't speak or move."

Unable to be diagnosed, her condition had got to a point where she was not able to look after her family. It was a very difficult time in their lives. Incredibly, the parents at her children's school organised a roster of 40 people to help the Franklin family at home.

"One of the mums on the roster was a nurse. She thought that MSWA might be able to help us and she advocated for them to come and help my family."

"It changed my life completely. MSWA brought us through the journey to get a diagnosis and got us to the point where we got the help we needed. I am so thankful that we got there because it was such a relief to know that I wasn't crazy and that what I was feeling was real."

"If anything goes wrong or we need help, I know that I can rely on MSWA to support me through any challenges."

Jasmin has received support coordination, counselling and access to nurses and carers through MSWA, but it's the weekly Outreach she is most grateful for. "The Outreach staff are incredible and so positive. It's always such a happy place to go to and they support me so much with my artwork."

AWARD-WINNING ARTWORK

With the assistance of Outreach staff, Jasmin entered a charcoal and pastel pencil drawing (pictured) into the 2021 Canning Show and it won multiple awards. "It was amazing. It's so cool to get the recognition for the study and the work that I've done."

"There's no way I could have done it without help. I need to sharpen my charcoal pencils to a needle point and have a graduation. It takes a long time to prepare because you want to have the precision. With a portrait, if it's a millimetre out, it will not resemble the person."



As well as Outreach, Jasmin attends an MSWA coffee group and values the shared experiences of fellow attendees. "There are so many amazing people out there who are just doing life with neurological conditions."

THE FUTURE

Jasmin says her future is a 'daily future'.

"Every day that's good, is a good day. Positivity is everything. I have my family to get up for every day. A good day is just getting out of bed. And even if you're lying on top of the bed rather than in the bed, that's a great day! You're blessed every day you're alive and can do something with your life and help others if you can."

"I plan to continue to go to MSWA Wilson and attend the Outreach there, but I would also love to go back to university and do my PhD in Classical Art. Hopefully my health will hold out so I can do so many things. I want to be around for my kids when they get married and be around for my husband. They're the biggest plans in my life."

Jasmin's biggest advice to others is to take one day at a time.

"Don't over think it. Don't push too hard. Be kind to yourself, and be kind to people around you as well, because you never know what somebody is going through."

50 YEARS OF MSWA

I am so proud, honoured and excited to celebrate 50 years of MSWA making a difference.

What an incredible milestone. It's with much gratitude that I reflect on all the good work of those who have come before me, and those working here now.

Thank you for your ongoing support of MSWA and all that we are trying to do for the people we serve and support.

You are the reason MSWA exists, and we are looking forward to the next 50 years of helping people with neurological conditions to live their best lives.

**MELANIE KIELY
CEO**

Take a trip down memory lane with these vintage Bulletin excerpts!

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You are the reason MSWA exists, and we are looking forward to the next 50 years of helping people with neurological conditions to live their best lives.

**MELANIE KIELY
CEO**

CERAMICS – M.S. STYLE

My introduction to the M.S. Day Centre was to say the least, a reluctant, apprehensive one. "I'll help out on the odd Thursday afternoon," said Monday is cool."

The first Thursday afternoon was most enjoyable, a deciding factor in my turning up the next Thursday. Maybe I wouldn't hurt if I tried Monday morning as well – just for a couple of hours.

On my way to delivering the geriatric delinquents' golf clubs, I dropped off some greenware.

It was a Thursday morning and there were the Ceramic Gals sitting around the table, just waiting! These days Ceramics start about 10.15 and continue until bus time – Monday and Tuesday.

The results achieved are unbelievable. No one seeing the finished article would guess that it was made by a pair of pretty shaky hands.

It is embarrassing, when in some cases, the standard of work outstrips the teacher's capabilities.

One of my jobs was to do the fine edges, but as skills have increased, with power has controlled the hands and calls on my supposedly steady hand are rare.

There is undoubted talent among the group and a ton of enthusiasm.

Maureen and Peter, the Printer are now attending lessons at a Ceramic Centre. Hopefully, what knowledge they attain, they will pass on to us.

The incalculable of our own kiln has further heightened everyone's interest.

Joyce, the right-hand man, has the job of loading, firing and unloading the kiln. Lucky kid!

Ceramics day is a fun day; a few tall stories, relating humorous incidents from home, friendly shacking.

The room is easily found, just track down the noise!

Mind you it's hard to keep some of them on the job – they escape to pleasure cruises to the Far East, holidays in Queensland or the South West.

Some even have the opportunity to sneak off to hospital for a couple of weeks – but they eventually come back.

Maybe the therapy works; that is for others to judge, but for me, Ceramics M.S. Style are a couple of fun days beyond price.

Carmen

Everyone hard at work, with some of the finished products in the background.

Carmen Gerke, MS Society Centre Volunteer Ceramics Teacher.

Ro Ireland and Pauline Smith working on their masterpiece.

MULTIPLE SCLEROSIS PAGE

Vol. 3, No. 10 October 1987. Registered by Australia Post Publication No. W.B.H. 0115.

MS RESEARCH Update

Research vital link to future

The National M.S. Research program began in 1977 when all Australian States elected to transfer that role to the National Society to provide more efficient assessment of projects which investigate causes, prevention or treatment of M.S. Another role is to stimulate more M.S. research by other bodies.

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MULTIPLE SCLEROSIS, SPRING 1983

BULLETIN Vol. 7, No. 1 1989 Registered by Australia Post Publication No. W.B.H. 0115.

SOCIETY APPOINTS SUPPORT COUNSELLORS

Patrick McGurk (left) & Eddie Masson, your new Support Counsellors.

In what now appears to be a stroke of genius, a position of "Support Counsellor" was devised by Centre Co-ordinator, Marion Morrissey. The "Support Counsellor" was to be an MS person, and the position itself was to assist in the counselling of newly diagnosed and other members in crises.

From the many excellent applications received two outstanding people were chosen. Popular member and raconteur Patrick McGurk was so committed to the idea that he resigned as a member of the Society's Board, a position he had held for seven years, so that he could take up the position of "Support Counsellor".

The other successful applicant was Eddie Masson, a 62-year-old Scotsman (but naturalized Australian, of course). Eddie was coaxed out of retirement after 44 years in journalism, 27 of them with the West Australian to fill the position which he and Patrick now share.

Eddie, as becomes Scottish, is more trained journalist excellent listener telephone provides a listening ear to another problem, to be able understanding,

Both Patrick and Eddie positive, confidential at the job. They now spend (Patrick from 10am to 2pm Tuesday and Friday; Eddie 2pm each Wednesday, and Friday) on the telephone, sharing and understanding problems in a manner possible through kindred illness called MS.

For Patrick there is understanding, called on when two people meet. Only people with ability to touch each other suddenly transformed from behind which confide with, support reach out to each other.

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50 YEARS OF MSWA

I am so proud, honoured and excited to celebrate 50 years of MSWA making a difference.

What an incredible milestone. It's with much gratitude that I reflect on all the good work of those who have come before me, and those working here now.

Thank you for your ongoing support of MSWA and all that we are trying to do for the people we serve and support.

You are the reason MSWA exists, and we are looking forward to the next 50 years of helping people with neurological conditions to live their best lives.

**MELANIE KIELY
CEO**

Take a trip down memory lane with these vintage Bulletin excerpts!

LIVING WITH COVID-19

It has been a long and challenging year navigating COVID-19 in the community. and thankfully, we are now seeing COVID-19 case numbers decline.

Pandemic fatigue is real and many people are experiencing it in different ways. At this time of year, you may feel that you are running close to empty emotionally and mentally – you are not alone, and it is important to realise that there are ways to overcome these feelings.

The National Mental Health Commission has put together a helpful resource to recognise the feelings and behaviours that may indicate pandemic fatigue in yourself and others, and the practical steps you can take to alleviate them. Take a look here: www.mentalhealthcommission.gov.au/news-and-media/mental-health-awareness-programs/pandemic-fatigue



While we may feel ready to put this all behind us and start fresh in 2023, unfortunately COVID-19 is still a significant risk to vulnerable people. Whilst we need to learn to live with it, we also need to manage it in a way which maintains the safety of our Clients and staff.

For our community Clients, please continue to let us know if you become unwell, are a close contact or test positive to COVID-19 so that MSWA can continue to support you. In most instances, if you receive services at home, these can continue while you are unwell or isolating.

If you have symptoms, are a close contact, or are COVID-19 positive, our staff will wear PPE when providing your care. This is to protect staff from possible infection and to prevent the spread of infection to other Clients, or the community more broadly. The safety of Clients and staff will always be our priority.

MSWA continues to have a dedicated COVID-19 Team to support any of our Clients or staff who are affected by COVID-19. Those impacted this year would have likely already spoken to our friendly team of dedicated casuals, who are on hand to support you seven days a week from 9am – 5pm if you are unwell or are impacted in any way. You can also contact the COVID Support Team by email at COVIDAppAdmin@mswa.org.au

**JAMIE PULS
MSWA COVID-19 RESPONSE
COORDINATOR**



COUNSELLING: MORE THAN TALK THERAPY!

Who wants to sit in a chair for an hour and talk about themselves, right?

Luckily, counselling at MSWA can be so much more than that.

Counselling is about you. It's about creating a safe space to explore your emotions, gain skills in communication, strengthen relationships and sometimes navigate hard choices.

Counselling is about your choices. How you choose to nurture and honour yourself and your mental health.

Engaging in counselling gives you the freedom to direct your life where you want it to go. It encourages you to build emotional muscle that can help navigate life challenges.

It doesn't have to be just talk therapy.

You may choose to join one of the many groups we run that provide support, education, experience and community connections.

It's amazing what you can learn about yourself through meditation, expressive or art therapies and mindfulness meditation practices. In turn, in a group setting you can learn from others and share stories and skills that may be of help.

The best part of accessing the counselling team at MSWA is that you can be yourself, no exhausting pretence. You can safely say what you think and feel without judgement.

Our skilled therapists create a safe environment for you to 'let it all hang out' and safely put it all back again (maybe a little differently) at a pace of your choosing.

Feedback from some of our participants says it all.

"It has been so helpful to be able to have this safe place and time to make sense of what is going on inside of me. I felt so overwhelmed when I first started counselling with many mixed feelings to deal with. I now feel better equipped to manage my strong emotions and now I'm not so fearful of feeling them. Thank you"

"From the moment I entered the room, Shaun created a supportive and caring space for us all to express our dreams, concerns, etc with no fear of judgement and connect with other Clients in a non-confrontational way. The impact these sessions have had on my mental, emotional, physical and spiritual health are invaluable. It would take me a day to list them all!"

Contact the counselling team on 9365 4811 to find out how we can help you take care of you.

Can't wait to hear from you!

**LISA PAPAS
MSWA MANAGER COUNSELLING
PEER SUPPORT AND HEALTH
EDUCATION**



BETWEEN SESSIONS™



Don't be afraid to stand out from the herd.



THE COMPENSATIONS OF GRIEF

Trigger warning/ death and grief

Today I received word that a friend of mine was no longer with us, having passed away a couple of days earlier. I didn't know him that long in the grand scheme of things, but we had some great conversations and I loved getting a wry smile from him. I was sad to know that I wouldn't be having any more of those conversations, but a part of me was relieved for him, that there was no more pain and that he was now free.

Freedom: As Mahatma Gandhi said, "Life becomes liveable only to the extent that death is treated as a friend, never as an enemy."

I have often reflected that life can be quite cruel and nature the accomplice, but I think I am changing my mind. I have had occasion recently to consider that what might appear to be cruel, may be a disguise for the kind and compassionate side of nature.

The jury is still out. Learning to live life on life's terms is the inherent challenge of life.

What I have been told and have since observed is that there are 'compensations in grief', the number one rule being that there are no rules. End of life experiences of death, bereavement and mourning are entirely individual experiences, but there are some things that quietly carry us through these life events.

Death gives us an opportunity to pause and consider mortality, that of others – and our own. It is an opportunity to review the trajectory of our life. Are we being the person we want to be, doing the things that we want to do? Are we living the best life we can? If not, why not?

Grief changes your address book. People will come and go from your life. There will be those who will be lost for words, but that won't stop their kind and loving actions. They will fill your freezer, wash your floors, hold your hand, give hugs and listen – if you want them to.

You will know they are truly there for you. Others may be noticeable by their silence and their absence. This is okay. They just can't do it. But you may reconsider if these are the people you want to spend your now precious time with.

Compassion, patience, kindness, empathy. These qualities seem to come more readily to those who have known sadness. They have learnt to pick their battles. It doesn't mean that they don't get sad, angry and frustrated, but they notice, acknowledge and accept these feelings, rather than be overcome by them. They would rather be enjoying their time in quiet contemplation, or burning energy, or doing any of the things they love to do. They would rather be living their life to the best of their ability in a way that leaves no room for 'I wish I had...'

**KATHRYN BUDZINSKA
MSWA COUNSELLOR**

Reference: Cain, S. 2022. Bittersweet: How Sorrow and Longing Make Us Whole. Penguin Books Ltd.

BOOK REVIEW: MAN'S SEARCH FOR MEANING BY VICTOR FRANKL

When I was asked to do a book review for the Bulletin, I thought of a quote I heard recently of Victor Frankl's:

"Between stimulus and response there is a space. In that space is our power to choose our response. In our response lies our growth and our freedom."

With these wise words ringing in my ears, I decided to revisit Victor Frankl's book *Man's Search For Meaning*. Far superior minds than mine have read, written about and reviewed this book, so what follows are just some brief thoughts of my own and some quotes from the book to tempt you to read it for yourself.

Victor Frankl was an Austrian psychiatrist and neurologist, and in the first part of his book he describes his own experiences of extreme hardship in Nazi concentration camps.

He writes from a psychological perspective, observing his own reactions and behaviours, as well as those of other prisoners and guards.

He wonders how anyone at all can survive such conditions and reflects on the sources of his strengths and will to survive. His observations and insights lead to the second part of the book and his subsequent theory known as 'Logotherapy' (logos is the Greek word for meaning). In Frankl's own words he explains that Logotherapy "focuses on the meaning of human existence, as well as on man's search for such meaning" and believes finding meaning in our lives is our primary motivation in life.

There is much I find inspiring and encouraging in this book, so I will let Victor Frankl have the last word, with some of his stand-out quotes:

"Everything can be taken from a man but one thing: the last of the human freedoms – to choose one's attitude in any given set of circumstances, to choose one's own way."

"When we are no longer able to change a situation ... we are challenged to change ourselves."

"I do not forget any good deed done to me, and I do not carry a grudge for a bad one."

"Instead of possibilities, I have realities in my past, not only the reality of work done and of love loved, but of sufferings bravely suffered. These sufferings are even the things of which I am most proud, though these are the things which cannot inspire envy."

"There was no need to be ashamed of tears, for tears bore witness that a man had the greatest of courage, the courage to suffer."

"Decisions, not conditions, determine what a man is."

**LIL O'TOOLE
MSWA COUNSELLOR**

GET INVOLVED: FATIGUE MANAGEMENT

We are back in action! We have commenced our new and improved fatigue management groups at MSWA. These small groups are focused on defining fatigue specific to multiple sclerosis, delving into topics such as contributors to fatigue, coping strategies to reduce and manage fatigue, and how to discuss fatigue with others.

The aim of the group is to build on personal experiences with guidance from our Occupational Therapists to manage fatigue. Our fatigue workshops provide a solid foundation to fatigue management, with the intention that participants can follow up individually or with the support of their Occupational Therapist for a more personalised program. These groups are established at our Butler and Wilson facilities and we are looking to expand to more locations and Telehealth options. In future groups, we are looking to provide more information inclusive of other neurological conditions.

Feedback from participants has been positive, citing that the topics were relevant and applicable to them. They also enjoyed the information and interaction with presenters.

The feedback from the group also told us that the more participants the better, so please get in touch if you are interested!

Our next fatigue management group is on Friday 25 November from 9am-12pm in our Wilson hub.

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

FATIGUE MANAGEMENT WORKSHOP

Do you have fatigue?

Come to our interactive workshop to learn more about fatigue and how to manage it.

Where:

MSWA Wilson -
29 Parkhill Way, Wilson, 6107

When:

Friday 25 November
9am - 12pm

Topics discussed:

- / What is fatigue
- / What contributes to fatigue
- / Importance of rest
- / Types of rest
- / Work simplification
- / Prioritising

Morning tea will be provided!

If you are interested or what further information about the fatigue group, contact your OT or phone 9365 4854.

If you are interested in attending one of our interactive groups, please don't hesitate to contact our OT Contact line on 9365 4854 or email us via ot.referrals@mswa.org.au. From there, one of our Occupational Therapy Assistants will get in touch and discuss further details and criteria.

Light morning refreshments and lots of laughter are also provided! We look forward to welcoming you soon.

**SARAH COUTINHO AND GWEN LEE
MSWA OCCUPATIONAL THERAPISTS**



NEW TECHNOLOGY TAKING THE PRESSURE OFF

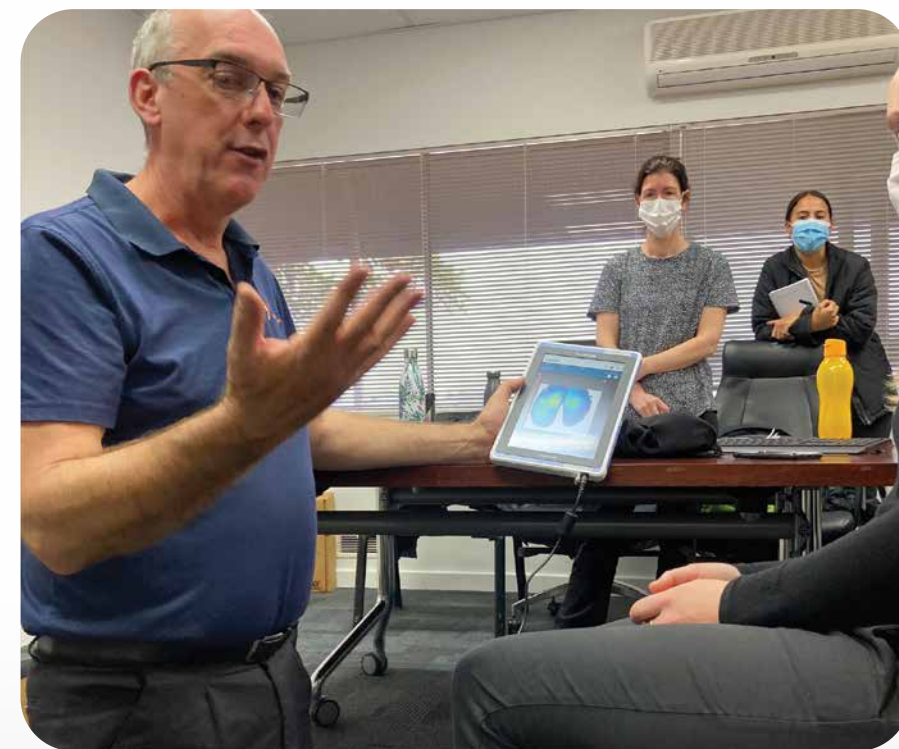
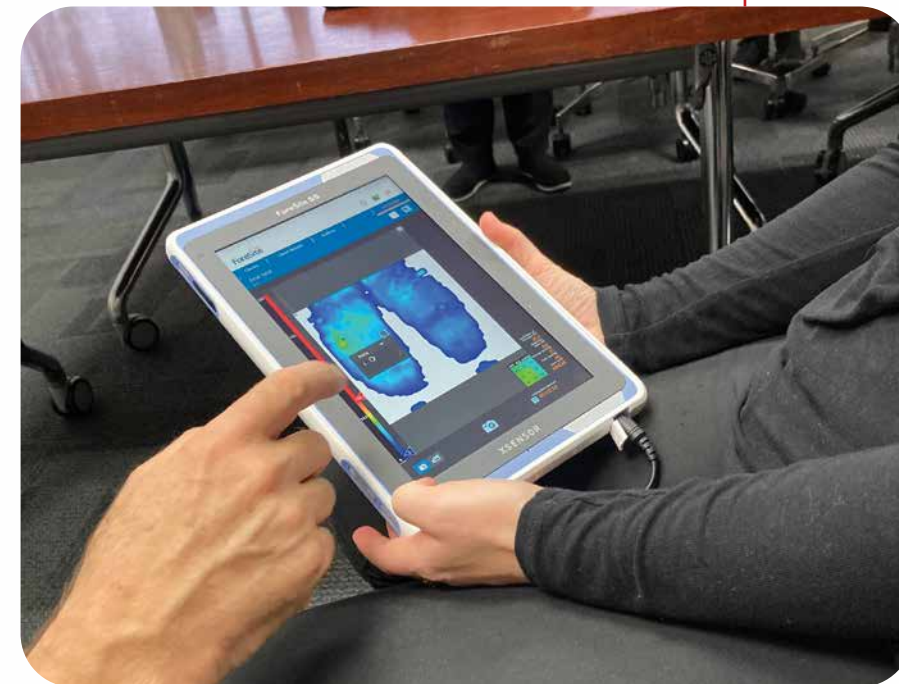
The MSWA Occupational Therapy team has recently implemented a new pressure mapping system to improve our postural assessment process.

This technology allows our clinicians to identify areas within a Client's seating that may be experiencing higher pressure, which can increase the risk of developing a pressure injury. These pressure injuries can cause pain, discomfort and are more likely to occur if our Clients do not have the right seating and cushioning to suit their specific needs.

With the information gathered from the pressure mapping process, we can make recommendations and adjustments to the Clients seating system to improve the pressure distribution around any high-risk areas, reducing the risk of these pressure areas developing, and improving position and comfort. This information can also help us choose the most appropriate and comfortable cushion for Clients using wheelchairs and other pressure relieving devices.

It's a fine art, and by implementing ever-improving technology we can tailor a seating system to suit every individual's needs!

**ANNA JESSOP
MSWA SENIOR
OCCUPATIONAL THERAPIST**



SAY 'CHEESE!': LET'S KEEP DAIRY IN THE PICTURE

Dairy foods like milk, cheeses and yoghurt can bring a great source of joy to our meals. But are these foods safe to eat for people with MS? Recent research suggests that dairy is safe to include in your diet and is not likely to aggravate your MS symptoms. This is great news!

So, what does the research say?

Many studies have compared the amount of dairy eaten by people with MS, against their level of fatigue, relapse rates, disability progression and quality of life. Results across these studies have not found a consistent link between eating dairy and worsened MS for any of these factors. This means that eating dairy is not likely to make your MS symptoms worse and can be enjoyed within a healthy diet.

Why is dairy good for us?

Dairy foods are a great source of protein, calcium and other nutrients. Protein is important to maintain our muscles, immunity, bones and strength. Calcium is also very important to keep our bones strong. These are important nutrients for people living with MS – to keep bones and muscles strong for movement and wellbeing. Dairy foods also provide a healthy energy source, which can help with fatigue and weight management.

What are healthy dairy foods?

The best sources of dairy are milk, cheeses and yoghurt. Lactose-free options are also available for each of these options if needed. Healthy milk choices include fresh or long-life milk and soy-based milks. Other plant-based milks have less protein, but if you prefer these, be sure to pick one that has added calcium and where possible, added protein. Look for products that have 'calcium plus' or 'high protein' on the packaging.

The best cheese options are cheddar or other hard cheeses, ricotta, or cream cheese. Greek or natural yoghurts are also great sources of dairy, and if you prefer plant-based yoghurts, make sure you also check these for added protein and calcium.

If you need a diet that is texture-modified, milks and yoghurts can be easily thickened to meet your needs, and can provide great flavour, variety and nutrition to your diet.

The choice to use full-fat or reduced-fat options would be based on personal tastes, nutrition goals and recommendations from your dietitian.

So in summary, people living with MS can enjoy dairy foods as part of a healthy diet. Think about your favourite dairy foods and add them to your plate today!

HANNAH PAPENDORF
MSWA PRACTICUM STUDENT
CURTIN UNIVERSITY MASTER OF DIETETICS
SUPERVISED BY MSWA SENIOR DIETICIAN
MISTY REINKOWSKY

References:

Australian Dietary Guidelines. (2013). National Health and Medical Research Council Canberra: National Health and Medical Research Council.

National Health and Medical Research Council (NHMRC). (2013). Eat for Health: Educator Guide. Australian Government, Department of Health and Ageing.

https://www.eatforhealth.gov.au/sites/default/files/files/the_guidelines/n55b_eat_for_health_educators_guide.pdf

MIXED BERRY SMOOTHIE WITH YOGHURT

With summer on the way, we have a great mixed berry smoothie recipe for you to try!

Mixed Berry Smoothie with Yoghurt
(serves 2)

Ingredients:

- / 1 banana
- / 2 cups frozen mixed berries (or berries of your choice)
- / 1 ½ cups milk
- / ½ cup Greek yoghurt

Method:

1. Combine all ingredients in a blender and blend until smooth
2. Divide between two glasses and enjoy!

A note for texture-modified diets & mealtime management plans

1. If required, thicken the smoothie to a safe consistency for your needs, by either:
 - / Adding more Greek yoghurt or banana, or
 - / Add oats and blitz to a smooth consistency, or
 - / Use flavourless thickener such as Resource ThickenUp
2. For a smooth puree diet, make sure you strain the smoothie before serving to remove any seeds or lumps



Source: <https://cookingformysoul.com/mixed-berry-yogurt-smoothie/>

SPILLING THE BEANS ON CAFFEINE CONSUMPTION: HOW MUCH IS TOO MUCH?

Coffee or tea might be your favourite morning drink, but how much caffeine is healthy? And are there any benefits?

Research has investigated the effects of caffeine on Parkinson's disease, multiple sclerosis and dementia, with positive findings. While there is still a lot of work to be done in this area, preliminary findings have shown a positive link between moderate caffeine consumption and the trajectory of damage to the brain. This means your morning tea or coffee is still in, yay!

What is caffeine? Is it in more than just tea and coffee?

Caffeine is a mild stimulant which speeds up the actions of the brain and messages sent around our body. It can be found naturally in plants, beans and leaves used to make coffee, tea and cocoa, and is added to other products like cola, energy drinks and sporting supplements.

Product	Caffeine content
50 mL espresso	145mg*
250 mL energy drink	80mg
1 tsp instant coffee	80mg
220 mL cup of black tea	50mg
375 mL cola can	36mg
50 g milk chocolate bar	10mg
1 cup decaf coffee	3mg

*Coffee from a café may have a different amount of caffeine each time.

So how much caffeine should I be having in a day?

The Food Standards of Australia and New Zealand (FSANZ) have suggested that adults over the age of 18 should have no more than 400mg of caffeine per day and a maximum of 200mg in one sitting. Over a whole day this may look like

two regular coffees, one cup of tea and two small chocolate bars.

For children under 18 years, safe amounts are suggested at no more than 3mg of caffeine per kilogram of body weight. For example, a 40 kg child should have less than 120mg of caffeine in a single serving (ie. 3mg x 40kg = 120mg).

If you are having caffeine daily to manage your fatigue, keep this intake below suggested amounts and avoid caffeine at least five hours before bedtime to prevent disruptions to your sleep.

Why can my friend have three cups of coffee every day and feel fine, but I feel nervous and shaky after only one?

Like many things in life, we are unique. This means there are lots of differences in what we like, what makes us feel good and our tolerance to different things. Some people may feel the effects of caffeine quickly and these feelings may go on for up to six hours, whilst others may not. You may feel more awake, dizzy, restless, anxious, dehydrated, breathe faster, or need to urinate more often.

If you are concerned about your intake or tend to feel the physical effects of caffeine, try reducing the amount you have, choosing decaffeinated drinks, or talking to your dietitian at MSWA.

Hot tip: There are plenty of options at the supermarket or your local café. Why not try a cup of decaf coffee or tea for your next morning brew!

EMILY FORBES
MSWA PRACTICUM STUDENT
CURTIN UNIVERSITY MASTER
OF DIETETICS

SUPERVISED BY
MSWA SENIOR DIETITIAN
MISTY REINKOWSKY

BOCCONCINI AND BEETROOT PASTA SALAD

Nutrition information:

Energy: 2100kJ
Protein: 24g
Total fat: 29g (Saturated: 8g)
Carbohydrates: 32g
Fibre: 10g
Sodium: 195mg
Calcium: 335mg

Serves 2

Ingredients

- / 1 large fresh beetroot
- / 10 cherry tomatoes cut in half
- / 80g of bocconcini cheese, roughly shredded
- / 30g walnuts, roughly diced
- / 2 teaspoons of sesame seeds
- / 2 cups of rocket
- / 1 tablespoon of Australian Extra Virgin Olive Oil
- / Juice of ½ a lemon
- / Salt and pepper to taste
- / 100g of pasta. A few of our favourites are the Vetta Smart Pasta, the San Remo Red Lentils Spirals Pulse Pasta, San Remo Pasta Pro Protein Penne Pasta or the Slendier Edamame Bean Organic Fettuccine.



Method

- 1) Roughly dice up beetroot into squares and cook in the oven (or air fryer) at 200°C until tender. Once cooked, remove from the oven and leave to cool.
- 2) Meanwhile, boil a medium pot of water and cook pasta until tender. Once cooked, drain and set aside to cool.
- 3) In a serving bowl spread out rocket and tomatoes. Sprinkle over walnuts, sesame seeds and bocconcini. Add roasted beetroot and pasta and toss together with lemon juice and EVOO as dressing.
- 4) Enjoy!

References:

- <https://www.foodstandards.gov.au/consumer/generalissues/Pages/highly-concerntrated-caffeine.aspx>
- <https://adf.org.au/drug-facts/caffeine/>
- <https://www.coffeeandhealth.org/topic-info/caffeine-sources-of-caffeine>
- <https://www.foodstandards.gov.au/consumer/generalissues/pages/Caffeine.aspx>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7353179/>
- <https://doi.org/10.3389/fnut.2018.00133>
- <https://doi.org/10.3389/fnagi.2021.744872>
- <https://www.ncbi.nlm.nih.gov/books/NBK223808/>

WATER, LIFE, THE UNIVERSE AND EVERYTHING! - PART 1

Water is the true essence of life. For your body to operate at its maximum efficiency, you need to ensure that you stay well hydrated by drinking water and consuming moisture-rich foods. Amazingly, up to 60 per cent of the adult human body is made up of water.

Drinking enough water keeps your:

- / skin and hair looking its best,
- / helps prevent disease and illness, and
- / improves your overall health and wellbeing.

To achieve and stay in optimal health, you need to ensure you drink enough water daily. Most people feel thirsty regularly, prompting them to intake an adequate amount of liquid, but others do not feel thirst reliably.

A good guide for water intake is eight to 10 glasses (250ml) of water per day. This includes all drinks except those containing caffeine (such as coffee, tea and cola). Of course, this depends on your age and sex and medical condition.

This might sound like an alarming amount of water to consume, but remember that we also take in around 1000ml of additional fluid daily through food, based on a normal balanced diet.

If you are living in a hot climate, like we do in Australia, or when you exercise, you will need to increase your water intake. It is important to discuss with your GP or specialist what amount is adequate for you, depending on any underlying conditions.

We must consume enough fluid to replace the amount our bodies lose each day, which is usually around two litres. Of this, 1.5 litres is eliminated through urine, with the remainder lost due to perspiration and water vapour through breathing.

So what are the take away points? What can I do for myself?

- / Pay attention to how much water you are consuming. Is your body prompting you to drink enough? Or do you need to be more conscious of your intake?
- / For men, it is recommended to consume a total of 2.5 litres per day For women, it is recommended to consume a total of 2.0 litres per day
- / Watch out for signs and symptoms of dehydration; the chart opposite gives a good indication on what to look out for.

**ROCHELLE BROWN
MSWA NEUROLOGICAL
LIAISON NURSE**



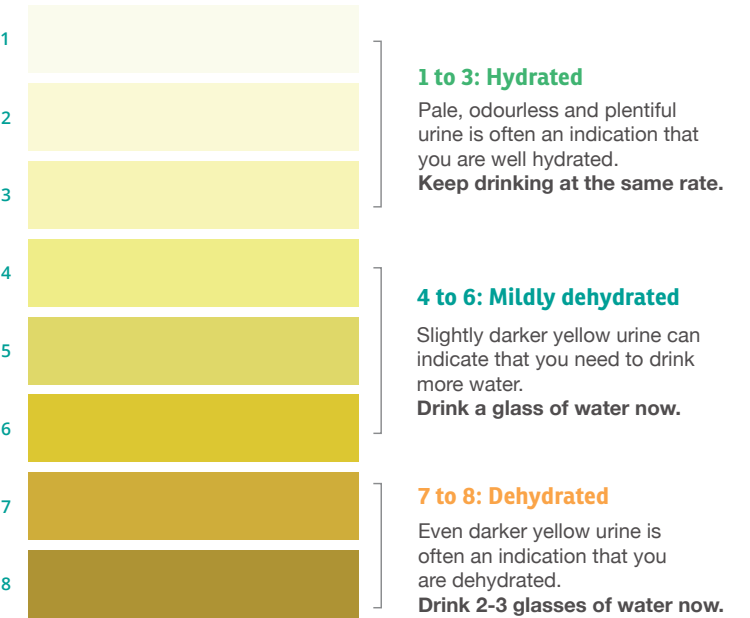
In this series, our upcoming articles will focus on ‘The role water plays in our lives’. We will expand on each of these roles as listed below:

- | | |
|-----------------------------------|---------------------------------------------------------|
| / Saliva production | / Assisting your body to absorb nutrients |
| / Temperature regulation | / Impact on individuals with continence challenges |
| / Protecting tissues and joints | / Making up for the fluid loss from certain medications |
| / Removing waste products | |
| / Preventing constipation | |
| / Assisting the digestion of food | |



Am I drinking enough water?

Use this urine colour chart to assess how hydrated you are. It is important to drink plenty of water each day to stay healthy.



What can change the colour of my urine?

Certain foods, medications and vitamin supplements may change your urine colour even if you are hydrated.

Important

The colours on this chart should only be used as a guide and should not replace the advice of a health professional. Speak to your doctor if you are worried about the colour of your urine, the amount of water you drink or dehydration.

Sources:
Kidney Australia - Drink water instead factsheet
Armstrong et al.; Urinary indices of hydration status; Int J Sport Nutr. (1994)
Armstrong et al.; Urinary indices during dehydration, exercise and rehydration; Int J Sport Nutr. (1998)



www.healthdirect.gov.au

OUR COMMUNITY SUPPORTERS

It has been a busy quarter for team MSWA, with our loyal supporters working hard to raise money and awareness for our cause. Check out their inspiring stories below! Eager to do your part? Get in touch with our events team on 6454 3131 or events@mswa.org.au.

Andrew Warnock

Andrew Warnock took part in the Goldfields Pipeline Marathon as a community fundraiser for MSWA, raising more than \$5,000 for people with neurological conditions.

Andrew had chosen to raise funds and awareness along the way for MSWA, a cause very close to his heart as his mother lives with multiple sclerosis.

Andrew is a third-year medical student from Notre Dame University on placement at the Rural Clinical School of WA. He is no stranger to a challenge, as in 2021 he took part in the Rottneest Challenge Swim and raised over \$4,000 for MSWA.

This time around, Andrew decided to take on the 42km marathon along the Kalgoorlie-Boulder Pipeline with support from his family and friends, raising a total of \$5,208.50 for MSWA – an outstanding effort!



Alex Shorter – Mandurah Masters

Alex Shorter, together with the Mandurah Masters Swim Club, hosted a 'Joke and Auction Night' in July, with funds raised directly supporting MSWA. Alex is a loyal MSWA supporter, who lives with MS. She previously took part in the Port to Pub challenge in 2021 where she raised just shy of \$2,500 for MSWA.

The Mandurah Masters Swim Club host an event annually to raise money for a chosen charity or organisation. This year the club generously chose MSWA. The auction items from the night were donated by local businesses, with an amazing \$5,700 raised on the night!

Wojciech – Busselton Ironman

Wojciech Adamczyk has been busy raising money for MSWA for the upcoming Busselton Ironman. Our cause is a personal one for Wojciech. After experiencing dizziness, his girlfriend encouraged him get an MRI in November of 2021. The results indicated that it might be MS, which turned his world upside down. After more scans and tests, a neurologist confirmed the diagnosis of multiple sclerosis in March this year.



He made the decision to compete in the Ironman in December while he still could. Thankfully, his condition is controlled and his outlook is positive. The GWN 70.3 Ironman takes place on Sunday, 4 December and will consist of a swim, run and ride. Over 2,500 athletes will take their places at Geographe Bay in Busselton for the event.

Wojciech has been tracking his training on Strava and updating his fundraising page. His journey with MS has been shared on his social media pages to raise awareness of the condition and to support his upcoming challenge.

He has set himself the goal of raising \$10,000 for MSWA to continue to provide services to those who need them. Currently over \$3,400 has been raised with the support of friends, family and colleagues. We wish him the best of luck in his endeavours.

EVENT WRAP UP

Dinner Auction

On 11 August 2022 MSWA welcomed over 200 guests to celebrate the MSWA Annual Dinner Auction at Fraser's in Kings Park.

This year's event also saw the celebration of MSWA's 50-year milestone of supporting and providing services to people with MS and other neurological conditions in Western Australia.

On the night, our annual commitment awards for both individuals and businesses were presented to Vera Reeve and Wood Australia Pty Ltd respectively. These awards acknowledge outstanding contributions and efforts and we thank both Vera and Wood Australia for their commitment to our cause.



The night was an enormous success, the highlight being the \$27,000 raised to go towards the Wilson Services Centre Physiotherapy Gym. We want to extend heartfelt thanks to all of those who have supported and continue to support MSWA.



CLIENT AND VOLUNTEER CHRISTMAS PARTY 2022

- Date:** Monday, 5 December 2022
- Time:** 10.00am – 1.30pm
- Venue:** Lifestreams Christian Church, corner Murray Street and McNabb Loop, Como (Please note this is an alcohol-free event)
- Included:** Spit roast buffet lunch with all the trimmings, drinks, entertainment and a small gift
- Cost:** Free to Clients and volunteers, \$20 for all other guests
- RSVP:** No later than Monday, 28 November 2022
- Clients:** Please RSVP to Melissa Coombs on 9365 4830 or Outreach@mswa.org.au
- All others:** Please RSVP to Donna Hill on 9365 4869 or Donna.Hill@mswa.org.au

RESPITE: MY FIRSTHAND ACCOUNT

I had my first stay at Margaret Doody Respite on a Tuesday. Apart from staff, the first person that I met there was a lovely Greek woman named Mary. My sister Anita was there at the time and, as her husband is Greek, she knows a lot more Greek language than me and they were able to have a conversation. The only Greek I know is Den Milou Elenika, which means "I don't speak Greek"!

On Tuesday afternoon my friend Lynn came and visited me and when I asked if she could stay for dinner, the staff very generously said yes. It was lovely to see her. On Wednesday afternoon my manfriend David came with his old English Sheepdog, and everyone was very excited about the big hairy dog.

Later that day my friend Kathleen came for a visit and it was lovely. She has just come back from visiting Ireland where she grew up, and had lots of lovely stories to tell about catching up with brothers, sisters, nieces and nephew.



Ros Harman (front right) enjoyed getting to know staff and residents during her stay at Margaret Doody House.

Later in the year, when my daughter, her partner and two young kids will come over from Queensland, I am having my late birthday party. My birthday was in March, but COVID-19 restrictions meant a party was out of the question then. I am having a DNA party. As my father was Greek and my mother had a mixture of Irish, Scottish and German in her ancestral heritage, we will enjoy food from all those countries and I have made up a playlist of music from those countries too.

Respite is an interesting concept. I have got to the stage where sometimes I have trouble getting out of bed in the mornings and sometimes I have trouble standing and transferring to my wheelchair from the toilet. So my older sisters thought it would be good if I experienced a couple of weeks in respite to see what it's like.



On one hand I would rather be at home in my own house, but I accept that I need a full-time carer. On the other hand, I have met some lovely people here.

The staff are gorgeous and some of the other guests are very interesting too.

Margaret Doody House is a nice place and has a lovely outdoor area just off the main living room. Everything is wheelchair accessible and staff are always there to help with anything that is needed.

As long as I get plenty of visitors, I am happy to be here. The shopping centre is just down the road and it has some nice cafes, so if one gets a chance, one can go down there and have some rest and relaxation.



The rooms are pleasant here, with fully mechanised beds that move up and down in all directions. The gardens are lovely and in the morning one hears many birds singing.

Nevertheless, I am looking forward to going home again. My sisters are trying to find someone who would live in with me so I can stay in my own home. I hope they are successful. Respite is a wonderful service provided by MSWA for people with neurological conditions and I'm sure Clients are very grateful for the service.



FAMILY SIZED FUN AT MSWA CAMPS

As the weather warms up and people shed their layers of winter wear, the spring season brings the promise of better days to come. With WA's COVID-19 cases on the decline, life as we know it is inching closer to what it was prior to the pandemic.

Like most things, camps took a big hit this year with over 50 per cent cancelled when infection rates were on the rise and staffing numbers were diminished. The decision to withdraw camps was not taken lightly, but the risks of exposure, especially for our Clients, was a risk we weren't willing to take.

Following the WA Health Department's lifting of COVID-19 restrictions, we were fortunate to organise and run two small Carers Retreats and the annual Family Camp on short notice.

All camps took place in the September/October period, with the Family Camp running in the Term Three school holidays. Five families with their primary school aged children participated in the three-night camp at Woodman Point. Activities ranged from pool-noodle hockey to beach play, archery and the crowd favourite, the flying fox.



Children on Family Camp enjoying beach play.



Our carers enjoying bowling as part of the Carers Retreat in Safety Bay.



The competition heats up during a game of hockey at Family Camp.

VOLUNTEERS UPDATE

In the last *Bulletin*, we called out to our readers asking if they, or someone they knew, would be interested in volunteering with us as we have a number of positions to fill. I'd like to say a big thank you to those who've come forward to help.

However, we still have a number of opportunities to fill. If you, or someone you know, would like to be a part of the MSWA Volunteer Team, please contact Mala Padmanathan, Volunteer and Camp Coordinator on 6454 3184 or via email at Mala.Padmanathan@mswa.org.au.



Our carers head out on the water as part of the October Kilmoree Carers Retreat.

WE WANT YOU!

Positions available:

Admin Assistants (2 positions): Kelmscott, Vasse

Kitchen Assistant (2 positions): Wilson, Beechboro

Activity Assistant (1 position): City Beach

Gardener (2 positions): Beechboro, Hamilton Hill

WOULD YOU PREFER TO RECEIVE *BULLETIN* ONLINE?

Help us to reduce our environmental impact by going digital! Not only does this save trees and minimise our contribution to landfill, but it also allows you to better engage with our *Bulletin* content. Get in touch via communications@mswa.org.au to sign up to our e-magazine.



BUTLER SERVICES CENTRE INCREASES OFFERINGS

Our purpose-built Butler Services Centre was officially opened in October 2019 to provide services and accommodation for people with neurological conditions filling a gap in the community north of Perth.

Following the relocation of our Joondalup services to Butler in October 2022, we now have the exciting opportunity to expand our service offering and create more opportunities for social engagement.

Our Butler Services Centre offers the whole range of allied health services including Physiotherapy, Occupational Therapy, Speech Pathology, Dietetics, Nursing and Counselling, as well as Support Coordination.

The Services Centre also serves as a base for staff coordinating home support and Client engagement.

We will be running some exciting group education opportunities from our Butler Services Centre, including:

Newly Diagnosed Seminars

Counselling Workshops

- Mindfulness workshops

Occupational Therapy

- Fatigue management workshops
- Low-Cost assistive technology workshops
- Cognitive & sleep strategies

Physiotherapy

- Falls prevention workshops
- Evening group circuit classes

Dietetics

- Nutrition workshops

Speech Pathology

- Voice therapy groups

Peer Groups

What's more, we have also recently added a large range of new equipment to our gym.

Want to know more?

Get in touch on

08 9365 4888 or online at

mswa.org.au/locations/butler



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.

