



WE KNOW NEURO

THE OFFICIAL MAGAZINE OF MSWA

Summer 2019

mswa.org.au

BULLETIN



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MSWA President George Pampacos, Kate Gild, Disability Services Minister Hon. Stephen Dawson MLA, Brian Dawson and MSWA CEO, Marcus Stafford at the official opening of Butler Services Centre and Supported Accommodation facility.



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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**
General feedback or complaints please contact Liz Stewart 6454 3173 or feedback@mswa.org.au

EDITORIAL COMMITTEE

Greg Brotherson (Editor), Marcus Stafford (CEO), Paul Cavanagh, Sue Shapland, Nicola Washington, Ros Harman, Libby Cassidy, Lizzie Thelwell, Carol Chong, Aileen Ward and Geoff Hutchinson.
The Editor 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.

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NURSING

Our MS nurses are usually the first point of contact after the neurologist's diagnosis of MS.
JILL CROMBIE, MANAGER: 9365 4888 OR COMMUNITY NURSE: 9365 4888

PHYSIOTHERAPY

Our team aims to provide treatment interventions to develop and maintain mobility and function.

DAVE HATHORN, MANAGER: 9365 4837 OR PHYSIO DEPARTMENT: 9365 4834

OCCUPATIONAL THERAPY

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

ILISSA LIEW, MANAGER: 9365 4804 OR OT DEPARTMENT: 9365 4888

SPEECH PATHOLOGY

Our Speech Pathologists provide support by assessing, diagnosing and creating individualised treatment programs for Members who experience swallowing and/or communication difficulties.

PAMELA WINDRAM, MANAGER: 6454 3140

DIETITIANS

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. We have a Peer Support & Health Education Coordinator who organises peer connection & events and supports health and wellness education services.

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

SOCIAL WELFARE

Social Welfare Officers assist Members 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

INDIVIDUAL OPTIONS

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.

AILEEN WARD, MANAGER: 9365 4851

THE NDIS TEAM

Our experienced team can help determine whether you may be eligible for NDIS support and assist you with your application. This includes developing an individual plan that best suits your needs.

GEOFF HUTCHINSON, MANAGER CUSTOMER ENGAGEMENT: 9365 4879

CAMPS & RECREATION

MSWA provides separate recreation camps for Members, 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.

COORDINATOR FOR CAMPS & RECREATION: 9365 4843

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FROM THE DESK OF THE CEO



MARCUS STAFFORD
CEO

All of us at MSWA were delighted to officially open our modern, new Services Centre and Supported Accommodation facility in Butler this October. At the opening were the Disability Services Minister, Hon Stephen Dawson MLA and many residents who helped us celebrate this impressive achievement. This \$8M facility provides a range of vital services, as well as high-support accommodation, for people with neurological conditions who can no longer stay living in their own homes.

Butler is part of our long-term strategic growth plan to continue to develop metropolitan and regional facilities for our Customers.

With 14 MSWA facilities currently operating in Western Australia, we are ready to increase that number to more than 20 in the next few years. On the cards are high-support accommodation facilities in Albany where the land is purchased and designs are being developed, and for Shenton Park where we are negotiating the purchase of a parcel of land at the old Shenton Park hospital site. This growth is necessary to ensure we continue to meet the needs of our Customers; to support them in living their lives well and independently.

Some of you will have received communications about a review of our in-home care support service. This service forms an integral part of what we do at MSWA. Services such as personal care, meal preparation, shopping and home cleaning make a significant in-road into making lives easier, more comfortable and more enjoyable.

Just as important is the social support these roles provide our Customers; accompanying them to the movies, taking the dog for a walk or simply a companion for a coffee and a chat. With all these things in mind, we are reviewing the processes around which we deliver this service to ensure we provide it in the best possible way.

This year was our tenth year holding Ocean Ride – Powered by Retravision. I was there, on my bike, proudly wearing my MSWA jersey. The turnout is always terrific, and the community spirit is strong. This year was no exception with 1,473 participants raising an impressive \$343,000 that goes directly to people with neurological conditions.

It's so great to see both cycling enthusiasts and novices getting involved to demonstrate their support of colleagues, family members and friends, just as it is wonderful to hear of those with neurological conditions getting on their stationary bikes to clock the kilometres required. Over the past 10 years, this event has raised an impressive \$2.1M and I look forward to another 10 years and beyond of getting on my bike and pedalling with so many others committed to the cause.

If you haven't already, I strongly recommend you visit our newest event, an art installation project, SensAtion, in East Perth. It will provide you with a memorable and challenging sensory experience. It's on until 23 December and you can find out more in the What's On section of this edition of *Bulletin*.

The Editor of *Bulletin*, Dr Greg Brotherson, was unable to contribute his regular message for this edition of our MSWA magazine. We look forward to hearing from him in the following Autumn edition.

As the year comes to a close, I am reflecting on an exceptionally successful 2019. May 2020 bring us more success and happiness. I wish you all a very happy Christmas and holiday season, spent with loved ones.

STRATEGIC SUPPORTS AND RESIDENTIAL OPTIONS



SUE SHAPLAND RN, BN, MSCN
GENERAL MANAGER
STRATEGIC SUPPORTS AND
RESIDENTIAL OPTIONS

"Even if you're on the right track, you'll get run over if you just sit there."

Will Rogers.

I thought this quote was an interesting one but relevant to many situations including our MSWA journey. We kept moving forward when there was uncertainty about the NDIS and which model would be selected. This put us in good stead and has seen us help so many Members and Clients get their best from the NDIS. Albeit the process is often protracted which is not within our control.

When we built Treendale Gardens and included a respite facility, there was no funding guaranteed for respite, but our Board approved the use of MSWA funds to support Members to access this wonderful facility. We are now turning the corner thanks to those Members and Clients with NDIS funding to purchase their respite stays.

Over the years we have significantly topped up our government grant funding, allowing more Members to access at least some of the supports they needed when individual funding was limited, and HACC hours just weren't enough. Obviously the NDIS has really changed the game and so many are able to access the funding they need, and have it reviewed when their needs are changing.

As we well know, the over 65s aren't eligible for the NDIS, however, we recently received great news that the Federal Government Continuity of Support Program funding will be available for those Members who have accessed Disability Services Funded Programs and packages! This is fantastic news and as an approved provider, we will soon contact those identified by the program as recipients of the funding based on their eligibility criteria.

The year continues to fly past. Each year we wonder where the time goes but I think that reflects how busy we all are. MSWA has had another fabulous year and we continue to kick so many goals in so many areas. Our events, raffles and lotteries; our research funding allocation; our Member and Client service delivery hours; and of course, our supported accommodation and respite options.

I can't quite believe that Butler has now been open for 10 months, and what a fantastic complex it is. At the official opening held in October, the guests couldn't quite believe how luxurious our accommodation units and surrounds really are. They were blown away! The residents proudly showed off their wonderful homes to several special guests including the Hon Minister for Disability Stephen Dawson MLA. I would like to personally acknowledge the hard work and creative input from Senior Manager Andrea Taylor and our architect Alec Whyte.

We are so proud of all our MSWA high support accommodation locations and of course, the respite facilities – not just for the actual facilities, but for the real difference the staff make in the lives of the Members and Clients who reside or stay in them. I am looking forward to our coming projects in Albany and Shenton Park. With more funding through the NDIS and word of our great facilities spreading, we have a growing waitlist of potential residents.

As the year draws to a close, we will remain busy working towards ensuring our full compliance with the NDIS Safety and Quality Commission which rolls out next July and with Aged Care Provider compliance.

I wish you and yours a safe and happy break over the Christmas and New Year period; stay cool as I suspect it's going to be a warm summer!

MEMBER & CLIENT SERVICES



NICOLA WASHINGTON
GENERAL MANAGER
MEMBER & CLIENT SERVICES

Welcome to the summer edition of *Bulletin*.

As I started to write this summer update, I realised I have been with MSWA for a year – how fast time has passed. I thought it would be a good time to reflect on my experiences of the past 12 months.

I don't think there would be any surprises if I said it has been busy, very busy, but it has been an interesting journey.

The NDIS has brought about significant change, both positive and not so positive, but always very interesting. There is no doubt that we have seen some fantastic benefits for people who are now able to obtain and manage their own services, but we have also experienced difficulties with the roll out of the NDIS and unfortunate delays in the activation of funded plans.

As I reflect on the past year, what is a standout for me, is the passion, commitment and hard work I see every day from our wonderful staff. Whether it is through our allied health services, in-home care or assistance through NDIS planning, I have been amazed at the dedication of the people who work tirelessly to improve the quality of life for all our Customers.

Joining MSWA was a big change for me and since starting, we have continued on the path of transformation with the implementation of the NDIS. Our focus remains on building and delivering our Customer-centric model that enables us to put you, the Customer, at the centre of everything we do. Our mission is to be here to help you with understanding and accessing the NDIS. If you have any concerns or queries please do not hesitate to contact a member of the team at ndisenquiries@mswa.org.au.

It was a pleasure to attend the graduation ceremony for 10 staff members who completed their Certificate III and IV in Disability. This is a fantastic program that MSWA provides to support our Care Support Workers to gain further skills and deliver quality service to our Customers. Congratulations to all those who graduated.

The Butler Services Centre and Supported Accommodation facility official opening was held on 3 October and it was fantastic to see so many people attend and enjoy a tour around our wonderful Centre. We have received fantastic feedback regarding the outstanding quality and design of the site. It was a very enjoyable morning and a big thank you to everyone involved in the organisation of this event.

We are now running events for our newly diagnosed Customers at our Belmont facility. Several Members, partners and family members took part in an informal session at MSWA Belmont for two hours one evening in October. MSWA Nurse Rosie Hunt gave information about MS and stories were shared about living and working with the condition. These groups are run throughout the year. Please contact Sabena Lund at Sabena.Lund@mswa.org.au to find out more.

It has been wonderful to meet and talk with so many of you over the past twelve months. I always appreciate hearing about your journey and your feedback is important to ensure we continuously improve our services, so if you would like to provide any feedback please email customerservice@mswa.org.au.

As we draw a close to 2019, I would like to wish you all a very merry Christmas and a safe and happy start to the New Year.

THE ANNUAL GENERAL MEETING

Annual General Meeting held

11am Tuesday, 15 October 2019 at Wilson:
MSWA delivers most successful year ever.



DR GREG BROTHERSON

For those of you who could not attend the MSWA Annual General Meeting, the following is a précis of the Annual Report and audited financial statements. Copies of this Report and Financial Statements, including the statement of comprehensive income, are available on the MSWA website.

The President, Mr George Pampacos, reported 2019 was MSWA's most successful year, with significant milestones being achieved, record-breaking income and a resultant contribution to research. This success has been the result of strategic planning by the CEO, senior managers and Board over the past five years. MSWA stayed on the originally planned path, whilst being adaptable with the National Disability Insurance Scheme (NDIS) and always remembering that everything the organisation does is for its Customers.

He talked of the amazing and record-breaking events that were delivered to the MSWA community throughout the year. It was a great community program filled with fun, professionalism and clear MSWA branding. He thanked the events team, led by Gail Szabo, who go above the call of duty to make sure the events are a great success.

Mr Pampacos also spoke about the opening of the Butler facility in Perth's north, providing residential care and services to northern suburbs Customers. In addition, property has been purchased in Albany, with construction starting in this financial year for a similar facility to that in Butler. The new premises in Belmont is also an important central hub for the newly diagnosed, as well as a new home for the Brand, Marketing and Sales and Administration teams. Mr Pampacos's full report can be read in the Annual Report.

The Treasurer, Horst Bemmerl, reported that the Mega Home and Luxury Lottery campaigns were extremely successful this year, allowing MSWA to post a surplus for the year of \$2,178,457, and achieving record revenue of \$67,193,618.

The total income from Brand, Marketing and Sales was \$39,219,188. Expenditure on services to Members and non-Members was \$42,757,440 (up from \$37,763,458 the previous year), including the research contribution of \$3.5 million.

Our organisation's balance sheet reflects an increase in net assets to \$30,692,766 and total assets increased to \$47,124,189.

The CEO Marcus Stafford AM announced MSWA posted a record result against all measures. This result was delivered at a time of great challenge for the disability sector, with recent research findings showing 28% of service providers operating at a loss and 13% of organisations considering closing their doors.

Mr Stafford thanked and congratulated the MSWA team of over 800 people, without whom these stellar results would not have been possible. The wider MSWA community is equally important - the broad range of volunteers, Board Directors and Government partners, Members and Clients, and business and retail customers. Each group plays an important role within the organisation.

Mr Stafford also talked of MSWA securing its position as the leading funder of MS research in the nation, together with growing funding into broader neurological research. The record contribution of \$3.5 million will include both scientific and importantly, translational research.

Through the incorporation of sound commercial principles and by placing our Customer at the heart of MSWA's operating model, the organisation has performed strongly within the NDIS environment. The marketplace encourages scale to minimise the impact of fixed costs; a reality that MSWA both understands and embraces.

Choice and control for people with disabilities and their families is a foundation principle we support wholeheartedly, as it places the power of decision-making where it belongs – with the Customer. Our results show both the attraction of new Customers, most notably from the broader neurological segment and the retention of Members. The ratio of people with disabilities who we serve under the NDIS now stands at 60% people with MS and 40% people with other neurological conditions.

The 2019-20 year will see the complete roll out of the NDIS and the continued growth of all facets of the organisation. Further development launches from the firm foundations that MSWA has built over the last ten years and aligns with the clear roadmap contained within the organisation's strategic plan.

New Board Members were confirmed, and Mr Pampacos announced that Michael Linto, Nebo Franich, Michael Fay, and Glennys Marsdon were elected to the Board.

RSM are appointed auditors for the coming year.

There being no questions from Members, the meeting closed.



Copies of the Annual Report and audited Financial Statements, including the Statement of Comprehensive Income, can be found online at mswa.org.au

RESEARCH ROUND UP

SUE SHAPLAND RN, BN, MSCN
GENERAL MANAGER STRATEGIC SUPPORTS
AND RESIDENTIAL OPTIONS

FROM MS RESEARCH AUSTRALIA

Full articles are available at msra.org.au

New genetic map shows different immune cells involved in MS onset

Whilst there has been much research into the contribution of genes to the risk of MS and the immune cells involved in MS onset, there is still a lot that remains unknown. Australian and international researchers have developed a genetic map of MS, which has more than doubled the gene changes known to play a role in MS.

These studies shed light on the role of the adaptive immune system in MS onset. The adaptive immune system is the part of the immune system that reacts to specific attacks and gains memory after being attacked the first time, allowing it to react faster to future attacks. Recent studies, including this new one, suggest that other parts of the immune system may also be involved in MS.

Published in the prestigious journal, *Science*, Australian and international researchers, as part of the International MS Genetics Consortium, looked at 47,429

people with MS and 68,374 people without MS to determine any further genetic changes that play a role in how MS starts and the cells that might be involved.

The researchers found a total of 233 independent gene changes linked to MS risk – 32 were located in a genetic region called the major histocompatibility complex (MHC), the area of the genome which contains the most significant risk MS genes.

This new MS genetic map has doubled the previously known MS risk genes. It is exciting that a genetic change was identified on the X chromosome, although it's unlikely this is the only factor contributing to the higher MS incidence in women. This is a first step towards understanding the genetic contributions of this strong bias.

These exciting findings show that a variety of immune cells contribute to MS risk and that both the adaptive and innate arms of the immune system play a role. This research sets the stage for further studies to uncover the sequence of events that lead to disease onset and may pave the way for new effective therapies.

What determines conversion to secondary progressive MS?

Secondary progressive MS (SPMS) usually follows on from relapsing-remitting MS (RRMS), but it's not easy to determine when this might happen to an individual, if at all. Thus, there is an urgent need to identify risk factors that influence conversion of RRMS to SPMS.

A large international study led by an Australian researcher studied cohorts with RRMS to identify demographic and clinical features that may be linked to a higher risk of developing SPMS.

The study found several factors influencing conversion to SPMS, paving the way for clinicians to identify those at risk earlier.

Of the 15,717 people in the first analysis, 85% received disease modifying therapies (DMT) and 10% converted to SPMS. The average time to convert was 32.4 years. The results show greater disability, rapid disability progression, higher number of relapses in the previous year, longer disease duration and older age were each linked to increased risk of SPMS. DMT and an improvement in disability based on the expanded disability status score (EDSS), were linked to a reduced risk of SPMS.

HERE WE PROVIDE SUMMARIES OF RESEARCH SOURCED FROM WEBSITES IN AUSTRALIA AND AROUND THE WORLD.

READ MORE AT
[MSWA.ORG.AU/RESEARCHUPDATE](https://mswa.org.au/researchupdate)



They also show that DMTs may reduce the risk of conversion to SPMS, which is supported by other studies. This study confirmed that the average time from MS onset to SPMS has increased from 15 years to 30 years over the last two decades, highlighting the efficiency of treatment options available.

These findings will be important for clinicians to help those who are at high risk of developing SPMS at an earlier stage. This means that interventions can be started earlier, reducing people's chances of ever developing SPMS.

FROM MS NEWS TODAY DAILY DIGEST

Full articles are available at <https://multiplesclerosisnewstoday>

Interleukin-22 may be biomarker to monitor how well RRMS patients respond to therapy.
Abdel-Dayem MA, Shaker ME, Gameil NM.

A new study shows that levels of the inflammatory molecule interleukin-22 (IL-22) may be a potential biomarker to evaluate disease severity and the effectiveness of treatments in patients with relapsing-remitting multiple sclerosis (RRMS).

IL-22, IL-32α, and IL-34 are three different cytokines detected in patients with various inflammatory diseases and are thought to have either pro-inflammatory or anti-inflammatory properties. Very few studies have investigated the role of these cytokines in MS.

In this study, researchers evaluated the levels of IL-22, IL-32α, and IL-34 in the serum of RRMS patients, to assess how well these cytokines correlate with the level of MS-associated disability – evaluated through the expanded disability status score (EDSS).

The researchers assessed the changes in these interleukins after treatment with three disease-modifying therapies: interferon beta-1b; interferon beta-1a; and fingolimod. Results showed a higher concentration of IL-22, but not IL-32α or IL-34, in untreated patients with RRMS compared to healthy individuals.

Treatments with both types of interferon and Gilenya led to a significant decrease in levels of IL-22 and IL-32α, but not IL-34, after six and 12 months of treatment, compared to initial concentrations before treatment. Further analysis revealed levels of serum IL-22 and, to a lesser extent, IL-32α correlated positively with the EDSS score.

Those results suggest that the lower the IL-22 levels, the lower the disability score. Thus, the team believes that IL-22 can be used as a tool to monitor how well patients are responding to treatment.

Researchers wrote: “IL-22 and, to a lesser extent IL-32α, may be potential markers for MS disease severity and efficacy of DMDs [disease-modifying drugs]. Meanwhile, there is no relation between the therapeutic mechanism of the used DMDs and the concentration of IL-34 in the blood circulation.”

Higher intellectual ability, early-life physical activity may protect against cognitive impairment in MS, study suggests.

Maria Pia Amato et al.

The aim of this small Italian study was to assess risk factors for Cognitive Impairment (CI) in MS patients, focusing on environmental exposures, lifestyle and comorbidities. One hundred and fifty MS patients with RRMS, and primary and secondary progressive MS were included. CI was identified in 30% of the participants and was associated with older age onset of MS, higher EDSS score, progressive disease course and lower pre-morbid IQ.

The findings suggested that physical activity in childhood-adolescence could be a contributor to cognitive reserve building, thus representing potential protective factors for MS-related CI susceptible to preventive strategies. The study also reviewed the influence of smoking, BMI, alcohol and caffeine.

In MS, physical exercise may be protective against the development of cognitive dysfunction and exert a synergistic effect together with cognitive rehabilitation in patients with established CI.

Is secondary progressive MS going to affect my life expectancy?

Receiving a diagnosis of MS, a progressive neurological disorder, can be frightening. People often ask what does this mean for me? Will my life expectancy be affected? Life expectancy is a 'best guess' of how long people will live, based on their date of birth, where they live, gender, and other considerations. It doesn't refer to individuals, but the population.

Currently data indicates the average life expectancy for MS patients is shortened by five to 10 years compared to people without MS. In the United States, the average life expectancy is 81 years for women and 76 years for men. However, most experts think that early diagnosis and new advances in treatments mean that this gap is narrowing.

How does MS change life expectancy?

This depends on several factors, including for example, susceptibility to chest and bladder infections which can be life-threatening if not treated properly.

Currently it's unclear why RRMS sometimes transitions to SPMS. But the gradual progression of symptoms means that patients need to keep a closer eye on their health. They will no longer have periods of remission as before, and many will experience a loss of mobility, which can increase the risk of injury and further lower life expectancy.

FROM THE ANNALS OF INTERNAL MEDICINE

Full articles are available at <https://annals.org>

Red and processed meat consumption and risk for all-cause mortality and cardiometabolic outcomes; a systematic review and meta-analysis of cohort studies

This study sought to evaluate the association between red and processed meat consumption and all-cause mortality, quality of life (QOL) and diet satisfaction in adults. The researchers reviewed cohort studies of a minimum of 1000 participants. They reviewed 55 cohorts with more than four million participants; none addressed QOL or diet satisfaction.

Findings: The magnitude of association between red and processed meat consumption and all-cause mortality and adverse cardiometabolic outcomes is very small and has low-certainty evidence.

Comments: Current dietary guidelines recommend limiting red and processed meat consumption. These results, however, demonstrate that the evidence implicating red and processed meat in adverse cardiometabolic outcomes is of low quality; thus, considerable uncertainty remains regarding a causal relationship. Moreover, even if a causal relationship exists, the magnitude of association between red and processed meat consumption and cardiometabolic outcomes is very small.

FROM AN ECTRIMS 2019

Review on [Researchreview.com.au](https://www.researchreview.com.au)

Continuation of natalizumab versus interruption is associated with lower risk of relapses during pregnancy and postpartum in women with MS. Landi D et al.

This small Italian study evaluated the continuation of natalizumab (Tysabri) treatment in pregnant women with MS, to minimise relapses during pregnancy and postpartum.

Eighty-six pregnant women with MS in 19 Italian MS centres were divided into three groups according to time of last infusion of natalizumab; Group 0 = before last menstrual period; Group 1 = within the first trimester of pregnancy; Group 2 = beyond the first trimester.

Mean gestational age and birthweight of newborns didn't differ significantly between groups. Five Group 2 newborns had anaemia (three were premature), and one Group 0 newborn, four Group 1 newborns, and three Group 2 newborns had malformations.

Comment: Washout of natalizumab in women with MS planning pregnancy brings with a risk of significant MS reactivation. This small Italian study involving 19 centres, collected data from 86 female patients (90 pregnancies) who either continued natalizumab until prior to their last menstrual period, until the first trimester of pregnancy, or who continued treatment beyond the first trimester of pregnancy.

Although the study had small numbers and was underpowered to comment definitively, continuation of natalizumab beyond conception reduces the risk of relapse during pregnancy, compared to washout or treatment interruption. It was not associated with major foetal risks, with self-resolving neonatal anaemia being the commonest adverse event (seen in five neonates) in those mothers treated throughout pregnancy.

BUTLER NOW OFFICIALLY OPEN

The team at MSWA was proud to officially open our new \$8m Services Centre and Supported Accommodation facility for people in Butler and surrounding areas living with neurological conditions.

Manager of Accommodation Claudia Taylor said it was a pleasure to celebrate this great new facility.

“Even though we had been open a little while already, it was wonderful to be able to thank everyone involved in making it such a success and to celebrate us becoming part of the community,” said Claudia.

“We already feel at home in Butler and that our hard work is making a positive impact on the lives of many with a neurological condition.”

The opening in October was attended by Disability Services Minister, Hon Stephen Dawson MLA; MSWA President George Pampacos; and MSWA CEO, Marcus Stafford AM.

“The number of people using our high-support accommodation facilities has significantly increased and it’s important that we can continue increasing our footprint to enable us to provide support and services for people experiencing the effects of disability,” said Mr Stafford.

“With its state-of-the-art facilities and passionate staff, Butler will be a valued asset for the local people living with a neurological condition for years to come.”

Butler provides a range of services including physiotherapy, occupational therapy, nursing, speech pathology, dietetics, counselling, social welfare services and peer group sessions.

To cater for 10 of MSWA’s high-support Customers, 24-hour 7-day a week care is also offered as an option for those who can no longer stay in their own home.

Kate Gild, diagnosed with MS when she was 33 years old, loves her new home at Butler.

“Before the move, I was living in Treendale for almost three years and my life was fine but it was just so far away from my friends and family,” Kate said.

“It makes me appreciate the simple things like having friends over for a coffee or going to my parents’ house which has proved difficult whilst living regionally. The on-site care and support allows me to lead a fulfilling and independent life – I can take myself to physiotherapy sessions or go grocery shopping and I can’t begin to tell you what that means to me.”

Currently, MSWA has 14 facilities across Western Australia, with ambitious plans to increase that to more than 20 within the next few years.

Please visit mswa.org.au/butler to find out more.



Brian Dawson and Kate Gild at their home in Butler.

PHYSIOTHERAPY KEY CONTRIBUTOR TO HEALTH AND WELLBEING

Physiotherapy plays a key role in the health and wellbeing of people with a neurological condition and importantly, can help keep people in the comfort of their own homes for longer.

Physiotherapist James Beckett has been working at MSWA's Rockingham Services Centre for one year and sees the benefits of his work every day.

"People with neurological conditions can have issues with reduced mobility which can interfere with daily activities such as work, school, sports and even getting around the house and neighbourhood. This can lead to other problems such as deconditioning, fatigue and social isolation," James said.

"Physiotherapy has a wide range of benefits including improving cardiovascular health, strength, flexibility, balance and mobility, managing pain and fatigue, and helping to keep our Customers in the comfort of their own homes."

James says the benefits also go beyond physical health.

"We're not only helping to maximise our Customers 'physical function, but we also provide emotional support, friendship and a space to enjoy the company of others with neurological conditions.

"All these components are so important to the lives of people who are dealing with often complex and debilitating conditions."

After a decade of working in physiotherapy private practice, James decided it was time to make a change and help people with neurological conditions.

"I looked back at how much I enjoyed doing my practical university component at MSWA's Wilson Services Centre and how I loved coaching at a swimming club for people with disabilities.

"MSWA gave me the perfect opportunity to make a real difference to the lives of people; to see people on an ongoing basis, monitor their progress and create tailored programs to make their lives better and easier."

MSWA offers group physiotherapy sessions, one-to-one sessions, home visits, as well as ongoing assessments.

"We provide less hands-on, more rehabilitation-based exercise that empowers people to take control of their health," James said.



Physiotherapist James Beckett with Tanya Murphy in a physiotherapy session.

"We are always looking at new ways of doing things; new ways to treat and improve the service we provide our Customers.

"Ultimately, we are here to ensure they get the support they need."

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



MS AND THERMOREGULATION

The body's ability to regulate its core body temperature, even when the temperature of the environment changes, is called thermoregulation. Regulation of the body temperature is controlled by the autonomic nervous system.

Problems with thermoregulation may occur in 60 – 90% of people with multiple sclerosis (MS). This means they may experience inappropriate increases or decreases in body temperature and can be very sensitive to small changes in internal and external temperature. An increase in core temperature of people with MS causes reduced nerve conduction speed. Even small temperature elevations may exacerbate existing MS symptoms temporarily until the core temperature has reduced. Symptoms may include blurred vision, change in sensory symptoms, decreased strength and fatigue.

PRACTICAL TIPS

Be aware that increases in temperature may occur during or after exercise, hot showers, an infection or illness causing an increase in body temperature. Driving in a warm car without air conditioning, sitting quietly in a heated room during winter and even a bath can aggravate MS symptoms in those whose body is intolerant of heat.

Strategies to minimise the impact of thermoregulation difficulties include:

During exercise

- / Exercise in a cool environment – consider the time of day, temperature of the pool water (27 – 32 degrees Celsius), fan or air conditioning, home or gym
- / Exercise regularly for short periods and change the intensity of the exercise program
- / Maintain hydration by drinking cool water before, during and after exercise
- / Wear a cooling necktie, cooling vest and/or loose, light clothing
- / Cool down with a cool shower after exercise
- / Do not exercise if you are unwell

Air conditioning

- / Assess your air conditioning needs before summer and update your home unit if required. Refrigerated air conditioning is the most effective
- / Check the air conditioning in your car before summer
- / Park car in the shade, allowing for the shift in the sun over time

AIR CONDITIONING GRANTS

MSWA can assist Members on low income with funding towards the purchase of an air conditioner in their home (through Lotterywest).

There is also a Thermoregulatory Dysfunction Energy Subsidy Scheme available from the Department of Treasury and Finance. The impact of heat must be significant, and the applicant must hold a pensioner card, health care card or health care interim voucher. This subsidy contributes towards the costs associated with higher than normal power usage when running an air conditioner.

NEED HELP?

The Social Welfare team at MSWA can help you with information, forms, applications and obtaining funding grants for air conditioning and the Thermoregulatory Dysfunction Energy Subsidy Scheme. Please contact the Social Welfare team on 9365 4888 for more information.

THE CHALLENGES AND BENEFITS OF GRATITUDE

SIMON ROLPH
MSWA COUNSELLOR

If you try googling 'benefits of gratitude', like I have just done, you will likely find over 69 million results with multiple lists of proven benefits. Whilst the information available is plentiful, the reality of being grateful can, however, be challenging.

Gratitude is having the ability to focus on what is good in our lives and being thankful for the things we have.

When life is rosy and stresses few and far between, it can be much easier to take this approach. When the stresses become overwhelming and life is more stormy than rosy, being grateful can be challenging. Include the most recent political crisis or global climate issues, and we can easily take a negative attitude towards our lives and the world we live in.

When life is hard, telling people to count their blessings and be grateful for what they have can be particularly unhelpful. Gratitude is not ignoring the existence of our own individual difficulties with an attempt to only focus on the positives. No amount of positive thinking will take away the reality that life can be hard and incredibly painful at times. But dwelling only on the hardships of life can be equally unhelpful.

An approach of gratitude can be helpful by providing balance and perspective to our attitude on life. It is both acknowledging the bad, but also reminding ourselves of what is good; what we can be thankful for. It can help us reframe loss as a possible gain, mistakes as life lessons, obstacles into opportunities. A reminder of what is still available to us.

Some people naturally find it easier to take a grateful attitude. Others find it much harder. Fortunately, gratitude is something we can intentionally practise to help counteract the negative bias our minds frequently have. Visit positivepsychology.com/gratitude-exercises to find 13 popular gratitude activities and exercises with additional information and resources on gratitude.

Gratitude isn't the magical answer to life's problems, but it can be a wonderful attitude to choose and call upon to both enhance our experience of life when times are good, and to support us when times are hard.

If you want to learn more about gratitude and how to develop a more flexible and helpful attitude towards yourself and life, you can contact the MSWA Counselling department on 9365 4836 to organise a referral to one of our tertiary trained counsellors.

JUST DO IT

Sometimes I need to be kept in check. Sometimes I need to be made accountable, to answer to someone. Otherwise I can be a completely lazy, lay-about slouch who never does anything except read, drink tea and look at social media on my computer.

My friend Kathleen told me she was embarking on a rigid diet and exercise regime, which involves getting up each morning and doing a physical workout before breakfast. I have for a long time, (and I mean decades!) thought that I could benefit from some daily exercise. I've thought it. Physiotherapists have told me. Friends and family have suggested it. Up until now I've always taken the approach that "it's the thought that counts, isn't it?" and never got past thinking about it.

But Kathleen inspired me. I decided I would start getting up each day and doing some exercise on the Pilates reformer that I have in my spare room. We decided that each morning we would send each other a message when we have done our exercise, to keep each other on track.

Kathleen calls this project JFDI, which stands for Just Friggin' Do It! So, each morning, after doing my exercise, I send her a text message saying something like "JFDI tick." It's great! I've discovered that somewhere deep inside me I'm afraid of disappointing her if I don't do it.

Even when it's cold and I'd really rather stay in bed, I tell myself – "Just Friggin' Do It" and I do. I've done it now for five weeks and only missed two mornings. I decided to forgive myself for that.

I like the way this makes me feel about myself. I suddenly feel like someone with self-discipline; someone who can achieve something. I feel like someone who has energy and purpose. I like to imagine that my abdominal muscles are getting slightly harder. And although I can't really say that I've noticed a great physical improvement, mentally I feel great.

I've even signed up to do the MSWA bike ride. No, I won't be on the road, but on the Motormed bike in the physio gym. I have set myself a goal of riding 25km over the six weeks of the event, and let my friends and family know, and I have a bunch of people who have offered to sponsor me. It feels quite exciting to be doing something physical which will help raise funds for MSWA to provide services to people with MS and other neurological conditions. I'm glad to be doing my bit, as I receive so much support from MSWA.

Yesterday, someone said to me, "When are you going to write that book you're always talking about?" Ever since I was about ten years old, I've wanted to write a novel and become a famous author. Back then I wanted to be Enid Blyton, but these days I aspire to be a female Tim Winton. I think about it. I talk about it. I've even got the book launch party planned, but up to now I haven't started. Well, that is going to change. I've had a revelation. I've realised I can take the same approach to writing as I have taken to exercising.



I've set myself an initial goal of writing for 15 minutes a day. To keep myself accountable, I will message Kathleen after doing it. For now, I will just write anything, exploring some of the ideas I've had over the years, but eventually I hope I will know how to start my 'Great Australian Novel'. Once the habit is established, I will increase the time I set aside to write, and maybe one day I'll have a book. Maybe one day I will invite you to join me over a glass of celebratory champagne and canapés, and I'll sell you a copy. Maybe one day... but don't hold your breath.

For now I'm going to Just Friggin' Write.

ROS HARMAN
MSWA MEMBER

MONEY MYTHS WITH THE NDIS

Money makes the world go around or so they say, and while the introduction of the NDIS has brought with it many changes, perhaps the biggest change has been the way organisations like MSWA and our Customers interact with the subject of money. Funding has always been a hot topic across the disability sector; it has always been a concern and dictated the amount of services we could provide. But now it is more visible and requires a new way of thinking.

One of the goals of the Scheme was to take away the year-to-year funding questions that used to exist under the block-funding model. New governments, wars, droughts and general changes to national priorities could influence the size and availability of funding for disability services. However, while NDIS funding is now guaranteed, there are new worries, questions and myths starting to emerge. So, I thought it would be appropriate to answer some of these.

MYTH 1

I'm going to run out of funding.

This is mostly incorrect. In late September, Treasurer Josh Frydenberg announced that the final budget for 2018-2019 would be in surplus for the first time since 2007-2008. The subtext of this announcement was that this surplus was built on a \$6.4bn underspend across the NDIS. Part of this was the delay in getting people onto the program, the other was that on average, customers only spent 75% of their available funding. Funding is designed to last for the length of a plan (around a year) so while some management is required, most people will be ok.

MYTH 2

If I don't spend my funding on services, I will get it back or have it added to my next plan.

Also, incorrect. If at the end of the plan you have funding left over it will go back to the NDIA and you may receive a question from your LAC as to why the underspend occurred? Funds are provided based on your year goals so work with your MSWA team to ensure you reach them.

MYTH 3

It's my money and I can spend it on what I want.

Sorry but no. The NDIS is not actually a free market as some people have suggested. It's a monopsonist where one entity (the NDIA) does all the buying and sets the price. The NDIS determines what you can purchase and how much it costs. There are some things within your plan that you can move around (that's the choice and control) however others are well and truly set.



GEOFF HUTCHINSON
MANAGER CUSTOMER
ENGAGEMENT

MYTH 4

I will need an accounting degree to manage my NDIS Plan.

It wouldn't hurt but ultimately incorrect. The NDIS has three different levels of support for plan managements. You can choose to have your funding agency managed, choose a designated plan manager, or choose to self-manage if you want ultimate power. Your involvement is dependent on you and your preferences so if you would like to talk through these options, give the MSWA NDIS team a call to discuss.

You've probably heard it said that you should never discuss religion, money, or politics with people. And while I am happy to stay clear of religious and political debates, it is important that we talk more about money matters when it comes to the NDIS. MSWA is putting new supports in place to help you navigate this new frontier and understand the NDIS funding system. As always, if you have any questions, please let us know.

From myself and everyone in the Customer Engagement team, have a happy and safe summer.

POWERED MOBILITY DEVICES

VERITY DE FRIES
MSWA SENIOR OCCUPATIONAL THERAPIST



Walking can be difficult for many people with MS due to several reasons which may include reduced leg strength, impaired balance or fatigue. Some people may benefit from using mobility devices such as a wheelchair or scooter. There are many factors to consider when working out which device is going to best suit you and your needs.

SCOOTERS

Scooters are ideal for accessing the local community, with larger models being able to ascend hills and travel distances of up to 50km in one battery charge. Smaller models are also available, as well as scooters that can be dismantled for transport in the boot of a car. These will have less power so are often not able to travel long distances. Most will come with a basket for small items, and some may be fitted with a sun canopy or larger rear storage bag.

POWERED WHEELCHAIRS

Powered wheelchairs are generally more compact than scooters and can be more easily navigated around tight corners, such as in a house. However, they can still boast enough power to be used out and about, depending on the type of wheelchair. The other benefit of many power wheelchairs is that they can be customised to suit your needs, incorporating different style seats, backrests, headrests and a range of other features. These can then potentially be modified in the future if your needs change rather than having to get a completely new device.

Some power wheelchairs can be dismantled for transport in a standard vehicle. These wheelchairs lack the ability to be customised and have fewer features available, so it depends on your priorities and needs as to whether these would be suitable.

POWER ASSISTANCE

Another option is to retrofit battery powered wheels onto a manual wheelchair – known as power assistance devices. These can take different forms, such as converting the wheelchair to having joystick control (like a powered wheelchair), using an accessory item such as a watch to control 'go and stop', or emulating the use of a regular manual wheelchair but reducing the amount of physical effort you need to put in yourself.

Contact the Occupational Therapy department on 9365 4888, and we can work with you to find the mobility solution that will best suit your needs.

CREATIVITY FLOWS IN ART GROUP

"Creativity is contagious, pass it on." Albert Einstein

Every child is an artist. Give a child paints, crayons, clay or Lego and the majority will be happy for hours. The problem is, how to remain an artist as we grow up?

My childhood Christmas list was for paints, brushes and sketch pads, apart for the one time when I asked for a puppy but sadly that never eventuated!

I went to art college and my career started in graphic design, changing direction in the 1990s to supporting children with special needs. In later years another move led me into working with people with dementia.

Throughout my working life I used my creative skills to support people of all ages to enjoy the fun that art, in its many forms, brings.

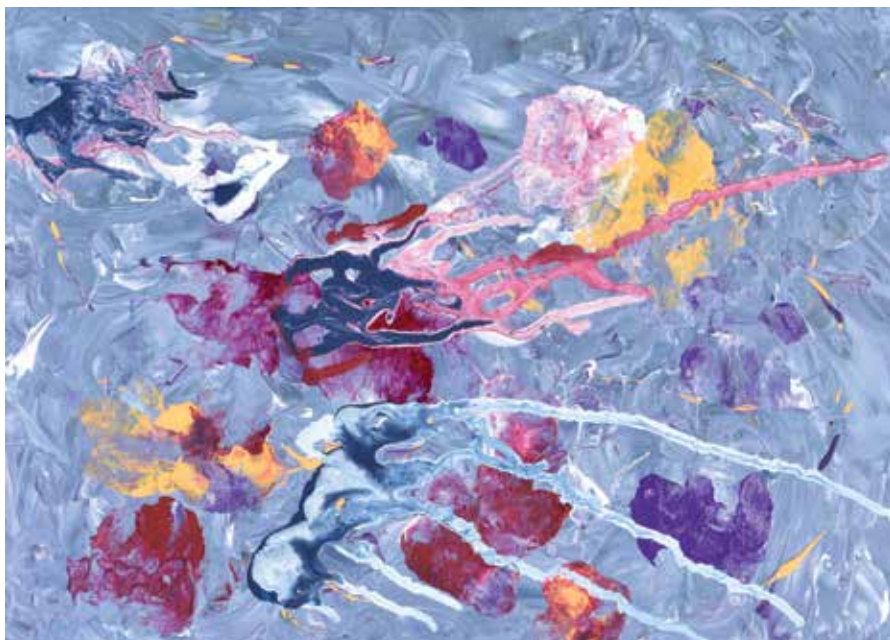
This year I met three lovely ladies at the MSWA gym in Joondalup who were keen to join me in a small art group. We meet weekly and I support each person in whatever they would like to do.



I always wanted a dog, so I made one! This is Rupert. He's a cross Irish wolfhound boxer/ cocker spaniel.



Sandra loves making craft items. This is her extremely rare Bird of Paradise lovingly made from wire, papier-mâché and feathers.



Sandra's vibrant acrylic artwork.



Amanda told me she couldn't even draw a straight line. I said, "That's okay, we don't need to do straight lines!"

Amanda's acrylic paint pouring work above was a beautiful example of colours, curves and flowing shapes. This was so successful that she made a cup and saucer designed to hold herb plants (above right).

Rhonda wanted to learn how to draw and paint. Her ability to really look and see shapes, colours, depth and perspective really shows in this watercolour. Below are two of her artworks..

I challenge anyone who says, "I am not creative". Find your inner child and get messy. Get out the paints and mix your favourite colours. Be aware, you may get lost in time by letting your mind go free. Play your favourite music, or just listen to the sounds of nature. You may be surprised what you can create!

I have had so much fun with my fellow artists. It has been very rewarding for me to see how happy these ladies have been, creating their individual works of art and seeing their achievements.

Best wishes to all for a very happy Christmas, and who knows what we will show and tell next year!

Thanks to Rhonda, Sandra and Amanda for your permission to show your work for this article.

"I begin with an idea, and then it becomes something else."

Pablo Picasso.

**SHEILA LAPPING
MSWA MEMBER**



ENJOYING LIFE

Jessica Trew is one of approximately 200 Australians living with a rare and complex neurological condition, neuromyelitis optica (NMO).

When she was diagnosed with the condition six years ago when she was 29, not much was known about NMO and there were only two websites available for Jessica to learn more.

"Thankfully now, more research has been done so we understand more about it," Jessica said.

An MSWA nurse accompanied Jessica to her first specialist appointment and although she refused many of MSWA's services initially, she eventually accepted help when her partner was in an accident.

"My partner Clint became a paraplegic, so it became more and more difficult for us to manage the house and our daily life," Jessica said.

"MSWA has been a great support – I access nursing and receive domestic services once a week which is especially helpful with things like cleaning the floors and hanging out the washing which neither of us can do."

"I also go to group counselling sessions, which I love and feel really comfortable in."

Jessica's symptoms began in 2013, when she was working as a nurse on a remote Papua New Guinean island and sleeping on a nearby ship at night.

"It felt like the ship was moving all the time, even when it wasn't," Jessica said.

"Then I picked up a pen and suddenly, I couldn't write."

Jessica returned home but ignored the symptoms for many months until they became unmanageable.

"My partner gave me a glass of wine which I poured all over myself. The next one went all over the sofa. I had lost all coordination in my hand."

Jessica was initially diagnosed with tumefactive MS, a rare form of MS which is characterised by large brain lesions and symptoms similar to those of a brain tumour.

But she seemed to get worse, rather than better.

"I had a bleed on my brain, and it became clear it wasn't MS."

"An excruciating six months followed when no one knew what I had until I started vomiting. We then knew I had NMO."

NMO is a central nervous system disorder that primarily affects the optic nerve and spinal cord. Due to their similar symptoms, experts used to view NMO as a type of MS, but it is now treated as a different condition.

People with NMO often have pain in the eye and vision loss. They can also develop weakness or paralysis of the arms and legs, numbness, as well as loss of bladder and bowel control.

These days, Jessica has weakness in her left-hand side and as a left-hander, she had to learn how to write with her right hand. She has spasms in her hands and feet and can still experience severe vertigo and vomiting. But unlike most people with NMO, Jessica's vision is mostly unaffected.



These days, Jessica lives her life much as it was before her diagnosis, just with a few modifications.

Instead of working as a nurse at a facility, she works from home as a clinical reporting nurse and during the night, gives health advice over the telephone for unwell people in detention centres.

"I still work as a nurse, just from the comfort of my own home – it's fantastic."

In her free time, Jessica still plays her beloved volleyball and netball – eight games a week!

"Although it can be frustrating that I can't play as well as I used to, I am so happy I can still play."

What is different now however, is that she accepts help.

"I didn't reach out for support until I was really struggling, but once I did, things became easier. MSWA has been a big help, in so many ways. My hopes are that Clint and I stay well in the foreseeable future so we can continue to live as well as we are right now."

VOLUNTEER COORDINATOR UPDATE

Welcome to our summer edition of the *Bulletin*. There is always so much happening here at MSWA, and I love keeping you informed.

In the past few months I have been busy interviewing new volunteers, attending Members' camps and carers' retreats and planning for my European holiday! Yes, I said Europe and holiday all in the one sentence. When you sit down and start relaxing and reading my article, I will have been to Europe, whizzed around a few countries and arrived home again in time for the MSWA Christmas Party. I find it amazing that so much can happen in a short space of time. While all of you have been warming your souls and getting your natural top up of Vitamin D, I will have been rugging up to keep the cool air out. Luckily, I will have thawed out by the time this article reaches you.

As I mentioned, I have been on the MSWA camps for which we receive a Lotterywest grant each year. We held a carers' retreat in August, a Member's camp and a family camp at Woodman Point, and a South West camp for our Members down south. It has certainly kept Camp Coordinator Sumit and me busy. If any Members, carers or Members with children would like to attend one of our camps or would like more information, please don't hesitate to contact Sumit or me on 9365 4843. I am also always looking for volunteers to assist with the Members' camps and it would be great to have you on board.

We had a wonderful milestone celebration in October for our lovely volunteer, Mary Cross. Mary celebrated her 90th birthday with a morning tea with Members, volunteers and staff at the Wilson Services Centre. Mary has been volunteering in the kitchen at



Volunteers taking registrations for the MSWA Arena Ascent.

Wilson for 15 years, which is an amazing achievement in itself. She is a quiet achiever and such a joy to have around. It was an honour to be part of her celebration and everyone at MSWA wished her a wonderful year ahead.

This year, both the Members' and Volunteers' Christmas Party and International Volunteers' Day were celebrated on 5 December, giving us the opportunity to thank and recognise our precious and valuable volunteers at the same time. MSWA is so lucky to have such a dedicated, loyal and efficient team of volunteers. If you aren't a volunteer and you are reading this, please take the time to say, "thank you for a job well done". People who volunteer aren't looking for recognition for what they do, but a simple thank you always goes a long way.

Our MSWA Events team has also been busy over the past few months with the Central Park Plunge, Arena Ascent stair climb and the MSWA Ocean Ride. Can you imagine plunging down the side of a building? I don't know about you, but I would be just a tiny bit frightened. Volunteers are

always needed and welcomed as these events don't just happen and volunteers help to ensure they are run safely, efficiently and successfully. If you are keen to volunteer and cannot commit long term, then volunteering with our Events team may be a great option for you. Please call the lovely Trish Watson on 6454 3116 to register your interest in future events and you may get a sneak peek into what is on the agenda for 2020.

With 2019 coming to an end, it's usually a time for some volunteers to move on for various reasons. It is with heartfelt thanks I say goodbye and wish you good luck for your next adventure. To those staying on, have a great break and as always, it will be lovely to see the New Year in with you all.

Of course, with volunteers leaving us, it paves the way for newbies to come in. If you would like to volunteer or to consider any future possibilities, please call me and we can discuss it further.

Take care, and bye for now.

DAWN BURKE
VOLUNTEER COORDINATOR

CHRISTMAS CLOSURES AND REDUCED COVER

Some of our services will be closed or reduced over the Christmas period whilst others, like Individual Options, will run as usual.

OUTREACH GROUP AND RESPITE CLOSURES AND REOPENING DATES

Outreach Group	Last day for Member attendance	Reopening date
East side (Beechboro) Outreach	Monday, 16 December 2019	Monday, 13 January 2020
Bunbury Outreach	Wednesday, 18 December 2019	Wednesday, 15 January 2020
Wilson Outreach	Thursday, 19 December 2019	Monday, 13 January 2020
Rockingham, Albany and Northside	Friday, 20 December 2019	Friday, 17 January 2020
Margaret Doody Respite House	Friday, 20 December 2019	Monday, 13 January 2020
Treendale Gardens Respite	Friday, 20 December 2019	Monday, 20 January 2020
Wilson Hydrotherapy Pool	Friday, 20 December 2019	Monday, 6 January 2020

- / **Wilson Reception, 9365 4888**, is unstaffed from 2:30pm Friday, 20 December 2019 to 8:30am Monday, 6 January 2020.
- / **MS Nursing cover** is reduced between Monday, 23 December 2019 and Friday, 3 January 2020. If you would like to speak with an MS nurse during this time, please telephone **9365 4870**, excluding weekends and public holidays.
- / **Individual Options** out of hours contact number, from 8:30pm to 6:30am is **0417 982 814**.
- / Our **Get-In-Touch@mswa.org.au** email is monitored over the break.
- / If you are interested in booking your respite stay for 2020 please contact: Chris Rush for MDH on 9385 9574 or Linda Kidd/Paula Kennedy for Treendale on 9725 9209.

The MSWA Member and Client Services team wish you a safe and happy festive season and look forward to working with you again in 2020!

TICKETS TO WASO PERFORMANCES - OUR EXCLUSIVE DISCOUNT FOR YOU

At MSWA, we truly believe in the power of music to enrich the lives of people living with a neurological condition which is why we're incredibly proud of our partnership with the West Australian Symphony Orchestra (WASO).

Our 2019 partnership is focussed on providing our community with wider access to music and is an opportunity to bring the power of music into everyone's lives.

We are pleased to offer MSWA Members 20% discount off all tickets until the end of 2019.

Simply enter the promotional code '**MSWA2019**' when purchasing tickets online at waso.com.au (please read the terms and conditions).



**West Australian
Symphony Orchestra**

YOUR FINANCIAL AND PERSONAL AFFAIRS

While thinking about the inevitable is sad, it's always a good idea to make sure you're prepared.

If you don't already have a will, it's never too late. Some people write their own, but it is highly advisable to seek the help of a solicitor to help you ensure your will is not only valid, but enforceable by your nominated executor.

Once your will is in place, the WA Will Bank is a free service allowing for the safe storage of your will in a purpose-built, fire-proof vault – keeping it from being lost, stolen or damaged. Visit the WA Will Bank at www.publictrustee.wa.gov.au/W/wa_will_bank.aspx



If you'd like to leave a bequest to MSWA and help us continue the important work we do for our neurological community, contact us today, call 6454 3126 or email giftplanning@mswa.org.au.

RAISING COMPLAINTS - YOUR FEEDBACK IS IMPORTANT TO US!

In accordance with the National Disability Standards and our government contracts, MSWA has a Complaints Management Procedure. My role is to support our Members and Clients, or their carers, with the process. I coordinate the receipt and follow up of all formal complaints, working with the relevant teams to acknowledge the complaints and resolve any issues.

Feedback is vital; it helps us to understand what we are doing well and congratulate our staff on a job well done, and where we need to make improvements.

LIZ STEWART
MANAGER QUALITY
AND COMPLIANCE

We assure you that your complaint will be handled respectfully and in a timely manner.

First port of call is with the relevant coordinator or manager, giving them the opportunity to investigate the issue and resolve it promptly.

If you are not satisfied with the outcome, or prefer to contact me directly, I will chat with you about your concerns, explain our process, review the concerns with the team involved and work with you to achieve a positive outcome.

Complaints are handled quickly, objectively and respectfully.

HOW CAN PROVIDE A COMPLIMENT, COMPLAINT OR SUGGESTION?

Contact your MSWA Program Coordinator or Manager or Telephone Liz Stewart on 6454 3173 or 045 806 0566

Email feedback@mswa.org.au

Write to Quality and Compliance
Locked Bag 2 BENTLEY DC 6983

ALBANY SERVICES CENTRE UPDATE

The fantastic Denmark Ukulele group was a real hit as this year's camp entertainment in Denmark.

We had a busy start to the year here in the Great Southern and it just kept going.

MSWA Albany Ride in February was a great day for MSWA with so many people getting involved. A big thanks goes to all those who went in the Ride as well as the many staff and volunteers who made the day possible. Spectators were very supportive, cheering the riders on as well as welcoming them back. A job well done!

In March, we had the eighth MSWA Albany Swim which was even bigger than the year before. So many swimmers of all ages and abilities made for another successful day so thanks again to staff, volunteers, swimmers and spectators. Next year is scheduled for May so keep an eye out!

Guest speakers this year have been well supported. We have had a defibrillator demonstration, a healthy eating talk from a nutritionist and a recycling information day (which we will repeat in the New Year as it was very informative and there will be coming changes). Chris from Amity Rose Funeral Directors and Albany Community Legal Centre also talked to us about wills, power of attorney and information that you may need to know when planning wills or funerals.

Our CEO Marcus Stafford was a very welcome guest with great news on what's happening at MSWA, as well as an update on the proposed facility for Albany. We have purchased land so once a builder is in place and the plans are finalised, it should get under way in the New Year. Very good news for us all.

CAROLINE CLARKE-SMITH
ALBANY OUTREACH CARE
COORDINATOR

**WOULD YOU
LIKE TO RECEIVE
THE *BULLETIN*
ONLINE?**

Register your email address today to start receiving our monthly Vitality e-newsletter or the *Bulletin* magazine online.

Email damien.hill@mswa.org.au or call 9365 4814 and let us know your current email address, or to update your contact details.

BUTLER ACCOMMODATION NEWS

We were all very excited and proud to show off our wonderful facilities to those attending the official opening ceremony in October, including the Minister for Disability the Hon Stephen Dawson MLA.

With the help of staff and local Bunnings team members, residents have been enjoying several themed events, including Halloween and craft activities.

The 'Butler Busters', staff and family, were proud to do our bit for people living with MS and all neurological conditions, by taking part in the very first MSWA Arena Ascent at the RAC Arena in Perth. We climbed the equivalent of Everest and were still able to walk back to the car at the end of it! We managed to raise over \$300 and won the best dressed team award! We are looking forward to having a bigger team next year, including our own cheerleaders.

If you want to be a part of our team or cheerleaders (no experience or ability to flick flack needed), please contact Claudia at Butler Accommodation.

We just love doing the MSWA events, not only supporting a great cause, but getting fit and having fun at the same time.

CLAUDIA TAYLOR
MANAGER BUTLER
SUPPORTED ACCOMMODATION



Best dressed team at the MSWA Arena Ascent.

TREENDALE GARDENS RESPITE

MSWA Treendale Respite is proving more popular this year which is great news! As more people learn about us and have NDIS funding in their plan, we are welcoming both new and return guests.

Treendale, a suburb of Australind, is only five minutes from the inlet and 20 minutes to Bunbury. We have a lovely park with a lake next door. Across the road is a great shopping centre and cafés, so fresh coffee and muffins aren't too far away!

If you didn't know about us, we are an MSWA-owned and managed, purpose-built, six-bed respite facility with a separate adjoining three-bedroom family unit.

If you are interested in learning more or want to book early to save your spot in 2020, please telephone 9725 9209 or email Treendale@mswa.org.au. To arrange an in-person visit, please contact our friendly team.



We are available Monday to Friday between 9am and 3.30pm. Please note we are closed from Friday, 20 December 2019 to Monday, 20 January 2020, but we can still take your enquiries.

PAULA KENNEDY
COORDINATOR SUPPORTED
ACCOMMODATION - TREENDALE

SENSORY EXPERIENCE PROVIDES INSTA GOLD

SENSATION

SensAtionGallery.org.au

The SensAtion Gallery, an art installation project created by MWSA, is a unique multi-sensory adventure in East Perth for everyone.

Immerse yourself in this amazing interactive event at which you will have all your senses challenged by more than 20 interactive installations.

Perth-based creatives have teamed up for this one-of-a-kind installation, including popular YouTube vloggers Kim Behetsis and Ana Cadence, chef and former MKR contestant Jordan Bruno, and major influencers Zak Hasleby and Jamey-Lee Franz.

Each artist-created installation explores one of the senses: sight, sound, smell, touch and taste, as well as the complexity of the brain.

And when you need to recharge you can grab a bite to eat or drink at the SensAtion Café, or explore the SensAtion Shop crammed with great gifts and mementos.

Visit sensationgallery.org.au to buy tickets and find out more.

WHEN

Open 7 November – 23 December

Tuesday – Sunday: 10am – 5pm (closed Mondays) – last admissions 4pm

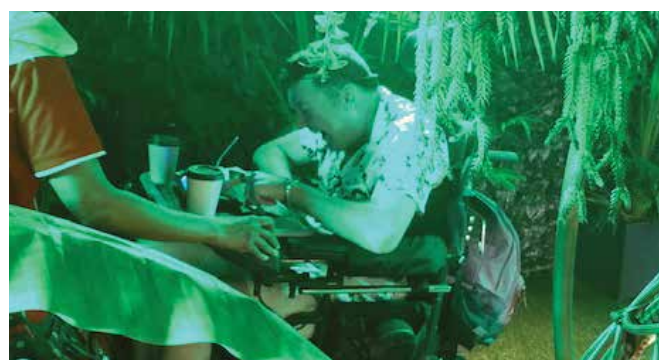
Monday and Friday nights: 6pm – 9pm – last admissions 8pm

Please visit sensationgallery.org.au to find out Monday and Friday night dates.

WHERE

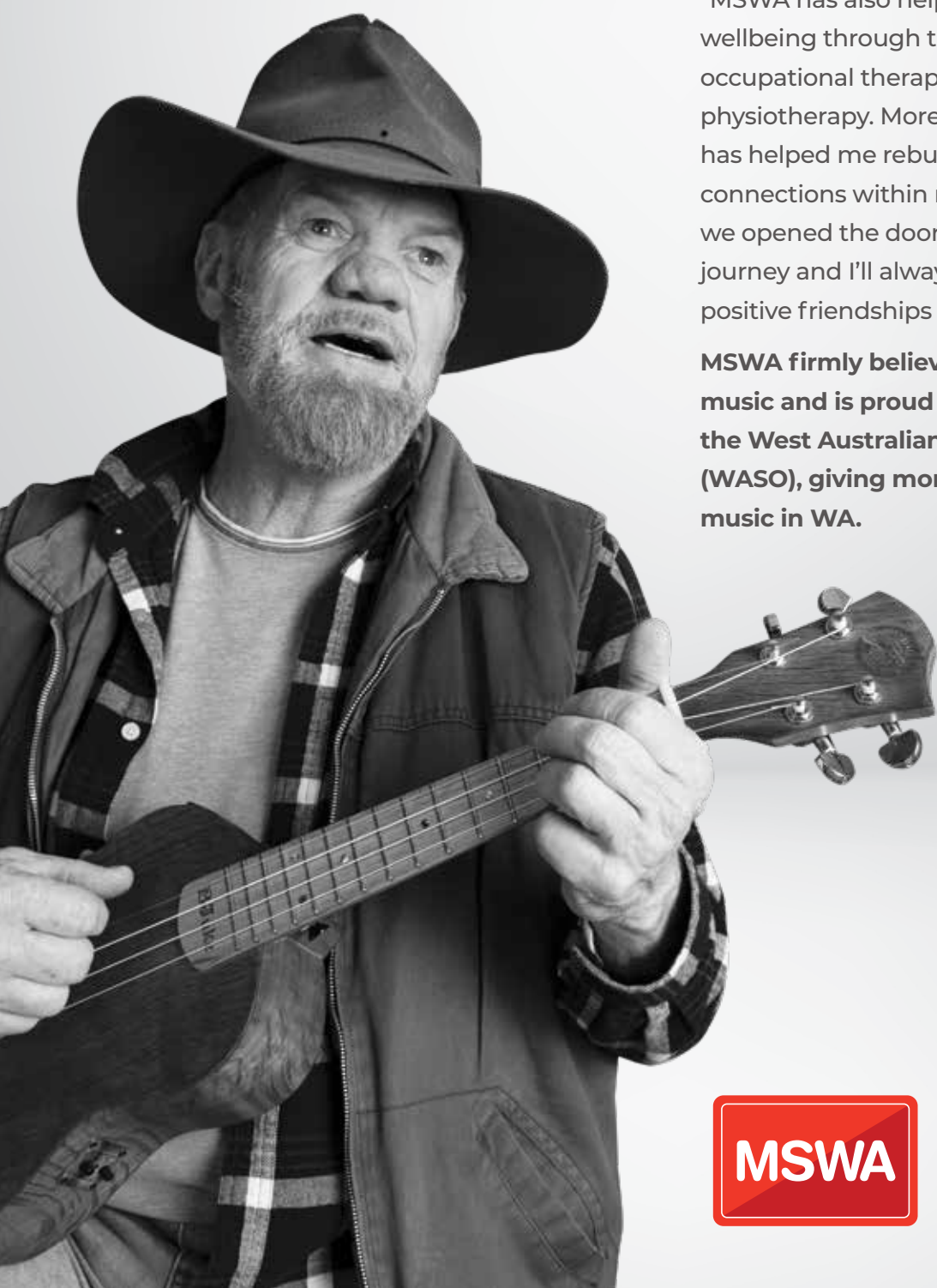
Queens Riverside Precinct, 3 De Vlamingh Ave, East Perth

We're a fully accessible venue with easy connections via public transport and the free CAT bus. There is plenty of nearby parking with ACROD parking available on De Vlamingh Avenue.



MWSA Customer Neil Cumming enjoys the ambiance of the Green Room.

PROOF THAT MUSIC IS MEDICINE FOR THE MIND



Professional musician Brett John has been living with Multiple Sclerosis (MS) for nearly two decades. He believes music gives him the strength he needs to cope.

Diagnosed at 43, Brett shut the door on music, but not forever. "Music has always had a positive effect on my life by calming my mind and giving me joy. Once I was introduced to MSWA they helped me re-open the doors to music and let it heal my mind and spirit once again. Music has really helped me cope during times filled with confusion, stress and doubt," said Brett.

"MSWA has also helped my personal wellbeing through tailored services including occupational therapy, counselling and physiotherapy. More importantly, MSWA has helped me rebuild and strengthen my connections within my community. Together we opened the door to others on a similar journey and I'll always be grateful for the positive friendships I've gained."

MSWA firmly believes in the power of music and is proud of our partnership with the West Australian Symphony Orchestra (WASO), giving more people access to music in WA.



WE KNOW NEURO

TAKE A BREAK IN THE SOUTH WEST.



MSWA

WE KNOW NEURO

WHATEVER YOUR NEURO, WHATEVER YOUR NEEDS, WE ARE READY.

Whether you or a loved one need a break from daily routine, we have a range of rooms with 24-hour care at MSWA Treendale Gardens Respite for a much-needed break.

Call us on 1300 097 989 or visit mswa.org.au/residentialrespite to find out more.