Spring 2014

NDIS Update

Epstein-Barr Virus

How much sun is enough?

To dye or not to dye?
Letter from the Editor .................................................. 3
From the desk of the CEO .................................................. 4
A message from the General Manager – Member Services .................................................. 5
Air-conditioner grants .................................................. 5
Round-up of research and other items of interest .................................................. 6-7
National Disability Insurance Scheme (NDIS) WA trial update .................................................. 8
The role of the Epstein-Barr virus in the cause of multiple sclerosis .................................................. 9
Nothing changes if nothing changes .................................................. 10
10 tips for making and maintaining lifestyle changes .................................................. 11
Fundraising round-up .................................................. 12-13
How much sun is enough for people with MS? .................................................. 14-15
The law of cause and effect .................................................. 15
Care of equipment .................................................. 16
Driving and multiple sclerosis .................................................. 17
To dye or not to dye? .................................................. 18
Volunteering news .................................................. 19
The Smith Family Saver Plus Program .................................................. 19
A New Year’s Cruise (Part One) .................................................. 20-21
That’s Life with Narelle .................................................. 21
MSWA Camps .................................................. 22
Employment Forum .................................................. 22
Wilson Outreach News .................................................. 23
Southside Outreach News .................................................. 23
Bunbury Outreach Group News .................................................. 23

NURSING Nursing team is usually the first point of contact, after their Neurologist, for anyone diagnosed with multiple sclerosis. We’re committed to providing holistic support so you have a greater understanding of what to expect from your condition.
Manager Nursing: Lou Hatter on 9365 4809
Hospital Liaison Nurse (S.C.G.H.): 9346 3333
Community Nurses: 9365 4812, 9365 4838, 9365 4870, 9387 4846 or 9365 4888

PHYSIOTHERAPY Physiotherapy aims to provide treatment interventions to develop and maintain mobility and function. Our Physiotherapists are experts in movement and function, and work in partnership with Members to attain the highest possible level of independence.
Manager: Marilyn Sylvester on 9365 4818
Southside - Friday on 9592 9202

OCCUPATIONAL THERAPY Occupational Therapists work with Members, and clients, to enable them to continue their work and other interests for as long as possible, where they may otherwise have been limited by their condition.
Manager, Sandra Wallace: 9396 4818
Heather Mears: 9396 4894
Robyn Luxley (Assistive Technology): 9396 4866
Taryn Mokrzycki and Dawn Burke. 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 the Society’s staff, advisors, Directors or officers.

COUNSELLING Some people need support to deal with the news that they have MS, and the challenges that may present over time. Our qualified counsellors provide a safe space for you to explore your concerns, in a safe and confidential environment.
Manager Counselling, Lisa Papas: 9365 4836
Support Counsellors: 9365 4808 or 9365 4811 Peer Support Program: 9365 4808
Welfare Officers & Funding Locators: 9365 4899 or 9365 4835

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 In-home care 9416 4505
Letter from the Editor
Dr Greg Brotherson

“Change” is the main theme in this edition of your Bulletin, and it is all a coincidence. From the editorial desk it appears that as we look forward to Spring, the Society must also prepare for other seasonal changes.

You will have already received a letter from the Society’s president, Mr George Pampacos and Marcus Stafford, our CEO, explaining that changes to the Society’s Constitution are necessary to meet the challenges and opportunities the National Disability Insurance Scheme (NDIS), will bring with it. There will be further mail-outs but I urge you to put Saturday, 25 October 2014, the date of the Society’s Annual General Meeting (AGM), in your diary, now.

In his article, Marcus will also tell you to anticipate further excellent news when the Society’s audited accounts are presented at the AGM. There is another record-breaking grant that the Society will contribute to MS Research Australia, and plans to further increase our already innovative suite of services to the membership will be announced.

In her article, Sue Shapland, General Manager of Member Services, brings us up to date with the NDIS, where once again the theme is one of emerging change. This time, however, the beneficiaries are people with multiple sclerosis and similar neurological disabilities living in the Rockingham area, a hub which will link up nicely with the purpose-built plans in the pipeline for Bunbury and Busselton. Once again, the Society is harnessing the positive affect of “change” and translating it into bricks and mortar.

“Nothing changes if nothing changes”, and Leonie Wellington explores this theme in her article. Dr Andrew Ong is in much the same frame of mind, he talks about good Karma and learning from adversity. There is no such thing as bad Karma in the world of Dr Ong. Then the indomitable Narelle, another positivist, tells of her experience of now having moved into supported-accommodation! And, Ros contemplates whether to “Dye or not to dye”, and the consequences of change.

Finally, permit me to share my experiences with “change” and how the Society has coped over the years. In 1982, when the late Patrick McGurk and I first joined the Board of Directors, the Society’s Constitution stated that only two people with multiple sclerosis could sit on the Board. Fortunately, we were supported by like-minded people and the Constitution was amended.

Since those salad days, I have come to see the Society in organic terms because the focus has remained squarely on people with multiple sclerosis, their carers and families. In that sense, we have grown organically, supporting each other as a collective and together we have evolved as a Society.

It is, therefore, not by chance that as a group we are seen as Members; and certainly not as “clients” as some eastern-states Societies like to call people with multiple sclerosis who access services. We have won the good fight on that one, and written it into the Constitution.

The Society’s Constitution should therefore be seen as also evolving, to meet the demands of changing circumstances which affect people with neurological conditions. Between the lines, it is also possible to see the development of a hard-earned distinct identity born out of adversity and a resulting stubbornness to resist change, which is change without good reason. People with multiple sclerosis have and will continue to define themselves, and the Society mirrors our image, and that will not change.

It has been in this manner, however, with all the checks and balances in place that the Society has evolved into the most successful MS Society in Australia. Supported by the Western Australian community and Government agencies, now we prepare ourselves for the future when the NDIS arrives.

With the NDIS now taking shape in its trial stages the AGM is the time when the Society will again evolve to cater for this change, but not without the membership being fully informed. There is more information to come, but the point to remember here is that only those Members present at the AGM will be asked to vote on the proposal, and only Members who have paid their membership fees are eligible to vote. The invoices have been mailed to Members and Associates, otherwise phone the Society on 9365 2444.

The President and the Board of Directors, along with the Management Team, look forward to you participating at the 2014 AGM, Saturday, October 25.

Do you want to receive the Bulletin online? Want monthly information updates?
Register your email address today to start receiving our monthly Vitality e-newsletter and the Bulletin magazine online.

Just email nicolette.madry@mswa.org.au or call 6454 3114 and let us know your current email address.
Happy New Year! Before you jump to the conclusion that the CEO has finally lost it, let me explain! July marks the start of the new financial year, where the slate is wiped clean and it’s on again! Although future editions will focus on current performance and future goals, we should allow ourselves a moment to reflect on the 2013-14 year. And what a year it was.

Financially it was very sound indeed. Gross revenue posted a new record high, comfortably over $30 million and the Society’s net surplus (after all Member services, research and other costs) came in on forecast at just under $1 million.

But, as I always say, money is only as good as what you do with it, and that is the essence of our organisation. I’m not a huge fan of the term ‘not-for-profit’ and looking at our performance in recent years I’m not sure that is an accurate reflection of our status! I much prefer ‘profit for purpose.’

Well, our ‘purpose’ included an 11 percent growth in Member Services from a delightfully high base. That means real things to real people, with services like physiotherapy, occupational therapy, nursing, counselling, support work, accommodation and respite.

In addition, we delivered 9 percent growth for broader client services to people with other neurological conditions.

Quantities of service, therefore get the tick, but how about quality? Our independent and anonymous client services’ data shows a quality ranking in the high nineties. That reassures me that we have a highly professional balance in place.

Plus, a history-making record contribution to research has further cemented our leadership position in Australia; $1.25 million has been contributed to MS Research Australia, with $500,000 reserved for the best and the brightest researchers in Western Australia.

And, from that stable base, we embrace the challenges and the opportunities that the National Disability Insurance Scheme (NDIS) offers. As you know, only organisations with scale, courage and imagination will prosper. The feedback I have received from our Members has been very supportive as we recognise the need to extend further beyond MS to welcome people with other disabilities… and their NDIS funding!

Unfortunately, not all MS Societies around Australia are performing as well as we are. The MS Society of South Australia and the Northern Territory finds itself sailing in uncertain waters where its very existence is threatened. As a consequence, MSWA has been asked to lead a recovery and we have taken the first difficult steps to turn their business around. Those steps included the necessary removal of significant costs and being part of an Australia-wide syndicate group to find extra funds to keep their Society afloat. For our management time and expertise we will, over time, be deriving a management fee.

We have started to implement our business model, underpinned by the values that we hold dear. Over the years, you may have heard some of my principles – things like ‘focus on the right volume of the right activities and the dollars will look after themselves’ or ‘the right thing isn’t always the easy thing, but it’s always the right thing’. It’s these very philosophies – and others – that we intend to operate by in South Australia and the Northern Territory.

And so, I only have time for a quick sip of champagne as I toast our past successes in Western Australia. Now it’s time to focus on the year ahead. We have people with MS to serve. Happy New Year!

**MSWA Online Shop**

Support Western Australians living with MS, and check out our online store. All the merchandise is ‘Stand Up to MS’ branded including t-shirts, caps, travel mugs and more. Also available for sale are Entertainment Books and Bosko, the MSWA mascot.

All money raised will help people living with MS in three major ways; funding research projects to better understand the causes of MS, and ultimately find a cure, providing professional healthcare services and delivering the best quality accommodation for those who need 24/7 care.

As we farewell another financial year, we reflect on our successes and challenges; from a Member Services perspective we have had another great year. Our growth in service hours for Members for 2013/14 was 11 percent and these relate to increases across most programs. Our programs and supports for people with other neurological conditions also experienced a 9 percent growth.

We have recently successfully re-tendered for our Health Department funding and we have lots of great plans in the pipeline, including new purpose-built premises for the Rockingham and Bunbury Outreach Groups, and establishing an office base in Busselton.

The two WA trial sites for the NDIS and My Way programs commenced on July 1 (see page 8 for more information on this), and we look forward with excitement to see if the WA experience will help shape the final NDIS program.

MS research continues to be prolific, which is always a good thing, as we continue to grow our knowledge about all aspects of MS, and new treatments continue to come to market, making more options available.

We recently hosted two neurology nurses from Singapore, who work in hospitals and see some MS patients. They spent a week shadowing our MS nurses in the community and MS clinics. They were very impressed with how MSWA is set up and the range of services we are able to provide, and took home some of our information resources for their own use back home. We were very proud to be asked to host these nurses, as the invitation came following two of our team, Lou the Nurses Manager and Lisa the Manager of Counselling, being asked to present an MS workshop in Bangkok last year. It is great to see that our MSWA staff are recognised as being highly experienced and sought after to help teach others.

We hope you enjoy this copy of the Bulletin and find something of interest and relevance for you.

Don’t forget if you would like any information about any aspect of MS, or to speak with one of our experienced health professionals, please contact us on 08 9365 4888. We are here to help you access relevant information and support.

“"The will to win, the desire to succeed, the urge to reach your full potential... these are the keys that will unlock the door to personal excellence.”

(Confucius)

Air-conditioner grants

People with multiple sclerosis on low incomes (full pension), are able to apply for grant funding to assist in the purchase of an air-conditioner for their home.

It is recognised that people with multiple sclerosis often have body temperature regulation issues. Some people report problems with the heat, others with the cold and others have issues with both the heat, and the cold. Humidity is also a problem; thus evaporative air-conditioners are not effective in humid climates.

MSWA receives block funding from Lotterywest to provide grants for eligible people on low incomes who require an air-conditioner for relief from the heat or cold in one area of their home. Successful recipients of the grant must be on full pension and receive the Thermo-Regulatory Subsidy from the Office of State Revenue.

For more information, or to apply for a grant, contact Sandra Wallace in the Occupational Therapy Department on 9365 4804.
Australian Stem Cell Network
Workshop Overview

Stem cell therapy for multiple sclerosis (MS) has been a hot topic in the news for the past few months. Several Australians have travelled to centres in Russia, India and Mexico hoping for a cure, to halt progression or reverse some of the damage done by their MS.

In May, MS Research Australia collaborated with the NSW Stem Cell Network to host a research workshop on Stem Cells in MS and Neurological Disease. This was very productive and included different stem cell types and researchers from the fields of MS, Alzheimer’s, Parkinson’s, Stroke and other autoimmune disorders.

The only stem cell-based treatment that is currently in use for people with MS is autologous Haematopoietic Stem Cell Transplant (HSCT), also known as bone marrow transplant. The purpose of HSCT is primarily to reset, or ‘reboot’ the immune system to prevent the autoimmune attack on the central nervous system.

International data indicates, that HSCT may benefit a small proportion of people with MS who are still in the active inflammatory phase of the disease, who do not respond to currently available approved treatments. However, it remains a highly risky procedure with a mortality rate of at least 1 percent.

In Australia, less than 40 people with MS have received bone marrow transplants to treat active, highly aggressive cases of MS that have not responded to approved MS therapies. The procedure has been carried out successfully at a number of sites, including sites in Perth and Sydney. Internationally, only a few hundred patients have been documented to have been treated this way.

This level of risk, the lack of larger scale randomised clinical trials and the availability of a number of clinically proven MS medications, means that clinicians and hospitals continue to take a cautious approach to HSCT. MS Research Australia is working with clinicians in the Australian MS HSCT Register, funded by MSWA, to gather further Australian data on this procedure.

We recommend that anyone with MS considering overseas stem cell therapy options seeks information from a variety of reputable sources and discusses their intention with their treating neurologist.

Lemtrada - previously known as Campath
Alemtuzumab, to be marketed as Lemtrada, is the latest drug treatment for people with relapsing remitting MS. It was approved by the NHS in the UK, and we have just received news that it has recently been approved by the PBAC in Australia for the PBS subsidy. This is good news indeed, and following negotiations between the pharmaceutical company and the PBAC it should become available in early 2015.

Results of two large phase III studies were published in 2012, including patients in Australia, and were very promising, showing that the majority of people on the treatment experienced an overall improvement or stabilisation in disability over seven years.

Alemtuzumab is given as a course of daily infusions for 5 days for the first dosing, followed by a 3 day course after each 12 months.

How alemtuzumab works
Alemtuzumab is a monoclonal antibody and acts by killing T-cells which form part of the immune system, which in MS mistakenly attack myelin. It is thought that the T-cells regenerated following treatment with alemtuzumab will not include those that destroy myelin.

Side effects and contraindications
Almost a third of participants develop thyroid-related side effects; these are treatable but can mean lifelong thyroid medication.

Infusion related flu-like symptoms were reported as alemtuzumab suppresses the immune system. Those on treatment will be more vulnerable to infections such as colds and viruses for some time after the infusion.

Immune Thrombocytopenic Purpura (ITP), a blood clotting disorder, affected approximately 1 percent of people involved in trials; although potentially serious, it is treatable if caught early enough.

Less serious side effects were common with 90 percent experiencing infusion site reactions and 77 percent reporting infections.

Ongoing monitoring is essential
Given the potential side effects, patients receiving Lemtrada must agree to ongoing monthly monitoring of their blood chemistry for 48 months after the last infusion.

Round-up of research and other items of interest
Sue Shapland RN, BN
Can levels of vitamin D at birth predict who will develop MS?
The cause of MS is not well understood, but previous research has shown that low vitamin D at birth may be associated with a higher risk of developing MS.

In Sweden, blood samples taken from all new born babies have been stored since 1975. This study involved 459 people with MS in Sweden born after 1975. The researchers tested each participant’s blood sample to measure the level of vitamin D in their blood just after they were born.

The study found that there was no relationship between the level of vitamin D in the blood just after birth and the risk of developing MS later in life.

Why do people with MS want to change their Disease Modifying Therapy (DMT’s)?
There is an increasing number of DMTs available for treating MS. Each of these drugs has known risks and benefits, but all are used to prevent relapses and slow the build-up of disability.

This American study looks at the reasons why people changed their DMT drug.

Statins in neurological disorders: an overview and update
There is increasing evidence to suggest that the benefits of statins may extend beyond their usual use to treat high cholesterol, to include neuroprotective properties.

Disease modifying therapy use in fathers to be: what effect on pregnancy and baby health?
Seventy eight pregnancies were examined, 45 were fathered by men taking a DMT and 33 were conceived when the father was not taking any medication.

The study found that there was no association between DMT use by the father at the time of conception and the risk of miscarriage, complications or birth defects.

Do flu vaccines work in people with MS and do Disease Modifying Therapies (DMT’s) make a difference?
Vaccination is the best way to prevent some infectious diseases such as influenza (flu). The disease modifying therapies (DMT’s) currently available suppress or modify the immune system. This study reviews the previous research to see if the DMT drugs have an impact on the effectiveness of flu vaccination in people with MS.

Complementary and alternative medicine (CAM) use and nutrient intake among individuals with multiple sclerosis in the United States.
The results support previous findings that CAM therapies are commonly used by individuals with MS. Inadequate intakes of certain vitamins and minerals by those following the Swank and Paleo diet suggest these diets may be too restrictive, thus further research is warranted.

Study suggests people with HIV don’t get MS
The study reviewed the records of over 21,000 HIV-positive individuals and showed a statistically significant lower incidence of MS in comparison to the HIV-negative individuals. In the HIV group, seven people developed MS, equating to a risk reduction of nearly two-thirds the expected rate.

What do people severely affected by MS need?
No two people with MS will have exactly the same set of symptoms, meaning that the needs of people with MS are complex and wide ranging as everyone’s MS is different.

This study sought to ask people who feel they are severely affected by MS what they felt they needed.

The results suggest that integrated services with a multidisciplinary approach, linking experts in neurology and rehabilitation, best support people with MS and their relatives, and improve care and wellbeing.

Read more at: mswa.org.au/researchupdate
July 1, 2014 marked the simultaneous launches of the Commonwealth NDIS and the state based My Way schemes trial sites in Western Australia. The NDIS represents the most significant reform ever undertaken for the disability sector in Australia.

During negotiations for the set up of a trial of the scheme in WA, the WA Government, the Disability Services Commission and the Disability sector were determined to maintain the best features of the existing WA model. Hence, we are the only state in Australia to trial two separate models of the NDIS in different locations. The trials will last for two years.

The main differences between the two schemes being trialed are largely administrative. Both schemes will have a consistent approach to increased choice and control for the individual, and family members. As with all of the trial sites around Australia, there will be an independent evaluation of both WA schemes to identify the best features that may contribute to the ultimate future scheme.

The Federal Government managed site in the Hills covers residents living in the local government areas of Swan, Kalamunda and Mundaring, and will be gradually rolled out, by groups of postcodes, over the next 12 months.

The State Government managed My Way scheme will initially be available to people in the Lower South West region, around Busselton, and will then be rolled out to people living in the Cockburn – Kwinana areas from July 2015. It is anticipated that, approximately 8,400 eligible participants in Western Australia will benefit over the period of the trials.

To be eligible to participate in these trials, the person must live within the designated trial sites, be aged under 65 years, have a permanent disability, and the disability must have a big impact of the person’s day to day life and their ability to participate in the community. The person must also demonstrate that they will need supports for the rest of their life. A link for the “Eligibility Checking Tool” is included in the contact details below.

People living in areas of WA not included in the trials will still be able to apply for funding through the existing WA Disability Services Commission model.

It is an exciting time for people living with a disability, and it is anticipated that ultimately the NDIS will deliver a fairer service and greater opportunities for all.

MSWA will be providing information and support for our Members living in the trial sites, and also actively seeking feedback on their personal experience with both schemes.

We will provide ongoing updates throughout the trial and send letters to our Members living in the areas notifying them when they may be eligible to participate.

We are here to assist however we can. If you would like any further information, please contact the NDIS Project Officer for Member Services, Mark Douglas, on 9365 4824.

NDIS and My Way contact details:

- For people living in the local government areas of Swan, Kalamunda and Mundaring:
  NDIS: ndis.gov.au
  Telephone: 1800 800 110

- For people living in the South Western (Busselton) Region:
  NDIS – My Way: disability.wa.gov.au
  Telephone: 1800 996 214

- Eligibility Check: myaccesschecker.ndis.gov.au
I was able to attend this year’s Australian and New Zealand Association of Neurologists (ANZAN) conference, in Adelaide, in May. Presenting was, Professor Michael Pender from Queensland, who discussed his extensive work researching the role of Epstein-Barr virus (EBV) in the cause of multiple sclerosis (MS).

Professor Pender first proposed the theory that MS, and some other chronic autoimmune disorders, resulted from EBV infection of the body’s B cells (immune cells in the body), which then accumulate in the “target organ” and released autoantibodies. Under normal circumstances, EBV infection would be controlled by the removal of infected B cells by the immune systems T cells. However, the theory suggests that this mechanism fails due to a genetic defect in people with MS.

EBV is typically associated with illnesses such as glandular fever, but around 90 percent of healthy people show signs of a previous EBV infection. Previous research has shown, almost 100 percent of people with MS carry the virus. Professor Pender has shown that people with MS have decreased immune responses to EBV, which could theoretically allow the accumulation of EBV-infected cells in the brain which may then contribute to the development of MS.

Professor Pender outlined subsequent discoveries confirming his theory, including the presence of EBV-infected B cells in the brains of MS patients. The beneficial effect of a B-cell depleting treatment, rituximab, shown to kill EBV-infected B cells in MS, also supports this theory. Other research has shown, the presence of EBV-infected auto reactive plasma cells in the joints of patients with rheumatoid arthritis, and the saliva glands of patients with Sjögren’s syndrome.

Professor Pender then discussed his ongoing work aiming to boost T-cell control of the EBV using a B-cell vaccination process (adoptive immunotherapy). A case study was presented of the first patient to undergo this procedure; a 42 year old man with secondary progressive MS who showed improvement not only clinically with reduced fatigue and improved cognition, but also in terms of MRI imaging and some laboratory tests. A phase I clinical trial is currently being planned.

This was a very interesting and inspiring presentation, covering almost 20 years of his research. Professor Pender and other researchers are looking at the role of EBV, and this is gradually building toward what appears to be a link between the EBV and genetic susceptibility to the development of MS, through immune dysregulation.

This work is potentially important for the future development of new therapies aimed at preventing and treating MS, and other autoimmune diseases by controlling EBV infection.

Professor Pender’s work is funded through MS Research Australia and you can read more on our website.

This presentation, and others, reinforced for me the high standard of researchers we have in Australia, and how important all of these research projects are in providing greater understanding of the cause of MS, and lead to better treatment, and hopefully a cure in the future.
Nothing changes if nothing changes

Leonie Wellington

“Any change, even a change for the better, is always accompanied by drawbacks and discomforts.” (Arnold Bennett)

What makes us so resistant to change when around us each and every day things are changing? Our adaptation to change is most often related to how we make meaning of it. As humans, we like to feel in control of our lives, and part of that is developing a routine and predictability to what we do. No problem of course, until for some reason this routine is disrupted or completely shattered.

Research into how people respond to change has provided some interesting results. It has shown that, in our minds, if something has been around longer we are more likely to believe it is better for us and more resistant to changing it. In one study, people who were told Acupuncture had been around for 2,000 years were more inclined to see its benefits than those who were told it had existed for only 250 years.

Again and again, studies tell us people equate how long something has been in existence with it being somehow better. This may well be true for some aspects of life, but definitely not all. We seem attuned to seeing what we may lose through change, rather than what we may gain.

The psychology of change has been explored extensively and models of change developed. I hesitate when I speak of models of change. A model is a generalisation of accrued research and observations, and not a definitive linear process. How one person manages and processes change is unique to them. So, having said all that, I will now share a little about the stages of change as they relate to changing behaviours.

Most of us will be familiar with the “pre-contemplation” stage. You know the one, where you believe that someone needs to change something but they don’t see it as a problem. There is no reason to change unless we believe that what we are doing is interfering with us living the life we want to live. This is a very personal perspective and one that can cause much conflict. In this stage, it can be helpful to acknowledge that it is a personal decision a person must be ready to make based on the information they have.

When someone moves into the “contemplation” stage, it is often because they have begun to think about how things could be different. It is a stage of “sitting on the fence”. People may evaluate the pros and cons, and be more open to alternative ideas but are in no way ready to commit to change. Supporting someone during this stage may require patience as there appears to be light at the end of the tunnel, yet they may never make that transition to the preparation stage.

During “preparation”, a commitment to change has been made. It can be a time of testing the waters or finding out what can I do? There may be research into the types of resources available and exploration of the implications of any changes made. It is helpful for people to have support in this stage and reinforcement that they have the ability to make change. It is also about taking small initial steps. What is done in this stage often reflects how well a person will remain committed to the process. Having done something one way for many years, maybe a lifetime, will take a realistic amount of time to change.

Once a person has reached the “action” stage they are committed and believe they can make the steps to change. They show willpower to be active in the change process and practice new ways of being. This is commonly the shortest of the stages, if the time has been spent preparing for action. This stage can often be difficult for those close to the person making the change, as they need to also adjust to the new behaviours and possibly make changes themselves. It may be a time of experiencing the saboteurs who aren’t comfortable and don’t want someone to change because it makes them uncomfortable.

So change has occurred but that means it needs to be maintained. “Maintenance” is an ongoing process of seeing the benefits of the change made and checking in to ensure that they continue to build skills. This stage usually involves the person accepting responsibility for striving toward what is meaningful to them and placing importance on that.

As I mentioned earlier, this is not always a linear process and it may involve “relapses” at any stage. Long held behaviours and beliefs about those behaviours are challenging to change, and it is not uncommon to fall back to what we know when put under stress. This is a normal and recurring part of the change process and also how we learn to action and maintain change.

Maybe that is just the natural process of change; admitting that change is sometimes great but then sometimes not, however, always happening. We may grump and groan, struggle or surrender, but at the end of it all make our way to our own meaning of the changes before us.
Ten tips for making and maintaining lifestyle changes

1. Be clear about why you are doing this. Assess what is most important to you and what you value in your life in order to pinpoint what you would like to change. If it is important to you then you will be motivated.

2. Select one thing to change at a time. Because, change isn’t easy to do, so don’t overwhelm yourself. Set yourself up for success by focusing on one thing.

3. Make a plan. Write it down. List why you are making this change, your supports, what may stand in your way, what triggers you to behave that way and how you will succeed.

4. Review your plan and be realistic. Do you need to break it down into more realistic smaller steps?

5. Prepare for obstacles and triggers. Brainstorm ideas to overcome any obstacles and have solutions for them before you get started. What changes can you make in your environment to clear a path for success? Reflect on past attempts to change and learn from that experience.

6. Plan a support team. The path to success is paved with cheerleaders. Look for the people who will help you change and steer clear from those who resist, and want to drag you back. This includes your own self talk. Celebrate your successes and don’t beat yourself up when the going is tough.

7. Make yourself accountable. Make a public declaration of your intent to someone; tell a friend or supporter, create a blog, a chart, a reward system linked to the changes you are trying to make and your progress.

8. Practise the skills you need to make change on a daily basis. Mastering new skills in coping and having positive alternatives to what you are trying to change will create new habits for lasting change.

9. Failure is an option. Our brains learn new things by being pushed beyond what they already know. We need to go beyond ourselves to learn something new and that means it will take more than one attempt to get it right. Don’t let failure be a negative, let it show that you are extending yourself and learning.

10. Ask for help. If it gets hard or you find yourself falling back into old ways it may be you need assistance from an outside source. Our counsellors at MSWA are trained to listen and create a safe space to explore how you can achieve what you aiming for.
Are you ready to ride?
The Ocean Ride for MS is on again! Join us on Sunday, 19 October for a beautiful coastal ride like no other. And, this year, not only can our Members take part in their usual Physiotherapy class, but their family members can also take part on the day as part of the MS Roadriders team. Plus, if they register to take part in the team we’ll even give them a discount on their entry fees.

Riders can choose the 10km Family Ride, 30km or 50km Ride, or the 70km Challenge, all ending at the Whitford Nodes Park in Hillarys.

Get pedalling now and register at oceanrideforms.org.au or call 6454 3131.

Swim for MS Joondalup
Fifty-eight swimmers took to the lanes of the Joondalup Arena for the annual Swim for MS in Joondalup on Sunday, 22 June 2014. And what a ripper it was!

“Not only was the fundraising effort amazing, the atmosphere and energy at the pool was fantastic!” says Gail Szabo, Events Manager at MSWA.

A total of 3,198 laps was swum over the 10-hour period. Pharmacy 777 was the team with the most laps swum, completing 664 laps and also raising a whopping $6,650. Congratulations to the whole team – what a great effort!

Most impressive were the fundraising efforts of the people of Joondalup, raising an amazing $14,672 to support people living with MS! Thank you to all who took part in the swim, and to all who donated. We look forward to seeing you again next year!

It’s a sell out!
After only 13 short days, we’re pleased to announce that the second MS Mega Home Lottery for 2014 is now sold out!

This is an amazing effort, and thanks go to everyone who supported this major fundraiser, for MSWA and people living with MS. Funds raised from this MS Mega Home Lottery will be used to build a new MS Outreach Centre in Bunbury and relocate the Rockingham MS Outreach Centre to better facilities. In addition, we will increase the level of healthcare services provided to Western Australians living with MS, and provide vital funding to research into the cause and cure for MS.

All of the 4,002 prizes will be drawn on Wednesday, 15 October 2014, with the major prize draws being televised on Channel 9 News the same day. All winners will be notified in writing and, a full list of winners will be available at mslottery.com.au from 6pm Wednesday, 15 October 2014.
MS Showcase

Crown Perth was the venue for the annual MSWA Dinner Auction, held Thursday, 31 July. With 190 people in attendance, it was always going to be a good night.

MC Deborah Kennedy kicked off the night with dancers performing a Great Gatsby inspired tap routine. Liz Tropiano, a wife and mother of two, spoke of the challenges that come with having MS at such a young age and looking after a young family. She also spoke of the need to stay positive and not let MS rule your life: a truly inspirational lady.

Principal and Auctioneer Rob Druitt, helped us raise a record amount of money to help people living with MS, whilst entertaining the crowd at the same time. And, the silent auction was again very successful, with items such as theatre tickets, weekends away, homewares, and professional photoshoots all up for grabs.

Check out Marcus’s blog

Have you read Marcus’s latest blog post? If not, why not check it out? You’ll find more information on the NDIS and other useful topics for living people with MS. And, occasionally he invites guests to blog about topics they’re particularly well versed in.

‘Like’ us on Facebook to be notified when the latest post is available or visit MSWesternAustralia.blogspot.com to view them all.

It’s officially open!

On Tuesday, 22 July, Minister for Mental Health; Disability Services; Child Protection, Helen Morton, officially opened the Hamilton Hill Stage 2 high support and accommodation facility.

This new facility features five high-support accommodation units, each with its own bedroom, living area, kitchenette and bathroom. Both Hamilton Hill locations are next to each other so residents are free to socialise with each other and enjoy the great facilities in both locations.

We’re really proud to be able to help keep more young people out of nursing homes, and look forward to building more facilities just like this one.

Thanks must go to everyone who bought a lottery or raffle ticket, participated in an event or made a donation; we couldn’t have built this facility without those funds. Thanks also to the Disability Services Commission, City of Cockburn, Perpetual Investments and Lotterywest for helping us make this dream a reality.

Running for the cause

Pharmacy 777 have long been a supporter of MSWA, but this year they are really upping the ante for the annual City to Surf fun run. After raising $20,000 for last year’s event, they’ve set a goal of $25,000 this year.

To help them on their way, we gave each team member a pair of MS shoelaces, so they know why they’re running, and some MS post-it notes to keep track of their times. And it must have worked because at the time of printing they’d raised a whopping $21,054 for the Sunday, 31 August event. Wow!

We’d like to thank all who took part in the team and everyone who donated to help Western Australians living with MS.
Professor Robyn Lucas is a medically trained epidemiologist and public health physician. Her research focuses on evidence to support public health messages around sun exposure. This includes a better understanding of factors related to vitamin D. She has a particular interest in understanding the effects of sun exposure and vitamin D on the immune processes involved in the development of multiple sclerosis. She is a long-standing member of the ACT Advisory Board to MSL NSW & Victoria.

Australia is a sunny country and Australians like to be outdoors. We pay for enjoying that lovely sunshine, particularly as we get older, with skin cancers and cataracts. For many years, researchers, health promotion specialists and Cancer Councils have been focused on the risks of sun exposure - hardly surprising with high and rising skin cancer incidence that puts us ahead of anywhere else in the world. Skin cancer is particularly a problem for fair-skinned people living in the sunnier areas of Australia – those closer to the Equator – like WA, Queensland and the Northern Territory.

But we do need some sun. Exposure of our skin to the ultraviolet radiation in sunlight is our main source of vitamin D. In fact, some people call this “the sunshine vitamin”. The role of vitamin D in the body is to control the levels of calcium in the blood. This is important because we need calcium levels to stay within a narrow range for our cells to function normally. When calcium levels are too low, the active form of vitamin D increases the absorption of calcium from the gut (and decreases loss in the urine), to bring the calcium levels back up again. If there is not enough calcium in the diet, or not enough vitamin D, then the calcium can be drawn out of the bones. This means that vitamin D deficiency causes the bones to be weaker. In children with vitamin D deficiency, these weakened bones can’t easily support the skeleton as it grows, and we see the knock-knees or bandy legs that are typical of rickets. This was a disease that was common in cities in the northern hemisphere during the Industrial Revolution, where there wasn’t a lot of sun anyway and children were indoors or living in narrow alleyways, and so not getting much exposure to the sun.

In recent years, there has been a huge increase in interest in other possible benefits of vitamin D. And, some of the strongest evidence is for MS. In many parts of the world, MS is more common the further you live from the Equator – so lower levels of ultraviolet radiation, and, logically, vitamin D. Other studies that compare people with MS to those without MS show that, people with MS tend to have lower vitamin D levels – but is that because they have MS and are not outdoors as much, or because the low vitamin D is increasing the risk of MS? We now think that both of these are true: low vitamin D, and maybe also low levels of sun exposure, can increase the risk of developing MS in some people. And in people with MS, their condition, and feeling worse if they get hot, can decrease their sun exposure and their vitamin D levels.

While we think, in general terms, that low vitamin D may increase the risk of developing MS, we don’t know how much vitamin D people should have, or whether taking a vitamin D supplement at the first signs of disease (or in people at higher risk of MS) makes any difference to the risk of getting MS. Researchers in Australia are working to find out the answers to some of these questions right now.

The PrevANZ Study is recruiting participants from Australia and New Zealand who will be randomly assigned to receive different doses of a vitamin D supplement or a placebo (with no vitamin D in it). Participants have had a first demyelinating event, which puts them at greater risk of developing MS. This study will show whether taking a vitamin D supplement can prevent MS in these people at high risk of MS, and also tell us the best dose of vitamin D supplement to take. The health of participants in the study is carefully monitored by doctors to ensure that each participant gets the best possible clinical care. The PrevANZ Study is important: at the moment, many people with MS or at high risk of MS take vitamin D supplements, including some at very high doses – just in case they help. But, in reality, we don’t know if they help or harm, and if they help, what dose to use.

The PrevANZ Study will tell us about vitamin D supplementation. But in the research that has shown that higher vitamin D levels are linked to lower risk of developing MS, those participants were not usually taking supplements; they had higher vitamin D levels because they had higher sun exposure. We know that sun exposure itself could, theoretically, also damp down the over-reactive immune response that is the cause of MS. So, in WA, another research
The MS Society of Western Australia - Spring 2014

study – the PhoCIS Study - is recruiting people who have had a first demyelinating event, to test whether having safe levels of artificial sun exposure, the same as that used by dermatologists to treat skin conditions, can decrease the risk of developing MS. The PhoCIS Study will be recruiting participants from Perth and surrounding regions during 2014 to 2016. In a small study overseas, where people with MS were given this type of phototherapy, there were some indications of benefit for their MS, but also, the participants liked it and it made them feel good!

So, how much sun exposure should people with MS have? We live in a very sunny environment and it is easy to get sunburned. The best way to make sure you are getting enough sun, without getting too much, is to go outdoors for short periods, e.g. 10 minutes, a couple of times a day. That is – don’t go out and sunbake. Most skin cancers occur on the head and neck – so always protect these areas with a hat and sunscreen. You will make vitamin D more efficiently if you expose more skin – so wear short sleeves and shorts, when the temperature permits. This pattern of sun exposure, with short periods outside only, should also work for people who are heat-sensitive. Most importantly, know your own skin and how sensitive it is to the sun – don’t get sunburned.

In Australia, weather forecasts in the paper and on the television usually include a forecast for the UV Index. This is a prediction of how intense the sun will be on that day. When the UV Index is less than three, no sun protection is needed – put on your t-shirt and shorts, and a hat, and go enjoy being outdoors, for as long as you like. If the UV Index is three or more, you can still go out for short periods as suggested above. But, if the UV Index is three or more and you are planning to be out for more than 10-15 minutes, then you should make sure you have adequate protection from the sun – Slip, Slop, Slap, Seek and Slide.

The law of cause and effect

Dr Andrew Ong

This is also known as the law of sowing and reaping, or the law of correspondence and karma. What you sow is what you reap. If you sow weed-seeds, you will reap weeds. Likewise, if you sow an apple seed you will harvest a crop of apples.

Whatever you have, or don’t have at this moment, is the result of your choices, decisions and actions you made in the past. Or, it may well be a result of you having done nothing and just let things slide, which is also a choice. Often these choices, however, are made unconsciously as a consequence of your past and unconscious conditioning by your parents, perhaps schooling, even your job can impact on your decision.

But, if we just pause to think of whether the choice we are about to make will bring us happiness or misery, and consider also the effect your decision will have on those around us, we may well make a completely difference choice. This is the law of cause and effect, and by itself it will then ensure that no debt goes unpaid, that all good actions will be rewarded and that all negative ones will attract their just deserts!

This law also allows us to change the karmic effect when things don’t work out as we first thought. We use this law as a lesson, and in this way, even in times of adversity, we will grow stronger and wiser, and put this experience to good use. In this way, we can transcend an adverse karmic episode and redirect our destiny towards greater fulfilment and happiness.

What we sow, is what we will reap.
But first we must sow and then we can reap.
If we have sown ill-will there is no undoing of what has transpired, save to atone for it and to learn from its harvest of pain and misery.
Therefore sow goodwill, understanding, tolerance, and unconditional love.
Plant seeds of forgiveness, patience, generosity and compassion.
The occupational therapist is primarily involved in the prescription of equipment to enable people to manage better in their environments and with the activities of their daily lives. Maintaining this equipment, for both safety and optimal functioning, is necessary and should be part of the training provided when equipment is issued. If equipment issued no longer helps to meet your needs, reassessment by an OT may be necessary.

Equipment issued by a hospital remains the property of the hospital and they are also responsible for the ongoing maintenance. If you have equipment that you think is not working as it should, phone the hospital who supplied the equipment and advise them of your concerns. This will give them an opportunity to arrange servicing or repairs.

Items that need ongoing servicing include, wheelchairs (powered and manual), scooters, wheeled shower and commode chairs, and hoists. These items are mechanical and subject to wear over time. For example, a common problem with wheeled shower equipment is that soap scum and hairs get trapped in the wheels causing the wheels to become stiff. Cleaning can easily fix this problem and maintain safety in the bathroom. This equipment will not be routinely serviced but you can request a service and it should be followed through.

When the OT obtains funding for an item of equipment for a Member, this equipment becomes the property of the Member. The Member is therefore responsible for the ongoing maintenance. Maintaining equipment can prolong the life of the equipment and ensure it functions at its best. The costs of maintaining equipment are not funded, and the Member must budget for this. The OT cannot seek further funding to replace an item that was not well maintained.

The best way to care for equipment is by following the manufacturers recommended servicing; and to have it looked at when it is not functioning as it should. If you have equipment and require advice regarding servicing, please contact the MSWA Occupational Therapy Department on 9365 4888. We have developed a number of care sheets for different equipment and can send these out to you as well as discuss your particular equipment and its needs.
For many people, driving is a symbol of independence. The worry or fear of ceasing driving may represent significant loss and possibly delay the investigation of driving options. Reporting your medical condition, however, does not necessarily mean a loss of driving.

Mandatory reporting of medical conditions

By law, all drivers must report any permanent or long-term medical condition that is likely to impair their ability to drive. Multiple sclerosis, and other neurological conditions, are classified as medical conditions and need to be reported. The same is true for anyone on blood pressure medication, antidepressants, or with diabetes, sleep disorders and so on; so tell your family and friends.

How do I report a medical condition?

You can report a medical condition in writing by either filling out the notification of a medical condition online, the form can be found at: transport.wa.gov.au/licensing/report-a-medical-condition.asp

Or by writing a letter that includes:
- full details of the medical condition you are reporting;
- your full name and address;
- your date of birth;
- your daytime contact numbers; and
- your drivers licence number.

Then, post it to: Mandatory Reporting Team
Department of Planning and Infrastructure
GPO Box R 1290
PERTH, WA 6844

What happens next?

Once the department has received your letter they will contact you to determine the action. There may be no action required, or your driver’s license may need updating, for example, detailing that you need to wear suitable visual aids whilst driving. You may be required to undertake and pass a medical assessment, usually with your GP. If your GP is uncertain, you may be required to undertake and pass a practical driving assessment.

Once the required action has been completed, you will need to send in the results. If you satisfy the requirements, you will be able to continue to drive. If you fail to satisfy the requirements, your license could be suspended or cancelled. Any action required has a date it must be completed by. Be aware of this date because failure to complete that action will result in your license being suspended.

People with multiple sclerosis require an annual medical assessment for fitness to drive.

Driving Assessment

If you are required to undertake an on road driving assessment, you may wish to talk to one of our occupational therapists (OT’s), who can prepare you for the process and answer any questions you may have prior to the assessment. Our OT’s are aware of driving aids that can enhance driver safety and the funding available to assist with vehicle modifications, if required. Please contact us on 9365 4888 and ask to speak to an OT.
‘To dye, or not to dye? That is the question.
Whether ‘tis Nobler in the mind to spend
On hairdressers an outrageous Fortune,
Or to take Arms against the grey roots with dye,
And by colouring end them? To dye, to colour –
No more; or by a colour, to say we pretend
The white strip, and the thousand Natural greys
Are gone forever?’
(With apologies to William Shakespeare)

Most of the time, I face the mirror with calm acceptance. I’m no Elle McPherson (I certainly don’t have the body), but on the whole I am happy with how I look for a woman of fifty-something. My eyes are still bright and only a little bit bloodshot, but I put that down to the late nights reading in bed. That, and the glass or two of wine with dinner. My teeth are nearly straight and I have no fillings, something of which I am inordinately proud. If I close my eyes a bit in a semi-squint without my glasses on, my skin still looks fresh. Sometimes, if the light is dim and I had a good sleep the night before, I imagine I haven’t changed much at all since I was in my thirties.

Every few weeks though, even dim light can’t hide the white streak appearing in the part in my hair. Chemicals help me deceive myself and others into believing in eternal youth, but hair continues to grow into old age. I regularly face the existential dilemma: should I dye my hair or go grey?

Since I was twelve years old I have been concerned with self-image. Growing up in a household with five women and one bathroom made me strong, especially when it came to elbowing my way through the queue to the bathroom door. Once there, with the door locked, I would spend long sessions in front of the mirror trying to master the art of looking sophisticated yet sexy with blue eye shadow, a skill not to be sneezed at.

I also discovered my older sister’s eyebrow tweezers, only to suffer abject humiliation after an over-enthusiastic attempt to master the art of plucking. I knew straight away that something was wrong when everyone stopped talking at once after I emerged from the bathroom. That night at dinner, while my mother and sisters looked determinedly at their food, my father gave me a long and complicated lecture which had something to do with men being wolves. While I didn’t understand it all, the implication was clear: eyebrow plucking brings them out of their dens. My father was Greek and had strong old-country family values when it came to his daughters. Although I do sometimes wonder, looking back, if his lecture that night arose more from concern for my virtue, or from his frustration with our feminine invasion of the bathroom. My father died when I was sixteen; what I wouldn’t give to have him here to lecture me on wolves today.

My sisters and I have bathrooms of our own these days and more mirrors between us than are really healthy for anyone who wants to stay sane. Mirrors, of course, are the ultimate symbol of narcissism. I’m happy today that I can look in a mirror without undue anxiety, most of the time anyway.

Everyone has different attitudes to growing older, at least as far as hair is concerned. One of my sisters has decided to abandon hair dye and has long flowing locks in varying hues of grey and white. She looks fabulous and it suits her earth-mother/hippie nature perfectly. My oldest sister uses dye and wonderfully manages to look like the same brunette she was at high school. My younger sister uses dye too, but has gradually gone a significantly lighter colour, which means she blends in better with her fellow Queenslanders who seem to be predominantly blonde.

Which brings me back to the white streak in my hair. You might think I have dark brown hair, but do you want to know the truth? If I didn’t dye my hair, I’d have grey hair all over with white streaks.

For some years now I have spent a significant amount of money every few weeks at the hairdressers, covering it up. I have to admit, I enjoy the pampering, and they give me a great cup of tea with a really nice spice biscuit. I always feel guilty about the cost of the haircut, until I eat that delicious biscuit, then I relax and forget all about the money. I’m a sucker for a good biscuit.

I can choose whether to dye my hair or not, and one day I’ll choose not to. I hope I will look wise and elegant with white hair.

Having multiple sclerosis is not a choice. I’ve lived with multiple sclerosis for over a quarter of a century, and I would very much like to choose to be rid of it. I am glad to know there is a bunch of scientists beavering away in laboratories trying to find the cure for MS, so that one day I will be able to make that choice.

Till then, I will practise being wise and elegant.
Hello all. I hope this Bulletin finds all of our MS Society Volunteers, Members, Carers, Families, Friends and Staff well, and enjoying the much-needed rain we’ve been having.

Firstly, I’d like to send a big CONGRATULATIONS to one of our volunteers, Lynda Whitton, President of Bunbury Outreach Group Committee, who has just received the Commitment to Volunteering Award for the MS Society of WA. Lynda is a National Advocate with MS Australia, for the MS Society of WA and a great supporter of fundraising and events in Bunbury. Well done, Lynda.

Working alongside the MSWA volunteers is always truly rewarding, and I wish to thank each and everyone one of you for all that you do for the Society. It’s lovely seeing your smiling faces and that in itself is enough to make a difference to all our Members and staff.

Volunteering is so rewarding which is why I also volunteer for the MS Society when and where I can. My most recent volunteering was at the annual MS Dinner Auction Showcase Evening which was absolutely fantastic. I was able to meet with Board Members, Senior Management, staff and some of our Members. I even spoke with Dean Clairs from 94.5 FM and the Mayor of my Local Council, Mr Logan Howlett.

During July, the theme at Wilson Outreach was 50s/60s Rock ‘n’ Roll. It’s wonderful when everyone comes together and dresses up for the occasion! Two of our lovely volunteers, Rosalind Beatty and Lesley Pitt, donned the 50s/60s gear and joined in the fun. Don’t they look stunning? Well done ladies, and to all those others who joined in the fun and atmosphere.

By the time this Bulletin is out I will be busy with the yearly “It’s a Knockout” Competition. I can’t believe it is that time of year again. The Metropolitan event is being held in Riverton on September 23. Bunbury Members are holding their event on the September 17 and Albany Members will be entering the competition for the first time on September 19. Good luck to you all, and let the games begin!

Lastly, I’d like to thank WASO for providing free tickets for a few of our volunteers to attend the Stravinsky’s Petrushka Opera in May. It’s always important to acknowledge and thank our volunteers; and it’s great when local businesses recognise their valued role as well.

The Smith Family Saver Plus Program

Saver Plus is a financial education and matched savings program that assists families to gain financial skills, establish a savings goal and develop long term savings habits.

Saver Plus is an initiative of the Brotherhood of St Laurence and ANZ, delivered in partnership with The Smith Family, Berry Street, The Benevolent Society and other local community agencies. The program is funded by ANZ and the Australian Government, with ANZ providing matched savings for participants.

Participants may be eligible to join Saver Plus if they:
• have a Centrelink Health Care or Pensioner Concession Card;
• are at least 18 years old;
• have some regular income from work (self or partner) including casual, part-time, full-time or seasonal work;
• have a child at school or attend vocational education themselves; and
• live, work, study or have a child at school in an area when Saver Plus is delivered.

Upon completing the program, ANZ matches the participants’ savings dollar-for-dollar up to $500 which can be spent on educational expenses including computers, text books, uniforms, excursions, music and sports costs.

To find out more contact Meagan Parry, Saver Plus Worker, at The Smith Family on 9440 4147, 0438 518 603 or email meagan.parry@thesmithfamily.com.au
A New Year’s Cruise (Part One)

Marija Nelson

For New Year this year ‘we went on a boat’. When my daughter Rebecca was around three years old we went on a dolphin boat in Jervis Bay, NSW. For months after, she would suddenly come out with the statement ‘we went on a boat’. We used Beck’s phrase quite a bit while we were on the cruise.

We flew to Sydney and spent the day before with my sister and her family, also visiting my aunts and uncle. Our 13 night cruise sailed from Sydney on Sunday, 29 December 2013 bound for New Zealand. I had never been there, my husband Willy had been with his family in his early teens, Beck and my son Lochlan had never left Australia. We met up with Willy’s Mum, Janice (from Melbourne) and sister, Annette (from Canberra), it was our yearly reunion.

We cruised on Radiance of the Seas; one of the Royal Caribbean Line. Just a few facts: she is 293m long, 39.8m wide and has 12 decks; weighs 90,000 tons and carries 2,501 passengers and 862 crew from 47 nationalities. 150 chefs prepare 15,000 meals per day. Cruising speed is around 19 knots and top speed is 22 knots. At top speed she uses 10 tons of fuel per hour and at economical cruising speed she only uses 3.5 tons. She can crash stop in 2-3 ship lengths from a speed of 20 knots. She can make 1,600 ton of water per day through desalination and reverse osmosis. She has the most glass of any Royal Caribbean ship to provide the best views.

Lochlan and Beck were in a window cabin on the 3rd deck, next to Janice and Annette. Willy and I were in a ‘disabled’ balcony cabin on the 7th deck. The cabin was spacious and easily accommodated my walker, and wheelchair.

The bathroom was equally spacious with a fold down seat in the shower and rails all around. We were all port (left) side to make the most of the views.

We had requested an early dinner seating, so we had our own family table and our waiters each evening were Ketut (yes, he knew all about Rhonda) and George. Ketut, when he saw Willy cutting up my meal for me, just quietly each evening cut it up for me. It was much appreciated as my left hand won’t play the game. All the staff on board were fantastic, as were the meals and we all came home a little heavier. The plethora of food available and included in the cost was amazing. There was Cascades, the restaurant; The Windjammer Café, a smorgasbord; Pool side Café and The Dog House where you could grab a specialty hotdog 24/7 (this was well frequented by Willy and the kids). The only extra costs were for alcoholic drinks and specialty coffee. There were other restaurants that you had to pay for; we didn’t see the point when we could dine on spectacular meals that were all included.

Unfortunately, Lochlan succumbed to seasickness for the first 3 days, Beck really looked after him, making sure he was well hydrated and had lots of light snacks. After his initial bout, he was fine for the rest of the trip.

The deal we struck with the kids was that we would all meet for breakfast at 8.30ish, or earlier if we were going ashore. Breakfast usually contained lots of smoked salmon (eggs benedict or omelet). Then we could do our own thing and meet for dinner again at 6.30pm.

The kids would disappear to Optix, the Teen Club, where they would ‘hang out’ with their new friends. Willy spent his sea days at the gym, playing volley ball or on the walking track. Annette, Janice and I would go to talks, on shore activities, movies, various demonstrations, listen to music performances or read.
After dinner, the kids would disappear to Optix, their curfew was 1am and we would go to shows, attend quizzes or play scrabble which was a favorite for all of us. When we returned to our cabin each evening, the staff had turned on our bedside lights and had placed an extra towel, folded into some critter (elephants, dolphin, seal, monkey etc) and place my sunglasses on the critter’s face if they were close by. It always brought a smile.

We spent two days at sea transitting to New Zealand. Dinner on the 31st (New Year’s Eve) was a formal night where people dressed up and there were top hats, beads and tiaras on the table when we arrived at the restaurant. All of us chose the pork belly entrée, the Maine lobster (nowhere near as tasty as our rock lobster) and prawns (which were sensational) for main and Pavlova for dessert. An early night for the ‘oldies’.

To be continued…

That’s Life with Narelle

In the first chapter of Alice in Wonderland, she falls down a rabbit hole. In the second chapter she finds that she has grown, just as I have lately. Alice cries. I am dieting. Something they do here is feed one often. My name is Narelle, and I live in an aged-care facility. There, I said it.

I live in an aged-care facility in the very suburb where Rolf Harris grew up. He opened the building. But his painting has been taken down from the dining room wall. The plaque commemorating the ceremony has been removed. None of us residents said anything about it.

Some of us didn’t even know it happened. Me? I didn’t care. I’ve been thinking about other things, like the culture shock I’m enduring. Everything here is regimented. We get bathed, dressed, fed, exercised, rested and fed again according to a timetable.

The staff are lovely and regard me as a novelty because I go out so very often. They even disclosed to me the entry/exit code so I can come and go as I please. They are also very tolerant if I come home tired and emotional.

Some people have very few visitors. I encourage my visitors to take me away from this place. Actually, not just the visitors. My dining companion recently complained about being served cooked carrot as if it was metal shavings. I saw my chance. “Let’s run away,” I said. She laughed. We did not bolt though.

I did run away with my sister Janine for a few days. She was visiting from Sydney. We booked Treendale, the MS Society’s holiday home in Australind just north of Bunbury.

It has three double bedrooms, each with an ensuite, scooter-friendly living area, a private courtyard and no steps anywhere. It was ideal.

There were carers on site, a shopping centre one block away and a bottle-shop very handy. Our friend David, a local, gave us a tour of the town. He shouted pizza for tea. We washed it down with some local wine. The evening got quite late. There was a fair amount of wine.

In the morning, we let David know we were about to leave and we would see him next time. He said: “I will alert the local vineyards that the threat from the marauders of the north will be over soon”.

It was a great spot for a holiday and I can’t wait to go again.

We could easily have stayed much longer because Treendale is so well-equipped. There is a laundry with washing machine and dryer, and a kitchen with every imaginable modern convenience. A local scooter shop delivered me a bike to get around on for the duration of our trip, and they picked it up again after we left.

Back at my aged-care facility, I looked to share my holiday story. I felt sorry that so many of my fellow residents would never be going there.

Seated at the dinner table, I felt we were a bit like Alice and her sister bored on the riverbank in the opening chapter of Lewis Carroll’s storybook.

Everyone should have an adventure once in a while.
A column in the Bulletin is not enough to share all of my memories of camps, but if I could sum it up in one sentence, I would say it has just been wonderful. Members often ask me about the camps and wonder what really happens on these camps. I often tell them that every camp is different; they are what the participants gain from them. What I have learned in past few years is, that for a few, it’s just a break from their daily routine, for some it’s all about relaxing, a few come to challenge themselves outside their comfort zone, and the majority come to catch up with their mates and have a good laugh. I believe the best way to find out about our camps is by experiencing it.

In March this year, we stayed in villas at Thomson Bay, Rottnest Island, for our Carers retreat. On the evaluation form one carer shared their experience: “A good rest away from the responsibilities and my caring role. Talking to other carers, enjoying their company, plenty of laughter, also the times you could be on your own and do your own things was beneficial. It was good to be able to do what you wanted to do, which you don’t often get as a carer.”

Upcoming camps in 2014 – 2015

- Family camp at Moore River: 6/10/14 – 9/10/14
- Carers retreat at Busselton: 21/10/14 – 24/10/14
- Southwest Members camp at Denmark WA: 18/11/14 – 21/11/14
- Carers retreat at Rottnest Island: 16/03/15 – 19/03/15

The MSWA camps program is supported by a Lotterywest Grant which allows us to keep the costs to participants minimal. For further information regarding our camps, please contact the Camps & Recreational Co-ordinator, Sumit Sandhu on 9365 4843 or email sumit.sandhu@mswa.org.au

Employment Forum

The MSWA Occupational Therapy Department is holding an Employment Forum for Members on the Wednesday, 26 November. This event brings together experts in the field to provide good information and to answer any questions you may have regarding employment concerns.

John Berrill from Maurice Blackburn Lawyers will be able to advise on your rights and responsibilities at work, accessing your superannuation, claims and disability benefits.

Job Access will explain how this Government funded program keeps people working by ensuring they have the equipment required to enable them to maintain their productivity.

In addition, our Occupation Therapists will be present to guide you, address your concerns and ensure you have good information to help make effective and informed choices.

This forum is free for Members and their families.
DATE: Wednesday, 26 November, 2014
TIME: 3.30 – 6.30pm
VENUE: Ernest Johnson Scout Hall - 20 Pilgrim St, South Perth
For any queries and to confirm your attendance for catering purposes, please contact Ilissa Liew on 9365 4832 or ilissa.liew@mswa.org.au
Wilson Outreach News
Nicola Ryan

May, June & July have certainly been exciting months for the Members, and staff, at Wilson Outreach.

We had a very generous donation of two raised garden beds, along with soil and plants, from the Willetton and Melville Bunnings stores. Their very willing staff “built” the garden beds in a morning, and planted vegetables and herbs as well. Our Members, and volunteer gardener John, have cared and watered them regularly and presently we have a very “healthy” looking patio area. All the vegetables and herbs are growing wonderfully, and the first crop of snow peas will be picked soon. Our idea is to become a “little” self sufficient in our kitchen at Wilson!

Over the last three months, the Outreach group has had two themes; the first being an “indoor cruise”. Our Members “boarded” the M/S Cruise liner sailing from the Atrium for a month. Thankfully, no seasickness was reported and everyone was extremely happy with the beautiful food Giselle and her brilliant kitchen volunteers prepared.

The highlight of the last week of the cruise was the “Captain’s Formal Dinner” which was a huge success.

July was a “Rock-n-Roll” theme which was lots of fun and included a visit from Gail’s son with his 1964 Vintage car, as well as dancers from the Rock-n-Jive Social Dance Club. Members and staff were treated to a special dance performance and everyone had a “Rockin” time as they danced, sang, and hand-jived their way through the morning to the golden tunes of the 50s and 60s!

The decorations in the atrium were fantastic and the pink “cardboard” Cadillac proved very popular amongst Members and staff alike.

Thanks to one and all for joining in on ALL of the activities and we look forward to having many more enjoyable themes in the future….watch this space!!!

Southside Outreach News

Southside Outreach Group has outgrown Seabrooke House and as a result we are on the move!! After 18 years in our current home, I’m sure there will be a few tears on departure day. Our new premises will be closer to Rockingham Town Centre and approximately 30 per cent larger with purpose-designed areas for physio, massage, visiting podiatrist/nurse etc. We won’t know ourselves.

Our beloved Barry is still in hospital (since June 29), recovering from a nasty break in his wrist, and bronchitis. We need you around here, Barry, to help move boxes! Kidding … just hurry and get well. One of our carers, Peta, has also had some serious time in hospital. Hope you are soon well!

Masseur Delinda tied the knot recently and her big smile seems ever more radiant. Congratulations!

Our Christmas-in-July party was a lot of fun, thanks to Nicola and thanks to cooks Rosalie and Tracey for the turkey dinner with the trimmings.

As a local charity initiative, two consultants from Nutrimetics recently held a Pamper Party for us. Facials, hand massages and aroma therapy were well received by the members. Thank you, for a fun morning ladies.

Bunbury Outreach Group News
Lynda Whitton

Where have the last couple of months gone! We have had a busy time at our Outreach Group, having held two fund-raising “Maddie the Mad Cow” soup kitchen mornings which raised over $100 dollars to go towards goodies for our Xmas lunch. It’s lovely to see our staff (Maddie the Mad Cow aka Susie, and our “quiet working in the background” Vivienne), getting into the swing of things to brighten up our days.

We had Marcus come down to give an up-date on the progress of our new premises. It is all looking very exciting and it’s great to know that we will not always be so squished!

I was also informed that day that I was being awarded the MSWA Commitment to Volunteering Award. It was a huge shock; there are so many great people doing things for the Society, so to be singled out from my peers is a great honour indeed. I received the award at the annual Dinner Auction in Perth. I was very proud, and so were my family.

Dee, one of our MS nurses, held a forum on incontinence and bowel problems, and it was very interesting to all who attended. For those who missed it, Dee has lots of literature for your information, so just contact her at the office.

The exercise group re-started this week, run by Alison our physio. There are places still available; it is fun and good for you! So call the office for more information.

Finally, it is sad to say that our masseuse, Kylie, has had to leave us and we all wish her a speedy recovery.

For any information on our activities, or to see the MS nurse or physio, please call 9791 2472.
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