

# Network

**MS**

News	6
Annual General Meeting	13
Our people	14
The role of rehabilitation in managing MS	16
Sunday Mail City to Bay	18
Multiple Solutions	20
Mick, Jane and Me – Living well with MS	22
Mobility Allowance	23
Cognition and MS	24
MS Assist	26
Peer support update	28
Making life a TAD easier	29
Client stories	30
Recipes	34
Fundraising	35





# In this issue

From the Editor.....	3
CEO report.....	4
Letter to the Editor.....	5
News.....	6
Annual General Meeting.....	13
Our people.....	14
The role of rehabilitation in managing MS.....	16
Sunday Mail City to Bay.....	18
Multiple Solutions.....	20
Mick, Jane and Me – Living well with MS.....	22
Mobility Allowance.....	23
Cognition and MS.....	24
MS Assist.....	26
Peer support update.....	28
Making life a TAD easier.....	29
Client stories.....	30
Recipes.....	34
Fundraising.....	35
Locations.....	36

**MS Head Office**  
PO Box 377  
Salisbury South DC SA 5106  
P (08) 7002 6500  
Toll Free 1800 812 311  
F (08) 7002 6599  
E ms@ms.asn.au

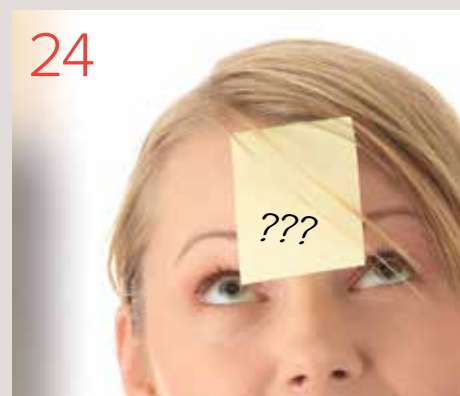
**MS Northern Territory**  
PO Box 867, Nightcliff NT 0814  
P (08) 8948 5300  
F (08) 8948 5344  
E nt@ms.asn.au

**www.ms.asn.au**

**MS Society Privacy Policy:** The MS Society of SA & NT is committed to the protection of private information. A full copy of the MS Society Privacy Policy is available by phone: (08) 7002 6500 or online at [www.ms.asn.au](http://www.ms.asn.au)

**Disclaimer:** Material published in Network may not be reproduced in any form without permission from the MS Society. Any views expressed are not necessarily the views of the MS Society. All reasonable efforts have been taken to ensure the accuracy of any content but no responsibility can be taken for any error or omission.

**Guest contributor:** Spiro Koulocheris.



## From the Editor



Hi everyone,

Another full edition for you this quarter!

It has been great to have so many people happy to share their stories and contribute to **Network**. This month I met with Brian Jones, who has led an interesting life as a baker up in Townsville before returning to Adelaide after his diagnosis of MS. Brian introduced me to his birds, which he finds are great pet therapy.

Sue Griffith, who is the leader of the peer support group in Tailem Bend, was happy to tell us about a local quilting group who managed to raise enough money to fund 10 Zen Chai Relaxerciser machines for their area. What a brilliant effort from quilting group and the Tailem Bend community.

Pam from our PwMS committee has reviewed George Jelinek and Karen Law's new book, 'Recovering from Multiple Sclerosis' on page 11. Pam is also involved in starting a new peer support group based on the Overcoming Multiple Sclerosis program. You can find more information about this in our Peer Support section on page 28.

Things are starting to get muddy in the office again... Is there anyone in your family or do you have friends who are participating in the mud run for you? We would love to hear the story of why they are getting muddy for MS.

Keep the stories coming in! If you'd like to share your story or have something else to contribute to **Network**, please email me at [feedback@ms.asn.au](mailto:feedback@ms.asn.au) or call **7002 6500**.

Some of the MS Society staff have been focused on their food habits lately. I've seen a lot less processed and more homemade goodies, so they know exactly what is going into their bodies. I have been happy to be taste-tester for new inventions! One of my biggest weaknesses is peanut butter cups. I know they are terrible for you, but peanut butter and chocolate together? Amazing! You can imagine my delight when Brigid, our Relationships Coordinator came into the office with some 'clean eating peanut butter cups'. They are still definitely a treat, but taste amazing and a million times better for you than the original. Not to be outdone, Kirsten, our Fundraising Development Coordinator appeared days later with some Walnut, Pumpkin and Chia muffins. You can judge for yourself which recipe is best on page 34.

I hope to see some of you at our AGM on 30 October. Remember this is your MS Society, if you want to make a difference or have a say, come along and share your views.

Until summer!!

**Renee Meredith**

Editor **Network**

MS Society of SA & NT Inc

[feedback@ms.asn.au](mailto:feedback@ms.asn.au)



## CEO report



Winter is over but spring is struggling to impose itself. It seems either too hot or too cold for it to be spring, so I imagine those with heat intolerance are finding it difficult.

The weather was very kind to all those people who joined Team MS for the City to Bay. Altogether, we had 130 in the team, and collectively we raised a total of \$21,085! This is a fantastic result from the enthusiastic runners and walkers on the team.

My thanks go to all the participants and their sponsors. Check out our Facebook page for photos!

MS Assist is proving its worth to the MS community. In July we had over 300 callers from all over South Australia and the Northern Territory. It is great to see so many people from the Territory and South Australian rural and country areas access information and assistance through the **'MS Assist' Line** on **1800 812 311**. Please remember that MS Assist is also available via email at **msassist@ms.asn.au**

The 5 year contract we were awarded by the Department of Education, Employment and Workplace Relations (DEEWR) to offer employment placement and assistance to people with disability is growing strongly. In August we placed 29 people into employment, and by assisting them in this way we know we have helped them to gain independence and self esteem, and to change their lives forever.

Please do not hesitate to contact Multiple Solutions if you are interested in entering the workforce, or if you are

experiencing difficulties in your current job, where the difficulties are related to a disability. Our expert staff will welcome the opportunity to assist in a very supportive way. A reminder to any employers who might be reading this; we are always looking for vacancies into which our job-seekers can be placed. We are also available to help with all sorts of assistance (including funded workplace modifications), for employers who would like to employ someone with a disability, or who need to make workplace changes to sustain the employment of someone with a disability. Lachlan Barr, the new manager of our employment service, Multiple Solutions, has had an immense impact on the organisation since he started in July. Lachlan is very determined to offer the best assistance he can to people with a disability who are in, or entering, the workforce.

With the Kiss Goodbye to MS awareness campaign now behind us for this year, attention in the office is turning to the 2013 Bernie Lewis MS Mud Run. We are expecting to build on last year's very successful event,



### Purchase your new 2013 | 2014 Entertainment™ Book

ORDER  
TODAY

Purchase your 2013 | 2014 Entertainment Book for just \$65 and you'll receive over \$15,000 of valuable offers. Choose what to do and when you want to do it with 50% off, 25% off and 2-for-1 offers, valid until June 2014.

Entertainment Books feature the best restaurants, attractions, cinemas, sports, hotel accommodation and much more.

Purchase your Entertainment Book and help raise funds for the MS Society of SA & NT.

Contact Sonya on (08) 7002 6500 or email [srowell@ms.asn.au](mailto:srowell@ms.asn.au)

and to have far more participants and visitors to the event. The Mud Run is about much more than fundraising; it is a great vehicle for promoting awareness of MS amongst the wider community.

Although many PwMS participated in last year's Bernie Lewis MS Mud Run, some were not able-bodied enough to enter. We are very conscious that this is an able-bodied event, and wish there were ways to make it more inclusive. Our insurers have taken a very strong stance on this, and there is little we can do. Of course, the MS Mighty Swim is an inclusive event, as will a planned cycling event we are currently evaluating for 2014. A segment of this event is being designed for the participation of people with disability. Of course, so many PwMS joined in the fun in the City-Bay event; I know because I saw so many of you as I proudly walked the 12km in my bright red Team MS t-shirt!

The Board of the MS Society has asked me to set up a process for the review of our current strategic plan, with a view to creating a new strategic plan for the years 2014–2016. Many things have changed since the last plan was created, and with the results of the 2013 analysis of the needs of people with MS available to us, and the introduction of DisabilityCare Australia over the next few years, it is timely that we review our activities to ensure that we are meeting the identified needs of PwMS, and especially in the context of services available through DisabilityCare in the future.

The PwMS Committee will play a crucial part in the development of the new Strategic Plan.

They are currently undertaking an analysis of the services we provide, against the services that the Needs Analysis have identified, to see where the shortfalls in service delivery are. I am very appreciative of their help in this task.

And don't forget, there are still vacancies on the PwMS committee for people who would like to participate! In the first instance, please contact me or Renee Meredith if you are interested.

In closing, (and I have kept the best till last), the Honorary President of the MS Society, Tony Abbott AM, has advised that Associate Professor Mark Slee has joined the Board of the Society. A/Prof Slee is Director of Flinders MD Program, and Regional Head of Neurology. We are very excited to have Dr Slee on the Board, as he will give us access to a whole new genre of information and expertise, including vast experience in the diagnosis and treatment of people with Multiple Sclerosis.

Let's hope spring arrives soon!



**Graeme Warnock**  
Chief Executive Officer  
MS Society of SA & NT Inc

## Letter to the Editor



On Monday I had to put my dearest dog Prue down as the Cancer had made her breathing too hard The kindest thing was to let her go.

Today has been the first time I can bring myself to tell my friends without losing it in a puddle of tears. She was only nine which is too young. The growth on her front paw had metastasised to her lungs. My Poodle now sleeps with Gemma up the back with the flowers.

**Jo-Ann Parsons**

**Editors Note:** Thanks for sharing Jo-Ann and sorry for your loss. It is so hard to lose a pet, they become our best friend, companion and exercise buddies. I lost my dog Ollie last year, he was 14 and it broke my heart too.

Send your letters to:  
Editor **Network**  
PO Box 377  
Salisbury South DC SA 5106  
or email [feedback@ms.asn.au](mailto:feedback@ms.asn.au)

## News



### Oral drugs get recommendation for PBS listing

The Pharmaceutical Benefits Advisory Committee (PBAC) has recommended 2 oral therapies to be listed on the Pharmaceutical Benefits Scheme (PBS).

Aubagio (teriflunomide) and Dimethyl Fumarate (Tecfidera) are oral treatments of relapsing-remitting MS.

The recommendations, if approved by the Federal Government, have the potential to make a significant difference to the lives of thousands of people living with MS across the country.

Keep an eye on our e-newsletters and future editions of **Network** for more information.

### A muddy call for volunteers

Crew at Dirt Headquarters are busy getting ready for the Bernie Lewis MS Mud Run – but we need your help!

If you don't fancy getting muddy but want to be part of the fun, consider volunteering your time on Sunday 1 December and help us put on the biggest event the MS Society has ever held!

Visit [www.msmudrun.com.au](http://www.msmudrun.com.au) for more info, or call the Crew on **(08) 7002 6500**.

### E-newsletters

The MS Society emails monthly e-newsletters which include updates on new services, relevant seminars, events and much more. You can sign up for the e-newsletter from our website [www.ms.asn.au](http://www.ms.asn.au) or email your details to [feedback@ms.asn.au](mailto:feedback@ms.asn.au) and we can add you to the list.



**THE THERRY DRAMATIC SOCIETY PROUDLY PRESENT**



**Wednesday 13 November**  
Adult \$25 | Concession \$20

For tickets & information  
contact Sonya from the  
MS Society **(08) 7002 6500**  
or [srowell@ms.asn.au](mailto:srowell@ms.asn.au)

## Can you lend a hand?





 bernielewis

# MS MUD RUN

Military styled obstacle course  
Festival atmosphere  
Fun for the whole family!



**1 DECEMBER**

**GETTING DIRTY NEVER FELT SO GOOD**

**[www.msmudrun.com.au](http://www.msmudrun.com.au)**





## News continued

### Paralympic Para-Canoe come and try day

Para-Canoe was added to the Paralympic Program in 2010 by the International Paralympic Committee. The sport will make its first appearance at the Paralympic Games at the 2016 Rio Paralympic Games.

Want to learn more? Head down to the come and try day:

**Sunday 13 October**  
**9:30am–11:30am**

**Where:** Canoe SA, West Lakes

Contact Ian Heard  
on **(08) 8240 3294**

### Jesse Frick's CD "27" Get your copy today!

Jesse Frick was diagnosed with MS at the age of 18 and many of the songs on his album are written about his experience with MS.

Jesse is donating the proceeds from "27" to the MS Society, have you bought a copy yet? To buy your copy call Sonya on **(08) 7002 6500** or visit **www.ms.asn.au**



### MS Quiz night

Are you the master of trivia?  
Are you up-to-date on all the celebrity gossip? Then grab yourself a ticket to the MS Society Quiz Night!

Students from the Australian Tourism College are hosting the quiz night on behalf of the MS Society on Friday 1 November.

If you are interested in attending, please register your interest with Megan on **mdown@ms.asn.au** or phone **(08) 7002 6500**.

### Go Global Travel support the Society

Samantha and Kirstie from Go Global Travel pictured (above) with Graeme handing over donation of \$2,500 for the MS Society.

Go Global specialise in organising holidays and travel for people with disabilities. Give Kirstie a call before you plan your next trip!

Call Kirstie on **(08) 8271 0026**  
email **kirstie@ggtravel.com.au**  
or visit **www.ggtravel.com.au**



# MS INFORMATION FORUM DARWIN

**WEDNESDAY 30 October 2013**

**VENUE: ECH – Gym Area**

**ADDRESS: 11 Creswell Street  
TIWI NT 0810**

**TIME: 9am – 12 noon**

**The Multiple Sclerosis Society of SA & NT  
invite you to an information forum for health  
professionals, clients and the community**

**Join us for light refreshments and a chance to  
chat with MS Society staff from 12 noon – 2pm**

## **The sessions will include:**

- MS Update – What's new in MS treatments
- Managing the minefield of day to day symptoms
- What's rehab? Is it worth it?
- Aquatic therapy?
- Home exercise?
- What is best?

Members of the MS Society's fundraising team will also be in attendance to speak to you about exciting fundraising initiative and events coming to the NT.

**Please RSVP to Hazel by Friday 25 October**

**Phone: 08 8360 0800  
or 1800 812 311 – MS ASSIST LINE**

**Email: [msassist@ms.asn.au](mailto:msassist@ms.asn.au)**

## News continued



### Taxi Fare Subsidy Scheme

A subsidised taxi travel program is available for people with permanent physical disabilities who have limited mobility and cannot use public transport.

- A 50% taxi fare subsidy is available for people who are able to walk (not confined to a wheelchair).
- A 75% taxi fare subsidy is available for people who are confined to a wheelchair.

An Application for Transport Assistance form is required to be completed. Help completing the application may be required from a general practitioner, medical specialist or mobility instructor.

For an application form or further information simply visit [www.sa.gov.au](http://www.sa.gov.au) and search 'Taxi fare subsidy scheme' or call **1300 360 840**.

### Badge Day

Can you lend a hand at our Badge Days?

We have various opportunities around Adelaide and local suburbs.

Please contact Sonya for more information on [srowell@ms.asn.au](mailto:srowell@ms.asn.au) or call **(08) 7002 6500**.



### Mental Health Training

Multiple Solutions recently sent 20 staff to a certified Mental Health First Aid training course with Ronda Pearce.



Ronda (pictured above) donates her time by delivering this valuable training at the Holden Hill Community Centre through the Tea Tree Gully Council.

By doing so, Multiple Solutions was able to get highly subsidised training, saving approximately \$200 per head.

Ronda is currently retired but has worked for 27 years in Adult and Juvenile Justice System as a social worker and a manager.

Prior to this she worked with women and children in crisis. Ronda sees the great need for education in the community of Mental Health and has the skills to help so is able to give back.

By doing so, she enables the centre to make some money which is used to purchase much needed equipment.





In her spare time she loves gardening and going to the ballet and theatre and walking in the hills. Multiple Solutions formally thanks Ronda for her generosity of time, experience and passion, allowing staff (pictured above) to have up to date skills and knowledge about Mental Health when working with their participants.

## MS Bookshop

*Book review **Recovering from Multiple Sclerosis** by George Jelinek and Karen Law*

Even if you rarely read books, *Recovering from MS* is a MUST read. Anyone with MS, their partners and MS Society staff should all grab hold of this easy to read book without delay.

These are the life stories of 12 people from all around the world – all diagnosed with MS and all adopting the OMS (Overcoming MS) program and recovering from MS.

Typically when my copy arrived I ripped open the package (I'm a big reader to with some guilt I confess to an online overseas purchase), glanced at the back cover to get the feel of the book and opened to the contents page. What looks interesting? What life stories touch a chord with me? I can't go past 'Proving them wrong' – sounds like me. Follow this with 'Harnessing a rebellious streak'. By this stage I'm hooked and I then read the book from the first to the very last page.

These are amazing stories of people from all walks of life who have all recovered

from MS. I was amazed to read that some of their MRI scans after the OMS program showed no lesions anymore and that they would not have been diagnosed with MS from that latest scan.

This is a book that challenges you to challenge the advice from GPs, specialists and neurologists. Clearly in the experience of many of those featured in the book, MS disability is not inevitable in spite of medical advice given. The story of Gaspar, a concert flautist, whose neurologist told him "I'm sorry but you have a particularly aggressive MS" and is now performing again in a world class orchestra really makes the point that it is important to challenge medical advice and not to accept a poor prognosis as inevitable.

Some stories will move you (yep I cried, but I cried at the end of *Red Dog*), some will make you laugh, all will fill you with hope and all will show that in spite of the best opinions, it is possible to recover from MS by making significant changes to your lifestyle by adopting a plant based whole food diet, exercising, getting plenty of sunshine and daily meditation.

This is a 'must read' book. Borrow it from your local library if you need.

If you have MS then you must also read Jelinek's main book 'Overcoming MS' – Jelinek is a respected doctor who himself has MS and whose mother was chronically affected by MS. This led him to thoroughly research MS, treatments and options that are all well presented in this easy to read book.



In a nutshell, his program focuses on 4 things to overcome MS, a low fat diet, regular exercise, lots of sunshine and Vitamin D and daily meditation. You can obtain a free copy of 'Overcoming MS' from the Gawler Foundation for no more than the cost of the postage <http://gawler.org/> If you are newly diagnosed this book will show you that there is hope and that disability is not inevitable. Even if your diagnosis was some years ago, there is still a way to achieve wellness. All too often we expect that a tablet or drug treatment is the only course to take – this program shows that there is evidence that a lifestyle change leads to recovery from MS.

Take the time to look at their website too at <http://www.overcomingmultiplesclerosis.org/> for more information to help you think about how you can influence your future.

An OMS peer support group has started up recently. If you are thinking of starting the OMS program, or have started the OMS program, this group meets regularly at Pembroke School. Please contact Pam (who has been on the OMS program for well over 10 years) for details on (08) 8331 9360 or [pschartn@inet.net.au](mailto:pschartn@inet.net.au) or through the My Society group on Facebook.

**Pam Schartner**

## News continued



### MS Lifestyle Clinic

Have you thought about how to best manage with your MS but not sure if you are on the right track?

We are offering a new service that may be able to assist you. It is particularly suited for those who have been recently diagnosed with MS or who have had little contact with us over the years.

Common questions often asked:

- What services can I access?

- How do I access them?
- Should I be exercising... when, where, how?
- Do I need to change my diet?
- How can I decrease the stress in my life?
- What else can I do???

If you would like to make an appointment for this face to face clinic with our health professionals (with no fee), please contact Hazel on **(08) 8360 0800** or **msassist@ms.asn.au**

### FOR SALE Thera-fit Exercise Pedals

The machine is a motor-driven Thera-fit Plus floor pedal exercise machine purchased from Scooter World at Welland approximately 4 years ago.

It has arm exercisers that can be used by placing the machine on a table. It has an infrared remote control. The machine comes with two instruction books that were purchased with the machine.



Previously used by a stroke patient who utilised the machine to help keep active and maintain assisted walking.

**Price:** \$1,400

Contact Julie Coombes  
**(08) 8255 3413**

**Note:** The pedals for sale do not have calf shells as pictured in the image.

### Cash Bonanza Lottery

Our latest \$100,000 Cash Bonanza lottery winner Margaret pictured left collecting her cheque from Graeme.

**Congratulations Margaret!**





# Annual General Meeting

Please join us for the 49<sup>th</sup> Annual General Meeting of the Multiple Sclerosis Society of South Australia & Northern Territory Inc to be held at:

**Goodwood Community Centre, 32–34 Rosa Street,  
Goodwood SA 5034 on 30 October 2013 at 10:30am  
(AGM commences at 11am)**



## Agenda

---

**Apologies**

---

**Confirmation of Minutes**

---

**Honorary President's Report**

---

**Presentation of Financial Statements for 2012–2013**

---

**CEO's Report**

---

**Election of Office Bearers and Board of Directors**

---

**Appointment of Auditors**

---

**Presentation of the Renee Thonard Award**

---

**Date and Venue for 2014 AGM**

---

Please join us for a light lunch and refreshments to be served after the meeting.

We would greatly appreciate it if you could confirm your attendance on or before Friday 18 October either by:

- Calling us on **1800 812 311**; or
- Sending an email to **msagm@ms.asn.au**

Kindly include the following details:

- Name of person(s) attending;
- Whether you will be staying for lunch; and
- Any specific catering requirements

If you cannot attend and would like to provide feedback or have any questions/concerns, please feel free to contact us at **feedback@ms.asn.au** and we will respond to you promptly.

## Our people



### **Alicia Kitchen** Staff

**Job Title:** Service Coordinator

#### **But what do you do?**

Organise and coordinate services for clients that they may not already be receiving or aware they are entitled to. A large amount of my role is advocacy work on behalf of clients, particularly to government organisations.

#### **How long have you worked at the MS Society?**

5 months... and it has gone really quickly!

#### **What is the most enjoyable part of your job?**

Being able to collaborate with wonderful staff and meeting some amazing clients. I enjoy achieving real outcomes for clients and making a small, but noticeable change in their lives.

#### **Describe yourself in 3 words.**

Friendly, kind, happy.

#### **What's your favourite food?**

Dessert! You know a good restaurant when their dessert menu is amazing

#### **When you're not working at the Society, what do you do?**

Spending time with my hubby and our beautiful, 17 month old daughter and our crazy dogs. Catching up with friends, eating out, visiting wineries.



### **Helen McCarl** Staff

**Job Title:** Registered Nurse

#### **But what do you do?**

My role in the MS Society as a registered nurse encompasses many areas of a persons journey with their MS. I meet with people who have been newly diagnosed with MS and try to help with demystifying the diagnosis, making sense of the treatments and then often sharing the journey of many MS clients.

I am just there to help navigate the bumps, twists and turns someone can experience. Following trends, research and new findings is also an important aspect of my role.



Sharing information with health professionals and providers in hospitals and the community, both city and county is also important.

**How long have you worked at the MS Society?**

Since 2003.

**What is the most enjoyable part of your job?**

The wonderful inspirational people I meet. This is both the clients and their families and the staff I work with who support each other.

I love working with our Multi D team. There is always a chance to acquire another skill and pick each other's brains. I think in this field there is always something new to be learnt and some new information to share.

**Describe yourself in 3 words.**

Optimistic, careful, conservative.

**What's your favourite food?**

Vietnamese Pho (soup)!

**When you're not working at the Society, what do you do?**

I enjoy my garden and have had great success with a vegetable patch... also enjoy an odd movie or two.



**Pam O'Sullivan  
Volunteer**

**What do you do at the Society?**

General reception work and any jobs that assist the staff.

**How long have volunteered at the MS Society?**

I have volunteered at the society for around 8 years starting back when they were located at Klemzig.

**Why did you become a volunteer?**

With an early retirement from work commitments and my sons being of an age of independence (except taxi services), I felt I was too young to just stay at home. Being able to volunteer at the MS Society gave me the confidence as I knew they would understand if I was unable to make it at any time.

**Describe yourself in 3 words.**

Practical, thoughtful and hopefully cheerful.

**What's your favourite food?**

Homemade pasties and take away Chinese (as I have not mastered the cooking technique).

**When you're not volunteering, what keeps you busy?**

Being a mum to two sons in their early 20s and a 9 year old pup, plus housework, knowing if they will be home for tea (what time approximately) and how many will be seated is a bonus. It's a pleasure to meet up with friends for coffee or lunch.

---

**Editors Note:** I think you neglected to mention your love of travelling Helen!

# The role of rehabilitation in managing MS

## The goal of rehabilitation is to improve and maintain function.

From the time of diagnosis onward, rehabilitation specialists provide education and treatment designed to promote good health and general conditioning, reduce fatigue, and help you feel and function at your best at home and at work. If symptoms begin to interfere with everyday activities, a rehabilitation team can address problems with mobility, personal care, role performance at home and work, and overall fitness. They also provide evaluation and treatment of speech and swallowing difficulties and problems with thinking and memory.<sup>1</sup>

Rehabilitation is considered a necessary component of comprehensive, quality health care for people with MS, at all stages of the disease.<sup>1</sup>

The overriding principle in setting goals for a person with MS is to maximise functional independence and safety, minimise complications and problems that result from decreased mobility, compensate for loss of function, and improve quality of life.<sup>2</sup>

Rehabilitation should be viewed as an ongoing process to anticipate problems and to maintain and restore maximum function and quality of life for persons with PPMS.<sup>2</sup>

The Cochrane Review of available research in MS and Rehabilitation concluded there was strong evidence that inpatient or outpatient rehabilitation can lead to improvement in activity (disability) and in overall ability to participate in society, even though there is no reduction in actual impairment.<sup>3</sup>

## MS Rehabilitation Service at RGH

Rehabilitation at Repatriation General Hospital has always had a keen interest in maintaining an effective MS rehabilitation service and has invested heavily in staff development and rehabilitation technology.

It offers comprehensive medical, nursing and allied health assessments to identify factors preventing people from living independently and then make recommendations for the required medical and allied health interventions. The MS Rehabilitation Assessment Clinic includes assessment of pain, emotional wellbeing, neurological symptoms such as weakness and spasticity, fatigue, impact on the carer and limitations imposed by the disease. The clinic then links the MS patients with the therapy they require, be this single discipline referrals or comprehensive therapy programs.

It is our experience that goal-focused therapies are more beneficial and we aim to establish clear and achievable goals through the extensive assessments.

These could include easing the symptom burden on activities of daily living or it could be more advanced goals such as returning to work or community activities.







The programs offered are short-term, highly individualised and goal specific, taking into account the needs of the rehabilitation client.

More recently there has been growing interest in the use of rehabilitation technology such as the Lokomat (see image opposite) – a body-weight supported assistive walking device, which allows patients who are struggling to walk the ability to do so in a supported environment, to enable a focus on improving function, endurance and lower limb strengthening while minimising risk to the patient or therapists.

Our clinic physiotherapist is specifically trained in the use of this machine and can advise on suitability based on client's need and presentation.

**It is our experience that goal-focused therapies are more beneficial and we aim to establish clear and achievable goals through the extensive assessments.**

One of the often ignored areas is the cognitive rehabilitation. Many people with MS develop cognitive impairments such as slowed thinking, difficulty in reasoning and planning, remembering information or concentrating on tasks. This is usually the result of interruptions to the brain pathways.

A small number of people have cognitive problems that interfere with daily activities and these people could benefit greatly from cognitive retraining.

The MS rehabilitation team at RGH includes Dr. V Farooqi (Rehabilitation Specialist), Anne Green (MS Clinical Nurse), Susan Forth (Registered Nurse) and Adrian Cowling (MS physiotherapist). Sharon Barlow (MS Clinical Practice Consultant) at Flinders Medical Centre facilitates the collaboration with the Rehabilitation and Neurology services.

If you have any of the above discussed difficulties and are willing to work towards physical recovery, all you need is to ask your doctor to refer you to the MS Rehabilitation Clinic at the Repatriation General Hospital, referral forms and information can be found on the website at [www.sahealth.sa.gov.au](http://www.sahealth.sa.gov.au) under '4th Generation Rehabilitation'. Please get your GP to include a copy of your health summary. You will need up to two and a half hours for the multiple assessments.

1. <http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/treatments/rehabilitation/index.aspx>
2. Review Article Symptomatic Therapy and Rehabilitation in Primary Progressive Multiple Sclerosis Fary Khan,<sup>1</sup> Bhasker Amatya,<sup>2</sup> and Lynne Turner-Stokes<sup>3</sup> *Neurology Research International*. Volume 2011 (2011), Article ID 740505, 22 pages.
3. *Multidisciplinary rehabilitation for adults with multiple sclerosis (Review)* 1 Copyright © 2011 The Cochrane Collaboration. Published by John Wiley & Sons, Ltd.



Government of South Australia  
SA Health



FLINDERS  
MEDICAL  
CENTRE



## Sunday Mail City to Bay

A big thank you to all the amazing runners and walkers who supported Team MS at the Sunday Mail City to Bay on Sunday 15 September.

Over 130 participants turned out in a sea of red to support the MS Society of SA & NT, raising funds and awareness for people living with multiple sclerosis and their families. We also had our friends from Multiple Solutions doing their bit for the MS Society – it was

great to see you there guys! We are overwhelmed to announce the total amount raised by Team MS was \$21,085, with more still to come – fantastic effort team! Thanks to our super awesome supporters too – Hope Valley Foodland for donating a voucher, Erindale Meats for the yummy sausages and the Mihas family for the apples, oranges and bananas. Now, we're off to ice our sore muscles and attend to our blisters... See you next year!









# Multiple Solutions

## Workplace Solutions

### Case Study: Luca

Luca contacted Multiple Solutions after reading an article about employment support in the MS Society **Network** magazine.

Luca had been diagnosed with MS 10 years ago, but had continued with a busy family life and managing a successful drafting business from his home office. As a structural steel draftsman Luca uses CAD software to design steel fabrication for buildings, and often has on-site visits for meetings and inspections.

When Luca first called Multiple Solutions he explained he was a very independent person and had never sought assistance before, however he was now finding some of his MS symptoms were making it hard for him to continue working at the level needed to sustain his business and family.

**‘I never thought such small changes would have such a large effect on my lifestyle. Multiple Solutions have assisted and suggested ways to help that I myself would never have thought of. I am thoroughly grateful and appreciative for what they have offered.’**

Luca



What he needed most was help to stay cool, reduce fatigue and make getting about a little easier.

Straight away Multiple Solutions were able to provide information about valuable resources such as a disabled parking permit, taxi fare subsidy and a Mobility Allowance, which would also give Luca a Health Care Card.

The next thing to consider was what supports could be provided to reduce fatigue and help Luca stay cool. After an assessment of the home office, a specialised chair, footrest, writing surfaces and desktop were funded and purchased. Voice activated software and a smartpen allowed Luca to dictate his way through emails, project reports, minutes of meetings and even to send hand-drawn plans from on-site meetings to the home office.

Cooling vests, neck ties and ankle wraps, and a 4-wheel walker were provided to be used when on-site, keeping Luca cool and safe.

**‘Not only can he now work longer, but when he does finish and re-join the family, he has that extra bounce in his step to be able to pay more attention to me and the kids.’**

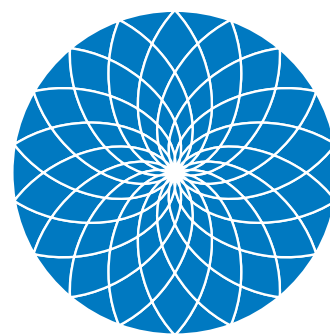
Wife, Amy

Following the provision of these items, Multiple Solutions closed their employment support program, as Luca was now able to again independently manage his thriving business and have energy remaining to enjoy family life.

**Photo:** Luca in his home office for CAD Drafting, showing some of the equipment provided by Multiple Solutions.



# multiple solutions



## Support for workers and the self-employed

Does your health impact  
your work? Does your work  
affect your health?

Multiple Solutions can you help  
you manage both by:

- Funding workplace aids,  
equipment or modifications
- Helping you develop strategies  
to continue working successfully

Reducing stress and fatigue at work  
helps to also increase the energy you  
have for family and home.

Contact Workplace Solutions staff to ask about this free workplace support:

**North (08) 8203 6600**

**South (08) 8198 1400**

**Email: [wpsolutions@ms.asn.au](mailto:wpsolutions@ms.asn.au)**

# Mick, Jane and Me – Living well with MS

My name is Carolyn Cordon.  
I am many things, wife, mother,  
poet, writer and I'm also a  
person living with MS.

I was diagnosed with this crazy illness back in 2010, and I'm learning more and more about it, both by living with it and talking with others who are living with it too.

This book began as a basic look at various issues that came with living with MS. Things like diet, exercise and medication. As I wrote though, other ideas began to come through, ideas about guilt, hope and resilience. When I found the quote by Gerard Way that begins this memoir, "Being happy doesn't mean that everything is perfect. It means that you've decided to look beyond the imperfections", I knew I wanted the book to be more, much more than just a basic look at the challenges that having MS brings.

At my book launch, I spoke briefly about the form of this book. I call it a verse memoir, but that claim has been questioned. Some have doubted my claim, and the phrase 'chopped up prose' has been mentioned. Sometimes I've wondered about that myself ... Looking at this memoir though, looking at it and reading the words there, I'm ok about the 'verse memoir' claim. I was lucky to be successful with my application for a grant with the Richard Llewellyn Disability and Arts Trust, to pay for a mentor to assist with writing this memoir in verse.

That mentor is Dr Ray Tyndale, an author who knows much about verse, having written the successful verse novel 'farm woman'. I've read



Ray's book and very much enjoyed the words. I certainly don't feel I've managed to learn everything Ray tried to teach me, but I tried... I hope my next attempt at a narrative in verse will be even better.

My main audience for this book wasn't a literary one though. My target audience are people like me, and people like you, the clients of the MS Society of SA & NT. People wondering, like me, how they can find a way to live well with MS. I wrote this book because I found a gap, a gap which meant there wasn't a book that told me the things I wanted and needed to know about living with MS.

After I was diagnosed, I decided I would have to write this book, and I'm proud of what I've achieved. My memoir has my thoughts about many things – medications, resources, hope, exercise and a few philosophical things. I write things, and writing gets my brain thinking. Some of these thoughts made it into my memoir about MS, because they relate to my feelings and thoughts about my life with MS.



**'Being happy doesn't mean that everything is perfect. It means that you've decided to look beyond the imperfections...'**

This book also has cute illustrations, and it has a photo of me, with my walking stick and cane on the front cover and another photo of me on the back. So, with cute illustrations, and me with Mick (the Stick) and Jane (the Cane), and with my thoughts about living well with MS, what more could anyone want or need. Apart from, of course, a CURE!

The book launch happened on Wednesday 28 August at the Tea Tree Gully library. If you would like to purchase a copy of my book please contact me on **0418 806 490** or **jeebers@aussiebb.com.au**

*Images by Martin Christmas*



# Mobility Allowance

## Did you know?

**Mobility Allowance** is paid as a fortnightly allowance to people with disabilities, illnesses or injuries who:

- are 16 years and over; and
- need to travel to and from home to look for work, do paid or voluntary work, or participate in study or training; and
- cannot use public transport without difficulty or extra assistance because of their disability, illness or injury; and
- are an Australian resident; and
- are physically present in Australia on the day they lodge your claim; and
- continue to meet the residence requirements for as long as they get this payment.

Newly arrived residents generally have a 104 week waiting period, with some exemptions.

For people with conditions such as MS, it is a very valuable allowance, helping them on the days they are unable to catch public transport and are faced with the additional costs of taxi fares or driving/parking their own vehicle (regardless of their need for or availability of public transport).

When completing the Centrelink Medical Report to submit with the application for Mobility Allowance, it is important for medical practitioners to consider their patient on a “worst day” scenario, such as during an exacerbation. For example on warmer days, it can be very difficult, if not impossible, for a person with MS to walk to/from a bus stop, wait at the bus stop, stand on a crowded bus and/or carry personal items.

A person may continue to catch public transport if appropriate or available, even if they are granted the payment.

They do however need to maintain work related activities and their medical conditions need to continue to present difficulties or symptoms which impact their ability to cope or undertake activities related to catching public transport.

A person may be entitled to a **Health Care Card** while they are receiving Mobility Allowance. A Health Care Card provides help with the cost of prescription medicine under PBS, Australian government funded medical services, and access to state, territory and local government concessions.

A person does not have to meet income or assets tests to qualify for Mobility Allowance.

Mobility Allowance payment rates are reviewed annually and updated on 1 January each year. Mobility Allowance payments are not taxed.

Type of rate	Payment rate per fortnight
Standard rate	\$87.00
Higher rate	\$121.80

These rates are current as at 27/8/13.

For more information visit <http://www.humanservices.gov.au/customer/services/centrelink/mobility-allowance>



# Cognition and MS

## Day-to-day living with MS-related cognitive problems

**Nancy D Chiaravalloti,  
Neuropsychology &  
Neuroscience Research,  
Kessler Foundation, West  
Orange, USA**

Cognitive impairment is common in MS, and people with the disease frequently report difficulties, such as following along in complex conversations, recalling information and forgetfulness. These cognitive challenges can impact the successful completion of everyday tasks.

### Impact on quality of life

Research has shown that people with MS who are cognitively impaired participate in fewer social and vocational activities, and have greater difficulties carrying out routine household tasks compared to people who have a purely physical disability. People with MS themselves report a reduced quality of life with a decrease in cognitive functioning, making cognitive difficulties a potentially significant detriment to productivity.

Additionally, the onset of MS typically occurs between 20 and 40 years of age, when individuals are most active in their professional lives, resulting in considerable disruption to employment status and yearly earnings. Many individuals with MS experience problems with processing speed, learning and memory, which can contribute to problems maintaining employment, and in some situations, the loss of gainful employment altogether.

Cognitive impairment can have a resulting detrimental effect on personal, occupational and social functioning, leading to a reduced overall quality of life. Although physical disability can impact the performance of everyday activities, it does not account for the extent of additional challenges encountered by those with significant cognitive difficulties.

### Techniques to improve cognitive function

Given the significant impact cognitive problems can have on daily life, there is a need for improved techniques that enable people with MS to better manage cognitive difficulties. While research on cognitive rehabilitation efficacy in MS remains sparse, there is some evidence that it can be effective. Short-term memory is commonly impaired in MS and recent research has demonstrated that the source of this memory dysfunction is in the area of initial learning. Targeted approaches to improve learning would therefore be expected to result in improved memory in people with MS. Several studies now support this notion.

### Self-generation

Self-generation is a method that has been found to be effective in increasing a person's ability to learn and remember new information, in both the general population and those with MS. The concept of self-generated learning states that recall and recognition of information is significantly better when a person generates their own correct responses to a problem, compared to when the correct answers are provided to them.

The application of self-generation to daily life requires knowledge of the concept on the part of both the person with MS and a partner or family member, as well as an understanding of how to restructure the learning situation so that the individual can better remember new information. This can be taught fairly simply and several ongoing studies are examining ways of teaching self-generation to people with MS and their families in the hope that this will improve everyday memory.

### Spaced learning

This technique has also been found to be beneficial for people with MS. Spaced learning involves repeating a learning activity with a delay between each learning session. People struggling with memory impairment can be taught to space out repetitions of information that they have to remember in an effort to maximise learning. This approach appears to result in significantly better memory performance than consecutive learning trials, in which a person undertakes a block of continuous learning with no delay.

Spaced learning requires restructuring of the learning environment, but this can be accomplished by the individual themselves. Support or help from a partner or family member would be expected to maximise outcome.

### Retrieval practice

Retrieval practice is yet another technique shown to improve learning for people with MS. This is a well known phenomenon by which testing memory for previously learned information (such as quizzing) improves subsequent recall more than restudying material.





Once again, a restructuring of the learning environment is necessary to apply the technique, which can be accomplished by an individual alone or with assistance from a significant other.

### Future techniques

There is growing evidence demonstrating that each of these techniques improves learning and memory performance in MS, supporting the idea that a known deficit in these areas can be effectively treated through cognitive rehabilitation. The next step in this line of work is the development of treatment protocols or methods designed to teach an individual how to apply these techniques in their everyday life. Such development is underway.

In addition to evidence supporting the use of these specific techniques to improve learning, evidence is also building in support of structured treatment protocols. For example, the modified story memory technique, which consists of training in context

and imagery, improves learning and memory in MS and results in changes in brain function on neuro- imaging.

By far, learning and memory has received the most attention in cognitive rehabilitation research in MS. However, limited work has been conducted in other areas, including attention and executive functioning (for example, problem solving or mental flexibility). Such studies have shown mixed results. Multiple groups have noted that treatment methods designed to improve attention and executive functions show some benefit in people with MS.

An important cognitive domain that has received relatively little attention in the MS cognitive rehabilitation research literature is processing speed. Processing speed can be a strong predictor of long-term cognitive decline and such deficits are typically observed alongside the other cognitive deficits commonly seen in MS. Focusing treatment on a basic cognitive skill such as processing speed is likely to lead to

widespread cognitive improvement in other realms of cognition. Research is necessary to begin to develop effective methods to improve the processing speed problems experienced by many people with MS.

In summary, while cognitive difficulties in MS exert a significant impact on daily life, researchers and clinicians are now developing and testing techniques to help treat these problems, in the hope of improving overall quality of life.

### Importance of support at home

It is important that the partner and/or family of a person with MS understands that cognitive problems can be a part of their MS and what some common problems might be. This understanding will allow the family to support the individual with MS by helping them apply techniques in their daily life. This will reduce the impact of the cognitive problems on a person's quality of life.

## Cognition and MS continued

Offering support in a social situation can be important too, as cognitive problems are some of the “hidden” symptoms of MS. Support may include reminders of people’s names or scheduled social activities and helping the person to prepare for situations and challenges in advance.

Additionally, simple reminders, such as a phone call or a sticky note can be very helpful.

*Thank you to the Multiple Sclerosis International Federation for allowing us to reproduce this article, which first appeared in MS in focus ‘MS and Cognition’ July 2013. You can access previous copies of the magazine from [www.msif.org](http://www.msif.org).*

### Tips for common cognitive problems

Taken from **[www.stayingsmart.org.uk](http://www.stayingsmart.org.uk)**  
(run by the UK MS Trust), reviewed on page 27.

- Have a set place for everything (your glasses, your car keys) and always put these essential items in their set place.
- If a word is on the tip of your tongue, don’t tense up or panic. Stress will make it harder to get it out. Instead, either use another word or words to say what you need to, if possible. If it is a specific name or place where another word won’t do, just say “I’ll come back to that”.
- If you find it hard to stay on task, you can manage distractions by finding a quiet environment and letting others know when you can and can’t be disturbed.
- If you have trouble remembering appointments, paper diaries and electronic organisers are unobtrusive and very useful. You may find that you need to use them more often and more scrupulously than previously, but they work.
- Most people with MS are able to remember information from a small prompt or cue. For example, a post-it note saying “dry cleaning” on your car dashboard will probably be enough to remind you to stop to pick up the cleaning.
- Try to schedule important discussions at a time when you won’t be fatigued, or arrange to have a rest beforehand.
- If your attention wanders during conversation, you can always repeat or summarise what the other person had just said before making your comment. For example, you could say “I hear that you enjoyed your holiday in France, because the weather was so good. Have you ever been to France when it rained?”. It might feel a bit strange at first, but it will soon feel natural. You will find that your friends will feel flattered that you are paying so much attention to what they are saying.
- Routinely check routes on maps in advance and if you need to, make a photocopy or brief route notes for reference. This will help in two ways. By thinking about the route in advance and preparing the route notes, you will have reminded yourself of the way. You will also have the notes for guidance when travelling.

## MS Assist

It has been an exciting and rewarding month for our new **MS Assist** information line team.

Our friendly team (pictured) of Bianca, Amy and Claire operate the phones during normal business to assist people with MS, their carers, family and other professionals with helpful information about services and resources available to help.

If we don’t know an answer to your question straight away, we will endeavour to find out for you.

In our first month the team has taken over 300 calls from all over the state and the Northern Territory. Calls came in from as far afield as Pt Lincoln, The Riverland, Mt Gambier, Wallaroo, Pt Pirie, Alice Springs and Darwin.

Calls have been to discuss a diverse range of topics including MS symptoms, depression, driving with MS, requests for Info packs, newly diagnosed issues, relationships, hire of special equipment, equipment purchase, travel and disability friendly holiday accommodation, disposal of sharps, access to physiotherapy, cancellation of appointments, fundraising, home maintenance and gardening help, employment assistance, MS Mud Run, cleaning and home help, occupational therapy referrals, disability benefits and applications, peer support groups, membership, notification of a client death, pension advice, carer support and many more.

Enquiries can be complex requiring lots of research or a referral to our other professional staff or quite simple. One country client was in Adelaide and desperately needed to buy a walking stick.





Bianca

Our friendly MS Assist team quickly tracked down a local nearby chemist who was able to help.



Amy

The MS Assist has been actively contacting and updating our MS Peer Support groups and contacts both in Metropolitan Adelaide and across the State and Northern Territory.

Last week we began the first of our new regular client follow-up calls, these friendly calls aim to regularly touch base with our clients with MS, particularly those currently having a rough time or those who are isolated.

These calls also help identify MS client needs and finding services or solutions that will help. So far we have only been calling clients referred to us by our professional client services team.

However, if you are struggling, have a question, want to find out where help is available, or feel isolated, socially or by distance, please call us on our free call number **1800 812 311**.



Claire

Other research has tracked down a Russian speaking counsellor and a disability friendly hotel in Wollongong.

Between incoming calls the team has been actively researching the services and resources available to help people with MS with over 400 services or organisations added to our information database already.



**ASSIST**  
**1800 812 311**

## MS Assist Telephone Information Service

**MS Assist** can help you with information such as:

- Transport options in your area
- Centrelink processes & forms
- Local Council & State Government services in your area
- MS Society services
- Continence support services
- Research updates
- List of Neurologists in SA
- And much, much more...

Our free call  
**MS Assist** number is  
**1800 812 311**

*Please Note: Calls to 1800 numbers from a landline are free however some Mobile Phone Services may charge for these calls so check with your provider first.*

The telephone information service will operate during business hours Monday to Friday, excluding Public Holidays. Callers will be able to leave a message outside these time and our operators will return their call on the next business day.

Email queries may also be directed to **msassist@ms.asn.au**

## Peer support update

The Peer Support program continues to connect people with MS to each other to provide opportunities to meet and discuss your MS with others experiencing similar issues. There are a number of programs and groups currently in action – please read on for more information!



### Peer Support Groups meet in the following areas:

Location	Day/Time	Venue	Group Coordinator
<b>Barossa</b>	3rd Thursday each month, 11am	Tanunda/Nuriootpa	Denise Hoffman (08) 8565 6245
<b>Hard Yakkas (Elizabeth)</b>	Last Wednesday each month	Café Aqua, Salisbury	Tallia Coulter 0403 766 157
<b>Fleurieu</b>	Random Tuesdays	Rotated around Fleurieu eateries	Jill Masters (08) 8555 0358
<b>Gawler</b>	2nd Monday each month, 10am	Gawler Women's Health Centre	Carolyn Cordon 0418 806 490
<b>Glandore</b>	1st Wednesday each month	Glandore Community Centre	TBC – Contact MS Society or attend a meeting to connect
<b>Modbury</b>	Last Tuesday each month	Independent Living Centre, Gilles Plains	Jennifer Cotis 0407 888 492
<b>Morphettville</b>	4th Friday each month	Tonsley Hotel, South Road, Clovelly Park	Christine Sutherland (08) 8276 3779
<b>Mount Gambier</b>	1st Friday each month, 12pm	Commercial Hotel, Commercial Street West	Jenifer Carpenter (08) 8738 2343
<b>South East</b>	TBC – Contact Samantha		Samantha Loechel 0427 662 156
<b>Noarlunga</b>	3rd Thursday each month, 12.30pm	GP Super Clinic, Noarlunga	Virginia Stanfield (08) 8382 5244
<b>Eastern Suburbs &amp; Foothills</b>	3rd Thursday each month, 2pm	Burnside Community Centre	Paula Hardy (08) 8379 8220
<b>Port Lincoln</b>	Every 2nd Tuesday	Group member's homes	Rick Cunningham 0427 999 029 Pamela Price 0427 824 145
<b>Stirling</b>	3rd Wednesday each month	Stirling Coventry Library	TBC – Contact MS Society or attend a meeting to connect
<b>Tailem Bend</b>	Wednesdays, mid-monthly	Group member's homes	Sue Griffiths (08) 8572 3914
<b>Western Suburbs</b>	Last Friday each month	Various venues	Irma Ferro 0439 801 849
<b>Parents &amp; Kids</b>	All areas		Irma Ferro 0439 801 849

### Family members and carers are welcome

If there have been any changes to your support group that we're not aware of, please contact the MS Society to advise us of any updates. Please also let us know if you are interested in setting up a group in your area.

### Overcoming Multiple Sclerosis Peer Support Group

If you are on the Overcoming Multiple Sclerosis program or would like to learn more about the program and are interested in joining a Peer Support group please contact Pam Schartner on **(08) 8331 9360** or email [pschartn@inet.net.au](mailto:pschartn@inet.net.au)





## Making life a TAD easier

### Online support

#### 146 members and counting!

You might find it a bit nerve-wracking to attend a group or speak with someone in person about your MS.

Maybe you're just not ready to speak or meet a person with MS yet, but would like some advice anyway.

Perhaps distance is an issue if you live in a rural or remote area, or you may be too ill to leave the house.

Online support might be an option for you. It's convenient – log in whenever or wherever you like. This is a closed forum, only accessible to members.

You can find it at [www.facebook.com/groups/MySocietySANT/](https://www.facebook.com/groups/MySocietySANT/) – just request to be a member.

### Mentoring

We have an excellent group of supportive, caring mentors who are more than happy to talk with other people with MS. They also have MS, so odds are they have had some similar experiences to you.

If you're hesitant to join a group or would just like to speak with someone privately, please contact the MS Society on **(08) 7002 6500** to be connected to a peer mentor.

For people with disabilities it is not always easy to find the equipment they need to assist with day to day activities. That's where a unique organisation – Technical Aid to the Disabled SA (TADSA) may be able to help.

TADSA is a state-wide charity that aims to help people with disabilities overcome problems by designing and building or modifying devices where there is no other solution readily available.

The devices built by TADSA's inventive volunteers improve the quality of life for clients whether they are in care or live independently. TADSA also assists clients to enter or return to work, study, recreation or sport through the equipment it builds.

TADSA provides one off solutions to one off problems – TADSA volunteers will basically invent a unique device to solve a unique problem.

A client with MS contacted TADSA with a request for assistance with a desk. The client, who runs his own business, would have to rely on his wife to drag

a table over to him if he needed to do paperwork, eat his meals or even help his children with homework. She would then have to drag it away when he was finished. The solution involved three TADSA volunteers – one designed the desk, one built the desk and a third did the mechanical and electrical work. The latter involved fitting a wheel with a motor assembly to the desk. The volunteer then constructed a control panel on the desk which operated the motorised wheel. At the push of a button the desk would swing in to the client sitting on his couch. Another button would move the table away.

TADSA projects can be as complicated as this desk or as easy as a device to open food tins or turn water taps.

If readers or a family member have a problem related to their disability that they would like help addressing contact the TADSA office on **(08) 8261 2922**, email: [admin@tadsa.org.au](mailto:admin@tadsa.org.au) or visit [www.tadsa.org.au](http://www.tadsa.org.au)

Volunteers also welcome!



## Client stories



### Sue Griffith

#### Her life long journey with MS

You have two choices in life, either be a survivor or a victim – I'm a survivor.

I was diagnosed with MS at the age of 50 – but my journey began much earlier than that. During the early part of my life I was prone to illness that would last longer for me than other kids and I would have to deal with regular fatigue. For family, friends and even the doctors who I used to see, I was considered a hypochondriac. Deep down though, I always knew that something wasn't right.

In my early 20s I had great difficulty getting pregnant which put tremendous strain on my first marriage. Despite having a daughter by the age of 25, my marriage fell apart due to the stress of the situation. It was particularly difficult because my first husband was all in all a good man.

**'...I was considered a hypochondriac. Deep down though, I always knew that something wasn't right.'**



My condition would also affect my job as a nurse with heavy fatigue and regular illness taking its toll on me and requiring many days off from work in order to recover. It was even suggested by doctors that I had depression. This frustrated me even more as I knew it just wasn't true.

Ten years ago, my father passed away and my health took a turn for the worse. I was bedridden and incapacitated to the point of blindness due to the stress I was under. I was at a point where I just wanted to curl up and die. At the time, my second husband and I were running a business which was suffering and he would plead with me to get out of bed.

While doctors would suggest the possibility of a stroke, a trip to a specialist and an MRI revealed that my condition was due to MS. According to the neurologists they had found lesions on my brain that were over thirty years old –and confirmed that I had suffered from MS from my teens.







For myself and my family this news came as a relief, at last I had an answer to my ongoing illness and I could finally put a name to my problem and get on with my life. I've since made a point to keep up with all the latest news and developments in MS treatment. I'm determined to turn a negative into a positive.

I have been the mentor of the peer support group in Tailem Bend for about 2 years now. There had been a support group before this, but it had dropped away, so when I got a letter from the MS Society asking if I would be interested in being a mentor for the group, I decided to give it a go.

I thought that this was a way I could help people with MS because as a sufferer myself I understand what they go through.

There are 10 people in our group, for a town of only 2,500, I was surprised there were this many people in the town with MS.

I find being a mentor really rewarding. I try to keep the meetings interesting by having a guest speaker every month.

I enjoy preparing the morning tea, and I think the group really appreciates the extra effort.

We have become a very tight group. One of the most rewarding moments for me was when I was able to connect two young girls in the town who both had MS.

They did not know of each other and through the group they were able to form a wonderful friendship and now they often help each other and go out socially together.

I am also a member of the Tailem Bend quilting group that has been running for approximately 17 years. It started as a group of women who got together every Friday to sew and do patchwork. Every two or three years we hold an exhibition of our work in the town and donate the proceeds to charity.



## Client stories continued



### **‘I have been the mentor of the peer support group in Tailem Bend for about 2 years now.’**

Julie Jordon is head of the group and this year and because I am a member, under her leadership, the group decided to support MS. Through their fundraising, they were able to help buy ten Zen Chi Relaxerciser machines for people living in Tailem Bend with MS.

The quilting group managed to raise \$1,200 through their exhibition and in conjunction with the Freemasons Foundation, who contributed a further \$1,300, were able to purchase the 10 machines. This purchase was also facilitated through the help of Mr Don Bray from Bray Bowden who was able to give us a \$50 discount on each of the machines. He also donated a lamb's wool pad for each machine to make them more comfortable.

As there are 10 members of the MS group, we each get a machine on loan to use, if we get more members, we will rotate the machines amongst the group. The machines work by having the user lay on a bed, with their feet resting on top of the machine. The machine then vibrates, providing excellent stimulation for your autoimmune system and circulation. The machines we purchased are a smaller and cheaper version of the whole body vibration machines. We all have our machines and are very grateful to Julie and the quilting group for making this possible for us.



### **Brian Jones**

I grew up in Adelaide before moving to Townsville in Queensland where I worked as a baker. The shop I worked for made all kinds of food along with baking and decorating wedding cakes.

I enjoyed living in Queensland. I was able to do extensive travelling around Australia, but Townsville was my favourite place.

I have a keen interest in photography and my house is now full of pictures of the beautiful scenery and wildlife that I had taken while I was there.

About 11 years ago I started to have trouble with my balance and coordination. My feet felt bouncy and I started to lose balance.

My company decided to send me to the hospital and shortly after I was given the diagnosis of MS.





This unfortunately marked the end of my baking career and also my time in Townsville. I decided to move back to Adelaide when my family was.

I made contact with the MS Society when I relocated to Adelaide and as I was no longer able to work, I decided to start volunteering. I volunteered at the MS Society when they were located in Klemzig for 3 days a week for 6 years.

I helped with a variety of administration tasks like sending out letters before Cheryl, who was the volunteer coordinator at the time, taught me how to use the computer.

I was then able to help with computer work, printing and sending out information. I was well known and popular at the MS Society office for my baking skills as I often brought in cakes for everyone to share. I was awarded a 'Go for Gold' scholarship (now known as MS Choice Award) for cooking equipment so I could keep up with my passion of baking.

After I moved back to Adelaide and following encouragement from my niece Tessa I decided to get some birds. I have always loved animals and had pet rabbits, dogs and guinea pigs growing up. I got Bob the budgie first and he was a wonderful pet to have. Bob was a very friendly bird and was really a pet to everyone.

He was happy to perch himself on the shoulder of anyone who came to visit and would happily fly and chirp around the house. I don't believe in keeping birds in cages, so I was happy to let him fly around.

## 'After I moved back to Adelaide and following encouragement from my niece Tessa I decided to get some birds.'

I was able to train Bob myself. It didn't take much work as he was very easy to train! I think pets, and birds in particular, are great therapy for people with chronic illness. Bob was a great companion for me, I enjoyed training him and having him fly around the house, it was a very sad day when he died.

I now have another bird Ben who is very pretty and happily sings all day long, but he is a little less social than Bob was. He likes to fly around in the bathroom and laundry, perching in sun when it shines through the window and often hiding behind the shower head where he can't be seen.

Although my MS means I have limited mobility, I work towards staying as strong as possible. My neurologist suggested I do exercises everyday to keep my strength. I think this has improved my walking significantly. I can now walk 3 miles in a straight line. Although these exercises take me 30 minutes to complete, I'm persistent and like to do them four times a day instead of once a day as suggested by the neurologist.

I have suffered some setbacks in the last few years. I started to experience seizures and was diagnosed with epilepsy last December.

I can't even remember anything from the first day I had a seizure, it's like the whole day has been wiped from my mind. This has meant that I've spent a lot of time in hospital over the last few years – which has been hard.

However, I have had a lot of support to help me and get me out of the house. My friend Lachlan regularly meets me at the markets. We have a walk around and a cup of tea and often meet up with my niece Tessa. Disability Services (previously known as Disability South Australia or DSA) have arranged for a support worker Debbie to come over once a week. Debbie cleans the house and takes me shopping – which makes things easier for me to manage.

The MS Society Occupational Therapists have worked with Housing SA to organise rails in my house to make my transfers safer and easier, and for equipment such as a walker and most recently a power wheelchair. The MS Society has also advised me how to apply for taxi vouchers through my GP to make it easier to get out and about.

---

**Editors Note:** You can read about the taxi fare subsidy scheme on page 23.

---

By contributing your story to **Network**, you can inspire others to be positive and active whilst living with MS. If you'd like to provide your story, please email [feedback@ms.asn.au](mailto:feedback@ms.asn.au) or phone **(08) 7002 6500**.

# Recipes



## Kirsten's Walnut, Pumpkin and Chia Muffins

### Ingredients

- 1 cup almond meal
- 1 cup cooked pumpkin
- 2 eggs
- 1/4 cup almond spread
- 1 tbl chia seeds
- 1 tbl raw honey
- 1 tsp cinnamon
- 1 tsp baking soda
- 1/2 tsp nutmeg
- 1/4 tsp sea salt
- 3/4 cup chopped walnuts

### Method

1. Preheat oven to 180 degrees.
2. Combine all ingredients in large bowl and mix until well combined.
3. Divide evenly into muffin tins and bake for 20–25 minutes.
4. Remove from oven, cool for a couple of minutes and then remove to finish cooling on cooling rack.

### Enjoy!



## Brigid's 'not-so-bad' Peanut Butter Cups

### Ingredients

- 4 tbls coconut oil
- 4 tbls natural peanut butter
- 4 tbls natural organic honey
- 2 tbls shredded coconut
- 3 tbls almond spread
- 3 tbls cocoa
- 2 tbls goji berries

### Method

#### First Layer

1. Combine 2 tbls coconut oil and 4 tbls natural peanut butter
2. Heat in microwave for 20 seconds.
3. Add 2 tbls organic honey and 2 tbls shredded coconut.
4. Mix ingredients.
5. Pour into muffin pans in mounds.
6. Freeze for 10 minutes.
7. Meanwhile make the second layer.

#### Second Layer

1. Combine 2 tbls coconut oi and 3 tbls almond spread.
2. Heat in microwave for 20 seconds.
3. Add 2 tbls organic honey, 3 tbls cocoa and 2 tbls goji berries.
4. Mix ingredients.
5. Add the second layer on top of the first.
6. Freeze for a further 15 minutes.

Store any leftovers in the freezer.

### Enjoy!

---

Do you have any feedback or recipes you would like to share, please email them to [feedback@ms.asn.au](mailto:feedback@ms.asn.au) or post to **Network**, PO Box 377, Salisbury South DC 5106



## Fundraising

### Torrens Transit 13th Birthday

Torrens Transit celebrated its 13th birthday in style at the Adelaide Convention Centre on Saturday 20 July 2013.



After a sumptuous three course meal some 500 Torrens Transit employees and their partners danced the night away with fantastic entertainment provided by the evening's MC, Amanda Blair and a number of talented artists including the very talented David Campbell.

As always, Torrens Transit used the event to raise money for a deserving cause and this year supported the MS Society.

Raffles, and auctions saw a number of generously donated items ranging from a children's swing set to an autographed Crows Guernsey to big screen TVs go under the hammer with \$12,096.20 being raised.

As always Torrens Transit matched the amount of money raised by its employees and proudly donated a total of \$24,192.40 to the MS Society.

All in all it was a splendid night which not only gave Torrens Transit an opportunity to thank its employees for all their hard work but also provided an opportunity for both the company and its employees to show their generosity in supporting the fantastic and vital work done by the MS Society.



**8TH - 9TH FEBRUARY 2014**  
**Unley Swimming Centre**

Join in the fun at the MS Society's 2014 MS Mighty Swim. Teams of 25 compete to swim the most laps in 24 hours - are you up to the challenge?

**REGISTER TODAY**  
[www.msmightyswim.com.au](http://www.msmightyswim.com.au)

find us on facebook 



Judith – Call Centre Operator.

# Locations

## **MS Assist 1800 812 311**

### **Head Office/Mawson Lakes**

Endeavour House

Technology Park

Module 6E

11–15 Fourth Avenue

Mawson Lakes SA 5095

PO Box 377

Salisbury South DC SA 5106

P (08) 7002 6500 F (08) 7002 6599

### **Brighton**

7A Sturt Road

Brighton SA 5048

PO Box 275

Brighton SA 5048

P (08) 8198 1400 F (08) 8377 0711

### **Christies Beach**

Level 1, 111 Beach Road

Christies Beach SA 5165

PO Box 885

Noarlunga Centre SA 5168

P (08) 8392 0100 F (08) 8392 0199

### **Darwin**

Nightcliff Community Centre

11/18 Bauhinia Street

Nightcliff NT 0810

PO Box 867

Nightcliff NT 0814

P (08) 8948 5300 F (08) 8948 5344

### **Enfield**

273 Main North Road

Enfield, SA 5082

P (08) 8360 0800 F (08) 8360 0899

### **Morphett Vale**

Unit 3

204 Main South Road

Morphett Vale SA 5162

P (08) 8187 2100 F (08) 8187 2190

### **Modbury**

31–33 Smart Road

Modbury SA 5092

PO Box 525

Modbury SA 5092

P (08) 8203 6600 F (08) 8203 6699

### **Salisbury**

6–8 John Street

Salisbury SA 5108

PO Box 1069

Elizabeth Vale SA 5112

P (08) 8256 3700 F (08) 8256 3749

### **Woodville**

51 Woodville Road

Woodville SA 5011

PO Box 16

Woodville SA 5011

P (08) 8345 8700 F (08) 8268 4224



[www.facebook.com/MSSocietyofSANT](http://www.facebook.com/MSSocietyofSANT)

[www.twitter.com/MS\\_SA\\_NT](http://www.twitter.com/MS_SA_NT)