Strengthen the bonds
Learn the secret of successful relationships

Spotlight on MS organisations
Why a hobby can improve your wellbeing

EMERGING TREATMENTS
Botox treats symptoms

FINANCIAL INFORMATION
A look at key pension payments
Welcome to the Winter 2013 issue of Intouch.

It was so pleasing to see the Federal Government introduce legislation for the DisabilityCare levy on 15 May, the day after the Federal Budget was delivered. The levy starts from 1 July 2014 and it will partly fund the National Disability Insurance Scheme (NDIS). In the weeks leading up to this, it was heartening to see the great bipartisan support for the scheme which is designed to improve the lives of Australians who have a disability.

During all this activity, it’s been incredible to watch the NDIS begin as an idea and then slowly take shape. The scheme is now at the stage at which there’s no going back. As of 1 July 2013, it will start to be made available so it can begin making a difference to the lives of the many people who are living at one of the locations at which the scheme is to be launched.

It has taken the passion and commitment of many individuals and organisations to get the scheme to this stage, and it’s a testament to their hard work. However, the ‘nuts and bolts’ are yet to be determined, and MS Australia – ACT/NSW/VIC will remain actively involved in providing ideas and sorting through the details so that the needs of people who are affected by MS can be met.

When the scheme is up and running, people with MS will be able to receive care and ongoing support from our organisation. They will also continue to require the support of their ‘significant other’, family members and friends, which is why it’s important to keep those bonds strong. For some practical advice about how to do so, read our special ‘Relationships and MS’ feature on page 13.

During May, MS attracted a good deal of media attention, and I want to thank everyone who got involved in the Kiss Goodbye to MS campaign, attended a World MS Day event or took part in the MS Walk and Fun Runs held in Melbourne, Sydney and Canberra on 2 June. Keep an eye out for the Spring issue of Intouch, in which we’ll feature photos of the events and showcase some of the highlights.

Robyn Hunter
CEO, MS Australia – ACT/NSW/VIC
Editor’s note

Maintaining relationships, family bonds and friendships has its challenges at the best of times, but when a chronic disease is added to the situation, even the most loving of people can be tested. Little wonder, then, that many people believe that the divorce rate among people with MS is higher than that in the general population.

I had accepted that ‘urban myth’ as fact until I was corrected by Dr Gary Fulcher, Senior Clinical Psychologist with MS Australia – ACT/NSW/VIC, during an interview for the special feature you’ll find on page 13 of this issue. He says that according to research, the divorce rate is about the same or slightly lower than that for the general population. However, it’s higher for people who’ve been married for fewer than five years. Read Gary’s advice for keeping your relationships strong, as well as the views of people who are living with MS.

‘Relationships’ is such a broad subject that for the Spring issue of Intouch, we’ve decided to take a closer look at ‘sexual functioning and intimacy’. Work, of course, is also important for your wellbeing, so the special theme of that issue is ‘MS and employment’. We’ve decided that ‘parenting and MS’ deserves its own feature, so we’ll be examining that topic in the Summer issue.

All human beings both look for and deserve love, so at the risk of sounding like a ‘Hallmark greeting card’ writer, I suggest you show your nearest and dearest that you love them today.

Toni Eatts
Editor
Dealing with MS
I just wanted to say to Veronica Lane of Victoria (‘Your Say’, Autumn 2013) that you’re not the only one doing it alone. I was diagnosed with Relapsing–remitting MS in May 2012.

Having two siblings with cystic fibrosis (CF) means that people have always avoided us. I’m not complaining, because I’ve always been a loner. I was primary carer for my sister during her battle with CF, her subsequent lung transplant, the failure of the transplant, and her death. It was just she and I battling through the medical appointments, and she taught me to be a stronger person.

I run my small bookkeeping business as well as working three days a week, and I’ve had custody of my 10-year-old nephew since my sister passed.

My life is full on, and for the time being, I need it to be. I haven’t decided what I’ll do when I can’t do things for myself; I’ll make that decision when the time comes.

For the moment, I’m one of the lucky ones, and I’m grateful I am. My heart goes out to all people with MS who aren’t as lucky as I am.

Rhonda, Vic

Editor’s note: Thank you for your letter. No person with MS has to feel alone: call MS Connect on 1800 042 138 to get some information about the Peer Support Program and other services you might find helpful.

A successful ‘tree change’
The Autumn issue of Intouch in which you looked at ‘tree changing’ was timely. A friend with MS is considering joining me in the tiny town I live in. I moved here at age 32 after being diagnosed with MS. I wanted to live a simpler, more meditative life and grow my own vegetables. Here, I could afford to work part time, so it all made sense.

That was in 1998. Now, in 2013, I’m still mobile, but fatigue means I need help with shopping, house cleaning and gardening. But I met my partner and became part of a community in which there’s always someone I can call on. I’ve built my own small business, and I haven’t had a moment’s regret.

My friend is 55 and still independent. I’ve listed the pitfalls for her: a three-hour drive to medical specialists and MRI; 35 kilometres to GPs and supermarkets, and next to no public transport. But the advantages are cheap rents and low property prices, a lovely environment, a healthy lifestyle, and a friendly community. I’ll leave it up to her.

Jen Severn, NSW

Write in to WIN!
Keep your feedback and stories coming in! Next issue’s theme will be ‘MS and employment’.

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Major events in May

May has been a huge month for fundraising with the Kiss Goodbye to MS (KGTMS) campaign starting on 1 May and culminating in World MS Day on 29 May. Meanwhile, excitement built for the MS Walk and Fun Run held in Sydney, Melbourne and Canberra on Sunday, 2 June.

The 2013 Kiss Goodbye campaign was launched at Wynyard Park in Sydney’s CBD on 30 April. It featured Megan Healey, who is a mother of three and has MS and was preparing for her fundraising challenge of riding a red lawnmower from Melbourne to Sydney. On Monday, 13 May, Megan was given an encouraging send-off when she departed the Melbourne Brain Centre.

The theme of the KGTMS campaign was ‘Wear, dare and share’, and people were encouraged to wear red, do something daring during May, or share photos on the KGTMS Facebook page in order to participate in the ‘Photo of the day’ theme.

Throughout May, the corporate community supported the campaign by using red lights to light up public buildings. In Melbourne, the GPO glowed red; in Canberra, the Telstra Tower was featured; and in Brisbane, the Conrad Treasury Casino, King George Square, QPAC, and the Brisbane Convention and Exhibition Centre were all involved.

Several fundraising dinners were held in Sydney, Melbourne and Canberra, including a cocktail party at Kirribilli House, in Sydney, which was attended by the Governor of NSW, Professor Marie Bashir.

For a full round-up of KGTMS, World MS Day, and the MS Walk and Fun Run, see the next issue of Intouch.

$5 million raised

The 24 Hour Mega Swim has raised more than $5 million since it began in 2001. So far this year, nine events have been held, and at the time of writing, had raised more than $700,000.

Recent events include the Melbourne 24 Hour Mega Swim and Mega Squash and Racquetball held on 13–14 April. More than $60,000 was raised from the two events. Other successful events include the Canberra 24 Hour Mega Swim, which raised more than $131,000, and the Wollongong 24 Hour Mega Swim, from which $45,000 was raised.

For more information, go to www.megaswim.com.

ACT pain symposium

More than 200 people attended the Consumer Pain Symposium in Canberra, which was hosted by MS Australia – ACT/NSW/VIC in partnership with Painaustralia, the Australian Pain Management Association, the Healthcare Consumers Association of the ACT, Pain Support ACT, and the RSI and Overuse Injury Association of the ACT. The speakers included Dr Peggy Brown, Director General of ACT Health; Professor Michael Nicholas, from the Pain Management Research Centre at the Royal North Shore Hospital; Professor Lorimer Moseley, Professor of Clinical Neurosciences at the University of South Australia; and Professor Rollin Gallagher, from the United States Veterans’ Pain Program.

Dolphin delights

Four clients from the NSW north coast enjoyed a ‘once in a lifetime’ experience, thanks to the generosity of Dolphin Marine Magic, located at Coffs Harbour. Helen Sikkens, our Registered Nurse and Community Service Worker who is based at Coffs Harbour, approached the marine park because she wanted to give some clients a treat.

Each client was assisted by a family member and spent about 40 minutes in the water with the park’s star attraction Clementine. “It was such a wonderful experience watching the clients that I couldn’t stop smiling!” Helen says.

New MS Clinic

MS Australia – ACT/NSW/VIC is providing the first-ever, nurse-led MS Clinic thanks to the cooperation of Goulburn Valley Hospital, in Shepparton, Victoria.

Julie Sleeman, one of our MS Nurses, attends the clinic at the hospital one day a fortnight in order to advise people who have MS about how to manage their symptoms and plan their care. People who have MS are referred to the clinic by their doctor or another service provider. Julie also undertakes home visits in the Shepparton region when required.
News from MSAC

By Andrew White, Chair, MS Advisory Council

Very often, MS seems to revolve almost completely around the practical issues of life. Which medication should I take? What disability aids will I find most helpful? How do I most easily get to that special function? And on it goes. Although these questions are both important and necessary to answer, it’s easy to lose sight of how MS affects our relationships with the people around us.

At present, MSAC in Victoria is engaging in conversation with our members in order to better understand the whole range of needs for carers of people who have MS. When we were deciding on the project’s focus, we found it relatively easy to identify some practical issues for the group and potentially just as easy to lose sight of needs associated with relationships and the emotions.

To start with, then, MSAC has initiated an opportunity, both directly and via technology, for identification and consideration of all the needs that carers have. To join this conversation, please email us at advisorycouncil@msaustralia.org.au or contact us via Facebook, at the MSAC Carer Project.

Regardless of where you live, we’d love to hear from you. We also look forward to soon telling you and the Board of MS Australia – ACT/NSW/VIC what we’ve found out so we can make a positive difference to the way the organisation provides you with support in relation to your practical and relationship needs.

It’s exciting to report that the MSAC team for NSW, under Mike Hemmingway’s leadership, is planning its activities in cooperation with the Victorian team and is most importantly talking directly to people who live in NSW. Mike will bring you news of the team’s progress in future issues of Intouch.

Remember that by registering at our website, www.msac.org.au, and visiting us on Facebook, you can provide us with a valued perspective we can in turn share with the board members, leaders and team members at MS Australia – ACT/NSW/VIC.

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Allan will be missed

The NSW mid-north coast has lost someone who worked tirelessly on behalf of people with MS, now that Allan Shaw has died, at age 71.

Diagnosed with MS in 1983, Allan became active in the MS community, especially after he and his wife Robyn and their family moved to the Forster–Tuncurry area, in 1988.

With Allan’s support, Robyn formed the Great Lakes Friendship Group in 1990 and the Manning – Great Lakes Fundraising Branch in 1992. Allan was active in both and held the position of branch president for many years. He was also president of the National Council of People with MS for several years, and was on good terms with MS-community leaders such as John Foley, Bill Northcote and John Studdy.

“MS Australia – ACT/NSW/VIC wouldn’t be the organisation it is today if it wasn’t for the inspiring work of people such as Allan Shaw,” says Robyn Hunter, CEO of MS Australia – ACT/NSW/VIC. “He’ll be greatly missed.”

Allan rose to the position of Chief Executive Liaison Officer at the State Rail Authority before retiring. He lost his life due to lung cancer and MS-related complications on 12 April.

Tim’s next adventure

Melbourne man Tim Spiteri is preparing for his second open-ocean rowing challenge in the hope of raising $250,000 for people with MS, because his mother Rhonda has MS.

In January, he and his crew successfully rowed non-stop from the Canary Islands to Barbados, crossing 5,000 kilometres of Atlantic Ocean. When Tim returned to Australia, he and Rhonda were featured on Channel Seven’s Sunrise program. In July, Tim and five fellow rowers will attempt to row more than 8,500 kilometres across the Indian Ocean, from Western Australia to South Africa, non-stop and without support. To follow Tim’s progress, go to www.facebook.com/TimsVoyage or visit his website at http://timsvoyage.com/

Progressive MS meeting

The first scientific meeting of the International Progressive MS Collaborative was held in Milan, Italy earlier this year. More than 170 experts attended, including Professor Bill Carroll, chairman of MS Research Australia. “There was a shared sense of urgency that global cooperation will lead to acceleration of progress in treatments,” he says.

Allan Shaw
NDIS UPDATE

NDIS becomes a reality

It was cause for celebration when Prime Minister Julia Gillard introduced legislation for the DisabilityCare levy on 15 May. The bill will increase the Medicare levy from 1.5 to 2 percent from July 1, 2014 to help fund the National Disability Insurance Scheme (NDIS).

This development follows the fact that on 21 March, the NDIS Bill received royal assent when it passed through Federal Parliament. Since then, this ‘reform of a generation’ has gained a second name, DisabilityCare Australia, and Federal Opposition Leader Tony Abbott announced the Opposition’s support for the proposed 0.5 percent increase in the Medicare Levy, to fund the scheme. At the time of writing, all states with the exception of Western Australia had signed up.

Although there is still a lot of detail to be resolved, these important milestones are an indication that the proposed national scheme will become a reality, according to Deborah Farrell, Acting Regional Manager South for MS Australia – ACT/NSW/VIC.

“If you’re a person with MS, a carer or a family member, it’s time to investigate how the scheme will affect you,” Deborah says. “It has the potential to contain the right supports for people when they need them. However, these supports have to be aligned with your goals, and they have to be reasonable and necessary.”

Deborah encourages people who have MS to read the scheme’s rules. To do so, go to the NDIS website: http://yoursay.ndis.gov.au/draft-NDIS-rules

Meanwhile, the countdown is on for some launch sites to be ready by 1 July this year. The four areas in which the scheme will commence are:

• NSW: the Hunter region
• Victoria: the Barwon region
• South Australia
• Tasmania

The scheme will be launched in the Australian Capital Territory on 1 July 2014 and will be rolled out in Tasmania by 2019. Queensland has committed $860 million to it for 2014–15 and intends to have it fully operational by 2018–19.

Launch sites

NSW

Encompassing the Hunter region, including Newcastle, Lake Macquarie and Maitland

• A total of 10,000 participants, ages 0–65
• Location of agency office: Charlestown

NSW is proposing to use postcodes in order to determine who will access the scheme, and Newcastle will be the first region to participate. There will be 3,000 Newcastle participants from 1 July 2013, 2,000 Lake Macquarie participants from 1 July 2014, and 5,000 Maitland participants from 1 July 2015. The full scheme will commence on 1 July

Access and eligibility

In order to aid the roll-out, the Federal Government has established the Launch Transition Agency, and under that agency, an entity entitled Agency Planners will confirm the person’s eligibility for DisabilityCare Australia.

Before some people meet the planner, they will have completed an online self-reporting tool – My Access – which will be available on the agency’s website. The purpose of the self-reporting tool is to indicate whether the person is likely to be eligible, and the planner will confirm his or her eligibility.

The planner will discuss the participant’s needs, goals and aspirations, and will thereby create a ‘statement of goals and aspirations’. The planner and the participant will work together to identify the existing and future types of support the person will require in order to make progress towards his or her goals. In this part of the ‘plan’ – the ‘statement of participant’s supports’ – the types of support that will be funded under the NDIS will be set out.

These two statements will constitute the ‘plan’, which will be based on what is considered to be reasonable and necessary in order for the person to have a good life. The plan might include one-off and/or ongoing funded types of support. What is ‘reasonable and necessary’ support will probably be checked against a set of ‘reference packages’ that the agency is developing.

Several additional processes are also involved, and if you live in a one of the launch locations, you might consider visiting www.ndis.gov.au/ and signing up to receive updates.
2016, and full state coverage is expected to be achieved by 2018.

St Vincent de Paul has been appointed the provider of the program entitled Ability Links NSW, which will be for providing local-area coordinators in the Hunter region. The coordinators will work with people who have a disability as well as with their family members and carers. The coordinators’ role will be to implement the various types of support and service required.

**VICTORIA**

Encompassing the Barwon region, including the City of Greater Geelong, the Surf Coast Shire, the Borough of Queenscliffe and the Colac-Otway Shire

- A total of 5,000 participants, ages 0–65
- Location of agency office: Geelong
- 4,000 participants from 1 July 2013; 500 participants from 1 July 2014; 500 participants from 1 July 2015

Victoria is proposing to enable the scheme to be fully implemented, commencing with people listed on the Disability Support Register who have unmet needs. Early-childhood intervention will be phased in during the same period, and a different group will be phased in each month.

**ACT**

Encompassing all the ACT

- A total of 5,000 participants, ages 0–65 years; 2,500 participants from 1 July 2014
- The full scheme to commence on 1 July 2016; full coverage to be achieved by 2019

The Federal Government recently announced a $10.6 million contribution for helping the ACT provide enhanced access to the various types of support and service in preparation for the NDIS. From July 2013, residents will have access to an enhanced suite of types of support related to their disability. The Enhanced Service Offer has been designed to meet the disability-related needs of the broadest possible range of people who are 64 or younger and have ongoing support needs that are related to the disability. The first round of grants will be announced in July 2013.

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**Can we help?**

Before you, your family members or carers meet with the Agency Planner, consider contacting MS Australia – ACT/NSW/VIC. If you are a client who has used our services, we will be able to support you when you are completing the details that are required for the eligibility assessment. We will also be able to help you prepare for your meeting with the planner by discussing your goals and the types of support and service you require in order to achieve the goals. You might find it helpful to conduct preparatory conversations such as these so you can empower yourself to make the best choices and decisions. For more information, go to www.msaustralia.org.au/ndis
Outcomes improving

The long-term outcomes for people with MS seem to be improving, according to findings published in the Journal of Neurological Science by researchers using the international clinical database MSBase.

The database contains information about more than 11,000 patients and was used to investigate whether the rate at which people with MS accrue disability has been changing over the past 15 years.

Many Australian patients are on the database, and Australian clinicians are collaborators, including Associate Professor Helmut Butzkueven from the University of Melbourne.

The database records longitudinal data on the demographic, clinical and treatment details of people with MS. The collaborators looked at the ages of people with different levels of disability when they were enrolled in the register using the Expanded Disability Severity Score (EDSS). The EDSS is used to measure disability on a scale of zero to 10, whereby a score of zero represents a normal neurological examination and six represents a significant disability for which the person has to consistently use a cane or walker.

Over the period 1996–2010, the researchers found that the age of the people who were enrolled in the register who had an EDSS of 4.0 or 4.5 increased by almost eight years, from 43 years to 51, and that the mean age of the people who had an EDSS of 6.0 or 6.5 increased by almost five years, from 48 years to 53.

The researchers concluded that the age delays at disability-milestone points are consistent with the hypothesis that long-term outcomes in MS have been improving in recent years. Contributing factors include changes in environmental exposure and health behaviour, such as decreases in smoking. However, the authors suggested that disease-modifying treatments for MS have been a contributing factor in the improvement.


Stem-cell promise

Two groups of American researchers have independently succeeded in converting a type of skin cell, called a fibroblast, directly to oligodendrocyte precursor cells (OPCs). OPCs are the final step in stem-cell specialisation before they turn into oligodendrocytes, which are the brain cells from which the myelin sheath that surrounds nerve fibres is generated.

Although other types of stem cell have previously been converted to OPCs, this is the first time that normal adult cells have been directly converted to OPCs.

The researchers have called the cells induced OPCs (iOPCs).

The researchers are from Stanford University, in California, and Case Western Reserve University, in Ohio, and were able to show that the iOPCs were capable of making the final transition to oligodendrocytes and did not lead to formation of other unwanted cell types.

The iOPCs were able to form the myelin sheath around the axons of neurons growing in a laboratory dish. When the iOPCs were transplanted into the brains of mice with a genetic disease in which myelin does not form properly, they were able to show that the transplanted cells survived and matured into oligodendrocytes that formed myelin in the brain.

However, much work is required before clinical trials can be conducted on humans.

For more information, go to www.msra.org.au/skin-cells-holds-promise-repair-ms.

Oral drug update

A new oral treatment for Relapsing–remitting MS, dimethyl fumarate (also known as Tecfidera and BG-12), has been approved by the US Food and Drug Administration (FDA) and the European Medicines Agency. In Australia, the drug is still awaiting regulatory approval.

Another oral treatment, teriflunomide (Aubagio) has been approved for MS in Europe. Teriflunomide has previously been approved by the FDA in the US and was approved by the Therapeutic Goods Administration (TGA) in Australia in November. However, it was rejected by the Pharmaceutical Benefits Advisory Committee for listing under the Pharmaceutical Benefits Scheme.
Q&A

Your MS-related, health and lifestyle questions answered.

If you have questions about MS-related concerns, please contact MS Connect™ on 1800 042 138.

What can you tell me about the medicinal cannabis-based mouth spray Sativex?
– Alec, Victoria

Sativex contains chemicals that belong to a family of chemicals called cannabinoids, which are extracted from the cannabis plant. It has been the subject of clinical trials, including the two most recent: MUSEC (Multiple Sclerosis and Extract of Cannabis), a Phase III trial, and the Sativex ‘long-term use’ trial, an open-label trial in patients who have spasticity due to MS. According to the results, which were published last year, cannabis-based medications are effective in reducing spasticity and associated muscle pain in people who have MS. These symptoms are a significant problem for many people living with MS, and at present, the therapeutic options for treating the symptoms are limited.

Use in Australia

In Australia, the Therapeutic Goods Administration (TGA) has registered Sativex for use by people with MS who have muscle spasticity. However, Australians in general are unable to obtain the medication because the TGA listing and poisons scheduling of new drugs usually take place in parallel. At present, cannabis is scheduled as a prohibited substance, and because the medicinal mouth spray Sativex contains chemicals derived from cannabis, a more lengthy process is required for the product to be scheduled. Any changes to the National Poisons Schedule will have to be followed by state-based regulatory changes.

Where to now?

On 22 November 2012, the NSW Legislative Council established an inquiry in order to investigate and report about cannabis use for medical purposes. The first purpose of the inquiry was to examine the efficacy and safety of using cannabis for medical purposes, whether and how cannabis should be supplied for medical use, the legal implications and issues involved in using cannabis for medical purposes, and any other related matters. The second purpose was to examine a range of modes by which the chemical properties of cannabis can be accessed for therapeutic purposes, from smoking the plant to manufacturing pharmaceutical products consumed via a nasal spray, tablet or in another form. In May, the report recommended the medical use of cannabis for people with terminal illness and AIDS.

Was the MS organisation involved?

MS Australia – ACT/NZW/NSW joined forces with Painaustralia to support a submission to the NSW Legislative Council Inquiry into the Use of Cannabis for Medical Purposes. Along with the information that the MS organisation provided, a statement from NSW resident Sue Hodges was tabled in which she shared her experiences of living with MS and the benefits she believes she will receive in relation to her MS symptoms by using the medication. We thank Sue for being the voice of people with MS who might gain some relief by using the medication.

Sativex use leads to symptomatic relief only; no evidence exists to date that it leads to alteration in the course of MS. It might be an additional treatment option for supplementing physical and other existing symptomatic therapies. People living with MS who require more information or wish to contact Sue can do so via MS Connect on 1800 042 138. They should also speak with their doctor.
My story: Top of the world

Bobby Bajram believes you should dream big, which is why he’s attempting to fulfil his long-held ambition of climbing Mount Everest.

When a 45-year-old who has never climbed a mountain announces he intends to conquer Mount Everest, you could be forgiven for thinking he has lost his marbles – but when the person is Bobby Bajram and you learn how much he has achieved so far, you could decide he just might make the conquest.

Not that Bobby entertains doubts. “I’m a resilient, positive person,” he says. “I was diagnosed at age 13. I was in and out of a wheelchair for 15 years, and I lost my sight for five years.”

One day during those dark months, Bobby decided he was going to “walk on top of the world and see the blue sky”. His inner strength was forged as a result of the tough times. “I didn’t want a life stuck in a chair.”

Bobby was raised in South Melbourne, the second of three children, and at the time of his MS diagnosis, he was the youngest Australian male to receive the diagnosis. “I’d heard of MS because of the MS Readathon, and I realised I probably wasn’t going to die.”

At 20, he became an MS Ambassador, a role he fulfilled for 22 years. Now, dressed in his trademark silver jacket, he’s a regular on the professional talk circuit. In 2007, he hosted the MS Show, which was screened on a community-television channel, and in 2010, he presented Behind Closed Doors, which was screened by the BBC. “It was one of the highest rating TV shows about disabilities, because the BBC is shown around the world.”

Bobby followed TV doctor and author Dr John Tickell’s advice and shed 48 kilos over a year. Supported by his project manager John Taip and professional manager Jon Michael, he also attracted sponsors such as Fitness First, which provided personal trainers, and Swisse Vitamins, which provided supplements and nutritional advice.

After much hard work, he has sculpted his body into a professional athlete’s – albeit a body that remains challenged by MS. “I had relapses in November, January and February. These put me in hospital, and I couldn’t work out – but I haven’t used a wheelchair since my thirties; I’d rather struggle with sticks. A relapse is no biggie – I’m used to it.”

Bobby lives with fatigue, pain and incontinence, and exacerbations usually affect his mobility and sight.

So, what does Bobby’s neurologist think of his plan to conquer Everest? “He’s concerned, and he’s right to be, but sometimes you have to do extraordinary things for people to take note.”

Surely Bobby must be afraid. “I know it’s dangerous, but I’m coming back – I won’t leave my daughter without a dad.” Indeed, he is the proud father of three-year-old Annie. “I don’t live with her mother, but we get on well. Annie spends time with me and is a total joy.”

His expedition leaders have explained the dangers. “I’ll turn around if I have to,” he says, “but I want to make a physical statement. Perhaps I can inspire someone to have a crack at a smaller challenge. Fear is just a word, so I’ll ‘do it anyway’.”

Bobby’s road to Everest

Two experienced mountaineers are preparing Bobby Bajram for his Mount Everest attempt.

John Watson has been taking him on training climbs in the Grampians. “The Everest climb should never be underestimated,” John says, “but it’s not as technically difficult as other climbs. It’s a tough trek on ice and snow. Fatigue and altitude sickness can happen to the best climbers. Bobby has limitations, but he’s strong, fit and extremely motivated.”

Mark Squirrell will lead two overseas climbs in preparation for Mount Everest, planned for April 2015. Mark climbed Mount Everest in 2006 and has also conquered Island Peak, the destination for Bobby’s first Himalayan expedition, in October 2013. Island Peak is 6,189 metres high, and in April 2014, Bobby will ascend Cho Oyu, which stands at 8,201 metres. “These staged undertakings will test how Bobby deals with altitude,” Mark explains.

Mark, John and Bobby will join a larger team for Everest. “We’ll be supported by 30 sherpas,” Mark says. Meanwhile, Bobby wishes to acknowledge the Pratt Foundation for its financial support. To find out more, go to Bobby’s Facebook page, bobbybajrammounteverest2013

Would you like to share your story with other people living with MS?
Contact the editor on (02) 8484 1316 or email intouch@msaustralia.org.au

12 | intouch | winter 2013 | www.msaustralia.org.au/actnswvic
When a person is diagnosed with MS, his or her spouse or partner, family and friends are also affected. How do you manage these significant relationships while meeting the challenges associated with the disease?

**Strengthen the bonds**

When a person is diagnosed with MS, his or her spouse or partner, family and friends are also affected. How do you manage these significant relationships while meeting the challenges associated with the disease?

There is one word you need to know, understand and act on if you want to maintain and strengthen your relationships with your ‘significant other’, your family members and your friends: ‘reciprocity’. It comes from the word ‘reciprocal’, and means ‘mutual exchange’, as in making return for something given or making interchange.

It is the basis of all long-lasting relationships, and in both sickness and health, we are constantly engaged in negotiations with our loved ones, family members and friends as to how much we give and what we receive. However, according to Dr Gary Fulcher, Senior Clinical Psychologist with MS Australia – ACT/NSW/VIC, people with MS must ensure they continue to ‘give’ even if all they are physically able to give is a heartfelt thankyou.

This is a ‘dance’ that Gary and his wife know well. In 1996, when the couple had been married for four years and been together for eight, Gary was seriously injured in a fire. He suffered third-degree burns to 60 percent of his body and lost his fingers. It took him many months to recover.

“When I was discharged from hospital for the first time, a nurse explained I needed someone to help with my personal care, including showering, cleaning my teeth and toileting,” Gary says. “She suggested that my wife would be happy to do it. I replied I didn’t think my wife should be the one to help; besides, because of my work, I was very aware of the
dangers of the ‘care giver – care recipient’ roles. I insisted we have nurses come into our home to do my personal care until I was able to do it.”

Fortunately, the expenses were covered under workers’ compensation insurance, but Gary understands that not everyone has that luxury. As a result of the experience, however, he has been prompted to think deeply about the impact that MS has on relationships.

**Divorce rates**

“The good news is it’s an urban myth that the divorce rate among people with MS is high; in fact, according to research, the divorce rate among people with MS is about the same or slightly lower than that in the general population.”

Gary suggests that the urban myth might have gained traction because of the high separation rate for couples who have been together for fewer than five years. “Couples in a longer relationship have established values and respect. There’s enough reserve built up for them to cope with the stress that comes with a chronic illness.”

Due to the intrinsic nature of MS, the roles of care giver and care receiver can be required from the onset of the disease’s first symptoms, during exasperations or relapses, or as the disease progresses.

“People in an intimate romantic relationship retain a sense of individual privacy,” Gary explains. “However, if a person has MS, over time, those boundaries get crossed when the person needs assistance with his or her personal care. Touch that has been used in a romantic, sexual or sensual sense has to become functional, and this aspect is significant and difficult for both people involved. It’s difficult to be someone’s lover just after you’ve helped the person with toileting. For both people to cope, they have to work out a different way of being.” In order to complete the task at hand, the care giver has to disconnect emotionally. Also, the care receiver might have to disconnect emotionally in order to enable the care giver to complete the task. For both people, the fact that this disconnection can happen at different times is an additional component in the complexity of the dynamic.

“When a person is first diagnosed, he or she is more likely to disconnect emotionally in order to enable the care giver to complete the task with a minimum of distress,” Gary explains. “However, the care giver can be left feeling as though the person with MS has become robotic.”

On the other hand, when the person with MS becomes more used to receiving the care, he or she might feel as though the care giver has disconnected emotionally. The person with MS can grieve about a loss of touch that used to be intimate. Whichever way the situation plays out, there is loss of the couple’s former relationship and both people will feel grief, mostly likely at different times. A difficult situation can become even more complex when these forces are in combination.

“I understand the process because of my experience,” Gary affirms. “That’s why I insisted a nurse do my personal care. I wanted my wife to remain my wife, not become my nurse or my carer.”

Coping with change

However, in spite of Gary’s precautions, he and his wife have had to negotiate and re-negotiate their relationship. “She still has to help me,” he says. “For example, I can’t do up the top button on my shirt. Sometimes I’ve required her help for other tasks a husband and wife don’t normally do for each other. When that happens, we go into functional mode, and we have very clear roles. When the episode’s over, we return to our roles of husband and wife in order to keep our intimate relationship separate.”

As a result of this first-hand experience, Gary has learnt the importance of reciprocity. “The care giver is doing more of the work and the care receiver is doing less, and as the disability increases, the imbalance grows. This situation is in marked contrast to most successful relationships, in which roles and functions are negotiated and split reasonably and equally.”

Gary warns that when the balance is changed, resentment can grow and can be to the long-term detriment of the person with MS if he or she does not take steps to address it. “I’ve sat with a person with MS and watched as their carer giver has re-arranged how they are sitting, given them a drink and wiped water from their chin and the care receiver has said nothing. People with MS need to be on the lookout for how they can reciprocate – at the very least, they can say thank you.”

Gary urges people with MS to cultivate this idea of mutual exchange. “I have no fingers, so my wife has to do a lot for me. However, I can use the stumps of my hands to give a massage, so when she’s done more than her fair share of chores, I’ll take time to pamper her.”

He also suggests avoiding the trap of self-indulgence. “Remain as independent and upbeat as possible, and do everything you can to stay fit and healthy. The care giver needs to see you’re trying rather than giving up.”
Family and friends
Awareness of the need for reciprocity is also the basis for strengthening other relationships. When a person is diagnosed with MS, the diagnosis has an impact on everyone he or she knows. Parents and siblings might become involved in completing tasks or taking on more of the load, and it is important to acknowledge their input.

Gary warns there’s an additional complication involving family members. “They might expect the person’s partner to become the ‘super-care giver’. In those circumstances, the person with MS has to be the champion of the person without MS. You might need to tell your family to back off. It’s important you do so, because pressure from your family can be a strong trigger in relationship and marriage breakdown."

In order to keep friends or cultivate new ones, the person with MS has to be extra-diligent. “We’re all busy,” Gary states. “You can’t expect friends to do all the work – you need to make the phone calls and be proactive, and if people help, you need to make sure you pay them back in kind.”

Gary advises newly diagnosed people to put effort into all their relationships. “Early on in your MS journey, denial probably isn’t a bad thing. Ignore the MS, and get on with your life – have a happy, active life. If you have a relationship, enjoy and nurture sex, because intimacy is one of the strongest guarantees of a solid, long-term relationship.

“You’ll set up a good foundation for the time that sexual functioning might become impaired. If you already have an open and honest sex life, you and your partner will find it easier to negotiate new ways to have that intimacy, and although they mightn’t involve penetrative sex, they’ll be satisfying. Remember that stroking, kissing and cuddling maintain that intimacy.”

Above all, Gary advises people with MS to avoid becoming a ‘sick’ person. “Put the MS on the backburner, and live life to the fullest for as long as you can. Spend time with family and friends, remember their birthdays, call them just to say hello, and help out whenever you can. If you make the effort while you’re able, you build up credit in your relationships which will pay dividends if things go wrong.”

Carers need breaks
It is important that carers take time out for themselves and do something they enjoy.

According to Dale Cox, Community Support Worker with MS Australia – ACT/NSW/VIC, male and female carers tend to react differently to the idea of taking a break. “For some men, the need to provide care comes at the same time of life as retirement does. This creates one identity issue on top of another identity issue. However, it’s amazing how many men work through the problems and have a loving relationship with their wife.”

Dale suggests that the couple agree that the carer has the right to pursue his or her interests and that he or she must allocate time to do so. “This is important for the longevity of the relationship. Male carers are usually quick to understand this aspect, and act on it, but women can spend years dealing with the guilt of handing their caring role to another person, even for a short period.”

Dale also points out that attitudes to caring can be culturally specific. “In some cultures, carers believe it’s the family’s responsibility to provide for their loved one, and accepting outside help brings shame to the family.”

However, Dale recommends that all carers accept the fact that regular breaks are essential for their wellbeing. “If the pressure to care for the person with MS becomes too great, the partner can feel trapped, and that feeling isn’t good for the marriage,” she says.

Next issue: In this feature, we have touched on sexual functioning, but there is much more to say about sex and intimacy, so be sure to read the Spring issue of Intouch for a more detailed examination of them. Also, the theme of that issue is ‘Employment and MS’, whereby we will be able to address the person’s relationships with his or her employers and colleagues.
FEATURE

‘Now, I’m living’

Name: Linda Hughes
Age: 39
Living with: Bill Duell, age 52, who has two children from his marriage
Lives: Melbourne
Diagnosed with MS: Age 30

Linda says: I was diagnosed with MS in 2005 and spent the next four years angry at everything. I then met a man and was with him for a year, at which point he told me that my “medical stuff” scared him, and our relationship was over.

I’d given up on finding anyone, especially when I found out my MS was secondary progressive – but I decided I needed support from other people with MS, so I attended my first MS Peer Support Group, in October 2012. It was the best decision of my life, because at the November meeting I met Bill. At first, I thought he’d just become a great friend, but we got to know each other, and on New Year’s Eve, he kissed me at midnight.

Bill had been married for 22 years. Two years ago, he was in a rehabilitation unit when his wife announced that their marriage was over. Bill has Primary progressive MS and gets shocking shakes in his right arm. He can’t work. I’m a diabetes educator, and fatigue gets to me, so I can work only four days a week.

When it feels right, you know it is, and we made it official when Bill moved in. Our families and friends are overjoyed we’re happy. We talk about the future, but it doesn’t scare us, because although we certainly have challenges, we can face them together. The best thing is I have someone who won’t run away, and I won’t run away either! Considering neither of us walks that well, it’s our joke.

I’ve found someone who understands me, and the frustrations, and the little wins. Before I met Bill, I was just existing; now, I’m living.

Bill says: I was 44 when I was diagnosed with MS, in 2006. I have difficulty walking, and get tremors and fatigue. My children are now 16 and 21. It was a shock when my marriage broke up, but I now realise that the challenges of MS brought the problems in my marriage to a head. I never expected to fall in love again – when you’ve got MS, you consider yourself to be flawed.

I urge anyone wanting a relationship to go to a Peer Support Group, because you never know who you’ll meet. The first thing I noticed about Linda was her wonderful smile. She’s very friendly, and as I got to know her, I started enjoying her company. We like a lot of the same things, such as going to the movies and to the gym. We also like being with each other’s family. My son’s getting to know Linda, which makes me happy, and now that we’ve MS-proofed our unit, our home life’s wonderful. Linda adores cooking, and she’s very good at it. I appreciate everything about Linda. We love spending time together, and she loves me for me.

‘Nick tried to protect me’

Name: Jill*
Age: 62
Married: To Nick* for 29 years; three adult children
Lives: Sydney
Diagnosed with MS: Age 55

Our youngest child was 16 when I was diagnosed. I’d had symptoms a few years earlier, but I loved my work as a researcher, and thought I was tired because I was finishing a big project. MS changed our relationship. Fatigue and mobility problems meant I had to give up work, and that changed our finances and the person I was. My social contact had come through work. After I retired, my conversation became less interesting. We’d also enjoyed walking and holidays in hot climates, and MS makes both difficult. We no longer holiday in the tropics, and I walk with a stick, so Nick had to learn to walk slowly.

MS isn’t a diagnosis for the individual; it’s a diagnosis for the couple – a lifestyle change – and the other person is
‘Sue thanks me when I do chores’

Name: John Lane
Age: 64
Lives: Wahroonga, NSW
Full-time carer since: 2007

Sue was diagnosed with MS about 24 years ago. She was in charge of all conveyancing matters for a solicitors’ office, and worked hard, but had to give that up. She uses a walker around the house, and a wheelchair if she needs to cover any distance.

We married in 1970 and raised two sons, who are now 32 and 34, and we’re the proud grandparents of one granddaughter and four grandsons.

Sue’s MS hasn’t affected our relationship. We’re still happy, and we rarely argue. I retired from my position as a sales rep with the dairy company Norco in 2007, and my caring duties have increased since then. I do the shopping and cooking, and run Sue to appointments. I don’t complain, because over the years, I’ve grown used to it. I’ve met a lot of carers who are in a position similar to mine. I think it helps that Sue and I are easy-going and we still make each other laugh.

Our social life has changed a bit because Sue gets fatigue, so if we go out with friends, we have lunch rather than dinner – but at our age, that suits our friends.

I do enjoy getting away by myself every now and again, because it gives me a break. In November, I went away for three days. A carer came during the day to look after Sue, and the boys and Sue’s sister each spent a night with her.

We also make sure we have short trips away together – that helps us both; luckily, though, we’re ‘home’ people, so we like spending time together. We read, or watch cooking shows, or movies.

Sue thanks me when I do chores. I feel as though she appreciates what I do.

often left in the shadows. Because our neurologist had said that stress is detrimental for a person with MS, Nick tried to protect me from his feelings.

We had a solid marriage, but Nick had experienced depression, and since my diagnosis, he’s become depressed twice. At my urging, he saw a counsellor to discuss how it felt to live with someone who has MS. He learnt he didn’t feel as though he could complain because his issues paled into insignificance compared with mine. That understanding was helpful for our communication, because Nick now knows that his issues are legitimate.

Nick says he wants me to take care of my health more than anything, so I spend about two hours a day exercising, so I can continue to walk and drive. Nick has joined the gym and we exercise together, and he also goes swimming with me.

I don’t socialise much; I prefer to keep my energy for the family or to go out to dinner with Nick. When we do eat out, we talk about common interests such as books, films and politics. We know there has to be a lot of ongoing communication for us to be able to handle our lives with MS.

* The names have been changed.
MS COMMUNITY

MS Ambassador profile

When Danny Potter was diagnosed with MS, he was spurred on to become a successful business person in order to ensure that his wife and two daughters were financially secure.

Tell us a bit about your MS journey.

I realised there was something wrong when I was trying to play competitive sport and my hand-eye coordination wasn’t as good as it had been. Being a typical man, I fobbed it off for six months. When I finally saw my GP, he said, “You have either a brain tumour or MS.” I said I’d take MS.

What happened next?

Three weeks later, I had an MRI, and MS was confirmed, and the same GP told me I should’ve picked the tumour because it could be fixed. That’s when I figured that MS mightn’t be something you want to have, but I’m doing extremely well. Although I’ve had bad days, weeks and months, most people wouldn’t know I had MS – mind you, I don’t do things I know I can’t do: I stay out of extreme heat, and I don’t exhaust myself.

What motivates you?

MS motivates me. I wanted to build a business empire so my wife and daughters would be provided for if I couldn’t generate an income in five or 10 years’ time. I achieved that goal within five years. I could drop off the perch tomorrow and nobody would be destitute in my house. We sold our main business four years ago, and I now have the luxury of consulting.

My daughters were about seven and nine when I was diagnosed, and then my goal was also to walk them down the aisle. Now that I’ve done that and I became a grandfather in April, my goal is to play with my grandchildren.

Tell us about being an MS Ambassador in the country.

There’s a general lack of knowledge about MS, and I saw the opportunity in regional Victoria to educate anyone who was prepared to listen.

The first function I went to, I was mistaken for someone else because I was walking. In my talks, I explain that there are varying degrees of MS. I also meet a lot of people in rural Victoria who’ve been recently diagnosed and who don’t know what to do. I’m happy to guide them.

What are some of the things you’ve done in your role as an MS Ambassador?

I was the face of the MS Melbourne Cycle three years ago, and rode over the Westgate Bridge. I have also been the face of one of the MS Walk and Fun Runs. I’m happy to speak to anyone who’ll listen. I’ve done a lot of corporate-speaking engagements, but I’ll also speak to 10 Rotarians at a dinner meeting. I’ve spoken to about 40 groups over the years.

What’s the message you most like to deliver?

Don’t focus on what you can’t do; focus on what you can do, because you can do great things – that applies to all people, not just people with MS.

Would you like an MS Ambassador to speak at your next corporate, school or community event? Contact the MS Ambassador Program team, via MS Connect, on 1800 042 138.
Can you raise $50?

Need an excuse to read? We have you covered! Registrations open this week for the 2013 MS Readathon, and by raising just $50, you will help us reach our target of $500,000.

By simply indulging in one of life’s greatest pleasures, you’re also helping to provide much needed support, services and assistance to the 23,000 Australians living with MS.

You can take part in the MS Readathon no matter how old you are. This year, the shout-out to get involved also goes to babes-in-arms, toddlers, teenagers, seniors and everyone in between! You can therefore also support your children, grandchildren, nieces and nephews by signing up for the program!

We also have a group of volunteers who are embarking on one of our biggest challenges: to visit hundreds of schools throughout the ACT, NSW, Queensland and Victoria. They will speak to students about MS and will encourage them to take part and make a difference to other people simply by reading.

Last but not least, for the first time, this year, we have some very special individuals involved: some school students who have volunteered to talk about the program to their peers. They want to explain the benefits of reading and that getting involved in the MS Readathon is a great idea.

To learn more about these inspirational, community-minded people, check out the MS Readathon website, www.msreadathon.org.au

Important dates for your calendar

- The MS Readathon website: goes live in June
- Registrations open: 3 June
- Reading period: August
- The ‘60 MinuteS for MS’ one-day event: 23 August

For more information and to register, go to www.msreadathon.org.au

If you are a teacher or you know a teacher who you think would like to get his or her school or kindergarten involved, please email us at 2013schoolvisit@msaustralia.org.au

Make a difference

Last year, we launched the exciting 60 MinuteS for MS one-day event in order to offer schools a new, fun way to read and to fundraise for people with MS. Either on its own or in conjunction with the MS Readathon month-long program, schools can choose how they will be celebrating reading while helping other people.

Joan Palenzuela Marks, a teacher from Toongabbie West Primary School, recommends this interactive approach. “We kicked off the day with a readers’ theatre performed by the teachers,” Joan says. “Then we had an hour of reading for the whole school, including group reading as well as ‘buddy’ reading. All the teachers read, too, and it was a showcase for a great day.”

To find out how your school can make a difference in just one day, email 60minutesforms@msaustralia.org.au
EVENTS

For bookings or more information, email educationnsw@msaustralia.org.au or call 1800 042 138.

INFORMATION SESSIONS

Registration is essential, because programs will run only if minimum numbers are achieved. For bookings or more information, please call 1800 042 138 or email educationnsw@msaustralia.org.au

Learn About MS
Suited to people recently diagnosed with MS, and their family members and friends. Meet other people with MS and learn about our services.
29 June, 1pm – 4pm Penrith
27 July, 1pm – 4pm Gloria McKerrow House, 117 Denison Street, Deakin, ACT. To book, call Deakin reception on (02) 6234 7000.

Conversation with Centrelink
A Centrelink Financial Information Services Officer will discuss how to manage your entitlements.
25 June, 6.30pm – 8pm Lidcombe
19 June, 6.30pm – 8pm Wagga Wagga

Get Active
Obtain advice about how you can increase your fitness level and build your strength.
Date and time TBC Lidcombe

TELECONFERENCES

Available to clients and their family members throughout all regions. To register, please call 1800 042 138

Managing Fatigue
Learn how to manage MS-related fatigue, in this two-part teleconference series.
13 and 27 March, 6pm – 7.30pm
5 and 19 June, 10.30am – 12 noon

Continent Care in MS
Learn about bladder and bowel problems: causes, assessment and treatment options.
23 July, 10.30am – 12 noon
17 September, 6.30pm – 8pm

Working with MS
(NSW and ACT only)
Explore your rights and responsibilities at work, as well as superannuation, insurance and financial matters.
22 August, 7pm – 8.30pm

CHAT ROOMS

Available to clients and their family members who have internet access throughout all regions. For registration instructions, please call Education Coordinator Diane Browne on (02) 9646 0657.

Managing Fatigue
Ask questions of MS occupational therapists, and discuss fatigue with other people who have MS.
9 August, 10am – 11am

Mobility Options
If you’re considering getting a mobility aid, come and talk about various options with our occupational therapists as well as with other people who have MS.
20 September, 10am – 11am

Register to swim
The more than 3,000 swimmers and squash and racquetball players who get involved each year have one goal: to support people who are living with MS. The events at the following locations are now open for registration:
4−5 May Canberra
22−23 June Sydney
6−7 July Casey and Monash

For more information, go to www.megaswim.com

Register to swim

INFORMATION SESSIONS

Learn About MS
Splied to people newly diagnosed and to people who want to meet other people and learn more about MS and our services.
1 June, 10am – 1pm Footscray
20 July, 10am – 12.30pm Geelong
24 August, 10am – 1pm Blackburn

Working with MS
Explore your rights and responsibilities at work, as well as superannuation, insurance and financial matters.
27 July, 10am – 1pm Footscray

Get Active with MS
Our physiotherapists discuss how to use fitness and exercise to help manage your MS symptoms.
12 August, 10am – 12 noon Benalla
12 August, 5.30pm – 7.30pm Echuca

Managing Fatigue and Coping with the Heat
An overview of MS fatigue and how to manage this invisible symptom. Managing heat intolerance will also be part of the discussion.
28 August, 10.45am – 12.15pm Footscray; hosted by the Footscray Peer Support Group
6 September, 11am – 1pm Geelong

Thinking and Memory
Learn about common MS-related thinking and memory changes, and how to manage them.
24 July, 1pm Blackburn

Sleep Well – NEW!
Explore the reasons that people with MS have difficulty sleeping, and discuss some strategies to improve sleep.
26 June, 10.30am Footscray; hosted by the Footscray Peer Support Group
26 June, 11.30am Kyneton; hosted by the Kyneton Peer Support Group
16 July, 10.30am Shepparton; hosted by the Shepparton Peer Support Group

Medication Update
The new and emerging medications will be discussed by MS Australia – ACT/NSW/VIC nurses.
31 July, 10.45am Footscray; hosted by the Footscray Peer Support Group

Conversation with Centrelink
Hosted by the following Peer Support Groups. Join one of Centrelink’s officers to discuss your entitlements.
8 August, 10am – 12 noon Blackburn
8 August, 6pm – 8pm Geelong
28 August, 12 noon – 2pm Lakes Entrance

Continence Care in MS
Learn about bladder and bowel problems: causes, assessment, and treatment options.
16 July, 11am Mornington; hosted by the Mornington Peer Support Group

Legal Matters Matter
Talk to a representative of law firm Maurice Blackburn.
20 August, 11am Mornington; hosted by the Mornington Peer Support Group

WELLNESS EVENTS
Explore ideas and strategies for living well with MS. You will receive an invitation via either mail or email.

Geelong 23 June
Featuring Dr Craig Hassed, who will be speaking about the ESSENCE of wellness when you’re living with a chronic illness. There will also be ‘come and try’ sessions so that the day is great fun.

MS Family Wellness Day 6 October
Aimed at families, couples and singles, the program includes a guest speaker and wellness activities such as yoga, tai chi and massage. Lunch will be provided. Contact us to register your interest.

2013 Family Camp
At the MS Australia – ACT/NSW/VIC and YMCA Family Camp, people with MS and their primary school-aged children are provided with an opportunity to meet other families, in a safe and supportive environment. The aim of the camp is to promote family connectivity, shared resilience, and sharing and learning about MS and self-management within the family unit. It will be held at Mount Evelyn over the weekend of 12, 13 and 14 July. To register or find out more, call (03) 9845 2700.

CARERS’ GROUPS

Footscray 14 August, 6pm Medication Update

View programs
Recordings of some education programs are now available via the following website: www.mssociety.org.au/education-programs.asp
FAMILY & CARERS

Adrian wins local award

Although he has spent 15 years caring full time for his wife, Adrian Ford never expected to win a NSW Carers Award. The award was presented last October as part of National Carers Week 2012, and Adrian, who lives in the inner-Sydney suburb of Rozelle, won for the Balmain electorate. “It came as a complete surprise,” Adrian says. “I don’t think of it as caring, more as doing what is required for the woman I love.”

Adrian has enjoyed a successful career as a musician, and met his wife, Maggie, as a result of their mutual love of jazz. “Maggie had been diagnosed with MS four years before we met, and she was still walking then, but by the time we married, in 1999, she was using a wheelchair.” Adrian ensures he incorporates piano practice in each day because he finds joy in music. “I’m a doer, not a spectator. I don’t watch television; I write songs and compose music.” Maggie affirms that Adrian deserved to be recognised for his devotion to her. “Without him, I’d have to go into a home,” she says.

Petition for MS drug

When the Pharmaceutical Benefits Advisory Committee (PBAC) decided not to recommend Fampyra, also known as Ampyra, for listing under the Pharmaceutical Benefits Scheme (PBS), Brenda Fisher started a petition. Brenda has been the full-time carer of her husband Mark Fisher, who has had MS for 17 years. The PBAC's decision ignited a discussion in the Carers Facebook group, because according to the results of clinical trials, the drug can lead to an improvement in walking speed in about 30 percent of people with MS. The drug had been approved by the Therapeutic Goods Administration (TGA) in May 2011 for treatment of walking impairment in people with MS, but the PBAC is responsible for recommending whether new drugs be listed for reimbursement under the PBS.

“I have created a Facebook group that people can join in order to download the petition and gather signatures,” Brenda says. “You can also access the information we have to date. We don’t know when the drug company, Biogen Idec, will be re-submitting the drug to the PBAC, but the Federal Member for McEwan, Robert Mitchell, has agreed to take the petition to the Government on our behalf.” To support this campaign or learn more, go to www.facebook.com/groups/424466214299177/.

NSW conference

The Carers NSW 2013 Biennial Conference was held in Sydney on 14 and 15 March. The conference’s focus was on the themes of caring, working and living, and attendees included Angela Gelch, a member of the Carers Working Party. Angela says that much discussion took place about what the National Disability Insurance Scheme (NDIS) means for carers. “Highlights included speakers who explained how long-term wellbeing is improved in Carers Australia’s counselling program,” she reports.
Communities support the MS cause

We’d like to thank the many people who take the time to raise funds to support people living with MS. Here is how some people have rallied together to help make a difference.

Adriana’s community raises $140,000

Just over 12 months ago, Adriana Grasso was accepted as a certified practising accountant. Twenty minutes later on the very same day, she was diagnosed with MS, at only 26 years of age.

“I thought I’d just pinched a nerve at the gym, and I was in complete shock,” Adriana says. Immediately after being diagnosed, she returned to her home town of Shepparton, Victoria to be with her family “to work out what I was going to do”.

While Adriana was getting used to living with MS, she took part in the MS Walk and Fun Run, and within a matter of weeks she had managed to raise $10,000.

“I realised I had two choices: I could feel sorry for myself or I could help out.” She then set her sights on her own fundraising event.

Plans were made to hold a barbecue in her family’s backyard in order to raffle a Vespa motorcycle a local business had donated. However, having attracted huge support from the local community, the event evolved into a luncheon that took place in February and was attended by 370 people and from which a staggering $140,000 was raised.

“I’ve been overwhelmed by the generosity of the community – words will never express my thanks to everyone who’s supported me.”

More recently, Adriana has returned to part-time work. “I’m not going to let multiple sclerosis control my life. I’m so pleased to have been able to do something so positive, while also raising awareness of MS and hopefully helping find a cure.”

Our birthday hero

When Tim Green was five, all he wanted was a jam-jar lid tied to a piece of string so he could be like the prince who wore a medallion on his chest, used all his might to fight the bad guys and made those bad guys pay.

For readers who are ‘not of a certain age’, Tim’s hero was Prince Planet, the cult Japanese anime super-hero who pre-dated Astro Boy.

Forty-five years later, Tim celebrated his 50th birthday at the Deus ex Machina Café, in Camperdown, inner Sydney. “I wanted my party to be a gig – music shared with my friends – and I really didn’t want to complicate it by getting presents,” Tim explains. Instead, he asked his fellow partygoers to make a donation in lieu of a gift in order to help people living with MS.

More than 100 guests joined Tim to share some great food while enjoying the music of Perry Keyes and the Bernie Hayes Quartet, and in doing so, they raised $2,777. “It was so easy,” Tim says. “After setting up the event on the MS Everyday Hero website, all I had to do was attach the web link to my invitations, and Hey, presto!”

Roll of Honour

We would like to thank the following community members who helped raise funds for MS over the past three months:

- Michael Paul – Moomba Birdman Rally
- Vivienne Gallagher – a percentage of Exotix Jewellery sales
- Teresa Savage – a percentage of Phoenix cards sales
- Nicholas Walls – the Tough Mudder obstacle course
- James Brooks – the Melbourne-to-Sorrento bike ride
- Paige Lee – a calendar
- Annette Johnson, Nick Johnston and Keith Simcock – The Sydney Morning Herald Cole Classic
- Blue Illusion – Kotara, an in-store promotion
- Tim Green – donations in lieu of 50th-birthday gifts
- Vincent and Lina Galimi and the SS Crocifisso de Terranova Committee
- Zaley Cooke – shaving her head
- Westpac Group – an office event
- Carl Rafferty and the Opera by Candlelight – the charity of choice
- Rotary Club of Woden Daybreak – a trash-and-treasure stall
- Capital Hotel Group – the charity of choice


MS COMMUNITY

Volunteers in action
How our dedicated volunteers are helping to make a difference for people living with MS

Make a will

During their lifetime, most people accumulate assets, but many don’t make post-death provisions for disposing of the assets; in fact, more than 50 percent of people die not having written a Will or properly disposing of all their assets. For example, they might have bought property since they last wrote their Will or not nominated a beneficiary for their superannuation or life-insurance policy.

Many people assume that if they do not have a Will, their whole estate will automatically pass to their surviving spouse. However, that might not be the case!

If you do not have an up-to-date Will, the government uses a set formula in order to decide who will inherit your estate. For example, a spouse and children from a previous relationship will usually share your estate in varying proportions. Is that arrangement what you want?

By making a Will, you can structure your inheritances to best suit each beneficiary’s circumstances. You can access professional legal advice in order to receive answers to any questions you have.

To obtain a list of solicitors who would be able to assist you, call Donna Bradley in Victoria or Jacqui Sumner in the ACT and NSW on 1800 443 867, or email bequests@msaustralia.org.au

Thanks to Christine Page, Partner and Accredited Specialist – Wills and Estates with David Landa Stewart Lawyers, for her assistance in composing this article.

‘We became mates’

When I saw the advert, I was married with two kids in primary school, and working shift work for the television station in Ballarat. I had some spare time, so I volunteered and was matched with Graeme Baldock. He was four years younger, had recently been diagnosed with MS, and was living at home with his wife and family.

I discovered that Graeme wasn’t a talker – and neither was I. During my first visit alone with him, I wondered what I’d gotten myself into! However, I’d made a commitment to visit. Over the months, I saw the MS, but I got to know Graeme the person. We talked, watched TV and laughed.

As the years passed, I followed Graeme from home to hospital to rehab, and eventually from nursing home to nursing home. He’d get around in an electric wheelchair, always too fast. You’d know when he’d been up to trouble because of the holes in the wall, from his wheelchair.

His health declined, he was confined to bed, and his memory wasn’t the best. The staff got him an exercise book so they could record who’d visited him and where he’d been between my visits. I’d arrive and ask Graeme what he’d been up to. He’d always reply, ‘Nothing,’ and I’d open the book and see he’d done more than I had.

Over the years, I came to know Graeme’s father, and he came to work to tell me that Graeme was in hospital and it wasn’t good. I went to see Graeme that night, thinking of all the years I’d been visiting him. Graeme’s eyes were firmly fixed on the ceiling and had little to no movement.

“You always have to be the centre of attention,” I said, and with that, he gave a small smile.

A week or so later, I returned and stayed for a couple of hours. His dad and I told stories about him, and now and again he’d respond with a smile.

Two days later, my mate lost his battle with MS. At 49, he was too young to die. I was honoured to be a pallbearer at his funeral. It’s been a rollercoaster of a journey but one I don’t hesitate to recommend. When you visit someone, even if you sit watching TV, you leave feeling so glad you’ve been. The sense of value and worth you leave with your friend is beyond measure.

Graeme’s passing has been hard, but the happy memories live on.
Volunteer opportunities

We are always looking for more volunteers, and here are some opportunities we’re aiming to fill right now:

**VICTORIA**
- Volunteers are required to support the MS shops in Daylesford, Fairfield, Geelong, Kew, Melton, Monbulk, and Waverley.
- Singing partners are required in Delahey, Footscray West, Watsonia and Williamstown.
- A literacy tutor is needed in Williamstown.
- An administration-support person is required in Benalla.
- A gardener is needed in Bendigo.
- Art-support volunteers are required in Balwyn, Noble Park, Wyndham Vale, and the Regent–Reservoir area.

**NSW–ACT**
- Volunteers are required to support the MS shop in Baulkham Hills, Sydney.
- Volunteers are needed in the ACT to visit people with MS, at least once a fortnight, either in the person’s home or in a residential facility.

If you are interested in any of these opportunities or any other volunteer role throughout our regions, please call MS Connect on 1800 042 138.

**Maree wins award**

It is highly likely that successful businessperson and philanthropist Sir Louis Pyke would consider Maree Thomson to be a worthy recipient of the annual award given in his name in order to reward an MS volunteer. After Sir Louis’s wife was diagnosed with MS, in 1957, he volunteered to raise funds for the MS Society of Victoria, and continued volunteering until his death, in 1988.

Maree, who lives in Melbourne, was diagnosed with MS in 1990 but can trace her symptoms back to 1978. In 2001, she became an MS Ambassador, and she has since delivered more than 90 speeches to groups that range from Rotary Clubs and church groups to groups of school children. She has also launched 24 Hour Mega Swim events and been active in publicising the annual MS Readathon.

“I’ve sourced many of the occasions myself,” she says. “The reason I source them is that I know I can make a difference, because there’s always someone who knows someone with MS. Many times, people have told me that after hearing me speak, they’ve been able to talk about MS to the person they know. This can especially be helpful if the person is newly diagnosed.”

Maree says she was overwhelmed to receive the award. “It’s such an honour; I almost cried. I believe if you’ve been thrown a curve ball by life, you catch it and decide what to do with it. In my case, I decided to make the most of every moment.”

Sir Louis would be proud.

**Deakin backyard blitz**

Our ACT office has been ‘adopted’ by the ATO, and the result has been a much needed makeover to the garden.

Australian Taxation Office employees held fundraisers and collected donations of money and equipment before arriving at the Deakin premises of MS Australia – ACT/NSW/VIC, on 2 March.

More than 20 volunteers pressure-washed brickwork, mowed lawns, cleared weeds, re-planted flower beds, spread mulch and installed a new drip-irrigation system. Anthony Marchese was among the people who volunteered their time. “My involvement in the backyard blitz came about because of my membership of the ATO Canberra community group,” Anthony explains.

“The charter of this group is to help Canberra-based charities. As a person with MS, I’d been to the Deakin office a few times, and I was aware that the garden needed a big clean-up. I got in touch with other ATO staff members who are keen gardeners, and it all started from there. It was great to see the camaraderie of the ATO staff members who care about their community and donated their time for a good cause.”

As a result of their hard work, the garden looks fresh and tidy. Thanks, ATO! ■
‘I’ve met some magical people.’

Canberra resident Sue Goldberg says she gets a great deal of satisfaction from providing support to her peers.

I was diagnosed with MS 21 years ago. After about four years of Relapsing-remitting MS, I moved to secondary progressive, and 15 years ago, I was forced to give up work. At the time, I was a policy analyst in the disability area. I can laugh now, but back then, I wasn’t ready to leave the workforce. So much of who you are is what you do, and I had to reinvent myself. I replaced paid work with voluntary work, and joined Lifeline. In 2010, I realised it was time I gave back to the MS community, so I trained to be a Peer Support Volunteer.

I wish the program had been in place when I was newly diagnosed, because MS can be an isolating illness. I didn’t want to bother my nearest and dearest, and there was no one else I could talk to. If I’d had peer support, I wouldn’t have felt as alone.

By the time I became a Peer Support Volunteer, I’d come to terms with my MS. I’ve met some magical people via the phone. I’ve also enjoyed networking with other volunteers. It’s great meeting other people and finding out how they’ve come to terms with their MS and what they do to get the most out of life.

If you’re offered the chance to become a volunteer, grab it; volunteering is incredibly rewarding.

Melbourne mums enjoy a chat

When her son was a toddler, Melissa Katz wanted to spend time with other mothers who had MS. “There was no group in the northern suburbs of Melbourne, so when Jack was about three, I created one,” Melissa recalls. That was three years ago, and although Jack is now at school, Melissa continues to facilitate the MS Peer Support Playgroup, which meets fortnightly during school term at the Livingstone Community Centre, located in Ivanhoe.

“We have about six parents and eight kids. The room we use at the community centre is set up for playgroups so the children can play and the mums can relax.” Melissa wants to encourage other young mothers with MS to join. “We’re all in the same situation, so you can talk about your MS.”

To join, email Gayle Homann, Peer Support Leader with MS Australia – ACT/NSW/VIC, at gayle.homann@msaustralia.org.au or call MS Connect 1800 042 138.

Jasmin graduates

Jasmin Zaharijevski, a Peer Support Volunteer, graduated from the 2012 Leadership Plus Program conducted by RMIT University. The program has been designed for people of all abilities, and the purpose of it is to equip participants to become leaders across all sectors of society, including business, government, local communities and the disability sector. MS Australia – ACT/NSW/VIC sponsored Jasmin to attend the course.

“The program was inspiring,” Jasmin says. “I intend continuing to volunteer to help other people with MS.”

Good to talk

As much as they want to, friends and family can’t understand what it feels like to be diagnosed with MS, according to Peer Support Volunteer Jackie Zerafa.

Jackie, 32, is expecting her second child in July and is busy balancing three days a week working, in the marketing department of a large company, with her two-year-old son and two stepchildren, who are 15 and 17. “My whole life is a juggle, but there’s no other option than to balance everything, and my husband’s a great support,” Jackie says.

When she was diagnosed with MS, in December 2007, she didn’t know anyone else who had MS. “In hindsight, I could’ve benefited from joining the Peer Support Program. You can’t talk to friends and family in the same way, because they don’t know what you’re going through.”

By mid-2010, Jackie had come to terms with having MS to such an extent that she wanted to help other people do the same. She underwent training to become a Peer Support Volunteer, and is so glad she did.

“I’ve been very well matched, and I’ve found something in common with the people who have MS whom I’ve been providing peer support to. I put myself in their shoes and make sure they speak to me for as long as they want to. When you’re newly diagnosed, talking to other people who have MS is definitely a benefit.”

After her baby arrives, Jackie will put volunteering on hold for about six months, but she intends to pick it up again.

For more information about the Peer Support Program or to find a support group near you, please call MS Connect on 1800 042 138.
Support group profile

For a small town such as Kyabram, the Kyabram Peer Support Group is remarkably active. One of its facilitators, Denise Gemmill, explains that the town is located near Shepparton, in Victoria’s irrigation area.

How was the group established?
I was diagnosed with MS about 20 years ago, and I gave up work due to fatigue and mobility issues about five years ago. I have a friend who has MS, Anna Plummer. Anna’s sister Rosanna helped us organise a fashion parade a few years ago. Our intention had been to donate the money raised to MS research. However, at the event, on the spur of the moment, I asked any audience members who had MS whether they’d like to join us onstage for support. Three people came up, including Carol Tuhan, who later became our other group facilitator. As a result, we decided to use the funds to start this group and undertook group facilitation training through MS Australia – ACT/NSW/VIC.

How have you found the group helpful?
I’m lucky because I have a slow-moving form, which is in secondary-progressive stage now, but my mother had an aggressive MS and was soon confined to a wheelchair. After I was diagnosed, I didn’t tell anyone, but since the group, I’ve realised that if I’d opened up, I would’ve learnt about the services that are available.

Last year, I made a patchwork wall hanging and sent it into Blackburn to be exhibited in the MS Art Show. A lot of emotion went into the wall hanging, because it’s the story of my mother and my journeys. It includes a panel about peer support, because that’s been an important part of learning about self-help.

When does the group meet?
We meet on the first Wednesday of the month at the Kyabram Community Centre, after 5pm so our members who work can attend. About eight people turn up, but we have 12 regulars. We exchange information and have a laugh. Sometimes we have guest speakers, for example an MS nurse. On occasion, we’ll travel to a nearby town such as Echuca or Shepparton to attend another group’s meetings when that group has a speaker.

Are there any other activities?
We regularly have a dinner with our partners and carers, either at a club or in a member’s home. It’s important our partners and carers get together. We also have a few members who have a condition that’s similar to MS; for example, one member has an acquired brain injury, and he and his wife join in as well. Anna and I also helped out at an event that the local garden club held to raise money for the group. We were grateful for their help, and were also pleased to have the opportunity to raise awareness about MS.

Do you have any advice for people who are considering joining a support group?
Join so you have access to information and can enjoy the company of people who understand your condition. We’re there for support, a laugh, and a shoulder for anyone who needs it.

Electric Wheelchair Scooter
Portable in Car Boot

Quick Getaway!
No tools needed

Easy Rider
17 km range
Wide seat & retractable arm rest

Foldable
Airport Friendly
Total weight 30kg
Battery pack easily detached

1300 657 818
www.libertymobilityaids.com.au

Liberty portable mobility systems
Several drugs are used to treat MS symptoms, and one of them is botulinum toxin, commonly known by one of its trade names, Botox®.

Medical researchers have discovered that doses of botulinum toxin can be used to help people with multiple sclerosis by way of treating symptoms such as spasticity, tremor and shakes, and problems caused by an overactive bladder.

Botulinum toxin is derived from the bacterium Clostridium botulinum. It is a potent poison that was developed as a nerve gas before World War II. As a therapeutic drug, it works by preventing nerve messages from being transmitted to muscles, thereby causing paralysis. When it is administered via an injection, it can be used on individual muscles to prevent the nerve messages that cause spasticity and spasm from being transmitted to the muscles.

It is commonly used in cosmetic surgery and in treatment of medical conditions such as muscle spasticity in cerebral palsy.

It is not a cure for medical conditions, and the patient can require ongoing administration of it. Botox has been registered in Australia since 1995 for treatment of focal-limb spasticity in adults. (This condition is when spasticity is localised to a specific muscle.)

Botox use, however, has been extended to treatment of bladder symptoms in people with MS, and following the results of recent clinical trials, its use has the potential for treating tremor in people with MS.

Treating MS tremors

Last year, a research team at The Royal Melbourne Hospital released a report that included the finding that Botox caused significant reduction of shaking in the arms and hands of the study participants, all of whom had MS.

The scientists studied 23 people who had MS and for three months gave them injections of either botulinum-toxin type A or a saline placebo. For the next three months, the scientists administered the opposite treatment. They measured the tremor severity and the participants’ ability to write and draw before, during and after receiving the treatments. They also assessed the effects by producing video recordings every six weeks, for six months.

According to the results of the clinical trial, which were published in the 3 July 2012 issue of Neurology, Botox can lead to improvement in shaking or tremors in the arms and hands of people with MS. The two symptoms are common but under-recognised traits of the condition.

Royal Melbourne Hospital neurologist and study author Dr Anneke van der Walt says, “Our study found that people saw significant improvement in tremor severity, writing and drawing at six weeks and three months after the botulinum toxin treatment compared to after the placebo.

“In tremor severity, the participants improved an average of two points on a 10-point scale, bringing their tremor from moderate to mild. In writing and drawing, participants improved by an average of one point on a 10-point scale.”
“These findings support a new way to approach arm tremors and shakes related to MS where there is currently little treatment available and it also sets the framework for larger studies.”

Dr van der Walt adds that while the number of patients involved in the trial was small, the effects could potentially be life changing for many people with MS.

However, despite the fact that the results of this clinical trial are suggestive that Botox is beneficial in treatment of tremor, this effect is not as yet specifically covered under either the Therapeutic Goods Administration (TGA) or the Pharmaceutical Benefits Scheme (PBS) in relation to use of the drug.

**Over-active bladder**

Bladder problems can affect about 75 percent of people who have MS, and botulinum toxin is used to treat symptoms in people who have neurogenic detrusor overactivity, or an overactive bladder.

The drug is generally offered to people whose existing treatments, such as anticholinergics, have failed. Anticholinergics work by blocking signals between neurons and signals from nerves to muscles, thereby stopping the nerves from activating the muscles.

When botulinum toxin is used to treat bladder symptoms, it is injected into the bladder’s overactive muscle, whereby it aids bladder relaxation and leads to reduction of both urinary frequency (needing to urinate more often than normal) and urinary urgency (being unable to ‘hold on’).

Although its effect can be that the person with MS stops having to dash to the toilet, some people will still have to self-catheterise. The reason is that when the drug causes the bladder to relax, the bladder might not become completely empty. Urine retention can cause problems such as increased risk of infection.

It is interesting to note that the United Kingdom’s MS Society funded some of the early research into using Botox for bladder control because neurogenic detrusor overactivity can severely affect the quality of life of people who have MS.

In Australia, in March 2012, in the wake of international clinical trials in which Botox was used to treat urinary incontinence (UI), the TGA approved use of the drug for indication of UI resulting from spinal-cord injury and indication of MS.

In July 2012, the Pharmaceutical Benefits Advisory Committee (PBAC) deferred Botox’s listing under the Pharmaceutical Benefits Scheme (PBS) for treatment of UI. The drug company that produces Botox, Allergan, responded by announcing it was committed to working with the PBAC to ensure that the drug be listed under the PBS at the earliest opportunity. MS Australia and MS Australia – ACT/NSW/VIC supported the PBS submission.

* Two forms of botulinum toxin are registered for medical use in Australia: Botox® and Dysport®.

www.msaustralia.org.au/actnswvic
Pensions and other supplements

Sorting out your entitlements can be confusing, so in an ongoing series, we take a look at allowances that are available, starting with an overview of some payments you might be eligible for if you have a disability.

The Australian Government’s Department of Human Services delivers payments and services for Medicare, Centrelink, Child Support and CRS Australia, the last-mentioned of which provides jobs for people who have a disability.

In this article, we take a look at payments and services for people who:
• are unable to work because of a disability, an illness or an injury
• are temporarily unable to work or study because of a medical condition
• have a disability or are ill or injured but are able to do some work, study, training or volunteering if they have some extra help.

If you meet any of these criteria, you might be eligible for one or more of the following payments.

Disability Support Pension
Paid fortnightly, the DSP is granted if you have a condition that is physical, intellectual or psychiatric and causes you to be unable to work. It is also granted to people who are permanently blind. You can also receive a Pensioner Concession Card with this payment.

To assess your eligibility for the DSP, Centrelink requires a report from your doctor or specialist about your disability, injury or illness. You might also need to have a Job Capacity Assessment, which is a way of finding out whether you can work, how much work you can do and how much help you need in order to find and keep a job.

If you start work, you might still be able to receive the DSP, depending on the hours you work and the amount you earn. You will also need to meet the Income and Assets Test.

Newstart Allowance
You might be eligible for the Newstart Allowance if you are:
• 22 or older, and
• younger than Age Pension age, and
• looking for paid work, and
• prepared to enter into an Employment Pathway Plan and meet activity-test requirements, and
• not involved in industrial action.

Maximum fortnightly payment if you are:

<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single, no children</td>
<td>$497.00</td>
</tr>
<tr>
<td>Single, with a dependent child or children</td>
<td>$537.80</td>
</tr>
<tr>
<td>Single, aged 60 or over, after nine continuous months on payment</td>
<td>$537.80</td>
</tr>
<tr>
<td>Partnered (each)</td>
<td>$448.70</td>
</tr>
<tr>
<td>Single principal carer granted exemption for foster caring / relative (non-parent) caring under a court order / home schooling / distance education / large family</td>
<td>$683.50</td>
</tr>
</tbody>
</table>

Before you receive payments, you need to enter into and sign an Employment Pathway Plan, which is an outline of the activities you agree to undertake while you are looking for work, so you have the best chance of getting a job.

Also, to keep receiving the allowance, you need to participate in activities to increase your chances of finding work. This participation is called meeting the activity-test requirements. These requirements usually mean you need to apply for jobs, to train or study or to work part time. In special circumstances, however, you might be able to receive a short-term exemption from the activity test.

In addition, if you are 55 or older, the activity-test requirements are more flexible.

Like the DSP, this allowance is income and asset tested. For more information, go to www.humanservices.gov.au/customer/services/centrelink/newstart-allowance

Mobility Allowance
If you can’t use public transport without having substantial assistance, this allowance is for helping you meet your transport costs so you can participate in approved activities. These activities include job seeking or any combination of paid employment, voluntary work, vocational training, and training in independent living or life skills.

This allowance is not taxable, and you don’t need to be receiving any other government payments to qualify for it.
There are two rates of payment which is made as follows:

<table>
<thead>
<tr>
<th>Payment rate per fortnight</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Standard rate</td>
<td>$87.00</td>
</tr>
<tr>
<td>Higher rate</td>
<td>$121.80</td>
</tr>
</tbody>
</table>

You do not have to meet income or assets tests to qualify for the Mobility Allowance. For more information, go to www.humanservices.gov.au/customer/services/centrelink/mobility-allowance

**Sickness Allowance**

This is a payment for people who are employed or self-employed and who temporarily can’t work or study because of an injury or illness.

To be eligible for the Sickness Allowance, you must:
- be 22 or older and have a job, or
- be 22 or older and receiving ABSTUDY as a full-time student, or
- be 25 or older and receiving Austudy as a full-time student
- be younger than Age Pension age
- meet residency requirements.

You’ll need to provide a medical certificate from your doctor, and you must have work or study to return to when you are better; otherwise, you might be eligible for another Centrelink payment such as the Newstart Allowance.

Centrelink will review your circumstances regularly, and if yours or your family circumstances change, your payment might be affected.

<table>
<thead>
<tr>
<th>Maximum fortnightly payment if you are:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Single and 22 or older and you have no children</td>
<td>$492.60</td>
</tr>
<tr>
<td>Single and 22 or older and you have a dependent child (or children)</td>
<td>$533.00</td>
</tr>
<tr>
<td>Single and 60 or older, after nine continuous months on the payment</td>
<td>$533.00</td>
</tr>
<tr>
<td>Partnered and younger than Age Pension age (each partner)</td>
<td>$444.70</td>
</tr>
</tbody>
</table>

The amount of Sickness Allowance you receive depends on both yours and your partner’s income and assets. For more information, go to www.humanservices.gov.au/customer/services/centrelink/sickness-allowance income or assets

**Income Support Bonus**

A tax-free payment is made twice a year to help people who are on certain income-support payments to prepare for unexpected living costs.

The Income Support Bonus started being paid in March 2013. You’ll automatically receive it with your next regular payment after 20 March and 20 September each year if you’re receiving one of the following payments on these two dates:
- Newstart Allowance
- Youth Allowance
- Parenting Payment Partnered
- Parenting Payment Single
- Sickness Allowance
- Special Benefit
- ABSTUDY Living Allowance
- Austudy
- Transitional Farm Family Payment
- Exceptional Circumstances Payment

If you qualified for the Income Support Bonus on 20 March 2013, you would have received:
- $105 if you’re single
- $87.50 if you’re partnered.

These amounts will be adjusted on 20 September and 20 March each year, in line with the Consumer Price Index (CPI). The bonus is a tax-free payment, and the amount you receive won’t be affected by how much you earn or how much your partner earns.

To check whether you’ve received the bonus, look at your Centrelink statement, which you can access through Centrelink Online Services or an Express Plus mobile app.

**Find out more**

To find out more and learn how to start the claiming process, visit the Department of Human Services website: humanservices.gov.au/disability, call 13 27 17 or visit a Service Centre.
Take charge of your health

Winter means long sleeves and less time outdoors, so be aware of the need to get some vitamin D.

According to studies, MS is generally more common the further you live from the equatorial zone, and this finding is suggestive of a link between exposure to sunlight, consequent lack of vitamin-D production and development of MS.

Some suggestion also exists that lower levels of vitamin D are associated with relapse rates; however, more research into that link is required. Meanwhile, it’s widely accepted that almost a third of Australians are deficient in vitamin D.

Vitamin D is essential for strong bones and muscles as well as overall health. A small amount is found in foods such as salmon, eggs and some types of mushroom. Without a doubt, the best source is from the sun’s ultraviolet (UV) radiation, which is also unfortunately linked with skin cancer.

Gentle sunbathing

During summer, you should expose your hands, face and arms to sunlight for just a few minutes on most days but not during the middle of the day, when the level of UV radiation is high.

In winter, however, in NSW, the ACT and Victoria, your vitamin levels can drop. The recommended ‘dose’ of sunlight is about 20 minutes a day, on your exposed face, arms and hands or the equivalent area. This amount of exposure to sunlight is especially important for people who are confined indoors because they have a disability and/or work in an office.

Try spending some time sitting in your garden, or spend your lunchtime outdoors. Also, you will lift your spirits if you go for a walk in the sun or take a book or newspaper to a park and stretch out on a blanket. If you are active, organise a game of tennis with a friend or grab the kids and head to the beach to fly a kite.

If you’re concerned about your vitamin-D level, seek advice from your doctor; he or she will also be able to advise you about a vitamin-D supplement if you need one.

In helping to address the healthcare needs of people with Multiple Sclerosis (MS) living in South Eastern Sydney and Illawarra Local Health Districts, the SESLHD has opened a MS Clinic at Prince of Wales Hospital (POWh).

The MS Clinic is dedicated to the diagnosis and long-term care of patients with MS and related disorders, and utilises the extensive multidisciplinary services available at POWH.

The MS Clinic is run under the direction of A/Prof Arun Krishnan, Consultant Neurologist, Prince of Wales Hospital who has a special interest in Multiple Sclerosis and is currently involved in related research.

Contact details:
Institute of Neurological Sciences
Prince of Wales Hospital
Level 2 High Street Entrance
Randwick NSW 2031

Fax all referrals to A/Prof Arun Krishnan: (02) 9382 2428

For appointments phone: (02) 9382 2414

All patients are bulk billed.

Low waiting times.

Email: Christine.Cormack@sesiahs.health.nsw.gov.au

Once a booking is made, patients will be sent a letter with appointment details.
Spotlight on: MS organisations

One man’s battle with MS led to the establishment of an MS society in Australia. Today, however, confusion can arise because there are several Australian MS organisations, so here is a guide to them.

When Ron Phillips was diagnosed with MS, in 1956, he must have been relieved. Born in Grafton, NSW in 1908, he joined the Royal Australian Navy when he was 13.

In 1939, at the start of World War II, he was appointed Lieutenant and Third Assistant to the Engineer Manager at Sydney’s dockyards, where he worked day and night converting merchant ships to fighting ships and repairing war ships. He found the position to be stressful, and when he started experiencing double vision, he put it down to stress, and pressed on.

In July 1940, Ron was appointed to HMAS Australia. He joined the ship in England as a Lieutenant-Commander and was engaged in active service until 1944. He was then appointed to HMAS Adelaide as Acting Commander and a few months later was promoted to Commander. When the war ended, in 1945, he was Base Engineer Officer, based in Darwin.

During those years, Ron experienced more episodes of double vision, along with loss of balance and spasmodic muscle failure in his legs. Unfortunately, these symptoms were the trigger for rumours about his lack of sobriety.

Meanwhile, in February 1956, John Godfrey, whose wife Edith had MS, approached the United States’ National MS Society to request information so he could establish a society for helping Australians who had MS.

That same year, Ron Phillips was diagnosed with MS, and in December, John organised a public meeting in order for people who were interested in forming an MS society in Australia to attend.

When Ron was ‘invalided’ out of the Australian Navy, in January 1957, he became one of the founding members of the Australian MS Society and worked tirelessly for it until his death, in 1966; in fact, for a decade, the society’s first office was located in his home.

The Australian MS Society was only the fourth MS society to be established in the world, only eight years after the first society was founded, in New York.

During the 1960s, Ron’s son-in-law Arthur Cockburn continued to develop the Australian MS Society in NSW and was one of the people who worked hard to form a national body.

The national body was established in 1972, and as a result of the National MS Society of Australia’s formation, the NSW society changed its name to the Multiple Sclerosis Society of NSW.

Over time, societies were established in other Australian states; the Victorian organisation, for example, was incorporated as a company in 1972, and a school teacher, John Foley, was appointed its Executive Director. He worked alongside a business leader, Louis Pyke, to pioneer funding programs, and together they were the driving force behind converting a small self-help group to a respected non-profit service agency. Later, Louis became Sir Louis Pyke when he was knighted for services to people who had MS.

Today, various organisations exist to serve people who have MS, in several ways.

**MS Australia – ACT/NSW/VIC**

Incorporated as MS Limited, this organisation is the result of the merging of the MS societies of NSW and Victoria, and later, the ACT.

According to its mission statement, the organisation exists “to minimise the impact of multiple sclerosis on individuals, their families, carers and the community while working to improve treatments for the disease and accelerating research to seek a cure.”

In order to do meet its mission imperatives, the organisation provides specialist programs to approximately 11,000 people who have MS, as well as to their families, carers, friends and health-care professionals. It also hosts educational events, runs the phone information service MS Connect, provides an employment service, publishes *Intouch* magazine as well as brochures and information sheets, and oversees a comprehensive website.

The organisation raises funds to finance these services by staging iconic events such as the MS Sydney to the Gong Ride and the MS Walk and Fun Run. It has offices in Sydney,
Melbourne and Canberra as well as in several rural and regional towns and cities. It is overseen by a Board of Directors, and its Chief Executive Officer (CEO) is Robyn Hunter.

**MS Australia**

MS Australia (MSA) is the national body and has its own Board of directors, who are representatives of the Boards of the state MS societies and of MS Australia – ACT/NSW/VIC. In June 2012, the MSA Board adopted a business plan in order to become a stronger organisation and peak body for the state-based MS organisations. Its aim is to provide leadership in advocacy and collaborative relationships between the state members, especially in light of current broad national issues such as the National Disability Insurance Scheme.

The Board has appointed a national communications manager, a national social media coordinator, and a policy and advocacy manager. The organisation is led by Debra Cerasa, who became its CEO in early 2013.

MSA is funded via contributions from each of the state organisations, and accepts direct donations and bequests.

**MS Research Australia**

The first medical-research grant known to have been made was by Ron Phillips’s Australian MS Society, in 1963. Thereafter, for the next 30 years, each state MS society contributed small amounts to medical researchers in the societies’ states in an uncoordinated way.

In 1983, the National MS Research Foundation was established under the leadership of John Studdy, and sought donations from the state MS societies and donors in order to fund research. However, by 2003, the research funding had been halved, whereby the NMSRF was re-constituted as MS Research Australia (MSRA). As MS Australia’s research arm, it had a mission to raise funds from all sources and administer research grants.

This independent national MS-research initiative was...
Get involved

For an annual-membership fee of $22, you can join Multiple Sclerosis Limited (MSL), which is operated as MS Australia – ACT/NSW/VIC.

“It’s open to people with MS and anyone else who has an interest,” says the organisation’s CEO Robyn Hunter. “When you’re a member, you have the opportunity to increase your knowledge and make a difference.”

Member benefits include:

• subscription to Intouch (if you don’t already subscribe to the magazine)
• access to the MS Australia – ACT/NSW/VIC library and information services
• voting rights and attendance at the annual general meeting (AGM) and special meetings
• receipt of the annual reports.

For the details about how to join, go to www.mssociety.org.au/msl-membership.asp

MS International Federation

Australian MS organisations are part of the MS International Federation (MSIF). Based in London, it collects information that is developed by MS experts worldwide, publishes a magazine entitled MS in Focus, and coordinates the annual World MS Day. Go to www.msif.org/language_choice.html

State MS societies

The societies in the other Australian states operate independently, although they contribute financially to the national body, MS Australia, and to MSRA.

The state organisations are as follows:

• MS Australia – ACT/NSW/VIC (Multiple Sclerosis Limited)
• The Multiple Sclerosis Society of Western Australia (Inc.)
• Multiple Sclerosis Society of Queensland
• The Multiple Sclerosis Society of South Australia and Northern Territory Incorporated
• The Multiple Sclerosis Society of Tasmania

MS Advisory Council and MS Advisory Board

In the late 1980s, a council of People with MS (PwMS) was formed in each state, and the councils had as their national body the Australian Council of PwMS. Over time, the councils evolved additional organisations, which are called the MS Advisory Council (MSAC).

The MSAC was formed in Victoria in 2000 in order to advise MS Australia – ACT/NSW/VIC. It comprises people who have MS and provides the organisation’s board and senior managers with information about the MS community’s needs.

Andrew White is the chair of the MS Advisory Council Victoria. After an earlier NSW chapter failed, the council was re-formed in November 2012, and is chaired by Mike Hemmingway.

For more details, visit www.msac.org.au

In the ACT, the MS Advisory Board was established in 2008, when the local society merged with the MS organisations in Victoria and NSW. The Advisory Board reports to the MS Australia – ACT/NSW/VIC Board via the minutes of the Advisory Board’s meetings. Its members include people who have MS, a carer, and an academic who is involved in MS research. Two of its representatives also sit on the MS Australia – ACT/NSW/VIC Board.

The role of the MS Advisory Board is to represent the interests of people who have MS who live in the ACT or south-eastern NSW and to support the regional manager.

incorporated in 2004, and its operations were begun with Jeremy Wright as its founding Chief Executive. It was based in the Philips MS Centre, in the northern Sydney suburb of Chatswood, until late 2012, when it was relocated to North Sydney premises it shares with both MS Australia – ACT/NSW/VIC and MS Australia. It is funded via contributions from each state MS organisation.

By way of the efforts of a small team, MSRA has developed national research partnerships with more than 25 Australian research institutes and has built a major national fundraising program. In 2012, it raised $4.7 million.

MSRA has also supported a community fundraising initiative involving people with MS fundraising for research. Originally called Foundation 5 Million (F5M), a name that reflected its aim, it now has raised funds of almost $7 million and has been renamed F5m+.
Whether it’s an activity you do alone or something that requires you to join a group, a hobby can be just as important as physical exercise in maintaining wellbeing for a person with MS.

“A hobby or passion can add joy and meaning to life, and reduce the focus on the hassles of daily life,” says Margaret De Judicibus, a Melbourne-based clinical psychologist who specialises in working with people who have MS.

Also, a hobby – especially one through which you engage your mind and have to learn new skills or process information – can lead to a reduction in the impact of MS on brain functioning, according to Wendy Longley, Senior Clinical Neuropsychologist with MS Australia – ACT/NSW/VIC.

“According to research, mentally challenging activities such as reading, playing a musical instrument, building a model, sculpting, painting, drawing, designing a website and writing poetry are linked to better cognitive function,” Wendy says. “These activities can also lead to a lessening of the everyday-function effects of any structural brain changes.”

The term that medical scientists use to define a hobby through which you exercise your brain is ‘intellectual enrichment’, and the conclusion of researchers who recently published a study was that “intellectual enrichment protects Secondary progressive MS patients from cognitive impairment”.

Although maintenance of brain function is a wonderful motivating factor for engaging in a hobby, several more-immediate rewards can be gained from having a hobby.

Many people seek satisfaction and social engagement from their work; however, you probably have creativity you cannot express through your job or, if you have left the workforce, your day-to-day life. You might also find that the bonds of your friendship with your work colleagues are fragile outside your place of employment, because ‘the job’ is the main thing you have in common.

“A hobby is usually an activity done by choice rather than one that’s necessary for earning a living or maintaining life,” Margaret says. “Even if there’s a cross-over between choice and necessity – such as in the case of cooking or gardening – you engage in the hobby enthusiastically and passionately and gain a sense of achievement.”

Expand your network

By pursuing your hobby, you are likely to come into contact with kindred spirits you have something in common with. By building a relationship with these people, you gain a secondary benefit. “When people expand their social network by joining a club, an interest group or a community group and they share the activity with other people, they have more topics of conversation to discuss with their family and friends,” Margaret asserts.

In pursuing an activity you gain pleasure from, you can also enhance your mood. Margaret explains that ‘behavioural activation’ is an important component in classic Cognitive Behavioural Therapy (CBT) for treating depression. “It works! There’s usually a focus on two aspects of activities: the ones simply for pleasure and the ones you gain a sense of achievement from. Engaging in a hobby may bring both benefits.”

Margaret understands that if you experience fatigue, you might be tempted to stop pursuing the hobby. “Due to fatigue, people can be discouraged from getting started on the activity. If this is the case for you, you might find it helpful to schedule a time in your diary to start the hobby and to opt for the time of day at which your energy level is higher.”

Although Margaret urges you to return to your hobby as soon as possible, she takes a cautionary approach. “Be realistic. You might be frustrated if you try to regain a passion for something that’s no longer suited to your physical capabilities – but look for an alternative, related activity.”

For example, if you are no longer able to play a musical instrument but are still passionate about music, consider studying the lives of the great composers.
More reasons to have a hobby

Time for you A hobby that no one else has to be involved in can be a pleasure you can give yourself whenever you want.

A relaxation aid When you engage in pleasurable activities, you find it easier to unwind and lift your mood.

A pleasure for life If you love doing something, health permitting, you can do it into your old age.

An ongoing gift By engaging in a hobby such as cooking, card making, quilting or gardening, you are able to give your creations to other people. Some hobbies can even lead to a small income stream. For example, a painter might be able to sell his or her paintings, and a gardener might find an outlet for the plants, seed or vegetables he or she grows.

Reconnection with your talents Perhaps when you were at school you enjoyed drawing, were a whiz at woodwork or loved building model aeroplanes. Consider rediscovering that talent.

Need inspiration? For ideas for hobbies or interests you can pursue, google your local community college; most community colleges have adult-education and ’lifestyle’ courses. Go to www.cca.edu.au

Preserving memories

Photography has been an important creative outlet for Robyn Bressington ever since she was a child, but in recent years, she has been using the camera to compensate for her failing memory.

“When I see something, I can’t always keep the memory, so I take a photo,” she says. “In that way, I can have the memory and share it with other people.”

Robyn was diagnosed with MS in 1990 but was displaying symptoms a decade earlier while busy working as a teacher and school principal who specialised in educating adolescents who had extreme behavioural problems.

As a result of the MS, she has been left with balance problems and mild mobility issues as well as some difficulties in cognitive and executive functioning. "I’m a positive person, and I don’t believe that anything is beyond me, so I just go for it.”

As a result of this attitude, she is able to combine her love of photography with her interest in wildlife. Now retired, she volunteers at Sydney’s Taronga Zoo once a week, collecting animal-behaviour data that the keepers use.

“I watch an animal for two hours, taking notes on its activities, and I always have my camera with me. I can spend hours at my computer, cropping photos and adjusting the light in my shots – I really enjoy it.”

Her husband Ron shares her interest in wildlife, and they have travelled the world as research-project volunteers. They have studied polar bears in Canada, lions in South Africa and pandas in China, and, thanks to a Go for Gold Scholarship that Robyn was awarded in 2012, they have spent time with orang-utans in Borneo.

Because of the scholarship, Robyn was able to join a 12-night tour of Tanjung Putting National Park, located in Borneo, in central Indonesia, guided by a professional photographer. “There were five other photographers on the trip, and I learnt a lot,” she says.

The Bressingtons extended their ‘orang-utan tour’ to seven weeks, and visited other parks. “I took 4,000 photographs,” Robyn enthuses. “Orang-utans are close to us genetically, and their environment is threatened. I selected some photos and sent them to a friend, who used them in her classroom to show the students what a rainforest is really like.”

Go for Gold Scholarships

You can pursue your hobbies via a Go for Gold Scholarship. The scholarships are open to any person who has MS and is a registered client of MS Australia – ACT/NSW/VIC. Applications will be received up to and including Friday, 5 July 2013. For more information go to www.mssociety.org.au/go-for-gold.asp or call MS Connect on 1800 042 138.

“People with MS whose mobility is reduced might have limited options for hobbies,” Margaret says. “Rather than simply watch whatever comes on TV, you can read about the history of the cinema, seek out specific films, and talk about interesting aspects of the films.”

Margaret also has a suggestion for people who enjoy reading but find it hard to read long chapters. “I recommend the books by Ian McCall-Smith, especially the 44 Scotland Street series, which has short chapters.”
Gone fishing

George Katalinic first went fishing in the Croatian section of the River Danube. At age three he was a mere minnow, but he was hooked. “I love my water,” he laughs. “It gives my life an extra dimension.”

Swimming and dancing were also favourite pastimes, but as a result of a series of back operations and an MS diagnosis in 2005 that was followed by severe anxiety attacks, the two pleasures were taken away. Fishing, however, has remained one of his great joys, as are his four daughters and three granddaughters.

“I go fishing every chance I get. When I’m fishing, I forget about everything. I still have pain, but my brain overrides it. Fishing makes me feel brand new again.”

George credits fishing for his being able to learn to manage the overwhelming anxiety that was engulfing him a few years earlier.

“Once you start feeling sorry for yourself, you go downhill,” he explains. “I gave up swimming because I was afraid I’d drown, and I stopped fishing. My psychologist encouraged me to fish again, and it helped me to deal with the anxiety.”

George, who divorced in 2000, also gains a much valued social connection. For a decade, he’s been a member of the Ramsgate RSL Fishing Club, in southern Sydney. Once a month, he joins 10 members on a charter boat for a day of deep-sea fishing. “I’ve always liked being a member of a fishing club because it’s a social thing.”

Over the years, George has made some good mates, and often goes fishing with them. “This week’s a good example: I went out deep-sea fishing with the club one day, and the next, I headed to Sussex Inlet with friends and fished for three days. Fishing relaxes me and makes me feel better; I’m so lucky to have it.”

George encourages other people with MS to find a passion. “That’s the beginning of dragging yourself out of that deep hole – it helps you to enjoy life,” he says.

Recipe for success

When former teacher-librarian Sandy Koutalis was no longer able to chop vegetables or stir food in a frying pan, she converted her passion for cooking to a passion for writing recipes.

Diagnosed with MS at 26, Sandy, now 43, continued to work until the birth of her daughter, Lauren, six years ago. “I’d been great during my pregnancy, but I went downhill afterwards. I can’t drive, and my brain isn’t up to teaching.”

These days, Sandy uses a walking frame at home and a motorised wheelchair when she goes shopping. She also requires home help. Sandy’s husband James loves the food she serves, so Sandy instructed her helper about how to prepare the meals. “I had to simplify the recipes to make the process easier, and one day my helper suggested I write a cookbook because my recipes were simple but delicious.”

That inspired Sandy to collect her favourites into The KISS Method of Cooking, ‘KISS’ being the acronym for ‘Keep it simple, sweetheart’. She used the computer program Dragon Natural Speaking in order to type the manuscript, found a self-publishing company, and paid for the printing of 200 books.

“These recipes were based on my mother’s, which meant I had to convert the measurements from imperial to metric. I did the calculations in my head, and it was a terrific exercise. When I had a neurological assessment, they said I didn’t need to come back for a while.”

Aided by a 2012 Go for Gold Scholarship, Sandy recently published The Gluten-free Method of KISS Cooking. Although she isn’t coeliac, she prefers not to eat gluten, and she also enjoys the challenge of creating gluten-free recipes – so much so that the recipes in the book she’s now working on will be free of sugar, gluten and preservatives. “I watch TV cooking shows for inspiration; work the recipe out in my head; and refine the recipe via my home helper, who cooks it following my direction. Sometimes I have to cook a recipe a few times to get it perfect.”

A recent exercise involved transforming a recipe in order to celebrate Lauren’s sixth birthday. “I took a triple-layered chocolate cake and turned it into a gluten-free, sugar-free, triple-layered carob cake. It was a success – tasty and light.”

By creating recipes, Sandy is able to do something constructive at home. “I look forward to my time at the computer, and it’s an absolute buzz to get a box of books and see my name on the cover. I’ve found a way of combining two things I love: books and cooking. If you don’t have a hobby, look for something you love and see how you can pursue it.”

To buy Sandy’s recipe books, use the search function on the website www.vividpublishing.com.au.
WHAT'S NEW: MS-RELATED RESOURCES
Check out the latest resources, sourced by the MS Library.

E-books
The MS Library has a small collection of e-books available for loan, and you access them if you have a computer and are connected to the internet. E-books can be read on a computer, an e-reader or a smartphone. As is the case with lots of technology, not all e-books are compatible with all e-readers. The e-books we have purchased are not compatible with Kindles or some other proprietary e-readers, but they can be read on most other e-readers and on computers, iPads and many smartphones.

If you would like to access our e-book collection, please contact the MS Library.

NEW EDITIONS

Multiple sclerosis for dummies Second edition
by Kalb, R. et al.
John Wiley & Sons
This edition includes updated information, and its aims are to empower not only people with MS but their family and friends.

Multiple sclerosis: The questions you have, the answers you need Fifth edition
by Kalb, R. et al.
Demos Health
This edition includes answers to even more questions about managing and living well with MS.

WHAT nurses know... Multiple sclerosis: The answers you need from the people you trust
by Saunders, C.
Demos Health
The author of this book is a member of the International Organisation of MS Nurses and has been a nurse specialising in MS for 25 years. One issue that is emphasised throughout the book is the importance of professional partnerships in managing an illness such as MS.

The book includes stories of patients who are facing real challenges related to their illness. Each chapter is written in a conversational tone. The chapters include:

- MS: what is it?
- Treatments for MS
- MS symptoms and how we treat them
- Treating an exacerbation or relapse
- MS and complementary and alternative medicine
- MS and your family, your friends and your workplace
- Taking charge if you have a chronic disease.

Also included are a glossary and a list of resources that include relevant books, magazines and organisations.

MS in focus: Young people with MS
by the MS International Federation
Website: www.msif.org/en/resources/msif_resources/msif_publications/ms_in_focus/index.html

This issue is aimed at people between 18 and 35, and includes articles about things to consider when you are starting a family, pharmacological-treatment considerations for young people with MS, and how MS organisations throughout the world support young people who have MS.

Additional contents include:

- Transition to independence
- Self-image
- Relationships and disclosing MS
- Education
- Career issues
- Having a healthy lifestyle
- Children with MS
- Results of the ‘young people with MS’ survey.

It is possible to sign up for an email or print subscription to this high-quality magazine.

NMSS Blog
by individual contributors
Website: http://blog.nationalmssociety.org/

This blog, provided by the US National MS Society, includes posts from a variety of contributors, including people who have MS as well as MS researchers.

Posts include topics such as the experience of living with MS and news from research conferences, for example:

- Interesting falls I’ve had
- What triggers MS and MS attacks
- The importance of exercising our body and mind
- Emerging therapies from the American Academy of Neurology meeting
- Connecting via MS.

To borrow books or for assistance in accessing online resources, please call the MS Library in Blackburn, Victoria on (03) 9845 2809 or email library@msaustralia.org.au
Contact your local bookshop to buy copies of printed books.
GET READY TO RAISE MONEY IN AUGUST FOR THE 23,000 AUSTRALIANS WHO LIVE WITH MS

Lock these dates into your calendar:

**JUNE**
- June/July: MS Readathon website live
- June 3: School visits including LIVE webcast
- August 1-31: MS Readathon registrations open
- August 23: MS Readathon reading period

August 23: 60 Minutes for MS one day event

If you are a teacher and would like more information, please email us at 2013schoolvisit@msaustralia.org.au

For more information go to www.msreadathon.org.au