Parenting and MS
You and your family can thrive

Tim Ferguson explains why he revealed his MS
Ways to beat Christmas blues

GO FOR GOLD SCHOLARSHIPS
This year’s winners

FINANCIAL INFORMATION
Rebates for energy bills
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MS Australia – ACT/NSW/VIC is a not-for-profit organisation that has been supporting and helping people with multiple sclerosis (MS) since 1956. Through an extensive network of centres, branches, support groups and health services, the organisation provides specialist programs to people with MS, their families, carers, friends and healthcare professionals.  

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www.msaustralia.org.au/actnswvic
Welcome to the Summer 2013 issue of Intouch. As this year draws to a close, it’s fitting that I reflect on what an amazing year it’s been because it’s the year that the historic National Disability Insurance Scheme (NDIS) became a reality. Now, in the final weeks of 2013, we’re beginning to learn what a big difference the scheme is making to the lives of people with MS. Read Amanda Samek’s story on page 9 for just one example of a life that’s been changed for the better.

The introduction of the NDIS is also having a huge impact on our organisation, so this year has been very much about setting our strategic direction in order to take the organisation into the future in a financially strong and sustainable way. We want to ensure that our organisation remains a constant source of information, guidance and support from the time that people are diagnosed with MS through to the day they need help to live their lives, should that day come.

Of course, to remain of assistance to people with MS, we need strong streams of funding, so it’s timely that we close the year with our major fundraising event, the MS Sydney to the Gong Bike Ride. At the time of writing, almost $3.5 million had been raised from it. To stage an event as large as the Gong ride, we depend on volunteers who generously give up their Sunday. In fact, all our events and fundraising projects such as the MS Community Shops are dependent on the work of selfless people who donate their time to help people affected by MS. There are also hundreds of volunteers who personally assist people with MS by taking them to medical appointments or simply out for a cup of coffee. There are others who volunteer at our offices, doing everything from filing to weeding the garden. Whenever I hear what these people are doing, it warms my heart, so I want to thank them for their efforts.

I also want to thank our staff members for their hard work during the year. And finally, I wish you and your family a wonderful Christmas and a happy New Year.

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

It seems only a few months ago I was writing, “Wow! Can you believe how quickly this year has gone?” for the Summer 2012 issue of Intouch. Now I’m writing the editor’s note for the Summer 2013 issue, but it feels as though we’ve just had last year’s Christmas and New Year’s Eve – hard to fathom the fact they’re upon us again so soon.

Christmas is a family time of year, so the theme for this issue is, appropriately, ‘parenting and MS’. Both things entail myriad challenges, but I hope this issue contains a wealth of tips so the festive season is a happy time for all. Starting on page 13, advice about parenting is provided by Dr Sally Shaw, a psychologist and mother of two who’s living with MS, and Wendy Williams, a mother of six who’s also living with MS.

In the ‘Health and Wellness’ section, you’ll find an article entitled ‘Beat Christmas Blues’, which contains tips for how to manage fatigue, anxiety and depression so you can make the most of the festive season. Also, if you’re planning to make a few new-year’s resolutions, be sure to read the extract from Tim Ferguson’s new book, on page 34, and the article ‘Happy, Thanks to MS’, on page 36. I’m sure you’ll be able to draw inspiration from both.

On behalf of my Intouch colleagues, I wish you and your family a merry Christmas and a happy and healthy new year.

Toni Eatts
Editor

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For more information and to purchase tickets, visit www.msraffles.org.au or Freecall™ 1800 287 367
Readathon helps

I can clearly remember a lady coming to our Grade 6 class to talk about MS, the ‘Mystery Sleuth’ and the MS Readathon. I can even recall which classroom I was sitting in! That was 1986 and the first time I did the MS Readathon. Fast forward to 2008 and I was diagnosed with MS. Our children were young, so we decided not to tell them until I’d come to terms with it. Imagine my surprise when my children came home from school saying a lady had come to talk about MS and the MS Readathon. Coincidentally, my daughter had been chosen to demonstrate what it was like to have MS! That year, my children raised around $250. They were so excited that we used the opportunity to tell them about my MS. Like Samantha Keir (Intouch, Spring 2013), I wish I’d read more books.

Sarah Matthews
Ballarat, Vic

Life is strange

When I read Samantha’s letter about participating in the MS Readathon, I thought I’d explain that something similar had happened to me. I was doing respite-care work for people who had a disability and lived at home with their family. I did it for about 13 years, and while I was working, I was diagnosed with MS. It’s left me severely disabled, like some of the people I cared for, although none of them had MS. I just thought I’d share this story because I’ve found the coincidence uncanny.

Marion
NSW

Editor’s note: Samantha’s letter drew responses from several readers who had memories of their MS Readathon experience. Unfortunately, we have room for only one letter, but our thanks go to everyone who wrote in.

Insight into sex

I’d like to thank you for the article ‘Spotlight on: Sex and Intimacy’ (Intouch, Spring 2013) and the empowerment it brings. No doctor, specialist or friend has ever broached this topic with me – too delicate a subject, I guess. When I was diagnosed, I had problems with a tremor in my dominant hand, weakness on my left side so I couldn’t walk, incontinence, and fatigue. I learnt to live with the symptoms, using my mantra of ‘Accept what is’, and sex fell into that basket too. I have a happy disposition, and I continue to live a great life! But after reading the article, I can now look forward, with greater insight, about trying to have sex again. Woo-hoo!

Janice
Sydney, NSW

Write in to WIN!

Keep your feedback and stories coming in! Next issue’s theme will be ‘MS and emotional wellbeing’.

All readers who have their letter published will win an organic tea and chocolate indulgence pack.
Our AGM

The Annual General Meeting of Multiple Sclerosis Limited (MSL) which operates as MS Australia – ACT/NSW/VIC was held in Canberra on 23 October. One of the main agenda items was the proposed re-election of three board members. Our organisation has almost 600 members, and the numbers of votes were revealed at the meeting, whereby Sophie Langshaw, Peter Day and Chris Gillies were re-elected as directors of MSL.

The votes are itemised as follows:
- Sophie Langshaw: 92.4 per cent in favour; 7.6 per cent against
- Peter Day: 85.5 per cent in favour; 14.5 per cent against
- Chris Gillies: 84.1 per cent in favour; 15.9 per cent against.

For more information about the organisation's performance over the 2012–13 financial year, view the annual report and financial reports at www.mssociety.org.au/corporate-reports.asp.

Residential units improved

Refurbishments have been completed at our Williamstown, Watsonia and Lidcombe residential units, and residents say they’re thrilled with the results. The residents were especially pleased that they were able to choose their own paint colours, furniture and décor. We couldn’t have made the improvements without the generous donations of our supporters and also the hard work of many of our staff members. Thank you.

Gong ride a success

The 32nd annual MS Sydney to the Gong Bike Ride was held on Sunday, 3 November. It was a sold-out event and 10,000 cyclists took part, making it the biggest mass-participation event in the NSW cycling calendar and a major community fundraising event for MS Australia – ACT/NSW/VIC.

At the time that Intouch went to print, almost $3.5 million had been raised. This year, we were thrilled to have the University of Wollongong (UOW) on board as a Gold Sponsor. Adam Gilchrist, cricketing legend and UOW ambassador, joined Team UOW in the ride and gave media interviews, so coverage on all the major TV networks and several other outlets was ensured.

The day was sunny and hot, and the participants took either a 90-kilometre route from Sydney Park, in St Peters, or a 58-kilometre route that started in Engadine. They headed for Wollongong aided by a good tail wind. At the time of printing, the 215 member–strong SBS–BA team had raised $145,000, the most funds from a team effort.

Stephen Renkert, a member of the Electrotech team, raised an impressive $34,000, so he was the individual who raised the most funds. The award for the team that had the best costume went to Super Flys, who wowed the other riders with their superman costumes, and the ‘best uniform’ award went to the Bayer team.

These teams excelled this year, but we also want to acknowledge the following teams for their continuing inspirational support: Westpac, Soft Cogs, Thiess, Sylvania BMW Top Raisers, and Acton Building.

We’d also like to thank the 400 volunteers, NSW Police, the Ambulance Service of NSW, the St John Ambulance volunteers, the NSW Volunteer Rescue Association, NSW Roads and Maritime Services, Transport NSW and Sydney Trains, all of whom helped make the day such a huge success. Thanks are also owing to ABC Illawarra and WAVE FM, both of which broadcast live from the finish site; Festival Hire which provided equipment; and oOH! Outdoor Media, the Executive Channel, Media I and SBS for their advertising support.

To see all the highlights, go to www.msgongride.org.au
News from MSAC

By Mike Hemingway and Andrew White, Chairs, MS Advisory Council, NSW and Victoria

Being a parent who has MS is challenging – but then being a parent always is, whether you have MS or not; just because we have MS doesn’t mean we’ll have a break from the other issues.

Often, when parents are diagnosed with MS, their reaction is “Oh, no: what’ll I be able to do for my kids now?” Fortunately, most people who have MS can keep living as they did before they were diagnosed. However, certain parts of one’s life can have an impact on them over time. As always, it’s important we ask for help when we need to. Most people are happy to help when asked, especially given our challenges in relation to MS.

But what about the reaction of the kids themselves to the news about Mum or Dad? They’ll usually worry about what it really means. They might also be concerned that the parent will be viewed as being “different”, and they might want the parent to return to “normal”. My children were angry that I wasn’t an “ordinary” dad any more. They didn’t intend to be angry, but they didn’t understand what they were feeling. Changes in behaviour can be a sign that the children are feeling the stress of having MS as a ‘house guest’.

The best way to handle the situation is to keep talking with your kids. Explain, as best you can, that you’re not going anywhere and that you’ll still be there for them. Counsellors can be helpful, and MS Australia – ACT/NSW/VIC can assist as well. The organisation also has some excellent resources such as books for helping you explain MS to your children. It’s important you understand that you and your kids aren’t the only ones who have feelings such as these. As is so often the case with our kids, communication is the key.

It’s fitting, then, as the festive season approaches, that Andrew and I and our MSAC colleagues wish you and your family a Merry Christmas and a healthy and happy new year.

– Mike Hemingway

ECTRIMS conference

A contingent of Australians attended the conference of the European Committee for Treatment and Research in MS (ECTRIMS), which was held in Copenhagen, Denmark. Dr Elizabeth McDonald, Medical Director of MS Australia – ACT/NSW/VIC and chair of the MS Research Australia Social and Applied Research Subcommittee; Debra Cerasa, CEO of MS Australia; Dr Lisa Melton, Research Development Manager at MS Research Australia; and Professor Bill Carroll, chair of the MS Research Australia Research Management Council, were among the Australians who attended, along with numerous Australian neurologists and researchers.

The conference is the largest international MS conference, and more than 8,000 delegates attended this year’s. It features a range of MS researchers and specialists from throughout the world, so Australian researchers are afforded the opportunity to learn about the latest developments in MS research and to strengthen their contact with their international collaborators. The conference included ‘side meetings’, for example of the International Progressive MS Alliance and of the highly successful International MS Genetics Consortium, in which Australian researchers are very active contributors.

For Dr Melton’s reports from the conference, go to www.msra.org.au/news

Following the conference, Dr Elizabeth McDonald and Debra Cerasa attended the meeting of the MS International Federation, which took place in Berlin. The pair presented at a number of workshops during which they shared the Australian experience of caring for people who have MS and advocating on the people’s behalf.

Dogs help out

Assistance Dogs Australia is a small national charity through which labradors and golden retrievers are trained to help people who have a physical disability perform tasks they can find either difficult or impossible to complete. Assistance dogs can pick up dropped items, open and close doors, bark to alert their human counterpart or get the phone for the person if he or she is in trouble. Each Assistance Dog takes two years to train and costs about $27,000 but is placed with a person in need free of charge. If you’d like more information, please visit www.assistancedogs.org.au or call 1800 688 364.

msac

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Employment Support Service starts in Sydney

The members of the new MS Employment Support Service (ESS) team have settled into the Phillips MS Centre, in North Ryde, under the guidance of Stephen Jolly, Manager, and Joanne Airey, Senior Employment Support Consultant, Employment Support Service, MS Australia – ACT/NSW/VIC.

Stephen established the ESS in Victoria, and since 2010, it has helped more than 550 people who have MS to either obtain employment or remain employed. “To start, we’re focusing on metropolitan Sydney,” Stephen says. “We’ll meet people at North Ryde or at the Studdy MS Centre in Lidcombe, or anywhere else that’s convenient for them.”

Stephen is pleased that a number of Sydney people who have MS have already expressed interest in the ESS. “We’re following up on those people, and we’re also taking internal referrals from client-services staff members and working to establish external-referral pathways.”

So far, two Occupational Therapists, Ashleigh Haskins and Juliet Fifita, have been hired as Employment Support Consultants, and Jo Wazzi, an experienced administration person, has been appointed the Employment Support Officer. “More staff members will come on board as the service expands,” Stephen says. “It’s an exciting time.”

If you’re interested in learning more about the ESS, call MS Connect on 188 042 138.

Club paid for paint

Once again, we’re grateful to DOOLEYS Lidcombe Catholic Club for the generous support the club provides for people living with MS. The club donated almost $40,000 to cover the cost of repainting the residential unit located at the Studdy MS Centre in Lidcombe.

“They’ve been wonderful to us over the years,” says Cynthia Cameron, Manager, Partnerships, Trusts and Foundations for MS Australia – ACT/NSW/VIC. “Thanks to funding for the repainting of the residential unit, the club has done a lot to lift the spirits of the people who live in the unit or who go there for much needed respite.”

Julie Milsom, the club’s Community Relations Manager, dropped into the Studdy MS Centre to see the results of the donation, which the club made through the NSW clubs-grant scheme. While she was there, she was shown around by Meena Moti, Residential Team Leader, Lidcombe.

Roy Williams (pictured) has spent many years caring for his wife Audrey, who has MS. In August, Roy organised a concert at his retirement village in Bateau Bay, NSW. The afternoon of music, singing and monologues was attended by more than 100 people, and raised more than $1,000 for people living with MS. Claire Whyatt and Jen East, who are MS Nurses and Community Support Workers with MS Australia – ACT/NSW/VIC, attended along with David Galea, an MS Ambassador.
NDIS is underway

As the National Disability Insurance Scheme is starting to lead to changes in people’s lives, MS Australia – ACT/NSW/VIC is watching with interest.

More than 400 people affected by MS live in one of the two launch sites – the Hunter and Geelong areas – and our staff members continue to support clients to engage with the scheme. We’re also gathering the experiences of individuals such as Amanda Samek as they become NDIS participants.

Name: Amanda Samek
Age: 57
Diagnosed: 1993
Lives: Geelong

I was diagnosed with Relapsing-remitting MS, and for 15 years my MS was hardly noticeable, but four years ago it became secondary progressive and I’ve since gone rapidly downhill. I use a wheelchair; however, I’m still able to transfer to a walker, and I can walk 10 steps. I’ve been worried about how I’ll cope because I live alone. I had 90 minutes of housekeeping done once a week. I love my home, but I thought I’d have to go to an aged-care facility, and that put me in a dark place.

Some months ago, I got an infection and had to go to hospital. After that, I was sent to rehab, and while I was there, a social worker suggested I get involved in the NDIS. When I returned home, a person from the scheme came and visited me three times, but she said the NDIS couldn’t help me until March 2014. I didn’t know how I’d cope, but a friend, Debbie Haygarth, who’s also the coordinator for the Geelong MS Peer Support Group, said she’d ask on my behalf. Debbie and her partner, Joe McAuliffe, are amazing friends.

Next thing, I had a call from an NDIS person who said they’d fast track me. It’s been wonderful. I have a carer come in every morning for an hour to shower me and make my bed. Twice a week, she stays and does housework for 90 minutes. She dusts, irons, empties the dishwasher – anything I ask her to do.

About a year ago, I had to stop going to hydrotherapy because I couldn’t manage it by myself. Now, a carer takes me once a week. Under the scheme, I also got a new adjustable bed because there were times I couldn’t get out of my old bed. Once, I had to phone my son at 4am to come and help me because I was stuck, so it’s a relief to know that won’t happen again.

Under the NDIS, I’ve been given a smaller wheelchair to use indoors because my other wheelchair is so big that when I was in it, I hit walls and knocked over chairs. The scheme representatives have also said they’d get some decking put in so I can get into my backyard.

My world has been opened up, and I feel as though I have a future. There’ve been hiccups along the way, because everyone’s learning, but if we work together we’ll get through. I hope the NDIS is spread throughout Australia soon so other people can be helped. The NDIS team has been terrific, and I feel so much better.

New name

DisabilityCare Australia has been renamed due to a decision made by the new Federal Government. It will revert to the original name that was used by the Productivity Commission in the commission’s report entitled The National Disability Insurance Scheme (the ‘NDIS’), or it can be shortened and referred to as ‘the scheme’. The public-service organisation that manages and administers the scheme will be known as the National Disability Insurance Agency (the NDIA), which can be shortened to ‘the agency’.

NDIS UPDATE

www.msaustralia.org.au/actnswvic
New genes identified

Forty eight new genes involved in the risk of developing MS were identified in the findings of a study released in September. The landmark paper was published in the journal Nature Genetics and is the result of the largest study to date of the relationship between genetics and MS. The new genes that the researchers identified are in addition to 57 genes that researchers already know contribute to the risk of developing the disease.

The study was undertaken by the International MS Genetics Consortium, and Australian and New Zealand researchers were strongly involved in it. The researchers examined genes that are known to have had an immunological involvement in the MS of a group of 29,300 people and in 50,794 healthy individuals. Of those people, 1,800 came from Australia and New Zealand as part of the ANZgene consortium. The gene pattern and significance of the genes that were identified constitute more evidence that the relapsing-remitting phase of MS has an autoimmune component.

Also, substantial overlap exists in relation to genes that are known to be involved in other autoimmune diseases such as inflammatory-bowel disease, Crohn’s disease and coeliac disease.

As a result, we’ve gained a deeper understanding of the mechanisms common to the diseases, and researchers are able to accelerate progress for autoimmunity research in all the diseases.

Although researchers can’t yet use this information from the study to genetically test people who have MS, or their families, they could use it in future to predict people’s MS susceptibility.

Dr Matthew Miles, Chief Executive Officer of MS Research Australia, said, “This work is a huge contribution to our understanding of MS and will underpin intensified efforts to translate these genetic findings into new therapies for MS.” For more information, go to www.msra.org.au/study-uncovers-48-new-ms-genes

Australian appointed

One of Australia’s most prominent neurologists, Professor William Carroll, has been appointed to the highly prestigious position of First Vice President of the World Federation of Neurologists (WFN).

Professor Carroll has been an active member of the WFN for 12 years and has dedicated 15 years of his life to raising the profile of MS research. His dedication has been recognised in his receiving the John Studdy Award in 2011 and the Western Australian of the Year Award in 2012.

Professor Carroll has stated that his intention is to help both maintain and increase sustainable funding for the WFN.

Updated Atlas of MS

In October, the MS International Federation (MSIF) launched an update of the Atlas of MS whereby the occurrence of MS was shown to have increased by almost 10 per cent worldwide since 2008. It’s now estimated that 2.3 million people are living with MS.

The Atlas of MS is a collection of epidemiological information about MS, from throughout the world, and the information was first collated in 2008. MS Research Australia and MS Australia contributed data to both editions of the atlas. In the updated atlas, more information is provided about how MS is being diagnosed and treated globally.

Also, as a result of the research that went into the atlas, we have confirmation that overall, women are twice as likely as men to have MS; that in some countries, women are three times as likely to have the disease; and that up to 5 per cent of MS occurrence begins in childhood, before the person turns 18.

According to Peer Baneke, CEO of the MSIF, “With this new edition of the Atlas of MS, we now have a much clearer picture of where the gaps are and where improvements have been made in the battle to diagnose and treat this debilitating disease.” The Atlas of MS is at www.atlasofms.org
On 28 January 1994, when John Borovnik walked into Wisteria House, a drug and alcohol rehabilitation centre at Sydney’s Cumberland Hospital, he turned his life around. After being devastated as a child due to physical and sexual abuse, at age 14 he began using alcohol to numb his pain, and escalated to marijuana, amphetamines (speed) and cocaine. “It took me till I was 32 to realise I had a problem,” he admits. “Other people can see it, but if you can’t, you can’t get better.”

During John’s stay at Wisteria House, one of the psychologists drew a circle on a whiteboard. “He said, ‘You can choose to break the circle and get better, or keep going as you are, and you might die.’ As a kid, I had it drummed into me I was hopeless. I thought everything was my fault and that I had no choice.” That ‘circle’ was the trigger for a ‘light-bulb moment’. “I’ve been clean and sober ever since.”

John kept working on his recovery and soon discovered he had a deep desire to help children who were facing the challenges he’d faced. He enrolled in a course for an associate diploma in social sciences and community welfare, and by June 1998, he was working as a child-protection worker in Mount Druitt, a tough Sydney suburb, for the then NSW Department of Community Services (DoCS). The following year, he was transferred to Katoomba, in the Blue Mountains. By then, he was a father of two young children: one of the reasons he was unable to ignore ‘red flags’ in what could have been a routine adoption case. On 8 July 1999, John made a phone call to a hospital in relation to the matter of Keli Lane, a single woman who was wanting to give her baby son up for adoption. “The more I dug, the more questions I had. I wanted justice for Tegan. No one knew she existed until I got the case.”

Despite his shaved head and tattoos, John strikes you as a gentle soul, but his manner belies his tenacity. His determination led to a six-year investigation; an inquest into Tegan Lane’s disappearance which began in 2005; one of Australia’s biggest searches for a missing person; in 2010, the conviction of Keli Lane, a former Australian water-polo player and physical-education teacher, on a charge of murdering Tegan; and a subsequent appeal against that conviction which was heard in July. (The result wasn’t known at the time of writing this article.)

For John, it’s been a long journey, complicated by his MS. As part of his sobriety strategy, John regularly cycled laps of Parramatta Park, walked the same circuit, and worked out. In 2001, he started finding he was suddenly getting tired at work. “I put it down to stress but it was the first symptom.”

In 2002, his marriage broke up, and in 2006, he was forced to quit DoCS due to a combination of fatigue, anxiety and depression. In May 2008, he was doing his usual circuit in Parramatta Park when he found he couldn’t cycle up a hill. “My legs were burning; later in the shower, I couldn’t feel the water on my head.” That night, he went to Westmead Hospital, and a few days later, he was diagnosed with Relapsing-remitting MS. “I was devastated, and I was given no information, so I searched online, found MS Connect and phoned them. They were fantastic.”

However, the MS has taken its toll. “It’s been aggressive. I’ve had a few relapses, and some mornings I’m too fatigued to get out of bed.” Most days he’s in pain, and many nights he can’t sleep. To manage the dark hours, he draws on the tools he learnt in rehab. “I say the Serenity Prayer on a daily basis: ‘God grant me the serenity to accept the things I cannot change, courage to change the things I can, and the wisdom to know the difference.’ I’m grateful for what I have, and I try to be aware of what I can do to make life better for someone else.”

It comes as no surprise, then, to learn that in July 2013, John attended court for Keli Lane’s appeal even though he was left fatigued for days afterwards. “A woman called me Tegan’s spiritual parent, and I felt that was appropriate. As a result of what happened to Tegan, there’ve been changes to the laws in relation to birth registration.” John has also ensured that Tegan will never be forgotten. He organised a plaque in memory of the baby, who within 48 hours of her birth had disappeared, for the NSW Homicide Victims’ Support Group to hang in Ebony House, where the relatives of murder victims go for respite. “If I was put on this earth to do this for Tegan, that’s great,” he says.

Would you like to share your story with other people living with MS?
Call the editor on (02) 8484 1316 or email intouch@msaustralia.org.au
I believe there’s been an advance with oral medications for MS – what’s happened?

— Ellen, Victoria

Yes, Aubagio (teriflunomide) and Tecfidera (dimethyl fumarate) are now available under the Pharmaceutical Benefits Scheme (PBS). During clinical trials in which people who have Relapsing–remitting MS were involved, both drugs were shown to cause a reduction in the frequency of relapses and a delay in progression. Tecfidera was also previously known as BG-12.

**Aubagio**

This drug is a film-coated oral tablet that’s taken once daily. It acts by interrupting the life cycle of specific types of white blood cell, called lymphocytes, which have a role in destruction of myelin, the protective sheath that surrounds nerve fibres and that aids efficient flow of nerve signals.

Aubagio works by causing a reduction in production of an enzyme – a type of protein – that lymphocytes require in order to divide and mature. As a result, the number of lymphocytes circulating in the blood and reaching the central nervous system is lowered, and in turn, damage to the nerve cells in the brain and spinal cord is reduced.

The most common side effects of Aubagio are nausea, elevated liver enzymes, diarrhoea, and hair thinning or loss. Less frequent effects are increased blood pressure and skin disorders. Rarely, some people develop liver or blood problems.

According to the results of animal studies, Aubagio can cause birth defects if used during pregnancy. It shouldn’t be taken by pregnant women or women of childbearing age who aren’t using effective birth control.

**Tecfidera**

This drug is taken as an oral capsule, and the recommended starting dose is 120 mg twice daily. After seven days, the dose can be increased to the recommended dose of 240 mg twice daily.

Tecfidera has been shown to have anti-inflammatory and neuro-protective properties. Medical researchers believe it works in MS patients by causing inhibition of immune cells, and it might have antioxidant properties through which the brain and spinal cord are protected from damage. During clinical trials, it’s been shown to cause a reduction in relapse rates and delay of progression of disability in people who have Relapsing–remitting MS.

In clinical trials, Tecfidera’s most common side effects were flushing, diarrhoea, nausea and abdominal pain. Side effects that were less common but more serious were gastrointestinal side effects that were more severe, effects on the kidneys and liver, and reduced ‘white blood cell’ counts. Although increased frequencies of infection weren’t noted during the clinical trials, it’s recommended that patients on Tecfidera have their ‘white blood cell’ count monitored at least every year.

Tecfidera hasn’t been tested in people younger than 18 or in women who are pregnant or breastfeeding. Seek advice if you are pregnant or planning to be pregnant.

MS Australia — ACT/NZW/VIC doesn’t recommend any specific disease-modifying treatment; please consult your neurologist.

This article has been reviewed by Dr Lisa Melton, Research Development Manager, MS Research Australia.
Although parenting can be challenging when you have MS, you and your family can thrive if you combine good communication with the correct information and support.

An MS diagnosis has a big impact on the person but also affects his or her family. Some children have to adjust to the idea that their mother or father has been diagnosed with MS at the same time as the parent and his or her spouse are also dealing with the disease. Meanwhile, other children are born after their mum and dad have been diagnosed, so their experience will be different. Either way, parents face similar issues in relation to living with MS while they’re raising their children.

Dr Sally Shaw is a Melbourne-based psychologist who mainly works with people who have MS. She herself was diagnosed with the disease in 2001 and is the mother of a four-year-old and a two-year-old. “I was diagnosed with MS after I’d been noticing a change in sensory perception and, on the left side of my body, numbness and tingling that lasted two weeks,” Sally explains. “At the time, I’d just begun my doctorate in health psychology, and I decided to focus my research on an area I was suddenly very interested in: how everyone copes differently with a diagnosis of MS. I’ve been very fortunate that my course of MS has been mild so far.”

Despite the fact that her MS has remained stable, Sally remains acutely aware of the challenges faced by other people living with MS and of the specific challenges that accompany parenting while you have MS.

What do you say?
“The big question that parents face is how and when to tell the children that Mum or Dad has MS,” Sally says. “The answer depends on the child, his or her age and the circumstances of the parent who’s been diagnosed. However, communication is the key. First, both the person who has MS and his or her partner need to have good communication strategies in place so they can be a united team and remain open when communicating with the children.”

Sally says that for children who are young, learning that a parent has MS should be an “organic experience”. She asserts, “It’s so much easier to take this path if you’ve been diagnosed before you have children or when the children are young.” If you’re in that situation, she recommends you talk about the symptoms as they appear or as they start to have an impact on the life of the child/ren or the family. “The emphasis should be on the symptom rather than on the often ‘overwhelmingly scary’ chronic health condition. ‘Multiple sclerosis’ isn’t a term that young children can understand – but they can understand that, for example, all mums are different and that you sometimes feel more tired than other mums do.”

In general terms, the younger the child, the more a parent should operate according to the principle of ‘Less is more’. “It’s easier for children to understand small chunks of information that are relevant to what’s happening in their lives. However, parents also need to be open if the child asks questions – in fact, it’s best to embrace the question and...
PARENTING AND MS

Name: Wendy Williams
Age: 50
Mother of: six children between ages 11 and 21
Lives: Melbourne
Diagnosed with MS: 2007

I was active and healthy, enjoying being a mother to six children – three boys and three girls under 10! Don’t ask me how I did it! Life was great – but things changed when I was doing kindergarten duty, when my youngest child, Harrison, was five. I’d been bending over a table, helping with jigsaws, and I couldn’t straighten up. I fell twice that day, and the second time, I hit my head on concrete. I was so scared I sat on the seat at the front of the kindergarten till another mother could drive me home. I ended up with a massive bruise on my eye, and my GP referred me to a neurologist, who sent me for an MRI. When he got the result, he said, “You have multiple sclerosis.”

What?! Those things happen to other people, but when I saw the MRI results, I almost started crying. Looking back, I can see I’d had my first attack when I was 16, and another when I was 17; then, nothing till I was 44. It seems the MS was put into remission due to my pregnancies. My children, my husband Mark and I have all had to deal with the changes I’m going through, and we’ve all dealt with them differently. My two youngest children, Isabelle and Harrison, have coped with them better – perhaps because I’ve become worse as those two have grown older.

One day, when I was trying to help Isabelle with her homework, I discovered I could no longer write. I was trying to write the word ‘planned’ for her. First, the ‘p’ looked like a ‘t’, and then it looked like a ‘h’, until Isabelle could see my frustration, and wrote the letter for me. Fortunately, by that stage, Isabelle and Harrison had learnt to write, so I was grateful for that.

Soon after I was diagnosed, I discovered I couldn’t step up or down without having a hand to hold, so that whenever I’d parked my car, I couldn’t step up from the floor.
Positive qualities
Another key area of guilt for parents is the worry that they’ll be prevented from being physically present for the child. “Often we narrow this worry down to not being able to kick a football with their child, but we need to remember that this is only one aspect of parenting; being a good parent is about providing interaction on many levels as well as about giving lots of love, keeping the child feeling secure, maintaining a daily routine, setting boundaries and having great communication.” Sally says it’s much more important that children see that their parents are modelling qualities such as:
• having courage
• being flexible
• expressing warmth
• maintaining a positive attitude
• being determined
• being resilient
• giving something a go when it seems too hard
• expressing empathy.

“Whether you have MS or not, we all have difficult moments in our lives,” Sally says. “Everyone has bad days so let your children know it’s okay to have bad days but show them how to come out of them – don’t let your bad moments or your experience of MS be your defining factor.”

Tips for parents
• Foster open and honest communication, but ensure it’s appropriate for the children’s ages.
• If your children are young, encourage them to get involved in the MS Readathon, because it can be a gentle way to promote discussion and learning.
• Consider taking the family to one of our MS Australia – ACT/NSW/VIC’s Family Camps. Being away at a camp can be a relaxing way for children of all ages to learn more about MS and meet other families who live with the disease.
• Identify and foster the activities your children enjoy doing with you.
• Be honest about your limitations, and ask for help that’s appropriate to the children’s ages.
• Ensure that your children are prepared for any changes that might affect them, such as when you have to go into hospital. Consider preparing a plan with them so they know who’ll be taking care of them and so they have the opportunity to express any concerns or fears.

I had to, but that was ‘how things are now’. After a while, the wheelchair became my preferred mode of transport – my balance wasn’t good, and I felt safer. I was soon to get my own wheelchair. I couldn’t believe how excited I was – who would’ve thought?! Certainly not I five years earlier.

My husband, my children and I have been through so many changes, and of course, they look to me for guidance. It’s up to me to teach them that no matter how bad things get, we can handle anything if we stick together. The older children have struggled, but the middle two children have had the most difficulty accepting the limitations that come with my MS. They just want their mother to be “normal”.

In 2010, however, I was diagnosed with Secondary Progressive MS, and the changes are continuing. I’ve felt a lot of guilt because I’m not the mother I used to be or want to be. For two years, I went through a dark period during which I considered suicide – but taking antidepressants was helpful, as was the realisation I’m still able to talk to my children and support them emotionally.

The best thing I can do is demonstrate you don’t give up because things are tough. My eldest daughter respects me, because she’s old enough to understand – in fact, it seems to get easier as the children mature enough to accept my MS. A sense of humour is also essential. If anyone else is facing what I’ve been through, the best things you can do are be strong, love your kids and be patient – they’ll come around in time.
PARENTING AND MS

For new mums

Even if you’re fit and healthy, the first year with your new baby can be dominated by lack of sleep and can often be coupled with feelings of inadequacy. While you were planning your family, you would’ve been warned that although relapses are less likely during pregnancy, there’s a 20 to 40 per cent chance that a new mother who has MS will experience a relapse within the first three months of the birth. It’s therefore important you have strategies in place in case you have a relapse and also so you can better cope with the stresses of mothering.

Dale Cox, Community Support Worker, MS Australia – ACT/NSW/VIC, who’s raised four children into adulthood, says, “A new baby is wonderful. There’s the intimacy you have with a new child – it’s a joy to watch your other children bond with their brother or sister, and you also watch your husband grow and develop as a man and a father.”

However, there’s no escaping the fact that for the first 12 weeks, taking care of a newborn is a full-time job, and you can be left with fatigue as a result of sleep deprivation.

“It’s important you not be afraid to ask for help – you can’t do it all. During your pregnancy, sound out your friends, family members and neighbours about ways they’ll be able to help you when you bring the baby home. Ask each person to do one simple thing, such as running any of your other children to school or sporting activities; delivering a cooked meal to you once a week; or visiting you for an hour, whenever possible, to do some housework or a load of washing. If each person has to do only a little thing to help you, most people will be only too happy to assist.”

Dale also suggests you consider the following advice:

- Don’t expect too much of yourself.
- Your role is to get you and your baby safely through this period. Make that your priority, and evaluate all the other things you want to do or be involved in against that priority.
- Enlist other people’s help, and make sure whoever you appeal to has a basic understanding of how MS is affecting you, for example you have fatigue, are sensitive to temperature changes or experience muscle weakness.
- Take action before you become too sleep deprived. Ask for extra help or ask a friend to mind the baby while you sleep.
- Consider doing your shopping online, and when you’re cooking, prepare two or three meals at once and freeze the extras for days on which you’re too tired to cook.
- If you have a partner, remember to factor in quality time with him or her, even if all you do is have coffee or a meal at a nearby café or restaurant.
- Don’t be afraid to seek advice via our telephone information service, MS Connect on 1800 042 138. Use the service as a sounding board, even if you think that what you want to talk about sounds stupid.
- Encourage your friends and family members to use the MS Connect service to talk things through.

- Keep a close eye on your mental health: depression and anxiety are symptoms of MS.
- Seek help from organisations that exist to help any new mother establish a sleeping routine for both the baby and herself.
- Be kind to yourself and your loved ones. Remember that your partner will have not only financial responsibility for the family but a lot of extra household tasks to complete. You’ll both be dealing with new challenges and stresses.

NSW

Parent Line: 1300 1300 52; a 24-hour service
Advice and information for all parents of children between 0 and 18 years of age who are living in NSW. www.parentline.org.au

Tresillian: (02) 9787 0855, or 1800 637 357 if you live outside Sydney; a 24-hour information and counselling service for parents or carers of children younger than five. www.tresillian.net


Victoria

The Royal Children’s Hospital, Melbourne
The hospital’s website contains a list of resources for mother-and-baby units.
For more information, go to www.rch.org.au/genmed/clinical_resources/Mother_Baby_Units/

The O’Connell Family Centre, Canterbury: (03) 8416 7600; the Queen Elizabeth Centre, Noble Park: (03) 9549 2777; and the Tweedle Child and Family Health Service, Footscray: (03) 9689 1577

These centres offer parents assessment, advice and education about parenting issues in relation to children between 0 and four years of age. Parents are usually referred to one of the centres through their GP or ‘maternal and child health centre’ nurse.

National

Heredity risks
Parents who have MS might worry about the risk that their children will also be diagnosed with MS. However, in 2012, the findings from a large, genetic study conducted by Professor Simon Broadley and colleagues at Griffith University and the Menzies Research Institute Tasmania were released. The research teams combined the results of 18 studies from throughout the world to provide definitive figures in relation to the risk of MS in relatives of people who have the disease.

In the general population worldwide, the risk of MS is about 1 in 1,000 and in this study was calculated to be 0.16 per cent. The number varies depending on where you live and your ethnicity. Professor Broadley and his team calculated the risk of developing MS in each class of relative, using age-adjusted data taken from studies of incidence of MS in families. They found that:

- in identical twins, who share all their genetic make-up, the risk of MS in the second twin over his or her lifetime is 18.2 per cent
- siblings have a 2.7 per cent chance of developing the disease
- non-identical twins, who have the same proportion of genes in common as siblings, have a lifetime risk of 4.6 per cent
- parents and children share half their genes, and parents of people who have MS have a 1.5 per cent likelihood of developing MS whereas children of people who have MS have a 2.1 per cent likelihood
- aunts and uncles have a 0.8 per cent risk, nieces and nephews 1 per cent, and cousins 0.7 per cent.

For more information, go to www.msra.org.au/risk-ms-in-relatives

MS Library resources
A print and online booklet
Has your mum or dad got MS? Produced by MS Australia, at www.mssociety.org.au/booklets.asp

Books available for loan
Benjamin: My mom is special, by Stefanie Lazai
Multiple sclerosis: A guide for families, by Rosalind Kalb
MS: Sharing the family experience, by Bruce Perham

Online resources
Kids’ guide to MS, from the UK MS Trust, at www.mstrust.org.uk/shop/product.jsp?prodid=286
Young person’s guide to MS, from the UK MS Trust, at www.mstrust.org.uk/shop/product.jsp?prodid=137
YoungMS, from the UK MS Society, at www.youngms.org.uk/Home
Digesting science, from the Queen Mary University of London, at http://digestingscience.co.uk/
Someone like me, from the MS Society of Canada, at http://someonelikeme.ca/
MS Ambassador profile
Listening to other people who have MS helped Andrea Flenley come to terms with the disease when she was newly diagnosed and inspired her to become an MS Ambassador.

How is your life now?
I’ve been lucky: I have ‘relapsing-remitting’ but I’ve had only two relapses and I’ve never been hospitalised. I still work four days a week, and I’m able to get the kids through school. I have a really supportive family and terrific friends. My husband Dale also picks up the load. My biggest challenge has been to ask for help, because I tend to want to be a super-woman. I had to learn how to let go of guilt.

Tell us about being an MS Ambassador.
I became an ambassador because when I was diagnosed, I found it was a positive experience to listen to MS Ambassadors talk about getting the most out of their lives. Challenges come up, but you deal with them the best way you can. We all have ‘pity party’ days, but everyone faces challenges, including people who don’t have MS.

What are some of the things you’ve done in your role as an MS Ambassador?
I’ve helped with the MS Readathon and the local MS 24 Hour Mega Swim. I’ve spoken to groups such as Probus, and I’ve also been interviewed for the local ABC radio station.

What’s the message you most like to deliver?
I talk about how to get the support you need, because there’s a lot of it out there. I also encourage people to gather supportive people around them, including a good medical team. Supportive people have a positive influence on your life. It’s also important to not let illnesses define you – I learnt I’m a person who has MS rather than someone who allows the disease to take over my life.

“ My biggest challenge has been to ask for help, because I tend to want to be a super-woman. I had to learn how to let go of guilt. ”

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

Name: Andrea Flenley
Age: 43
Occupation: Nurse-unit manager
Lives: Cardigan Village, outside Ballarat, Victoria
Diagnosed with MS: Age 32
Has been an MS Ambassador: Since 2008

Tell us a bit about your MS journey.
My two stepchildren Shani and Josh live with us. They were eight and five years old, and I was pregnant, when one day at work my left hand and foot and the left side of my face went numb. I’m a nurse, so of course I ignored the symptoms. Eventually I went to my GP, and he sent me for a CAT scan – that was all they could do, because of my pregnancy. The numbness never left, so when Rhianna was three months old, I had an MRI, and they told me I probably had MS. However, it wasn’t confirmed until a year later.

What happened next?
I contacted the MS organisation, which sent a Community Support Worker to talk to me. I also attended a day for people who are newly diagnosed, along with some other education sessions. It was good to get some tools such as relaxation and energy management in order to deal with having MS. For example, like a lot of people, I have fatigue, and I found it helpful to learn to call it fatigue and not think, I’m just tired. It was also great to meet other people who have MS.
Littlies raise big money

“Unless someone like you cares a whole awful lot, Nothing is going to get better. It’s not.” – Dr Seuss, in The Lorax

Another year has just about come to an end, and another year of the MS Readathon has come and gone. This year, almost 4,000 people throughout NSW, the ACT, Queensland and Victoria cared “a whole awful lot” and picked up their books in order to read and raise money for the iconic fundraiser.

This year, because the MS Readathon is no longer limited to school-age children, more than 500 children younger than age six took part. Also, some tiny superstars have emerged, proof that – to quote Dr Seuss again – “a person’s a person, no matter how small” and that anyone can make a difference!

A special mention goes to Victorian entrant Petra Kristcevic, who turned two in November and has raised more than $1,400. Meanwhile, little ACT entrant Zoe Margaronis also turned two, in October, and raised almost $900 – and this was her second MS Readathon! Little NSW entrant Izabella Smith asked her grand-dad to sponsor her rather than buy her a weekly bar of chocolate, and raised more than $1,000. She’ll turn five in December – happy birthday, Bella!

Six-year-old Makaira Muscat from Victoria read and raised as much as possible to help her mum Rebecca and other people who have MS. Makaira’s amazing effort has paid off to the point she’s one of the year’s top fundraisers, having raised a grand total of $3,345 in this, her first year of fundraising!

There are many more inspirational stories as well, such as the story of ACT entrant Kathryn Speeding, who ended her fundraising for 2013 by hosting an afternoon tea at which she raised more than $2,000!

Our sincere thanks go to every one of the participants and to the parents, who not only set their children on the path of loving books but taught them the importance of helping people in need.

This year was also the second year of the 60 MinuteS for MS program – a fun, one-day event in which people at more than 100 schools, pre-schools and libraries participate.

A will to give

Almost three in four Australians support charities, but only 7 per cent leave a gift in their will.

Ensure that your legacy lasts by leaving a gift in your will and thereby assisting people living with MS by helping provide even better programs, essential services and research into cures.

You can also remember a loved one by way of making an ‘in memoriam’ gift or by making an ‘in memory’ donation online.

To order a free copy of our booklet Your Future in Your Hands or some ‘in memoriam’ envelopes, please call your Planned Giving Officer Donna Bradley-Robinson in Victoria or Jacqui Sumner in the ACT and NSW on Freecall™ 1800 443 867, or email bequests@msaustralia.org.au

www.msaustralia.org.au/actnswvic

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EVENTS

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

TELECONFERENCES

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

Sleep Well with MS
Explore the reasons that people with MS have difficulty sleeping, and discuss some strategies for improving your sleep.
11 February 2014, 10.30am – 12 noon
20 March 2014, 7pm – 8.30pm

Managing Fatigue
In this two-part teleconference series, you learn how to manage MS-related fatigue.
March 2014: date TBA

Contidence Care in MS
Learn about bladder and bowel problems: the causes, assessment, and treatment options.
March 2014: date TBA

Working with MS
(NSW and ACT only)
Explore your rights and responsibilities at work, as well as superannuation, insurance, and financial matters.
13 March 2014, 7pm – 8.30pm

MS Exercise Class
(Wednesdays, 12 noon)
6X Fitness Studio, 171 Maroubra Road, Maroubra
Call Shaun Hockley on (02) 8084 0880 for details.

MS Stretch and Strength
(Monday to Friday)
Cost: $5 per session
Call Tracy Martinuz on (02) 9646 0692.

MS Family Camp fun
The first ever ACT and Southern NSW MS Family Camp was held in Jindabyne on 19 and 20 October. Six families travelled from Young, Goulburn, Bungendore, Berridale or the ACT to the Jindabyne Sport and Recreation Centre in the Snowy Mountains for a weekend of fun and friendship.

Activities included archery, a challenge course, a trivia competition, group discussions and a circus-skills workshop; however, the aim of the camp was to give the attendees an opportunity to share their experiences of living with MS.

The group also had a chance to try indoor rock climbing (see photo). A highlight of that activity was when the participants watched one of the parents who uses a wheelchair being hoisted to the top of the wall. The weekend concluded with a relaxing mindfulness session for parents while the kids had fun on the flying fox.

All the activities were conducted by highly skilled instructors from the Sport and Recreation Centre. The Centre’s disability-accessible accommodation was excellent, and the food was plentiful, frequent and fantastic.

Ann Lehmann, Regional Manager Central, MS Australia – ACT/NSW/VIC, praised the organisations that helped fund the camp: the Victoria Shakespeare Foundation; Carers ACT; and Soroptimist International, a Canberra women’s service club. “We also couldn’t have done it without the contributions of volunteers Laura Halmkusuma, who helped plan the event; Will Scott, who drove the bus and kept an eye on everyone; and Ben Lane, who videoed the weekend,” Ann says.

Massage Therapy at Gloria McKerrow House
Tuesday and Wednesday
Phone Glenda on 0407 918 500.
Thursday and Friday
Phone Isi on 0431 100 265.
The therapist will let you know the cost.

Iyengar Yoga for MS
Tuesdays in Petersham; Wednesdays in Lidcombe
Cost: $10 per class
Call Tracy Martinuz on (02) 9646 0692.

CHAT ROOMS

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

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.

Date to be advised

In the Kitchen
If you’re having difficulty cooking, our occupational therapists will provide information about equipment.

Date to be advised

PHYSICAL-ACTIVITY GROUPS

Yoga in Canberra
Wednesdays, 5.45pm – 7.15pm
During school term
Cost: $17 per session. Call Ruth on 0401 288 921.
INFORMATION SESSIONS

HOLIDAY PROGRAM
Please make use of the recordings of education sessions that are available through the website, www.mssociety.org.au/education-programs.asp, and are available to clients and their family members throughout all regions.

Working with MS
Explore your rights and responsibilities at work, as well as superannuation, insurance, and financial matters.

Managing Fatigue and Coping with the Heat
An overview of fatigue resulting from MS and how to manage the symptom, which can be invisible.

Mood and Emotions in MS
Explore the changes that MS can cause in relation to mood and emotions, with clinical psychologist Dr Judy Dunai.

Get Active with MS
Our physiotherapists talk about ways to get involved in physical activity.

Thinking and Memory in MS
Neuropsychologist Dr Maggie Ambrose discusses the changes to thinking and memory that MS can cause, and provides management strategies.

AMSLS Update
Rex Simmons talks about the Australia MS Longitudinal Study (AMSLS).

PNI Update
Clinical psychologist Dr Gary Fulcher explains psycho-neuro-immunology and how it’s related to MS.

A Word about Travel Insurance
John Berrill from Maurice Blackburn Lawyers talks about travel insurance for people who have MS.

INFORMATION SESSIONS

A date for your diary

6 April MS Family Camp
Lady Northcote Camp, Bacchus Marsh
For bookings or more information, email educationvic@msaustralia.org.au or call 1800 042 138.

MS 24 HOUR MEGA SWIM
The Mega Swim is a fun team-relay event for swimmers of all ages and abilities. Swimmers participate in teams of up to 15 people, and each participant decides when he or she would like to swim and for how long. Some participants swim for 10 minutes, others for four hours! Each team member has an online-fundraising page and raises money from family, friends and colleagues, in the form of a one-off donation or sponsorship for the number of laps swum.

The funds raised are for supporting our Go for Gold Scholarships and financial-assistance programs and for providing services that directly benefit people living with MS.

Go to megaswim.com to find a swim near you, and follow us on Facebook and Twitter to keep up to date with the latest news! (The dates are subject to change.)

Mildura 18–19 Jan Mildura Waves
Fitzroy 21–22 Feb Fitzroy Pool, Fitzroy
North Melbourne 22–23 Feb North Melbourne Recreation Centre
Geelong 1–2 March Leisure Link, Waurn Ponds
Wollongong 22–23 March Aquatic Centre (URAC)
Leeton 16–17 March Leeton Shire Pool
Shepparton 22–23 March Aquanoves, Lakeside Shepparton
Melbourne Swim, Squash and Racquetball 3–4 May Melbourne Sports and Aquatic Centre
Canberra 3–4 May AIS Swimming Pool

Edison programs
In Victoria, face-to-face education programs will resume in February. We apologise for the fact that no times were available when Intouch was being prepared for publication. Please keep all your contact details, including your email address, up to date so we can inform you when the programs have been planned.

www.mssociety.org.au/education-programs.asp

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

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Helping child carers

Most parents find it difficult to decide when to start giving a child chores and to decide which chores are appropriate. When MS is added to the mix, a parent or relative might require a child to help him or her complete everyday tasks, and he or she might consequently find it even more difficult to know which chores are appropriate.

Young carers might be asked to help with cleaning, cooking, and administering medications or therapy, taking the person to medical and other appointments, along with keeping the person safe or watching out to make sure that they’re feeling okay.

The Carers Australia website includes the comment that “children and young people who help care for a relative or a friend tell us that caring can be a very positive experience. They tell us that they often feel closer to their families, that they develop new skills and experiences, and that they feel good about caring for someone they care about.”

Carers Australia classifies young carers into groups associated with the chores listed as follows:

- **Children younger than 12**
  - Cooking
  - Cleaning
  - Helping with medications

- **Teens between 13 and 18**
  - Cleaning and cooking
  - Getting the person around the house
  - Taking the person to medical appointments
  - Giving the person his or her medications
  - Washing and dressing the person
  - Making sure the person is feeling okay

Meanwhile, our MS Australia – ACT/NSW/VIC Community Support Workers suggest you use these questions so you can better decide whether a task is appropriate:

- Is the task safe for the child to do? For example, is the child at risk when he or she is handling hot food from the microwave oven?
- Is another person better suited to help you complete the task?

According to Carers Australia, some children can miss out on opportunities for going to school, doing their homework, spending time with friends or advancing their studies. The result can be that they experience a high level of stress, they worry, and they feel confused and uninformed.

The organisation recommends you find ways to promote the positives and that you also find ways to keep the young person from experiencing some of the negative impacts of caring for you. If you suspect that the child or teenager is feeling alone, consider encouraging him or her to link up with other young carers. Also, keep an eye out for our MS Family Camps, and consider attending a camp if you can. The camps are an opportunity for youngsters to meet other children whose parent has MS.

### Other information

**Carers Australia** has a young carers’ information pack that can be accessed by calling 1800 242 636; also, visit [www.youngcarers.net.au](http://www.youngcarers.net.au)

**Reachout!** is a website for young people. It covers a range of topics and includes discussion forums; go to [www.reachout.com](http://www.reachout.com)

**Kids Health** is a website that features easy-to-understand explanations of health issues; go to [kidshealth.org](http://kidshealth.org)

### Carers Week events

The essential part that carers play was celebrated during National Carers Week, held between 13 and 19 October. In Victoria, Brainlink held a wellbeing seminar in Blackburn on 17 October. The guest speakers included Erin O’Loughlin, who gave a moving talk about her journey as a young carer caring for her mother who has MS. Erin is also a member of the MS Advisory Council, Victoria and the Carers Working Party, and is a Carer Peer Support Volunteer, providing support to carers in the MS Australia Peer Support Facebook groups. Christine Durham, recipient of the 2012 Brainlink Woman of Achievement Award, also shared her inspirational story during the wellbeing event. We’d like to thank Brainlink for organising the seminar.

Meanwhile, in NSW, on 16 October a Deserving Desserts Morning Tea was held at the Woodbury Park Community Centre, in Mardi, located on the NSW Central Coast. The carers enjoyed talking to each other, and the atmosphere was positive. There was such an abundance of food that it was shared among the carers to take home so that they didn’t have to cook a meal that night.
Community support

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

**Inspired by father’s MS**

Janek Speight is terrified of heights: he can’t stand close to high-rise balconies, has dreams about falling from cliffs and gets nervous thinking about rollercoasters — yet on 20 September, he jumped out of a plane at 14,000 feet (4,267 metres) to honour his father, Ian, who’d died in 2003 after waging an eight-year battle with MS.

Thinking about the tenth anniversary of his father’s death, Janek decided to raise money for people living with MS, so he signed up to skydive. “The amount of support’s been amazing, from friends and family and also from a lot of my mum’s friends from Germany, who I’ve never met,” Janek says. “Dad’s humour, wit and positive attitude throughout his illness were inspiring. He was an amazing dad and my best mate. I think a lot of his old friends have remembered that and have been really generous with the donations. Dad would be proud of them.” So far, Janek has raised $9,615. “I’m aiming to get to $10,000,” he says.

We’d like to thank Janek for his generous gift.

**Fundraising at 15!**

Enis Harbas is a typical 15-year-old. He lives with his parents in Dandenong North, an outer-eastern suburb of Melbourne, and likes football, kickboxing and running.

Unlike other youngsters, though, he grew up with a family member who has MS, and he’s seen the impact the disease can have.

“Something in my heart just clicked and I had to help,” he says, so he decided to challenge himself to run 100 kilometres in order to raise money to help people living with MS.

Enis enlisted his friend Ornal Memedovski, 16, to join him. Their parents were initially surprised at the daunting feat the determined duo had set for themselves, but they could see that the boys were committed. “Whenever I felt like giving up, they gave me the strength to keep going,” Enis recalls.

Enis says. “Just go for it — every dollar counts!”

We’re proud of Enis and Ornal, who raised more than $4,000 for people living with MS. Thank you!

**Roll of Honour**

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

- Zona Tripp and Kim Auswild, and the Dr Jeffrey Tripp Committee — Day of Indulgence event
- Eden Roberts — work barbecue
- Mile Stijanovsk and Conston Lions Football Club — trivia night
- Newcastle Rotary — donation
- Roy Williams — concert
- Coady Pharmacy — donation
- The Sun-Herald City2Surf — 48 participants
- Brian and Stephen Roach — birthday party
- Ann Linich — in lieu of a fiftieth-birthday present
- Anita Robertson — Pub 2 Pub
- Australian Institute of Music — RENT musical concerts
- Janek Speight — skydive
- Blackmore’s Sydney Running Festival — 37 participants
- Paul Swan — Mudgee Campdraft
- Jane Rose — wedding donation
- Nokia Solutions and Network — running event
- Victoria Brown, Swarovski — work barbecue
- Kirsten Clegg — wedding donation
- Solarino Social Club — MS dinner
- Blue Illusion Boutiques — style workshops in Mona Vale, St Ives, Mosman and Balgowlah
- Denis Reid — Canberra Running Festival
- Majura Park Shopping Centre — community cash promotion
- The Age Run, Melbourne — 21 participants
- Troy Towers — Dry July
- Donna Taranis — birthday donations
- Clinton Capuzzi — Yea Race Day
- Enis Harbas and Ornal Memedovski — 100-kilometre Run for MS
- James Tournas (National Australia Bank) — morning tea
Volunteers in action

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

Gong relies on volunteers

The annual MS Sydney to the Gong Bike Ride is a major fundraising event for MS Australia – ACT/NSW/VIC, and we couldn’t make it happen without the help of our volunteers.

On Sunday, 3 November, more than 400 volunteers pitched in to help stage the 32nd MS Gong ride so that 10,000 cyclists could pedal from Sydney to Wollongong. Some of our volunteers, such as the ones who put out the hundreds of signs along the route, started work as early as 2am, and others bumped in marquees and water supplies so the riders would be made comfortable at the rest stops.

The cyclists got off to a great start when cricketing legend Adam Gilchrist sounded the starting horn. Adam is also the brand ambassador for the University of Wollongong. Although the day was hot and hazy, most riders completed the course.

Our route marshalls kept the riders safe while guiding them from the Princes Highway to the Royal National Park, across the Seacliff Bridge and all the way to the finish line. Meanwhile, more volunteers distributed lunches and merchandise and transported luggage.

At the finish site, other volunteers wrapped the bikes in bubble wrap and drove them and their riders safely back to Sydney. There were even volunteer massage therapists, who eased the cyclists’ aches and pains after the long ride (see the photo above).

The activities were coordinated by volunteer base managers, base coordinators and sector managers, who managed groups of volunteers and acted as the eyes and ears for authorities in order to ensure safety along the course.

Once again, our volunteers demonstrated their professionalism, dedication and willingness to go the extra mile to ensure that the day was fun for all the participants. Thanks to the volunteers’ hard work, at the time we were writing Intouch, almost $3.5 million was raised for Australians who have MS, and their families.

Cutting the ribbon

Our new MS Community Shop in the Canberra suburb of Tuggeranong was opened for business for the first time on 15 July, but the ribbon-cutting ceremony was held on 4 October.

Robyn Hunter, CEO of MS Australia – ACT/NSW/VIC, was on hand to introduce Shane Rattenbury, the ACT Minister of Territory and Municipal Services, Corrections, Housing, Aboriginal and Torres Strait Islander Affairs, and Ageing (see the photo, above). Mr Rattenbury, who’s a supporter of the MS 24 Hour Mega Swim, was pleased to do the honours of cutting the ribbon, after which a clutch of customers were allowed to enter the shop.

The people watching the ceremony included two of our Board members, Ian Gordon and Ian Pennell, and Ian’s wife Jean; senior members of Disability ACT; and Ann Lehmann, Regional Manager Central, MS Australia – ACT/NSW/VIC. Several volunteers also attended and served food, and we appreciate their help in making the opening a success.
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 throughout Melbourne and regions to visit people who have MS.
- Volunteers are required to support the MS shops located in Fairfield, Daylesford, Malvern and Geelong.

NSW–ACT
- We’re seeking a handyperson to help maintain the premises at Gloria McKerrow House, in Deakin, Canberra.
- Volunteers are being sought for the new MS shop located in Canberra’s Tuggeranong area.
- At Bateman’s Bay and in the ACT, we require volunteers to visit people who have MS.
- We’re seeking a person who can do filing and document archiving at the Studdy MS Centre in Lidcombe.
- In the Carlingford area of north-western Sydney, a volunteer is needed for home visits and meal preparation.
- Volunteers are needed to help conduct yoga classes at the MS Studdy Centre in Lidcombe.
- In regional areas of NSW, volunteers are required to help people who have MS complete various tasks.

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.

Dedicated to helping

Volunteering is almost second nature to Trevor Dagley, so it comes as no surprise that for more than 30 years, the 85-year-old has been working on behalf of people who have MS.

“I didn’t know anyone who had multiple sclerosis when – in 1980 – I was reading our local paper and saw a paragraph to do with asking for people to attend a meeting about MS,” says Trevor, who in 1994 was awarded the Medal of the Order of Australia, for community service, including for the Scouting Association of Australia.

Trevor attended the MS meeting, and when it had finished, he agreed to help form an auxiliary body with the aim of raising funds in order to provide a van for what was then called the MS Society of Victoria. He became the founding president of the MS Ivanhoe and North East Regional Auxiliary, and has been holding the position ever since. “Within about 12 months, we raised enough money to buy the vehicle to carry people and their wheelchairs,” he says.

When that project was completed, the society asked Trevor and his committee to open an MS opportunity shop. “The project was daunting, but we thought we’d give it a go, and the shop was opened in about 1982, on Station Street, Fairfield.”

Since then, the shop has moved to the other side of Station Street.

Trevor is proud of the shop even though he’s no longer involved in running it, but these days his main pride and joy is his radio show about MS, which he hosts on community radio station 96.5FM every fourth Wednesday of the month. “I interview all sorts of people who have a connection with MS. They might talk about the medical side, fundraising, or what it’s like to live with MS. Everyone has an interesting story.”

Trevor’s been working on the show since 1999, and he’s lost none of his enthusiasm for it. “I look on it as something I can do, and hopefully it’s useful.” He also dedicates a weekly radio program to Scouts, an organisation he’s been involved in for 60 years. “I believe we’re put into the world to have a useful life and a life of caring for other people,” he says.

That’s why he continues to work on behalf of the MS auxiliary, holding street stalls every three months each year. Trevor’s wife passed away three years ago, so he likes to spend time with his four children and nine grandchildren. “I have a couple of great-grandchildren on the way!” he chuckles.

Lend Lease lends a hand

For several years now, volunteers from Lend Lease have been donating their time to improving our residential facilities, Watsonia in Melbourne and Lidcombe in Sydney. In September this year, the Lend Lease team added the sites located in the Melbourne suburbs of Blackburn, Footscray and McKinnon to their list. More than 50 Lend Lease volunteers were spread across the five premises, where they undertook improvements such as tidying the garden, clearing gutters, painting, and general spring cleaning.

They performed the work on their Lend Lease Community Day, which is part of the organisation’s global program that’s been running for three years and in which 11,300 Lend Lease employees, subcontractors and clients are engaged across 874 projects.

We’d like to thank the Lend Lease employees who took part and our staff members who helped the teams on the day.

www.msaustralia.org.au/actnswvic
Excellent advice

Talking to a person living with MS helped Bruce Frost when he was newly diagnosed, prompting him to return the favour.

I’ve been involved with Surf Life Saving Australia (SLS) for many decades, and in 2001 my wife, Julie and I attended a meeting of SLS NSW in Narrabeen, Sydney. During a walk, I started dragging my right leg. Back home in Narooma, on the NSW south coast, I went to my GP, and several tests later I was diagnosed with MS. I’m now 55, and I limp at times and walk with a cane because I have problems with balance. Fatigue is also an issue, and in 2007, I retired from running my bee-keeping business. I used to play the banjo, but my right hand gets fatigued. I’ve compensated for that by listening to music, but I haven’t found a substitute for snow skiing, which I can’t do because of my lack of balance. I can’t bring myself to ski on the beginners’ slope. I’d rather keep those memories.

In 2008, I gave up surf patrols, but I’m a Life Member of SLS Far South Coast NSW. Because of my association with surf lifesaving, I’m an experienced public speaker, so in 2005, I volunteered to be an MS Ambassador. I addressed various groups but resigned in 2008 to become an MS Advocate for MS Australia, the national organisation.

Around that time, I read about Peer Support Volunteers in Intouch and was reminded of my experience when I was first diagnosed. Back then, a friend put me in contact with a person with MS. We spoke several times, and he gave me insight into what I could expect, as well as some excellent advice.

I did the Peer Support Volunteer training in 2009, and I’ve since been matched with about 15 people. Talking with people who are newly diagnosed is good for me because when I explain how I manage my MS, my positive behaviours are reinforced. For example, I go to the gym three times a week because I’ve found that the fitter I am the better I’m able to handle my symptoms. I’ve also switched to a low-fat diet, and I meditate regularly. Having good friends is a big part of helping myself manage my MS, and I couldn’t do any of it without Julie and my children. I learn something every time I talk to someone who has MS. It’s always a win–win. Often, I’ve made a new friend.
Support group profile

If you have MS and you’re raising a family, you face unique challenges, which is why Dianne Barnes helped start the Geelong MS Parent Peer Support Group. Dianne co-facilitates the group and has four children between the ages of 12 and 16.

How was the group established?
Last year, I was asked to become a group facilitator to help start a new parent group in Geelong, and it was established earlier this year. I’d been attending the Geelong MS Peer Support Group for two years, but I was keen to start a group to support parents who have MS and who have a dependent family. I was diagnosed with MS five years ago, when my youngest child, Alex, was six. I’d had my first symptoms in my twenties, but things became more problematic after Alex’s birth. I also run a small gardening business, which is flexible, so I’m able to work around the family and my health issues.

Why parents’ peer support?
The people at the Geelong MS Peer Support Group are terrific, but I felt there was a gap between older and younger people who have MS, and I realised that quite a few parents were in a similar situation to mine in that they were facing the daily challenges of combining their MS management with their family life.

How have you found the group to be helpful?
It’s great to go to a group knowing you don’t have to explain anything. Our members are all different, but we have a common base. We can compare notes about subjects such as dietary suggestions, ways to get more sleep or rest, and the various medications and therapies that are available. We also talk about how we’ve coped with the challenges of having MS and looking after a growing family.

When does the group meet?
We meet once a month in the family playroom at Bethany, a community-support centre in North Geelong. We usually meet late in the month, but the day can change. I notify everyone by email about two weeks in advance. It starts at 9.30, after the school drop-off, and goes for two hours. I generally take some morning tea. There, we have access to tea- and coffee-making facilities, a safe play environment for the children, and sofas for any breastfeeding mums.

Are there any other activities?
We’ve got about 20 members. However, the group is still finding its feet, and a good meeting is when at least seven people attend. That usually happens when we have a guest speaker who talks about MS. In October we were involved in a Wellness Day, at a location near Geelong, and we’re planning a Christmas get-together, which could be a lunch or a weekend picnic.

Do you have any advice for people who are considering joining a support group?
It’s important to have a place where you feel you belong, especially because life with a family and MS can seem fast and furious at times. It’s wonderful to have a group to go to in which the members understand without the need for words. I’ve made a lot of new friends, and we don’t always talk about MS – we talk about our kids, our parenting and our busy lives.

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

And the winners are...

It’s important to retain your dreams even when you face challenges due to MS. This year, 52 people living with MS will be better able to achieve a goal thanks to a Go for Gold Scholarship.

Rediscover a love

Last year, Judy Collman was among the 55 people who were awarded a Go for Gold Scholarship. Judy, 57, chose the sports category to apply under because working in her garden provides exercise. Here’s her story:

I was diagnosed with MS in 1998, when I was 42. I have ‘atypical’ MS, and I’ve had only one severe relapse, but it left me with weakness in my right side. I use a walking stick, and if I kneel, I find it impossible to stand up again unless someone helps me. Before I had MS, I was a keen gardener. My husband Rod and I built a house on a one-acre block in Nimmitabel, near Cooma, in NSW. I’d created a good garden, but I had to abandon it when I got MS. I tried to keep gardening, but I couldn’t dig for more than five minutes without having my right leg get tired. Eventually, I gave the gardening away altogether.

In recent years, I’ve seen raised garden beds on TV gardening shows, and I started thinking about gardening again. I figured I could garden if I had a raised bed, but I’m on a disability pension, so a garden bed is outside my budget.

When I applied for a Go for Gold Scholarship in 2012, I never expected to win, and I was so excited to get the phone call. The scholarship was enough to pay for three raised beds. My passion is growing fruit and vegetables, and I wanted three beds, because I wanted to be able to rotate my crops. I had the first one built just before summer, and it was so exciting to plant it up, because I can stand or sit while I’m working. The silverbeet and garlic grew well. Just this week, I’ve been planting my spring seeds, including rhubarb and strawberries. I tend to the garden every day, which means the results of the scholarship are something that brings me joy every day.

I’m so grateful because it’s wonderful to be able to adapt around your disability so you can do something you enjoy doing. Because of the scholarship, I’ve been given a second chance to experience the satisfaction I feel when I nurture a seed into a seedling and then watch it turn green, grow high and wind up on our plates. I’d recommend other people apply for a scholarship because it’s a chance to rediscover something you love.

Huge thanks to Mega Swim!

In 2013, we held an award ceremony in each region to honour the people living with MS who had been awarded a scholarship. The recipients proudly shared their achievement with their family members and friends, the MS 24 Hour Mega Swim community hosts, and people who organised and supported the fundraising. We wish to thank all the sponsors who helped make the ceremonies memorable, and we’d like to congratulate the recipients.

The MS 24 Hour Mega Swim was founded by MS Ambassador Carol Cooke in 2001. Carol has since become a gold medallist at the 2012 London Paralympics. Carol is a keen swimmer who worked with some friends to conduct a swimming event at Fitzroy Pool, in Melbourne. The club raised $22,000 and the event became so popular it evolved into today’s highly successful MS 24 Hour Mega Swim program. These days, it also includes squash and racquetball events. The events are also a unique opportunity for swimmers, businesses and community groups to get involved.

To find out about upcoming MS 24 Hour Mega Swims or to talk to us about running an MS 24 Hour Mega Swim at your local pool, visit www.megaswim.com, email megaswim@msaustralia.org.au or call 1300 705 341.
2013 Go for Gold Scholarships
Since this program began, more than 550 scholarships have been awarded to people living with MS who live in the ACT, NSW or Victoria and who wish to follow a dream by applying for the scholarship under one of the categories of employment, sport, travel, education or the arts, or in order to join a gym.

The funding of scholarships is supported through the program that includes the MS 24 Hour Mega Swim and related events, including squash and racquetball, which attract more than 3,000 participants.

To be eligible for a scholarship, you must be a registered client of MS Australia – ACT/NSW/VIC and have completed an application form. For the date that applications for the 2014 Go for Gold Scholarships open on, please keep an eye on the website, www.mssociety.org.au/go-for-gold.asp

To get involved in the MS 24 Hour Mega Swim, visit www.megaswim.com

THE ARTS
David Maney, Vic
Justine Martin, Vic
Anonymous, Vic
Wayne MacArthur, Vic
Glenda Janes, Vic
Lisa Sheehan, NSW
Warren, Vic
Ana Corral Kelly, NSW
Anonymous, NSW
Ashlee Bucholtz, NSW
Anonymous, NSW
Maree Hamence, NSW
Anonymous, NSW
Anonymous, NSW
Anonymous, NSW
Phillip Carpenter, NSW

EDUCATION
Kerri Cassidy, Vic
Roslyn Emmerick, ACT
Courtney Griffin, Vic
Teresa Dalle-Negare, Vic
Anonymous, NSW
Anonymous, NSW
Veronica Lane, Vic
Anonymous, Vic
Anonymous, Vic

TRAVEL
Deborah Deckys, Vic
Virginia Vester, NSW
Van Thi Le, Vic
Angela, Vic

EMPLOYMENT
Anne Cook, Vic
Halina Hildebrand, Vic
Judy, Vic
Anonymous, Vic
Kelly McCabe, Vic
Jayne Rudderick, Vic
Robert Mitchell, NSW
Gaye Moore, NSW
Darryl Elias, NSW
Nina Crumpton, NSW
Dorothy Campbell, NSW

Elizabeth Wilson, Vic
Helen Stanley, NSW
Nina Gendell, NSW

SPORT or OTHER
Rodney Ziino, Vic
Anonymous, NSW

GYM MEMBERSHIP
Jane Hinton, NSW
Peggy Irwin, NSW
Simon Thomas, NSW
Anonymous, Vic
FINANCIAL INFORMATION

Help with energy bills

At this time of year, when you’re likely to have the air conditioning running for most of the day, it’s good to know you might be eligible for financial help.

In NSW, Victoria and the ACT, energy consumers have various types of rebate and financial assistance available for helping to pay their bills. Here’s an overview.

New South Wales

Low Income Household Rebate This is provided by the NSW Government, and for the 2013–14 financial year, up to $225 of a household’s energy bill will be covered under the rebate. It’s paid by way of credits on a household’s bill at a rate of slightly more than 61 cents per day. To be eligible, the account holder must have a Commonwealth Pensioner Concession Card, a Health Care Card or a Department of Veterans’ Affairs Gold Card. You must apply to your electricity retailer for the rebate. For more information, go to www.energy.nsw.gov.au/customers/rebates - Low-Income-Household-Rebate

Medical Energy Rebate The NSW Government funds this rebate, and it’s available to people, such as people with MS, who have a medically diagnosed inability to self-regulate their body temperature. The rebate will be paid at a rate of $225 per year from 1 July 2013, which is a $10 increase on the previous year’s rate. Eligible households are able to receive the Medical Energy Rebate in addition to other assistance such as the Low Income Household Rebate and the Life Support Rebate and assistance given under the Energy Accounts Payment Assistance (EAPA) scheme.

You apply for the rebate through your energy retailer, and you need to include medical evidence supplied by a GP who’s been treating the person for at least three months. Other eligibility criteria also have to be met.


Family Energy Rebate Under this rebate, up to $125 is provided towards eligible households’ electricity bills for the 2013–14 financial year. If you’re receiving the Low Income Household Rebate, your Family Energy Rebate will be a smaller amount. For people receiving both the rebates, assistance will be capped at $250 per year. You must send the application forms to the NSW Department of Trade and Investment, not your electricity retailer. You can either apply online or download the application form from the Department’s website and post the form in. To continue to receive the rebate, householders must re-apply each year. To be eligible, the applicant must be the electricity-account holder and a NSW resident. He or she must also be eligible for, and have received, the Federal Government’s Family Tax Benefit, Part A or Part B. The only time you can send your application for the Family Energy Rebate is after you’ve lodged your tax return for the previous financial year. For more information, go to www.energy.nsw.gov.au/customers/rebates

Energy Accounts Payment Assistance (EAPA) The aim of this scheme is to help financially disadvantaged people who are in crisis or an emergency situation. You can use EAPA vouchers to pay your electricity and gas bills, and participating Community Welfare Organisations (CWO) such as St Vincent de Paul, the Salvation Army and Anglicare distribute them. People who wish to secure EAPA vouchers should contact a distributing agency to make an appointment. Eligibility for the scheme is assessed by way of interview with a CWO staff member. Each EAPA voucher is worth $50, and the number of vouchers available per household is at the discretion of the CWO staff member. Payment for an entire bill isn’t usually covered under the scheme, and the vouchers aren’t available for consecutive bills; rather, the aim of the scheme is to help people in difficult circumstances stay connected to an essential service. EAPA vouchers can also be used to pay gas bills; however, the vouchers aren’t available for payment for bottled gas (LPG).

Go to www.energy.nsw.gov.au/customers/help

Customer hardship programs All electricity retailers are obliged to have a customer-hardship charter that is publicly available on their website. Under these charters, consumers who are experiencing payment difficulties have access to two payment plans and some additional protection from disconnection.

To obtain more information about your energy retailer’s program, call the retailer or visit its website.

Home Power Savings Program Households can bring down their household energy bills by reducing consumption, and this program is a free service whereby eligible low-income households are provided with help. This includes a powersavings kit and a household assessment by an energy expert who can provide an energy-savings action plan. The power-savings kit includes energy-saving tools such as energy-efficient light globes and an eco-switch, which is a device through which standby power is shut down.

According to the NSW Government, households can use the Home Power Savings Program to reduce their energy consumption by up to 20 per cent.

For more information, call the Home Power Savings Info Line on 1300 662 416 or go to www.savepower.nsw.gov.au/households/home-power-savingsprogram/about-the-program.aspx

For more information about all rebates, call the Energy Information Line on 1300 136 888.
**Victoria**

**Annual Electricity Concession** The aim of this concession is to help ease cost-of-living pressures by providing concession-card holders with a 17.5 per cent discount on their household electricity bills. You need to hold one of the following concession cards:
- Pensioner Concession Card
- Health Care Card
- Department of Veterans’ Affairs Gold Card

The concession applies to electricity costs all year round and is calculated based on the remaining account balance after application of any retailer discounts and/or solar credits. On 1 July 2012, a threshold for gas and electricity concessions was introduced in order to take into account the Federal Government’s proposed Carbon Tax compensation so that two levels of government don’t compensate households for the same expense. The Federal Government compensation represents a subsidy of $171.60 for electricity throughout the year, so for a concession-card holder’s annual electricity bill, the State Government concession won’t apply to the first $171.60. This change doesn’t affect the average net position of Victorians who receive energy concessions.

The Federal Government estimated that if the new ‘carbon price’ went ahead, electricity bills would be increased by 10 per cent. In dollar terms, that figure equates to an average of $3.30 per week, or $171.60 per year.

**Medical Cooling Concession** The aim of this concession is to provide a 17.5 per cent discount on electricity bills for card holders who have a medical condition whereby their body is prevented from regulating its own temperature. You must hold at least one of the following concession cards: Pensioner Concession Card; Health Care Card; Department of Veterans’ Affairs Gold Card. The discount is available over a six-month period from 1 November to 30 April each year. Multiple sclerosis is one of the qualifying conditions.

Contact your electricity provider or call the Department of Human Services Concessions Information Line on 1800 658 521 to obtain an application form.

Forms are also available from the Department’s Concessions website:

**Excess Energy Concession** The Department will be introducing this concession on 1 December 2013. Householders who have an annual electricity bill of more than $2,763 will need to apply for the concession in order to continue receiving the 17.5 per cent concession on energy consumed that equates to higher than that amount. Recipients of the Medical Cooling Concession are exempt from having to apply for the Excess Energy Concession; they will continue to receive the Annual Electricity Concession on all electricity used year round.

For more information, go to www.dhs.vic.gov.au/for-individuals/financial-support/concessions/energy

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**Australian Capital Territory**

**Energy Concession** To be eligible, you must hold at least one of the following concession cards: Pensioner Concession, Health Care, or Department of Veterans’ Affairs Gold Card.

Both electricity and natural gas are covered, and it’s calculated on a daily basis. The account must be in the card holder’s name. The maximum annual rebate is $292.82.

**Utility Concession** This is an $82 additional rebate for helping eligible concession-card holders minimise the cost of living. The rebate is added to the existing Energy Concession. The combined energy–utility rebate for 2012–13 is $374.82. The current daily summer rate for the combined energy–utility rebate is approximately 48.38 cents per day between 1 November and 31 May, and the winter rate is approximately 177.93 cents per day between 1 June and 31 October.

**Medical Heating and Cooling Concession** This is for $121.87 per year, and you must hold a concession card. MS is a medical condition that qualifies for the rebate.

Disclaimer: This information might have changed since the time of writing. Please use it as a guide only and seek your own advice about the concessions you might be eligible for.

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For more information, go to www.communityservices.act.gov.au/wac/concessions/energy_concession

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  Heaviest part only 13kg

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Beat Christmas blues

Even the happiest people can feel down during the festive season, so take steps to prevent yourself from feeling ‘blue’ because of anxiety, depression and fatigue.

**Challenges** can arise at this time of year, when you’re forced to stay inside on hot days and many people who provide you with support are away. When you add these elements to the fact that MS is linked with anxiety, depression and fatigue, you realise how essential it is that you’re kind to yourself during this period.

“Although the Christmas-holiday season is meant to be a time of joy and happiness, it can be one of the most stressful times of the year for many people,” warns Angela Gelitch, Community Support Worker with MS Australia – ACT/NSW/VIC. “You can tell whether Christmas anxiety applies to you if you start to panic when the Christmas decorations come out rather than say, ‘Wow, look at those pretty baubles!’.”

It’s natural to feel worried or anxious sometimes, but if you feel as though you have uncontrollable worries about a lot of issues, you could have an anxiety disorder. Symptoms include feeling on edge, feeling irritable, and having difficulty concentrating or sleeping. Anxiety can also lead to fatigue.

Meanwhile, it’s accepted that living with a chronic medical condition such as MS can be a contributing factor when a person becomes depressed. Examples of other contributing factors include chronic pain, overwhelming fatigue and social isolation.

Angela recommends that people living with MS consider organising some strategies in order to make this time of year easier to deal with. “It might also be useful to think about what Christmas really means to you and to base your Christmas on that meaning,” she says. “It’s easy to get caught up in all the things you feel you should be doing, but you should ask yourself, Am I really enjoying this? If the important part of Christmas for you is when you spend quality time with loved ones, think about whether you can do so if you’re too busy and stressed to sit down with your family because you have too much to do – or if you do manage to spend time with your family but feel irritable because you’re tired, or worse still, fatigued.”

**Manage your expectations**

In order to avoid burn-out, it’s a good idea to grade your tasks as being low, medium or high priority so you focus on what’s important and don’t waste energy. It’s also helpful to remember to delegate so you can keep some of your energy in reserve and be able to enjoy family gatherings.

If you face a big task in managing your expectations, consider pacing yourself by breaking the task into smaller jobs and having a rest in between completing them. One consequence might be that you have to harness your natural desire to finish the work as soon as possible.

“Keep reminding yourself not to overdo it,” Angela says. “If you exhaust yourself on ‘one big day’, you might put yourself out of action for a few days afterwards. It’s always best to rest before you feel tired.”

Resting is especially important if you’re inclined to feel anxious or depressed because fatigue causes you to have difficulty in taking the actions you might need to take in order to lift your mood. Undertaking exercise and seeking company are two examples of mood lifters you might be too fatigued to initiate.

**Moods and emotions**

This time of year, memories and grief in relation to loved ones who’ve passed away and relationships that no longer exist can be triggered. It’s important to acknowledge the feelings, but it’s also best to manage them because depression or anxiety can lead to fatigue. If you’re prone to feeling lonely, consider organising yourself to be able to phone a friend when you’re struggling. Three other good strategies are to plan some outings; volunteer to help other people, because having company can be a useful distraction; and remind yourself that Christmas and New Year will soon be over.

If you’re worried about spending too much time alone, see whether you can pair up with someone who’ll be alone during the holidays, so you can support each other.

Conversely, if you find it stressful to spend time with your family members, stay with them for only a period you can
Multiple Sclerosis Clinic

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.

Stress-reduction tips

- Take the pressure off yourself to feel happy and have everything perfect just because it’s Christmas time.
- Set realistic expectations: do you really have to cook a roast that has all the trimmings, or would it be better to serve seafood and salad and spend the day with the family?
- Buy pre-prepared food such as shredded cheese, dips, custard and Christmas pudding.
- Don’t wear yourself out thinking about all the things you have to do; make a list, and take things one step at a time.
- Reduce financial pressure by making gifts, suggesting a Kris Kringle for the family or buying presents for the children only.
- Don’t expect things to be different because it’s Christmas time; family conflict doesn’t disappear when ‘tis the season to be jolly.
- Plan early, prioritise, ask for help, and delegate.
- Remember to keep breathing and to have fun!

Positive steps

You probably know it can also be helpful to exercise in order to alleviate ‘the blues’ and improve your sleep. Consider taking a walk or going to the beach early in the morning or late in the day, when the temperature is cooler, or attending an air-conditioned fitness centre.

Heat can be a trigger for fatigue, so remember to implement strategies for keeping cool, such as staying in air-conditioned rooms during the heat of the day, having cold baths, sucking on ice cubes, and using garments that are designed to keep your core temperature down.

Also keep in mind that if you over-indulge in rich foods and have too many alcoholic drinks, you might impair your sleep and leave yourself feeling sluggish or in a low mood.

“For your sense of wellbeing, it’s better to avoid over-indulging, and you’ll also prevent yourself from having those extra kilos creep on,” Angela says. “That doesn’t mean you can’t enjoy yourself – you can, but moderation is the key.”

Useful contacts

- Lifeline, which is a 24-hour phone-counselling service for people in crisis: call 13 11 14 or visit www.lifeline.org.au
- beyondblue, from which information about treatments for depression is available: call 1300 224 636 or visit www.beyondblue.org.au
- The SANE Australia national helpline: call 1800 187 263, 9am–5pm weekdays, or visit www.sane.org
- The Suicide Call Back Service, which is a 24-hour, ‘seven days a week’ counselling service for people in crisis: call 1300 659 467 or visit www.suicidecallbackservice.org.au/
- MS Connect: call 1800 042 138.
In 1993, Tim Ferguson was 29 and performing in London with Paul McDermott and Richard Fidler as part of the successful comedy trio The Doug Anthony Allstars. One morning, he woke up to find that the left side of his body was weak. In 1996, he was diagnosed with MS, but it wasn’t until 2010 that he decided to disclose his condition. In this edited extract from his book *Carry a Big Stick: A Funny, Fearless Life of Friendship, Laughter and MS*, Tim explains what prompted him to go public.

I had reached a point where the burden of the secret was hard to bear. My left leg was permanently wonky. It had regained the stiffness, the painless cramping I’d felt in London in the ’90s. After one too many falls, the moment came when I had to take a leap (not literally, of course) and buy a walking stick. This took me a couple of weeks. The first time I entered a chemist to buy one, I tried a couple out for size, and then I found one that was tall enough for me. It was a willow stick, a real Nanna number. I put the stick back in its hold and walked out the door. “Not today,” I whispered, limping faster, as if my legs were working hard to avoid blame for this surrender to my new limitations.

Deciding to tell your family and friends you have MS is a major decision, and deciding to tell the wider world can be even more difficult, especially if you’re a celebrity such as comedian and writer Tim Ferguson.

Things might have stopped there, but over the next fortnight, I had another couple of falls. The worst was in the kitchen of my St Kilda home. The phone rang, and I swung around in a hurry to answer it. My feet tangled and I fell headlong, like an Esther Williams water dancer in handcuffs. The corner of the kitchen bench connected with my head. I don’t remember hitting the floor.

When I came to, I roared at myself with a stream of putdowns that might have amused me if I wasn’t so furious. “Slapstick; spackstick; handicapstick; schtickstick.” It took me a couple of minutes to stand up.

“Get the stick, you wimp,” said the dictator in my mind. “These concussions are uninteresting.” Calling myself uninteresting was the darkest insult I could fire. A childhood spent being of little interest to other kids had made it a sore point. And it highlights the flawed cornerstone of my contrarianism – standing out for being wrong is preferable to being right and ignored.

I returned to the chemist and bought the willow stick. I had to admit it: the walk home was a relief. Walking was easier and safer, and I saw Russell Browne, a bloke who lived in my street. Russell got around in a nifty electric wheelchair. He buzzed by me. “G’day, Timbo,” he said, in a hurry to get somewhere. “I like the stick!” he shouted over his shoulder. I’m sure Russell would have preferred to only need a stick to get around. I figured if he was okay with my stick, everyone else, including me, would have to follow suit.

One day in 2010, I caught up with Comrade Mark [a friend]. I admitted how hard it was to keep my diagnosis under wraps after 15 years of keeping it to myself.

“It’s a career killer,” I said, exhausted. “But it’s so heavy. I can’t carry it any longer. And it’s a burden for everyone.”
The concerns of my other close friends who knew about my condition worried me. One of Rich’s [Richard Fidler’s] colleagues had seen me limping down a Sydney street and asked Rich what was wrong with me. Now that my symptoms were visible, it was unfair not to tell my friends and ask those who knew to lie when quizzed about me.

Mark was pained to see me so desperate. He said, “Ferg, which is harder? Hiding it or telling people and putting a strategy in place to deal with it?”

The next day, I went to Cross Café, a tiny café hidden in St Kilda, to be interviewed for a feature article in Melbourne’s Weekly Review by journalist Peter Wilmot. I was excited. Peter’s imprimatur would give my latest book, The Cheeky Monkey, some weight in media circles.

Once we’d talked about my book, Peter said, “I hope you don’t mind me asking, but what’s the story with the stick?”

“Off the record, it’s MS.”

“Why off the record?”

I spoke about how I didn’t want the condition to define me, and that I didn’t want MS to be the star of my book release. Peter said if I told him the full story, he’d ensure it was only part of the story, not the headline.

Between Comrade Mark, Rich and Peter, it was a perfect storm. I told Peter Wilmot the whole story, from crossed eyes to walking stick. The day the Weekly Review hit the newsstands, I started getting calls. It was out. I began to make plans for a new world.

There was one more thing to do: I had to declare it on television. There was nowhere better for this than on Good News Week, Paul McDermott’s long-running topical comedy show.

One of the reasons I had kept my secret for so long was that I’d been scared. I didn’t want others to know because I didn’t want to come up in strangers’ conversations. I didn’t want their pity. I didn’t want people to see it as a guiding force in my life, or a limiting force, either; if anything, MS was the stick that kept me going, pushing me to keep busy.

Once I came out, I was adamant to the media: “MS does not define me; I wish to define MS.” It might have seemed as though I was downplaying it. Some people leapt to their laptops to complain they found my demeanour too light. One woman (whose MS status was not mentioned) complained on the web that “He’s ignoring the people who are doing it tougher than he is”. She was right: I most certainly was, and I’ll continue doing so. The darker side of MS is implied, and the Internet has countless sources of ringing bells of doom. But I am telling my story.

My story is my own, and my use of humour and conscious optimism is my choice. The conditions of others are not for me to define. I recognise the difficulties others experience with MS. The condition has a unique ‘personality’ for each brain – each individual experiences their own conflicting combinations of symptoms. Many have a hard time of it. And I won’t pretend that I haven’t had some bad days. But everyone has those.

You can’t please all the people any of the time. Sometimes being positive gains a negative reaction. But I’d rather annoy people with optimism than cheer them with misery. No matter the reaction after going public, I wanted to be clear: I don’t spend time worrying about it. I spoke to reporter Mary Gearin on the ABC’s 7.30 Report.

Mary asked me, “Have you ever been angry at MS?”

“No,” I said, “I figure, ‘What’s the point?’ That’s like shouting at the sky because it’s raining. ‘Damn you, clouds; damn you!’ There’s no point in getting angry. Anger is the precursor to whingeing.”

I meant it. I might have had brief flashes of anger, but they pass quickly. Whingeing leads to the dark side. It’s easier to take each day as it comes than to waste breath cursing the things I can neither predict nor control. Perhaps my childhood of shifting sands trained me to be a determinist. Some things are inevitable but nonetheless surprising. That’s one of the foundations of comedy. I don’t argue with it. Or, put it this way: a boat doesn’t understand or complain about the whims of the ocean; it rides the troughs and tumult, aimed for a fair wind. That’s as good as it gets.

Some people choose to see my attitude as bravery, but it isn’t. I don’t recognise MS as something to fear. It’s an obstacle, sure, and it seems to be worsening with time. But what doesn’t? Even fine wine has a use-by date.

MS has given me gifts. To being with, I am experiencing the trials of old age, and the walking aids that go with it, before most of my generation. When the year 2030 arrives, I will have had plenty of time to adjust to fate’s robbery of my faculties. I doubt I’ll freak out as my more able colleagues might.

MS has made me start a writing and teaching career that will last longer than my ‘stand-up comedy’ or ‘TV presenting’ career ever could.

And it has made me keenly aware of what is important in my life, more aware of each hour of each day. I have always resented sleep, and that resentment has grown daily.

I don’t live each day as if it’s my last. Homer Simpson was told to do that – he spent the day sobbing, in self-pity. I live each day as if it’s my lucky day. My pyloric stenosis could have stopped me at infancy. [Pyloric stenosis is a narrowing of the opening from the stomach to the first part of the small intestine, and it causes severe vomiting in babies who are fewer than six weeks old.]

The rest is a bonus.
Happy, thanks to MS

Living positively with MS is a challenge, but Melbourne man Tony Jordan believes it’s the only way to deal with the disease – in fact, Tony says that MS has been the making of him.

You might’ve already met Tony Jordan via the pages of *Intouch*. In the Spring 2011 issue, Tony stated, “It took me a few years to come to terms with having MS, but when I embraced it, the fog lifted. I’m now happy and content.”

Tony’s story is extraordinary. In 1999, he was living in the UK and was working long days as a plant operator, when he experienced blurred vision. By 2004, he’d been diagnosed with Secondary Progressive MS, and his mobility had been affected to the extent he had to use crutches.

In November 2006 he met Leonie, who also has MS, online via the website Whispers4u. After they’d exchanged emails and phone calls for six months, Tony flew to Melbourne to spend two weeks with Leonie. During a visit to the UK some months later, Leonie and Tony discussed the future, and decided that because Tony’s children were adults and Leonie’s daughters were still young, Australia would be the best option. Tony returned to Melbourne in December 2007; the couple married in January 2008; and after a stint back in England, Tony migrated in August 2009, to live in Melbourne with Leonie and her daughters Natasha, now 18, and Jacinta, now 20.

A year earlier, Tony’s condition worsened, and his movement became limited to such an extent that he was retrenched and couldn’t get another job. However, the couple weren’t deterred. Leonie works as an administration assistant and is grateful she’s able to manage her fatigue. As is the case with all blended families, everyone had to make adjustments, but Tony appreciates having a second chance at family life. “MS made me look at myself,” he says. “I’m in a wheelchair now, and I know you can be happy being disabled – I’m proof of that.”

Tony credits counselling for his ability to turn his life around. He recently completed a Diploma of Counselling with the Australian Institute of Professional Counsellors. “I want to help other people come
to terms with their disability,” he explains. He’s planning to gain experience via MS Australia – NSW/ ACT/VIC’s Peer Support Volunteer program. To find out more about Tony’s inspiring life change, we asked him the following questions.

How old were you when you sought counselling?

I’d just turned 40, and I was working as a plant operator on a housing development in Bristol, in the UK. I loved the job and was working with a good bunch of lads. I’d come out of a bad, nine-year relationship with my ex-partner, and I was also having difficulties with my three children and their relationship with their mother, my ex-wife.

What was your motivation to seek counselling?

I was asking myself why I’d been so unhappy for so long. Also, I realised that the only person who was going to make me happy was me. I asked myself lots of questions about how my life had come to that point, and I knew I needed to talk to a counsellor. Until then, I’d thought counselling was something men didn’t need.

What did you learn?

I enjoyed the counselling process and was excited about the prospect of change. The counsellor said I’d basically worked everything out for myself and that I should consider counselling as a career – but the best lesson I learnt was to take responsibility for who I am and the decisions I’ve made.

How did your life improve as a result?

I stopped being angry and blaming everyone else for my problems. I used to be a fiery person who was prone to outbursts of shouting and swearing – basically “throwing my toys out of the pram” when things went wrong. I became aware of how I
A surprise gift

Tony says MS is “a gift that keeps on giving”. Here’s why: “Although MS has taken a lot away from me, it’s given me a lot more in return. It’s allowed me to re-evaluate the things I thought were important, and it’s given me a new perspective on my life. Because we both have MS, we feel lucky we can empathise with each other when we have bad days and our MS decides to come out and play. MS has also allowed me to really see what I’m made of. When you’re in a world of crap, you discover what you and the people around you are like.”

We all have our opinions about our condition, and there are a lot of ideas for treatment and support out there. Find something that works for you.

LIFESTYLE

was thinking and how those thoughts affected my behaviour and emotions. Counselling was also helpful for me to come to terms with having MS, which was something I’d struggled to do since I’d been diagnosed four years earlier.

How do you live according to those principles?
I’m a firm believer in ‘Thoughts equal emotions equal behaviour’ and I now try to think before I react. Sometimes it can be difficult, but with practice, it becomes natural. A good example of that was when I moved to Australia to live with Leonie and her daughters. I had expectations about how her children should behave, which caused me anxiety because the girls didn’t behave as I expected them to. I looked at the difference between my beliefs and reality, and realised I had two great stepdaughters. As a result, I became more relaxed in my interactions with them and we had a more harmonious home life. A simple re-evaluation of my core beliefs made a massive difference to all of us.

Did anything lead you to change your attitude towards MS?
Yes: two events. The first occurred when I’d been admitted to hospital for a course of steroid treatment, when I was 40. I was feeling sorry for myself, and across the ward was a young man who was there for surgery for a brain tumour. I could see how frightened he was, and I realised that MS isn’t that bad. The second event came about five years ago, when my cousin died from cancer. He was in his early forties. I definitely realised that a hell of a lot of things are worse than MS. My legs might have a mind of their own, as do my bowels and bladder, but I’m alive and I’m happy. If I start to feel sorry for myself, I think back to those two events and I stay on course.

Why did you undertake a Diploma of Counselling?
I wanted to help people help themselves improve the way they deal with things such as disabilities.

What have you learnt from your study?
I’ve gained an in-depth insight into how I cope with my everyday life, and I’m able to make better decisions.

What would you say to someone who has MS?
We’ve all heard the usual clichés, such as ‘Soldier on!’ or ‘You can beat this!’ What I’d say is: if you’re not happy, try to change the cause. We all have our opinions about our condition, and there are a lot of ideas for treatment and support out there. Find something that works for you.

Have your relationships improved?
All my relationships have improved since I undertook counselling. I talk to my parents more now I’m living in Australia than I talked to them when I lived eight kilometres away from them. I’ve learnt how to talk to people and listen to them – things I was very poor at – and because I’ve learnt those skills, I’m better in my relationship with Leonie. I also feel so much more relaxed in my interactions with people and when I’m facing anything life can throw at me.

Does a positive attitude lead to improvement in your wellbeing?
Definitely: changing my attitude has had a big influence on both Leonie’s and my wellbeing, because stress is kept to a minimum. For us, that makes a big difference to how our MS affects us. I also tend not to think of MS as something to be fought or defeated; rather, I think about the reality of living with legs that don’t want to play the game, or a bladder that seems to like the sound of the washing machine being turned on, because it keeps sending wet tracksuit bottoms to the machine. Things are easier to deal with when you break them into small parts.

Although counselling isn’t a magic wand, if you can fully engage in it and are prepared for the work involved, the rewards can be life changing.
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 that are available for loan and can be accessed if you have a computer and Internet connection.

E-books can be read on a computer, an e-reader or a smart phone. As is the case with lots of technology, not all e-books are compatible with all e-readers. The e-books we have purchased aren’t compatible with Kindles or some other proprietary e-readers, but they can be read on most other e-readers and on computers and many smart phones.

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

Breaking eggs: Finding new meaning with chronic illness
by Amsden, L.
Outskirtspress

This book isn’t about finding a cure; instead, the author aims to teach people who have a chronic illness how to integrate their physical, emotional, mental and spiritual aspects and to live more peacefully.

Lucia Amsden was diagnosed with rheumatoid arthritis 30 years ago and has a Masters degree in social work. She’s been a practising therapist for 20 years and written extensively about the positive effect that spiritual psychology can have on living with a chronic illness.

Lucia writes about her own journey with rheumatoid arthritis and includes the stories of other people who are living with a chronic illness. The contents are as follows:
- Beginning the journey
- Looking fear in the eye
- Transforming dark into light
- Finding our place in the world
- Bringing meditative moments into the day
- Establishing healing connections

MS Get Fit Toolkit
by the Canadian Society for Exercise Physiology
Website: www.csep.ca/guidelines

This online toolkit was developed by the Canadian Society for Exercise Physiology, a voluntary organisation made up of professionals who are involved in the scientific study of exercise physiology, exercise biochemistry, fitness, and health.

The resource includes information about the intensity of exercise you should aim for and how much rest to incorporate. Additional contents are as follows:
- The benefits of physical activity
- Tips for avoiding injury
- Examples of exercise options
- How to overcome barriers
- Tips for avoiding overheating

An insert that goes with the toolkit is also available and includes information about setting realistic exercise goals and devising an action plan.

The Can Do multiple sclerosis guide to lifestyle empowerment
by Kennedy, P.
Demos Health

This guide was written in conjunction with Can Do MS, an American organisation that provides lifestyle-empowerment programs for people who have MS.

The aim of the guide is to help people who have MS take charge of their own health care, lessen the uncertainty involved in having MS and promote better health. Highlighted questions are included throughout the book in order to ask, “What can I do?” so the reader is encouraged to take personal ownership of the various aspects of his or her health and health care.

The chapters include:
- Motivating and goal setting
- Living with the challenge
- Mood and cognition
- Symptom management
- Physical activity and exercise programs
- Eating well, eating easy

The author aims to help people who have MS live a richer life.

On the shelf
The LIFE program for MS: Lifestyle, independence, fitness and energy
by Epstein, S.
Oxford University Press

This book was reviewed as an e-book in the Winter 2011 issue of Intouch, and we now have print copies available for loan.

In The LIFE program for MS, Susan Epstein provides a unique approach to living with MS by way of using diet, exercise and tips for daily living. She draws on her experience as a professional athlete as well as on her work at the Jacobs Neurological Institute in New York.

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