

INTOUCH

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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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CEO's Message

Welcome to the first edition of *Intouch* for 2010. I would like to take this opportunity to wish you all the very best for a happy, healthy and safe year ahead.

There has been a significant amount of activity on the MS research front recently in the areas of stem cell treatments, oral medications and Chronic Cerebrospinal Venous Insufficiency (CCSVI) – all of which we have an extreme interest in. Our Q&A will update you on some progress in oral medications, and we will feature more on CCSVI in a future edition once more information becomes available.

In this edition, we explain more about possible stem cell treatment for people with MS – what it is and where research is up to in this area. This article should answer many of your questions following recent media coverage on this topic.

Another article of importance in this issue is on employment, which is timely given employment is the theme of this year's World MS Day to be held on 26 May. Many people with MS leave the workforce within 10 years of diagnosis, which often leads to financial hardship and/or loss of self-confidence and worth. Following an employment workshop held during the MSRA Scientific Conference in October last year, it is evident that in many cases, the opportunity exists for people to remain in the workforce when support services and funding are used. However, there seems to be low awareness of these services or how to access them. Our employment article explains what is being done to address this issue for people with MS, highlighting the services provided by MS Australia – ACT/NSW/VIC.

We will be participating in a range of activities to coincide with World MS Day this year, which will lead in to MS Awareness Week. This will run until 6 June, upon which the MS Walk and Fun Run will be held in Sydney and Melbourne. Through this event we are aiming to raise \$750,000 to increase our services to the MS community. I encourage all of you to join us in the celebrations. Finally, on behalf of everyone at MS Australia – ACT/NSW/VIC, as well as the MS community, I would like to congratulate our former long-standing Board member Graham Tribe for being appointed a member of the Order of Australia (AM) during this year's Australia Day honours. This is testament to Mr Tribe's ongoing and unwavering commitment to Australians living with MS. I hope that you enjoy reading the Autumn edition of *Intouch* and that you find the articles helpful and informative.

Bill Younger
CEO, MS Australia – ACT/NSW/VIC

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EDITOR'S NOTE

Happy New Year! It is hard to believe that we have reached 2010. It seems only yesterday that we were celebrating the new millennium!

I hope you all had a wonderful festive season and that the start to the year has been enjoyable. I always find it's a good time to clear out the closet and set some goals.

Speaking of which, *Intouch* has a lot in store for you over the next year. As you know, the magazine has gone through some change but you will now begin to enjoy some consistency and be able to find exactly what you're looking for, each time you receive the magazine.

We're also looking at how we can deliver the magazine content via other mediums – for example, in audio format – to increase your options and the ease with which the information is accessed.

We welcome your suggestions and we will keep you updated as these plans progress.

The theme of this edition is 'Parenting and MS'. Questions around pregnancy and parenting often arise throughout one's MS journey, so we've provided you with some practical advice, as well as some stories from parents with MS in various situations. We discuss the hereditary nature of the disease as well as provide additional resources to assist you in whatever stage you may be with parenting.

Coming from a family who has had its own health challenges, it has been easy to relate to how, despite MS, families can still thrive through love, support, and being open and honest with one another. Nevertheless, everyone's situation is a personal one so I'd like to thank those families who shared their stories with us.

Among the other great articles in this issue, we provide you with a sneak peek into what we have planned to celebrate the 2010 World MS Day (26 May) and MS Awareness Week (26 May – 6 June). Mark the dates on your calendar and keep checking our website at www.msociety.org.au to find out what's happening near you.

If you have any feedback or comments about what you would like to see more or less of in the magazine, please email me at intouch@msaustralia.org.au or post your letter to *Intouch*, PO Box 210, Lidcombe NSW 1825.

I hope you enjoy this edition and I wish you all good health and happiness.

Rebecca Kenyon

Editor

Have you moved or changed your contact details?

Please contact MS Australia – ACT/NSW/VIC to update your address, phone numbers and email address.

Freecall™ 1800 042 138 or email msconnect@msaustralia.org.au

YOUR SAY

Thank you for sharing your hints, tips and feedback. We'd love to hear more!

Eager for more on oral meds

I just wanted to say that I really enjoyed this edition of *Intouch* (Summer 09). I particularly enjoyed the story on oral medications as I know they are a priority for myself and other people with MS. I will eagerly await future updates. Thank you.

W.K, via email

Read more about the progress of the oral drug fampridine on page 9, which has been approved by the US Food and Drug Administration to treat walking difficulties in people with MS.

We're all in this together

As a person with MS and a father of two boys under four, I am stoked to be able to offer some wisdom to your fantastic magazine. I've often argued that my boys show an incredible degree of empathy as a result of what they call "frustrated legs". This was put to the challenge recently when I was left wondering over an imminent diagnosis. Uncertainty left my wife and I a little frazzled and the boys readily picked up on the mood, causing outrageous trauma. It served as a timely warning of just how enmeshed our children are in our diseases and, in a good way, how we're all in this together.

A Cook, NSW

Read more about Andrew's experience on page 12.

My very own 'Indiana Jones'

Yesterday, my seven-year-old son Kobe saw an article in your Summer 09 edition of *Intouch* about the little boy who raised an amazing amount of money through the MS Readathon. Kobe then suggested he donate his entire savings to find the cure. I explained that what he does for me is enough – he is there for me as I go through life, including the tough times, helps with everyday tasks and is always pushing me to exercise.

My family is why I can be the mother of exceptional children – Kobe and my four-year-old twin daughters. MS aside, I am extremely fortunate. Regardless of all the trophies Kobe has and will win, he truly deserves the trophy for 'the most helpful and compassionate son!' Thank you Kobe.

C Payne, NSW

What is all this about CCSVI?

We are currently staying at the residential unit at the Studdy MS Centre in Lidcombe. One of the residents brought up the subject of Dr Zamboni's research into CCSVI as a possible cause (with a subsequent treatment) for MS. We have since done some research on the internet and this sounds promising. However, we have asked around and nobody seems to know much about it. As a result, we are writing to ask that we are kept up to date with all of the possible MS treatments available here, and abroad. For example, can you explain this potential treatment and procedure; who may be suitable for treatment; where is the research currently up to; and when might it be accessible to people in Australia?

We are eagerly awaiting more information and have our fingers crossed for a positive outcome.

M.C & B.C, NSW

Thank you for bringing this important topic to light. As we go to print, there is an increasing amount of information being released about CCSVI (Chronic cerebro-spinal venous insufficiency)

as a potential cause and treatment for MS. By the time our next edition is released (June 2010), we should have a lot more information to provide you with. In the mean time, I encourage you to call MS Connect on 1800 042 138 and/or keep checking our website (www.mssociety.org.au) for the most up-to-date information on this, and all other research being conducted on possible MS treatments.

Keep your feedback and stories coming in. Next issue's theme is 'Mind Matters'. Write to us at intouch@msaustralia.org.au or post your letter to 'Intouch' PO Box 210, Lidcombe NSW 1825

Each reader to have their letter published will win an organic tea and chocolate indulgence pack!

NEWS

Melbourne Summer Cycle Raises Over \$540,000 for MS

On 21 February, more than 5,000 cyclists took part in one of Melbourne's most renowned cycling events, the Melbourne Summer Cycle, in support of people living with MS.

As participants pedalled the 40km throughout marvellous Melbourne and over the West Gate Bridge, the energy and team spirit was electrifying.

Participants were committed and determined to achieve their fundraising goals, with more than \$540,000 raised, so far, in support of people living with MS.

Michael Egan raced to the top of the fundraising leader board just days before the event, raising more than \$15,000 after emailing all of his contacts in search of sponsorship.

For the second year running, 'Swan Hill Supporting MS' (pictured) were our highest fundraising team, raising over \$37,000. Each year, the Swan Hill community support their local resident Kerry Dullard who lives with MS.

On behalf of the MS Australia – ACT/NSW/VIC events team, we would like to thank all of our fundraisers for their outstanding effort and dedication to support such a worthy cause. Thanks must also go to our wonderful volunteers who put in an exceptional effort in making the event such a great success.

Did you know?

The 2009 MS Sydney to the Gong Ride has fundraised more than any other MS Australia – ACT/NSW/VIC event in history. Thanks to the enormous support received, the Gong Ride has exceeded the \$3.1 million mark. Thank you and congratulations to everyone involved!

MS Australia Represented in Europe

On 21-22 January, MS Australia – ACT/NSW/VIC's Senior Clinical Psychologist, Dr Gary Fulcher, and Medical Director, Dr Garry Pearce, both presented papers at the 1st International Conference on Patient Education in MS held in Hamburg, Germany.

Dr Pearce spoke on Newly Diagnosed Education Sessions while Dr Fulcher was invited to speak about the development of a Decision Aid to assist women with MS to make family planning decisions. The paper was well received and may be translated into multiple languages.

While in Europe, Drs Pearce and Fulcher also visited the National MS Centre in Melsbroek (Brussels), Belgium. Here they observed great differences in the way people with MS are supported in managing their disease, as well as different governmental and MS Society structures. They have brought this information back with them, as well as the long-term connections forged with key MS researchers and clinicians from Germany, Belgium, Italy, Scandinavia and Sweden.

2009 John Studdy Award Winners Announced

Congratulations to Carol Cooke and David Barnes – the winners of the 2009 John Studdy Award. This is the most prestigious award given by MS Australia to an individual in recognition of their consistent effort to make a difference for people living with MS and/or their families.

Carol Cooke has been living with MS for more than 10 years. In 2001, along with a member of MS staff, Carol created the concept for the 24 Hour Megan Swim. Now in its 10th year, the event has raised \$1.5 million for people living with MS.

David Barnes was first appointed on the Board of the MS Society of WA in 1994 and has been the President since 2000. The MS Society of WA's contribution to research and member (client) services has grown substantially under David's leadership.

Again, we thank Carol and David for their tireless support and contribution to the MS community.

MS Advocate Receives Australia Day Honours

MS Australia – ACT/NSW/VIC would like to congratulate our former long-standing Board member Graham Tribe (pictured) for being appointed a member of the Order of Australia (AM) during this year's Australia Day honours. This is testament to Graham's ongoing work and support to Australians living with MS over the past 37 years.

"Over the years, Graham's unwavering commitment has resulted in many significant developments for people living with this unpredictable disease," says Bill Younger, CEO, MS Australia – ACT/NSW/VIC. "For nearly four decades, Graham has served on our Boards and spearheaded momentous changes, like the creation of the MS Readathon as a national program to increase the money raised for the people that need it most."

Among many other achievements, one of Graham's most noteworthy would be the establishment of MS Research Australia – a move that revolutionised and accelerated Australian research into MS.

"This award was unexpected and it was a great pleasure to receive it," says Graham. "However, the most important thing is the progress being made in both research and increased support for people with MS. It takes a team of people to get these steps in place and I need to recognise the effort of many others in achieving better outcomes for people with MS."

Mega Swim Turns 10!

The 24 Hour Mega Swim held at Melbourne's Fitzroy Pool on 26 – 27 February, marked the Mega Swim's 10th anniversary, with a record number of teams participating.

This fun, community fundraising event was developed by Carol Cooke, a person living with MS, in 2001. Since the first swim held at Fitzroy, the event has grown nationally with swims taking place in NSW, the ACT, Victoria and SA. In fact, 2010 will see swimmers raising awareness and funds for MS in Japan and Alaska as well. The event has caught the attention of a few people with international connections so teams have been created in Japan and Alaska to swim at the same time as one of a number of different 24 Hour Mega Swims in Australia.

Over the ten-year period, the 24 Hour Mega Swims have raised \$1.5 million with all the proceeds going towards the MS Australia – ACT/NSW/VIC Go for Gold Scholarships and Financial Assistance Program.

As Carol Cooke says, "It is my dream to see the Mega Swim run nationally in every state and the scholarships made available to all Australians living with MS. This is slowly becoming a reality!"

We invite you to be part of the 24 Hour Mega Swim. For upcoming dates and locations, visit

www.megaswim.com

New Resource to Help Manage Pain

MS Australia – ACT/NSW/VIC is pleased to announce the release of its new resource, Managing Pain for People Living with MS.

With the generous grant received from The Marian & E.H. Flack Trust, this practical and informative booklet has been developed to provide people with MS, their families and carers, information about managing MS-related pain. An earlier project conducted by MS Australia – ACT/NSW/VIC that trialed a pain management program for people with MS identified that there was a need for easy to understand, Australian-specific information on this topic. This new booklet provides answers to commonly-asked questions about pain; information on relevant medications;

suggestions to work more effectively with your healthcare team; and practical strategies to self-manage MS-related pain.

Managing Pain for People Living with MS has been written by MS Australia – ACT/NSW/VIC Clinical Psychologist and pain specialist Megan Varlow, and was developed with the assistance of people with MS and MS health professionals. Download a free copy of the booklet from our website at www.mssociety.org.au/live/publications-books.asp or please phone MS Connect on 1800 042 138.

NEWS: ADVOCACY

Influencing Change

An update on how the advocacy team at MS Australia is creating a better future for people living with MS.

Prime Minister Announces Feasibility Study into Disability Support Scheme

In November last year Prime Minister Kevin Rudd announced a new feasibility study into a Lifetime Care and Support Scheme for people with disabilities in Australia.

This could change the way that disability services are currently funded, moving away from a rationing system to one that works on an entitlement basis, much like an insurance scheme. This announcement follows the very public campaign for a National Disability Insurance scheme as an alternative and sustainable system.

The Productivity Commission will conduct the feasibility study and an independent panel has been appointed to ensure that people with disabilities, their families and representative organisations can participate.

The study will focus on the scope and cost of a lifetime scheme, looking at ways that services – such as home care, equipment, home modifications, allied health etc – can be provided in coordinated and individualised ways.

The Productivity Commission will be seeking submissions and conducting public hearings around Australia. MS Australia will be making a detailed submission about the support requirements, costs and coordination issues for people with MS.

The Commission is due to report to the Government in June 2011.

For more information about the feasibility study or the MS Australia submission, please contact the Advocacy Team via MS Connect on 1800 042 138 or, visit the Productivity Commission website at www.pc.gov.au/projects/inquiry/disability-support.

Projects on the Go

The MS Australia Policy Team continues to address the issues announced in our 2010 – 11 *Policy Issues Statement*, which was delivered with your Summer 2009 copy of *Intouch*. In particular, we are compiling submissions to government inquiries into consumer involvement in the Pharmaceutical Benefits Scheme, the review of aged care funding arrangements (allowing us to highlight the unmet needs of young people in nursing homes), pursuing changes to the Victorian building code, and working with employer groups and other chronic illness organisations on advising employers on flexibility arrangements for employees with a chronic illness or caring responsibilities. We will provide updates in future editions of *Intouch*. For information about these initiatives please contact the Advocacy Team through MS Connect on 1800 042 138.

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responsibilities. We will provide updates in future editions of *Intouch*. For information about these initiatives please contact the Advocacy Team through MS Connect on 1800 042 138.

Update: NSW Medical Energy Rebate

The NSW Medical Energy Rebate became effective 1 January 2010 to provide an annual rebate of \$130 to assist people on low incomes (such as pension card holders) with MS, and other heat and cold intolerant conditions, with their energy bills.

However, some people in NSW may have encountered resistance from GPs in signing the required forms because 'advanced MS' is given as an example of one condition that may qualify. If you run into this problem, please advise your doctor that 'advanced MS' is given only as one example and that, because you have an 'objective reduction of physiological functioning at extremes of environmental temperatures', you do indeed qualify. This is the advice we have received from Industry and Investment NSW which administers the scheme.

Also, staff at some energy retailers are only now learning that the rebate exists and many retailers do not yet have the systems in place to provide the rebate on your bill. However, your rebate can and will be backdated. For further assistance on this or the Medical Cooling Concession in Victoria, please contact MS Connect at 1800 042 138.

Expanded MS Employment Service

From 1 March MS Australia – ACT/NSW/VIC will commence a new specialist employment service for people with neurological conditions in Victoria.

MS Australia – ACT/NSW/VIC has been contracted to the Job Services Australia Program – an initiative of the Department of Education, Employment and Workplace Relations.

Previously, MS Australia – ACT/NSW/VIC could only provide employment services to a maximum of 16 people at a time. This new contract has no limit, giving all Victorian clients employment support when needed.

The new contract enables MS Australia – ACT/NSW/VIC to provide employment preparation services, job search, job placement, workplace equipment/modifications and job retention support. After advocating for a long time for the introduction of job retention services alongside job placement, this contract provides for responsive on-the-job support for people with chronic illness and emerging disability. This is well suited for people with MS needing a range of assistance.

This new contract will also position us to tender for further contracts in 2012 that may open opportunities to expand employment services into the ACT and NSW. Call MS Connect on 1800 042 138 for more information on this and other relevant employment services in your area.

Q&A

Your MS-related, health and lifestyle questions answered.

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

Q.

I have been following all of the news in relation to the drug fampridine, which is supposed to improve walking for people with MS. If it is approved by the US Food and Drug Administration, when will it be available in Australia, and will it be subsidised for people with health care cards?

A.

Firstly, for some background, fampridine (also known as dalfampridine, Neuralan© and Ampyra©) is a compound which has been used for a variety of non-medical purposes, mostly in the laboratory setting. Recent phase III clinical trials have shown fampridine to improve walking for people with MS. Last year the US pharmaceutical company responsible for the medication lodged an application with the US Food and Drug Administration (FDA) for a licence to use fampridine to treat walking difficulties in people with MS. This application was approved on the 22 January this year.

However, for a medication to be approved for use in Australia, it first needs to be registered with the Therapeutic Goods Administration (TGA). It is up to the pharmaceutical company who is responsible for the medication to decide whether or not they wish to apply for registration. It would be quite unusual for a company to apply for registration in Australia before they have made a successful application overseas where there is a much bigger market, such as in the USA or Europe.

Once a pharmaceutical company applies to register a medication with the TGA, the TGA has eight weeks to decide whether to accept the application. Once an application has been accepted, the average time until a decision is made is around 60 weeks. So, from the time the pharmaceutical company decides to make an application to the TGA, it could take approximately 15 to 16 months to be approved. At the time of writing, MS Australia – ACT/NSW/VIC was unaware of an application being lodged with the TGA for fampridine.

Once a new medication is registered with the TGA, doctors can then prescribe it but the patient must pay the full cost if they wish to have the medication dispensed. If the company wants their medication available at a subsidised rate, they need to make a separate application for a Pharmaceutical Benefits Scheme (PBS) listing. This can only be done once the TGA has registered the medication.

The process of applying for a PBS listing includes a complex evaluation of the degree of benefit the medicine is likely to give measured against the cost to tax payers, and compared to already available treatments. This evaluation is carried out by the Pharmaceutical Benefits Advisory Council (PBAC) which meets three times a year in March, July and November. If the drug is approved at one of these meetings, it may be added to the PBS at the next major update which happens in April, August and September.

Unfortunately, manufacturers do not always consider it worth the cost to apply for a PBS listing given how small the market is in Australia. In other instances, the drug may be declined by the PBAC because the benefit it provides may be small in relation to how much it would take up from the PBS budget.

Overall, fampridine is unlikely to be available and subsidised under the PBS (if accepted) until August 2011 at the very earliest. However, this is a step in the right direction and a positive sign for improved treatment options for people with MS.

MY STORY

Embracing Change

While life has changed a lot for Mark Fisher since he was diagnosed with MS 14 years ago, his carefree attitude and willingness to take on any new challenge has helped him to look at the brighter side of life. He shares his story with Rebecca Kenyon.

I spoke to Mark Fisher just a few days before Christmas. His children (aged 16, 17 and 21) and his loving wife and carer Brenda were all home to celebrate the festive season. As we chat about his life, I feel inspired – inspired because Mark Fisher is a down-to-earth Aussie bloke who is grateful for his lot and can find the good in almost every challenging situation.

Mark was 34 and working in a “great” job for Ansett when he started to feel more tired than usual and developed a slight limp. Working anywhere between 50 and 60 hours a week while raising a young family, Mark put it down to “working a bit too hard”. However, to “keep the peace” Mark went to see a doctor and was referred to a neurologist. Four days in hospital and numerous tests later Mark had his verdict – it was multiple sclerosis.

With a young family, a good job, great income and an active lifestyle, what did an MS diagnosis mean? Desperate to find out more, he contacted the MS Society (now MS Australia – ACT/NSW/VIC) for information and also joined a support group. “I decided that I would still try to live my life as full as possible,” recalls Mark. “I wanted to work as much overtime as I could and still be very active for the kids.”

However, being diagnosed with progressive/relapsing MS, he admits that it wasn’t long before the MS started to take its toll. “I got tired and started to make a few silly errors. Things just started to snowball for me and I eventually had an accident at work.”

Something had to give and Mark was forced to take an early retirement at 37. While extremely disappointed, Mark was able to look at the positives. “I had to grow a lot and accept change. [Leaving work] was difficult to do, but I think it has improved me as a person and I haven’t given up.”

Mark was fortunate to receive a lump-sum disability payment from his employer, which was part of the company’s insurance policy. “I was actually quite lucky that certain things happened when they did because not long after I received the payment, Ansett went belly-up,” he says. “This has helped us pay for our house, which my wife designed with a long-term view for a wheelchair.

“Brenda works part-time and I do get the disability support pension, which helps. It has been hard raising three young children on our income. I’ve had to sit back and watch other people work their way up in jobs and really improve their income, whereas mine has slowly gone backwards. I have had my name down with a job agency for a while ... I’d love to feel like I was contributing in that way again.”

Through all this, Mark can still look at the glass half full. “The best thing I can take from leaving work early is that it meant I could spend more time with my family and be more involved,” he says. “If anything, MS has allowed me to be here for my kids.”

No Regrets

Six years after being diagnosed, Mark’s MS was progressing. He had slowed down quite a lot and needed help with many things. He began using a wheelchair sporadically to aid his mobility and since 2002 has been in a wheelchair almost full-time, enabling him to be much more mobile and involved in life.

Mark admits that the decision to use the wheelchair wasn't easy. "The wheelchair was something that was just so difficult to accept. For me, it was the final straw. When people see you in a wheelchair you're instantly recognised as a disabled person. I had really tried to avoid that. Lucky for me, though, common sense prevailed. If I still wanted to be included, I needed to accept change. Without the chair my family would go out without me because I couldn't move around very easily. Once I got into a wheelchair I became part of their lives again."

While there aren't any specific medications to treat Mark's type of MS, he is determined to fight it and never ask 'what if?' From immunosuppressants and steroids to chemotherapy and even naturopathy, Mark is willing to try anything. He has participated in a number of drug trials – including one of the first stem cell trials in Australia – with the hope that someday, something will work.

Seeking New Interests

With a motto to embrace life, Mark can now boast about doing things he never thought possible. Once an active sportsman, he has now taken to singing in a men's choir, writing about his own experiences and public speaking in his MS Ambassador role, which he shares with his wife. "Since the diagnosis, I've been living my life with different values – those well outside of my comfort zone. As a result, I've developed solace-seeking interests I wouldn't have done previously, such as singing loudly among a great group of guys in a choir. The changes in my persona are radical, but so is my life and the many choices that I am fortunate to make. I've also become a lot more selfless. I love Mark Twain's quote, "The best way to cheer yourself up is to cheer someone else up," and I think that makes a lot sense. I love talking to people to share my experience. I'm also very happy ... I love to laugh, smile, and because of all this I feel advantaged."

Mark's determination was rewarded with a \$3,000 MS Australia – ACT/NSW/VIC Go for Gold scholarship last year. This will go towards his family's travel expenses to perform in the World Choir Games in China in July. "I haven't been able to travel very much so it's going to be a wonderful experience for us in China, especially to be able to share it with my wife and daughter. If it weren't for the scholarship, we wouldn't be able to go."

So what is Mark's secret to living a full and happy life? "As long as I can still manage to smile when things appear to be getting on top of me, regardless and in defiance of all challenges, I can still feel like a winner. I would suggest to others: Don't give in, embrace the challenges life throws at you and find a way to overcome them. You just have to make the best of your own situation."

COVER STORY:

In the Family Way

Questions around pregnancy and parenting often arise throughout one's MS journey. Rebecca Kenyon unravels the research and talks to those in the know to discover, successful pregnancy and parenting can be enjoyed by many people with MS.

Key parenting considerations around health, finances, emotional wellbeing, as well as social and religious circumstances, are similar for everyone. However, for people with MS the questions run even deeper: Will MS interfere with my ability to have healthy children; will pregnancy and labour make my MS worse; can I still be a good parent with MS; how will MS affect my children..? Given the complexity and importance of these decisions, MS psychologists have developed a decision aid (see further reading list) to help women and their partners make family planning decisions. Here, we also begin to answer some of these questions, bearing in mind, however, that it is important to consult your healthcare team about your individual circumstances.

Can I still bear healthy children?

Research reveals that MS does not affect a woman's fertility or her ability to carry or deliver a healthy child. Nor does it have any long-term effects on disease progression and long-term disability.

In fact, it has been widely reported that MS relapses can significantly reduce during the third trimester of pregnancy. While relapses can also increase during the first three months after childbirth, breast-feeding has been found to potentially keep relapses at bay. As a result, further research is underway into the potential relationship between hormones that may be common to pregnancy, lactation and MS disease activity.

Despite the minimal risk of pregnancy for people with MS, there are a few things both men and women should consider when planning to start a family:

- **Consult your healthcare team.** Plan and discuss your options with your healthcare team – neurologist, GP, obstetrician, midwife, MS nurse, and occupational therapist (to assist with any adaptations needed in the home or with equipment such as prams). Also, be sure to talk to your employer about your leave entitlements.
- **Medication.** Some medications are not suitable for pregnant or nursing mothers. It is important to consult your neurologist and GP about the correct course of action prior to trying to conceive (or immediately following an unexpected pregnancy) and while breast-feeding.
- **Men with MS.** While fertility does not appear to be impaired in men with MS, nerve damage caused by MS and its symptoms can impact on sexual function. Medical treatments are available, as is the option to use IVF. Men with MS also need to be cautious about medications when a couple is actively trying to conceive.
- **Managing MS symptoms.** Some MS symptoms may become more prominent during pregnancy, including fatigue, bladder urgency and frequency, as well as balance and back pain. These symptoms can be managed with the assistance of your healthcare team.
- **Childbirth.** There is no indication that epidural or general anaesthesia carry an increased risk for women with MS. Depending on the fatigue related to childbirth or problems with weakness, spasms, stiffness or lack of sensation, some women may require additional assistance with labour and delivery.

- **Breast-feeding.** Discuss options with your partner and healthcare team around breast-feeding. While the research mentioned above is promising, women may choose not to breastfeed for a number of reasons, such as a relapse, weakness in one's arms or fatigue.
- **Plan for Parenthood.** "Parenting is a life-long commitment, so discussions about parenting and household roles may be needed to plan for the possibility of the MS-affected parent being temporarily or permanently disabled in some way," advises Dr Gary Fulcher, Senior Clinical Psychologist, MS Australia – ACT/NSW/VIC. "It is important for males and females to reconsider traditional gender roles, and for both parents to accept help when it is needed." MS health professionals can help couples to understand and resolve these challenges.
- **Emotional readiness.** This is important for all couples planning a family, with or without a chronic condition involved, warns Dr Fulcher. "Among people with MS, it is important to ensure that both Mum and Dad have resolved the trauma and other emotional distress related to the MS. Included in this resolution should be comfort in the relationship, a reasonable financial plan, and knowledge and comfort about seeking care and support from family and community resources." If individuals are having trouble with these issues, MS clinical psychologists can assist with advice or specific therapies. For couples having trouble, input from Relationships Australia (www.relationships.com.au) may help. Your GP can also refer you to local counselling services.

Will my child have MS?

The short answer is no, it is highly unlikely. "Genetics, as well as virus activity, environmental factors, stress, and immune system sensitivities have all been found to play a role in the development and progression of MS," explains Dr Fulcher. "MS is not contagious, and is not directly inherited."

Essentially, for every 1,000 people in Australia:

- One person on average will develop MS in their lifetime (a risk of 0.1 %).
- If one parent (or a brother or sister) has MS, the chance increases to about 2%.
- If both parents have MS, the chance increases to about 12%.

"Even in the unusual circumstance of both parents having MS, children are most likely (88 percent) not to develop the disease," explains Graeme Stewart AM, Professor of Medicine at the University of Sydney and Westmead Hospital, and member of the five-member governance committee for the International MS Genetics Consortium. "The risk is slightly higher for girls than for boys and the risk is also slightly higher when the mother has MS, but the differences are small. As yet, researchers do not have a good explanation for these findings.

"The clearest evidence for a genetic contribution to MS comes with the much higher risk if you have an identical twin with MS who has, of course, an identical genetic make up. Even then, however, MS only occurs in both twins approximately 30 percent of the time."

It is also worth noting that, if a child of a parent with MS does develop the disease, the severity or type of disease activity is not likely to be the same, adds Professor Stewart.

Why then, are genes so important? "If a parent has an inherited disease like Huntington's chorea, each child has a one in two chance of having the disease," explains Professor Stewart. "If a child is born with cystic fibrosis (CF), each subsequent brother or sister has a one in four risk of also having CF. This is because both of those diseases are caused by an abnormality in a single gene. These are called simple genetic diseases. MS, however, falls into the group of complex genetic

disorders – complex because many genetic factors need to come together in the one person. In MS, there is probably ten or more genetic factors that need to come together in the one person. “The real importance of studying the genetics of MS lies in the potential that it carries to provide scientists with the leads to discovering the cause of the disease and, subsequently, the cure. Great inroads have been made in this area and 2010 is poised to be an exciting year in MS research.”

How can I be a good parent with MS?

This question will arise whether you’re planning a family or you already have children when an MS diagnosis is confirmed. For the latter especially, this can be a difficult time as one questions their ability to continue supporting the family – physically, emotionally and financially.

Depending on a family’s circumstances as well as what the person with MS is experiencing, family dynamics may need to shift slightly and family activities adjusted. However, MS should not have a negative impact on the bond a parent has with their child. It is important to provide children with a secure and loving environment in which to grow and sometimes it may mean being a little more flexible and creative when thinking about ways to support your children to do the things they enjoy. Having open and honest communication and taking advantage of quality family time is important. MS Australia – ACT/NSW/VIC has, for many years, held Kids and Teens Days and Family Camps in Victoria. These programs have an educational approach aimed at providing children with the opportunity to meet others who have a parent with MS, have fun, learn more about MS and have their questions answered. Keep checking the ‘Events’ section in this magazine to see when our next programs are scheduled.

“For all children, the experience of living successfully with a family member with an illness or disability can help to shape them into more compassionate and empathetic individuals,” advises Dr Fulcher. “Rather than being a weight for children to bear, MS can be, if handled calmly and effectively, a helpful life lesson to better prepare children and adolescents for a mature adulthood.”

Questions around supporting one’s family financially often go hand-in-hand with concerns around future employment. We have included an article on this topic in our ‘Lifestyle’ section on page 36. It is also important to be aware of any financial benefits available from the Government. Contact Centrelink on 132 717, visit www.centrelink.gov.au or call MS Connect on 1800 042 138 for more information.

How do I talk to my children about MS?

MS Australia has developed a free *Family Matters* Information Kit to assist families and carers of people living with MS. It outlines many beneficial topics for family discussion, including how to communicate with children about MS.

Overall, it is important for a trusted parent or adult to explain MS in words and in ways that children understand. Children will have the greatest difficulty understanding symptoms that they cannot see. It is often useful to describe and demonstrate them in a practical way that they can understand. For example, getting the child to walk with weights on both feet for a few minutes to give the experience of MS fatigue.

Most children will, at some stage, want to know more about MS and there are several child-friendly options available. There is information they can read either alone or with a parent, such as our booklet *Has your mum or dad got MS?* Children can also look up information on the internet (together with a parent), watch a video, go on a doctors’ visit or speak with someone from MS Australia – ACT/NSW/VIC.

Where can I get help?

Your healthcare team will be your key contacts regarding help and questions around pregnancy and parenting.

MS Australia – ACT/NSW/VIC can also help. We currently provide a number of programs and resources specifically for parents and families living with MS, many of which have already been mentioned.

Spending time with other parents living with MS can also be reassuring. The MS Australia – ACT/NSW/VIC Peer Support Program offers both one-on-one and support group services to people with MS, their families and carers. Read more about this program on page 28.

In particular, MS Australia – ACT/NSW/VIC allied health professional teams provide specialist support for people with MS. Your Community Support Worker will be a key point of contact regarding any questions or concerns you may have, as will our other specialists, such as occupational therapists and clinical psychologists. To access our services call MS Connect on 1800 042 138.

Disclaimer: Information in this article should not be used for individual medical advice. Consult your healthcare team as required.

Sources: For a full list of information sources for this article, please contact the editor by emailing intouch@msaustralia.org.au

Further Reading

The following books on parenting and MS are available from the MS Library. Contact the library on (03) 9845 2809 or email library@msaustralia.org.au

- **Multiple Sclerosis: a guide for families**
By Kalb, Rosalind C., Demos Vermande (2006)
- **Multiple Sclerosis and Having a Baby**
By Graham J., Healing Arts Press (1999)
- **Multiple Sclerosis: the questions you have, the answers you need**
By Kalb, Rosalind C. (ed), Demos Medical Publishing (2008)
- **The Disabled Woman's Guide to Pregnancy and Birth**
By Rogers J., Demos Medical Publishing (2006)
- **MS In Focus** is a highly regarded bi-annual publication produced by the Multiple Sclerosis International Federation. The following installments provide useful information around genes, pregnancy, parenting and MS:
 - **Genetics & hereditary aspects of MS** (Issue 8, Aug 06)
www.msif.org/docs/MSinFocusIssue8EN1.pdf
 - **Special focus on family** (Issue 3, Feb 04)
www.msif.org/docs/MSinFocusIssue3EN.pdf
- **The Motherhood Choice: A Decision Aid for Women with MS**
Developed by psychologists from the University of Technology Sydney, School of Psychology and Dr Gary Fulcher, Senior Clinical Psychologist, MS Australia – ACT/NSW/VIC

CASE STUDY

Andrew Graeme-Cook

Age: 39

Children: Two sons, aged 2 and 4

When were you diagnosed with MS? In 2002 I suddenly went numb on my left side. An MRI revealed I had MS. It didn't affect me much until three years later when I had another attack. By this time I was married with a baby on the way.

How does MS affect you day-to-day? I mainly have trouble with mobility or what my son describes as 'frustrated legs'. I use a wheelchair when I go out into the garden and I use a walker when I go out to the shops. Shortly after the birth of my second son, I left work to become the primary carer of my kids. Now my condition has progressed to the point where my wife has left work to be my full-time carer.

How do you get by financially? We were fortunate to receive an inheritance with which we could buy our home on the NSW North Coast. I also receive the Disability Allowance and Cath receives the Carer's Allowance. The MS Australia Advocacy team also do a great job of helping people with MS secure other benefits, such as the recent NSW energy rebate.

How do you balance parenting roles? You have to accept your circumstances and allow people to help. I still do as much as I can. I take care of all the cooking and the late night problems with the children. A lot of our friends are fit and active people, so I can send the boys off with them to go surfing. They know their father can't do that for them and I don't let it bother me because I feel I can provide in other ways. I'm a scientist by background so I think the whole education aspect of life is what I can help them with most.

How do you explain MS to your children? For young children, they seem to have a very good understanding of what has to be. I grew up with an older father and I know he had issues about being old but to me, he was just Dad and it didn't really matter. That's what I'm finding with our kids.

How would you describe your experience as a parent? My boys are the best thing that has happened in my life – with or without MS. A great positive of parenting with MS is that you are present in your child's life. When it comes to parenting and MS, people need to realise that they're part of a mini team and you're all in it together.

CASE STUDY

Rachelle Stern

Age: 40

Children: 2-year-old girl and another on the way

When were you first diagnosed and how does MS affect you day-to-day? I was diagnosed with MS in 1995 when I was 25. My legs are mostly affected and I have some bladder concerns as well.

How do you manage your symptoms? I usually treat exacerbations with prednisolone and I also use a walking stick when I'm out and about.

When did you consider having children? The jury was really out for me, especially as I was getting older in my thirties, as to whether I could, should or would try to have children. I decided that I would really need a partner who wanted a child as well and who wanted to be an active parent. I married my husband Richard in 2007 and he is most definitely that man. I fell pregnant soon after and our daughter is now almost two.

How did you manage your MS through pregnancy and birth? When I was planning pregnancy, I talked to my neurologist, especially with regard to medications. He was very supportive about our decision to start a family. Once pregnant, I didn't have any formal attacks and my bladder issues improved slightly. They're even better this time around. I'm pregnant again! The baby is due in July.

I had the most amazing natural birth. My obstetrician was concerned about the fatigue levels but I wouldn't take any pain relief. All I needed was help to turn over because I was so exhausted by the end.

Did you have any concerns about managing parenthood and MS? I used to be concerned that our daughter wouldn't have a mummy who could run after her. However, I've been doing this for two years now so I've realised that there is a way around everything. Kids are also really intuitive and she realises my limitations without even knowing it. If you just keep kids informed about what's going on, they're okay.

There are certain things I can't do with my daughter but I just find other ways to bond with her. We cook together and meal times are special for us.

Overall, I believe that, if being a parent is something you really want, don't not do it because of MS. There is a way around everything and there is help if you need it.

FEATURE:

Stem Cell Treatments & MS

Following significant media coverage and interest in stem cell treatments for MS, we've sourced the latest information to help people with MS gain an introduction to what stem cells are, and where research is up to in this area.

Stem cell science shows much promise for the future treatment of a wide range of diseases and conditions, including MS. However, stem cells have had high levels of media and public attention and, while there is good cause for hope, much of the research is still in the early stages.

What are stem cells?

The body is made up of about 200 different kinds of specialised cells such as muscle cells, nerve cells, fat cells and skin cells. All specialised cells originate from stem cells. A stem cell is a cell that is not yet specialised. The process of specialisation is called differentiation and once the differentiation pathway of a stem cell has been decided, it can no longer become another type of cell.

Stem cells have different levels of potential. A stem cell that can become every type of cell in the body is called pluripotent, and a stem cell that can become only some types of cells is called multipotent.

Stem cells are found in the early embryo, the foetus, amniotic fluid, the placenta and umbilical cord blood. After birth and for the rest of life, stem cells continue to reside in many sites of the body, including the skin, hair follicles, bone marrow and blood, brain and spinal cord, the lining of the nose, gut, lung, joint fluid, muscle, fat, and menstrual blood, to name a few.

In the growing body, stem cells are responsible for generating new tissues and once growth is complete, stem cells are responsible for repair and regeneration of damaged and ageing tissues. Stem cells are often divided into two groups: adult stem cells (also known as tissue-specific stem cells) and embryonic stem cells (also known as pluripotent stem cells). Adult stem cells are derived from, or reside in, adult tissue, and can usually only give rise to the cells of that tissue, thus they are considered multipotent. Embryonic stem cells, derived from a small group of cells in the early embryo (five to seven days), are undifferentiated and are considered pluripotent as they can become every type of cell in the body. Recently, scientists discovered that mature cells, for example a human skin cell, in the right conditions could be induced to mimic the characteristics for an embryonic stem cell. These are known as induced pluripotent stem cells (iPS cells).

Stem cells are different from other cells in the body in three main ways:

- 1. Stem cells are unspecialised.** They have not developed into cells that perform a specific function.
- 2. Stem cells can differentiate.** This means they can divide and produce cells that have the potential to become other more specific cell types, tissues or organs. These new cells and tissues are used to repair or replace damaged or diseased cells in the body.
- 3. Stem cells are capable of self-renewal.** Stem cells are able to divide and produce copies of themselves which leads to self-renewal. Once a cell has become specialised (has differentiated) to a particular tissue or organ, it has a very limited capacity to self-renew (produce new stem cells) but instead produces only cells relevant to that organ.

What are stem cell treatments?

For the purposes of this article, stem cell treatments are either injections or transplantations of cells termed 'stem cells' which are said to stimulate the body's own stem cells. For example, in MS, the theory is that stem cell treatments may be able to repair MS lesions in the central nervous system through remyelination (the opposite of what occurs in MS – demyelination). It is also suggested that, in MS, stem cell therapy may be able to prevent immune damage to the nervous system.

In reality, the range of diseases for which there are proven treatments using stem cells is quite small. Within Australia the only proven treatment available involving stem cells is for the treatment of some blood and autoimmune diseases. These treatments involve either bone marrow or umbilical cord blood transplants. The remainder of treatments are still in the research phase or in clinical trials, and are yet to be proven safe and effective.

What about stem cell treatments in MS?

The Multiple Sclerosis International Stem Cell Transplant Trial (MIST) has been approved by the US Food and Drug Administration and is being run at three centres in the USA, Canada and Brazil. All three centres have enrolled patients in a randomised trial using autologous stem cell transplants (from the individual's own bone marrow) for autoimmune disorders, such as MS.

Associate Professor Richard Burt from North Western University in Chicago is heavily involved in the MIST and presented an update on stem cell treatments in MS at the MS Research Australia Public Lecture held in October last year.

“Our phase-1 trials are all autologous – so [they involve] using your own stem cells,” explained Professor Burt at the lecture. “We take your stem cells, kind of clean them up and give them back to you. We also have some early phase-1 studies using [the stem cells] from a brother or sister that have been going very well.

“This therapy is designed to stop an inflammatory immune mediated process. What I've been surprised to see is if you move to stop it early enough, an organ system is capable of repairing itself, but if you wait too long, it doesn't work.

“So the analogy for MS is, if we do it too late – i.e., during secondary progressive MS – it doesn't work. It's no longer an inflammatory immune disease, it's shifted into a neural degenerative disorder and our therapy was never designed for [that]... I believe [our treatment] can still help some people transiting from relapsing/remitting to secondary progressive and we will occasionally [involve some of those patients].

“I believe the future is in using the embryonic stem cell for neurodegenerative disorders, looking at secondary progressive MS. In terms of embryonic stem cells, though, we are still [only working] in animal models [of MS].”

There are, however, ethical concerns about embryonic stem cells, added Professor Burt. “I respect both sides of the argument because people arguing for and against embryonic stem cells are actually making the same argument – respect for human life. The cells we work with come about by in vitro fertilisation, and we use those cells that would have otherwise been thrown away. So, why not allow them to live on in another person to help that person?”

A Safe Approach

While there are many clinics around the world offering stem cell treatments, some of these are offered outside the mainstream medical research environment.

Australia has a well regulated health system and patients can be confident that when stem cell treatments are offered here they will be both safe and effective.

While there is a long way to go before stem cell treatments in MS may become mainstream, the current outlook is very positive. Before embarking on any treatment or becoming involved in any clinical trial, individuals should discuss all options with their doctor or specialist.

FURTHER READING

- **Stem Cell Therapies: Now and in the Future**
The Australian Stem Cell Centre Patient Handbook (Dec 09)
http://www.stemcellcentre.edu.au/For_the_Public/Patient/Handbook.aspx
- **MS In Focus, Issue 11: Stem cells and Remyelination in MS**
By the Multiple Sclerosis International Federation (Feb 08)
www.msif.org/en/resources/msif_resources/msif_publications/ms_in_focus/index.html
- **Stem Cell Therapies in MS**
By the MS Society (UK – Feb 2010)
www.mssociety.org.uk
- **Clinical Trials.** To find the latest information on clinical trials occurring with stem cells and other treatments visit:
 - www.clinicaltrials.gov – maintained by the US National Institute's of Health and lists all federally and privately funded clinical trials, including many Australian trials
 - www.anzctr.org.au – the Australian and New Zealand Clinical Trials Registry
 - www.mstrials.org.au – the MS Research Australia Clinical Trials Network

EVENTS: World MS Day & MS Awareness Week

World MS Day (26 May) and MS Awareness Week (26 May – 6 June) are rapidly approaching and MS Australia – ACT/NSW/VIC is in the thick of our work to increase awareness for MS and its impact on our community.

The theme of this year's MS Awareness Week will be 'Employment and MS'. Through targeted publicity campaigns, fundraising events and community engagement, our aim is to communicate to the broader public the impact that MS can have on a person's life.

If you have a story about how MS has affected your employment, or you know of someone that does, please contact Prue Guillaume on (02) 9646 0600 so that we can raise as much awareness as possible.

The MS International Federation is also conducting a global survey to find out more about how having MS impacts on employment. The results will be released on World MS Day. You can complete the short survey at www.msif.org/en/news/msif_news/take_our_employ.html In the meantime, stay tuned to your TV, look out in the newspapers in May and June, and keep checking our website (www.mssociety.org.au) for updates on the various activities being held throughout MS Awareness Week.

MS Walk and Fun Run – 6 June

Save the date! MS Awareness Week celebrations will again culminate in our annual MS Walk and Fun Run event held in Sydney and Melbourne on Sunday 6 June.

MS Australia – ACT/NSW/VIC has specifically created this event for people living with MS to participate with the broader community, meet new friends and actively fundraise for a cause that is so close to their hearts.

The courses for this year's Walk and Fun Run are between 5km and 16km and take in some of Sydney and Melbourne's most scenic and iconic parklands, gardens and bridges. All walking courses are stroller and wheelchair friendly, and watch out for our roving entertainers along the way. Recover, relax and replenish at the finish line in Albert Park, Melbourne or Hyde Park, Sydney with live music and a barbeque lunch.

Remember, you don't have to do the event on your own. In fact, the most fun you can have is by joining or creating a team! As Peter James, an event supporter who has MS, says, "It's wonderful to join with family and friends among many other likeminded and motivated people from all parts of our community to participate in such a great event experience."

Likewise, Perry Lopez, a person with MS, and his wife Annette joined the MS Walk and Fun Run in 2006, with a team of just eight. In the three years since, Team Gopez has grown to 119 members who raised more than \$40,000 in 2009 for people living with MS. "I cannot begin to tell you how it feels to be part of such a great fundraising effort in support of MS," says Perry. "I have turned my diagnosis into a positive, not just for me but for everyone with MS!"

So why not put your best foot forward and sign up for the MS Walk and Fun Run, or perhaps volunteer on the day to still take part in the excitement. Visit the official website (www.mswalk.org.au) to find course maps, fundraising information, preparation tips and volunteer application forms. Or, register your interest by phoning 1300 733 690.

Art for Health

The Hunter New England MS Clinic is calling for art-lovers to participate in its MS Awareness Week 2010 Art Exhibition. After a successful 2009 exhibition, the clinic is looking to display works of art

(of various mediums) in the foyer of John Hunter Hospital during the first week in June 2010 – MS Awareness Week.

Artwork can be framed or unframed and may be purely for exhibition or also for sale. An art tour and introduction of each artist is also planned during MS Awareness Week. If you would like to participate, please contact Susan Agland, MS nurse specialist, John Hunter Hospital on (02) 4985 5880 or email susan.agland@hnehealth.nsw.gov.au

Note: This event is not run by MS Australia – ACT/NSW/VIC.

EVENTS: ACT

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

INFORMATION SESSIONS

Learn about MS Information Session

Suited to those recently diagnosed – meet others and learn more about MS and MS Australia services

March, date and time TBC

Gloria McKerrow House, Deakin

Learn about MS Teleconference

Suited to those recently diagnosed – ask questions and learn more about MS and MS Australia services

17 June, 7 – 8.30pm

To register, call 1800 042 138

HEALTH MANAGEMENT

Managing Fatigue Teleconference

Receive information on how to manage MS-related fatigue

16 Mar, 6.30 – 8pm

To register, call 1800 042 138

Get Active with MS – Teleconference

Hear our physiotherapists present information on fitness and exercise.

21 April, 11am – 12pm

To register, call 1800 042 138

Fatigue Self-Management Program

A 6-week program focusing on a self-management approach to managing MS fatigue

27 Apr – 1 June (weekly), 10:30am – 12:30pm

Gloria McKerrow House, Deakin

Continence Care in MS – Teleconference

Learn about bladder and bowel problems, causes, assessment and treatment options

11 May, 7pm – 8:30pm

To register, call 1800 042 138

PHYSICAL ACTIVITY GROUPS

Dru Yoga Classes

A gentle form of yoga where postures are modified so that people with various levels of ability can fully participate, either from a sitting position or lying down

2nd Term, 27 Apr to 2 July, weekly, 5.30 – 7.30pm

Gloria McKerrow House, Deakin

Cost: \$15 (waged participants); \$10 (non-waged)

OTHER

Mega Swim

Raising money for the Go for Gold Scholarships

Australian Institute of Sport: 1 – 2 May

For more info, visit www.megaswim.com

Military College Band Supports MS Australia

On 15 November last year, 30 talented Royal Military College (RMC) musicians performed in a two-hour concert at the 'Q' Queanbeyan Performing Arts Centre in the ACT to raise funds for people living with MS. The audience took pleasure in the smooth sounds of their favourite compositions, while enjoying the knowledge that funds were being donated to a worthy cause.

“The RMC band members are enthusiastic charity fundraisers,” reported Musical Director Major Geoff Grey. “They are the official band for all regal, vice regal, diplomatic and state functions held in the National Capital. The band has been involved in community relations since it was formed in 1954 and has played a prominent role in the musical life of Canberra.”

On this occasion, the band helped to raise \$2,600 for people with MS. MS Australia – ACT/NSW/VIC would like to thank Denis Reid, Major Geoff Grey, the RMC Band and their team for their generosity in performing this concert to help raise funds for people with MS.

EVENTS: NSW

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

INFORMATION SESSIONS

Working With MS

Explore your rights and responsibilities at work, as well as superannuation, insurance and finance matters

20 Mar, 10am – 12pm

Studdy MS Centre, Lidcombe

9 June, 7 – 8:30pm (teleconference)

To register, call 1800 042 138

Learn about MS Information Session

Suited to those recently diagnosed – meet others, and learn more about MS and MS Australia services

5 June, 10am – 3pm

Phillips MS Centre, Chatswood

HEALTH MANAGEMENT

Managing Fatigue Teleconference

Learn how to manage MS-related fatigue

16 Mar, 6.30 – 8pm

To register, call 1800 042 138

Get Active with MS – Teleconference

Learn from our physiotherapists how fitness and exercise can help manage MS symptoms

21 April, 11am – 12pm

To register, call 1800 042 138

Thinking and Memory

Learn about common MS-related thinking and memory changes and how to manage them

28 April, 10am – 12pm

Phillips MS Centre, Chatswood

Continence Care in MS – Teleconference

Learn about bladder and bowel problems, causes, assessment and treatment options

11 May, 7pm – 8:30pm

To register, call 1800 042 138

Maximising Your Memory

Learn practical strategies to maximise memory functioning from occupational therapists and neuropsychologists. To get the most out of this session, we recommend that you attend the 'Thinking and Memory' session (above) on 28 Apr

26 June, 10am – 3pm

Phillips MS Centre, Chatswood

WELLNESS DAY

Sydney Olympic Park

Explore various health promotion activities relating to mind-body medicine, stress management and lifestyle.

28 Mar, 9am – 4pm Soka Gakkai International, Sydney Olympic Park

Speakers: Dr Craig Hasted, GP and senior lecturer at Monash University; and Sandy Davidson, practising naturopath, nutritionist and educator

Cost: \$25/person for catering (incl GST)

Contact Sharon Valks on (02) 9646 0728 or email_sharon.valks@msaustralia.org.au

PHYSICAL ACTIVITY GROUPS

Maximising strength, flexibility and aquatic exercise groups are held throughout regional and metropolitan NSW and Victoria. For exact locations and times call 1800 042 138.

Yoga challenge raises almost \$44,000 for MS

In November last year, more than 1,200 Australians participated in the international Yoga Aid Challenge, across 20 locations, nationally. Raising money for local and international charities, the event is designed to reflect the true meaning of the word 'Yoga' – unity.

Pictured above is some of the 400 keen Sydney-siders practising their salutations at Mrs Macquarie's Chair in front of a beautiful backdrop of Sydney Harbour.

Now in its third year, the Yoga Aid Challenge is undertaken in eight countries. The aim of the Challenge is to raise money for charity while raising awareness about the benefits of yoga.

Participants fundraise prior to the event and all money raised goes directly to the charity partners, including MS Australia. Thank you to the Yoga Aid Foundation, Eriko Kinoshita, Clive Mayhew, Mayumi Staley and all the Yoga Aid team for sharing your spirit and generosity for people living with MS.

EVENTS: VICTORIA

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

INFORMATION SESSIONS

Taking Control & Planning Ahead

Receive advice from the Office of the Public Advocate about enduring powers of attorney, guardianship and administration

19 March, 10am – 12pm (video-link to Benalla)

24 May, 10am – 12pm (video-link to Albury)

Both held at The Nerve Centre, Blackburn

Managing MS

Enhance your relationship with your GP and find out about other programs you may be eligible for

13 April, 10am – 12pm

The Nerve Centre, Blackburn

Build Confident Communication

Learn to communicate effectively through the challenges of MS

5 May, 10am – 12.30pm

The Nerve Centre, Blackburn

Working With MS

Explore your rights and responsibilities at work, as well as superannuation, insurance and finance matters

15 May, 10am – 3pm

The Nerve Centre, Blackburn (video-link to Footscray)

Learn about MS Information Session

Suited to those recently diagnosed – meet others and learn more about MS and MS Australia services

29 May, 10am – 4pm

MS Centre, Footscray (video-link to Blackburn)

HEALTH MANAGEMENT

Fatigue Information Session

An overview of MS fatigue and management strategies

23 March, 10am – 12pm

The Nerve Centre, Blackburn

27 May, 10am – 12pm

Federation Estate, Ringwood

Fatigue Self-management Program

A 6-week program focusing on a self-management approach to managing MS fatigue

Weekly, 14 Apr – 19 May, 10am – 12 noon

MS Centre, Footscray

Get Active with MS

Learn from our physiotherapists how fitness and exercise can help manage MS symptoms

21 April, 11am – 12pm (teleconference)

To register, call 1800 042 138

8 June, 6 – 8pm

Caroline Springs Library, Caroline Springs

Continence Care in MS – Teleconference

Learn about bladder and bowel problems, causes, assessment and treatment options

11 May, 7pm – 8:30pm

To register, call 1800 042 138

Thinking and Memory

Learn about common MS-related thinking and memory changes and how to manage them

17 May, 6 – 8.30pm

The Hub @ Docklands, Melbourne CBD

Mood and Emotions

Learn about the reasons for mood and emotional changes in MS, and the various treatment options

1 June, 10am – 12pm

The Nerve Centre, Blackburn

WELLNESS DAY

Mornington Peninsula

Explore various health promotion activities relating to mind–body medicine, stress management and lifestyle

30 May, 9am – 4:30pm, Cape Schanck Resort

Cost: \$25/person for catering (incl GST)

For bookings, contact Jon Adams on (03) 9845 2840 or email jon.adams@msaustralia.org.au

CARER PROGRAMS

Respite available if required

Brainlink Education & Support Course

A 4-week program of knowledge, support and assistance for carers (incl lunch)

Weekly, 16 Apr to 7 May, 10.30am – 2.30pm

The Nerve Centre, Blackburn

Caring for Yourself

A program for those who take better care of others than themselves

20 April, 10.30am – 12.30pm

The Nerve Centre, Blackburn

OTHER

Teens Day

A program for teenagers who have a parent with MS

31 March, Bowling at Galactic Circus, Melbourne

Kids Day – Zooperdooper Day Out

A program for primary school aged children who have a parent with MS, parents are welcome
8 April, The Melbourne Zoo

Mega Swim

Raising money for the Go for Gold Scholarships

Nunawading: 10 – 11 Apr

For more info, visit www.megaswim.com

The Journey Club

A 4-week program for families with primary school aged children to explore living with MS

Begins 1 May, 2 – 4pm

Southern Region, venue TBC

Videoconferencing

Some programs are now available via video conference. In 2010 we will be phasing in video conference technology as another option for clients to access education programs. If you are interested in these programs but are unable to attend the location listed, please contact us and we will explore the options for video conferencing in your area. Remote and regional clients will have priority as the participation numbers for videoconferencing is limited.

MS READATHON

Save the Dates for the 2010 MS Readathon

- Registrations open: April
- MS Readathon team visits schools across Australia: April and May
- MS Readathon 'Reading Period': 30 days throughout June, July and August
- Participants and schools return their sponsorship: July to September
- Reading Rewards delivered: July to October

To find out more information on the MS Readathon program, please phone 1300 MS READ (1300 677 323) or visit www.msreadathon.org.au

Fantastic Mr Fox

When the junior class students at Roberts McCubbin Primary School in Box Hill South heard about the MS Readathon's Fantastic Mr Fox competition, their eyes lit up at the chance of winning an exclusive preview to the movie itself – *Fantastic Mr Fox*, with all the trimmings!

The class knew the topic well as they had just completed a project on Roald Dahl – the author of *Fantastic Mr Fox* – but they also knew teamwork would be the key to success and joined together to answer the questions and tell the MS Readathon why they thought Mr Fox was so fantastic! When the junior class teacher Mr White received the phone call from the MS Readathon telling him his class had won the competition, he was ecstatic, and the class was even more excited when he shared the good news.

The students counted down the days until the big day. Finally the morning arrived and Mr White, the class and a handful of parents arrived promptly at Hoyts, Melbourne Central for the 10am screening. As their excitement mounted, each student was handed a choc top, box of popcorn and a drink to enjoy throughout the movie.

A few words of welcome and thanks were given by Gill Law, MS Readathon National Operations Manager, and then the film started.

Almost 90 minutes later, the credits rolled and the music played, and as the lights came up the whole class were singing, dancing and clapping along in their seats.

Each student received a 'Fox and MS Readathon' show bag and could hardly stand still as they discussed their favourite parts of the movie.

Congratulations to Roberts McCubbin Primary School, and thank you to 20th Century Fox Film Distributors for the donation of this prize.

Final Boarding Call for Angels!

With the MS Readathon school visit period fast approaching the ACT, NSW and Victorian MS Readathon teams are still looking for volunteers (or Angels in Disguise as we like to call them) in a number of regions. If you are a confident public speaker, organised, and enthusiastic about reading and raising money for people with MS then we would love to hear from you! You must have your own insured transport and be available during April and May.

Please contact the MS Readathon team on 1300 677 323 to get involved!

Meet Kayla Sandry

Kayla Sandry had high hopes of being the 2009 top fundraiser for the MS Readathon in NSW but ended up with a terrible bout of swine flu. Despite this, however, she worked incredibly hard to still raise money for people with MS. She sat at shopping centres on her weekends and went door-

knocking to help raise those extra dollars. Kayla was even able to convince a restaurant to donate \$5 from every 'Kayla Special' to her fundraising!

In the two years that Kayla has participated in the MS Readathon, she has raised an impressive \$10,636! In recognition of her hard work, Kayla was awarded the 'NSW 2009 MS Readathon Outstanding Effort' trophy. A presentation was held at her school and the MS Readathon Community Representative from Bathurst, Jane McWilliam, volunteered to present the top fundraising and top reading certificates to the school, as well as Kayla's trophy. Kayla is determined to top the state in 2010 – we wish her the best of luck!

A Top Reward for Our Top 2009 Fundraiser!

Cameron Cox of the ACT was the top fundraiser in the 2009 MS Readathon raising an incredible \$30,025! At just 10 years of age, Cameron has been involved in the MS Readathon for the past five years and was the ACT's highest fundraiser in 2006, 2007 and 2008 before taking out the top national fundraising award this year.

Generous sponsorship from Direct Mail and Marketing and Red Rock Leisure ensured Cameron was duly rewarded with a trip to Melbourne with his mother Dianne, brother Sebastian and sister Laura.

Their adventure began with a visit to the set of *Neighbours* where Cameron and his family were given a guided tour, watched a number of scenes being filmed and met some of the cast members.

They then climbed to the top of the Eureka Sky Deck (all 88 floors) where they experienced 'The Edge' (a glass cube which projects three metres out from the building, 300 metres above the ground). The view from the top of the Eureka Sky Deck would be amazing on any day of the year, but according to Bosko who accompanied the Cox family, the day Cameron visited it was a clear, sunny day and the view was spectacular. When it came time to climb inside The Edge, "Cameron was so excited he could hardly stand still," reported MS Readathon National Operations Manager Gill Law.

Finally, in true winning style, Cameron and his family rode in a limousine to Essendon Airport where they jumped into a helicopter for a joy flight around the city – what an adventure! Cameron is truly inspiring and is very deserving of such an amazing reward.

To read more about other inspiring MS Readathon fundraisers visit our website at www.msreadathon.org.au and look up our 'Hero of the Week' section.

MS COMMUNITY

All for a Good Cause

Thank you to the wonderful community members who have helped raise much-needed funds for people living with MS.

Melbourne Cup Lunch a Winner

More than 200 ladies came together on Melbourne Cup day last year to support the Pymble Golf Club Charity Lunch and raise funds for people living with MS.

Tantalising food and wine were aplenty, and a fashion parade and prizes for the best hat and best dressed added to the afternoon's joyful atmosphere.

Abounds with generosity, the event raised a huge \$19,793 for people living with MS.

Thank you to Fran Duran, Alvis Charlton and the Pymble Golf Club Ladies Committee for all your hard work in organising such an enjoyable, stylish and successful event. n

Roll of Honour

Special thanks to the following community members who helped raise funds to support people with MS over the past three months.

- Jan Smith – Christmas lights display raised \$9,515
- Jill Pinner – Shepparton Bike Ride raised \$7,500
- Hilary Britton and Committee – Melbourne Cup lunch raised \$4,470
- Rydalme Central Bowling Club raised \$4,105
- Kelly Utting – raised over \$4,000 in the Monbulk Classic Fun Run
- Scott Gustetter – raised \$3,200 for swimming in the World Masters Games
- Ursula Lockwood – MS Open Challenge in Cambodia raised \$2,900
- Dawn Brereton – Ravir Fashion Show, Blackheath raised \$2,681
- John Clark – art exhibition raised \$980
- SaddleSore Team and Collette McFawn Garage raised \$914
- Alena Vydra – raised over \$800 from Christmas tree sales
- Sally Price – raised \$575 through Christmas luncheons
- Luke Taaffe – No Fin Soup Art Exhibition raised \$500
- U3A Frankston Choir – raised \$450 through Christmas performances

Long Walk for MS

Having a close family member with MS has motivated Richard Davis to take a very long walk across the United Kingdom to raise money for MS Australia.

Richard will walk approximately 2,000km (depending on how often he gets lost) starting at Lands End (the most south-westerly point on the British mainland) and finishing at John O Groats (the most northerly point on the mainland of Scotland).

Richard will walk with a 20kg backpack for approximately 90 days (11 to 13 weeks). His walk starts in June but he has already made a fantastic start on fundraising. Show your support for Richard by visiting his fundraising web page at www.everydayhero.com.au/longwalk

Get Involved!

Would you like to become a community fundraiser for people with MS? There are all sorts of ways you and/or a group of friends can be involved. Visit the 'Events' section on our website at

www.mssociety.org.au to view the community events page for tips and ideas on how you can
fundraise. For more information contact:

ACT/NSW: Kerry Hill, (02) 9468 8341, kerry.hill@msaustralia.org.au

Victoria: Heather Rendell, (03) 9845 2710, heather.rendell@msaustralia.org.au

MS COMMUNITY

Volunteers in Action

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

In Loving Memory

After giving more than 26 years of her life volunteering in two MS Shops, Kay Tallents sadly passed away last year. On behalf of all the staff, volunteers, customers and people living with MS, MS Australia – ACT/NSW/VIC would like to acknowledge Kay for the amazing contribution she made to help people living with MS, their families and carers.

Kay not only ran an organised and tidy shop, customers would pop by just to say hello to this generous woman with a kind heart and great personality. The shop volunteers are certainly missing their dedicated boss who “always made time for coffee with the VOLLIES”.

Kay is remembered for being a great listener and always being able to share a good joke. She would claim anything for herself that was of the colour green, and was known as ‘Mrs Fix-it’. Kay was also instrumental in bringing the Fairfield MS Shop back to life after flood damage closed it down temporarily.

She was also the Vice President of the East Ivanhoe MS Auxiliary, for which she organised monthly trips for members and the public to raise funds to support medical research and services for people living with MS.

Kay had an aunt with MS, so the motivation to help others was always close to her heart. She was the proud mother of three and grandmother of three.

“Kay was a valued and respected member of the dedicated team of volunteers who support our organisation,” said Kerry Reiter-Lynch, Volunteer Programs Manager, MS Australia – ACT/NSW/VIC. “She was a well known and loved identity in the Fairfield community.

“Kay’s belief in the strength of her team of volunteers has resulted in a successful, growing shop where everyone continues to support one another. Kay will be sadly missed by all.”

Jan’s Story

Eighteen years ago I saw an ad in the paper from the MS Society (now MS Australia – ACT/NSW/VIC) calling for volunteers to train in hydrotherapy. I was a full-time mother at the time but I had decided to do some voluntary work in and around what was happening at home.

I have some family members with MS, so with a background in special needs teaching and a great love of swimming, I jumped at the opportunity to help.

I was trained in the Halliwick method, which involves assisting people with disabilities to safely participate in water-based exercises that are suited to their special needs.

For 14 years I volunteered at the hydrotherapy pool at the Lidcombe Studdy MS Centre which was the centre of excellence for people with disabilities to access hydrotherapy in a purpose-built environment. Since it closed four years ago, I have volunteered one day per week assisting people with MS at the hydrotherapy pool at Villawood. I also assist another man once a week with hydrotherapy who was disabled through a car accident.

I mostly work with people on a one-on-one basis, giving them maximum support and benefit from what can be achieved through water exercise.

People with MS never cease to astound me. They’ve been struck by this very debilitating condition and yet they have the most fantastic sense of humour. Every day I’m just so grateful for the lucky life and good health I’ve had. To be able to use that to help others is wonderful.

After 18 years, this role is still very rewarding and personally fulfilling. I have made some amazing friends and shared a lot of experiences.

We are looking for more volunteers to assist with our hydrotherapy program in NSW. If you are interested in this or any other volunteer role in the ACT, NSW or Victoria, please call MS Connect on 1800 042 138.

MS COMMUNITY

Support for Young Carers

Many young Australians provide assistance to family members living with MS, taking on more responsibilities compared to others their age. Here, we outline the support services available to these young carers.

MS Australia – ACT/NSW/VIC

We currently provide a number of programs and resources that may be helpful to young carers. These include:

- **Family Matters.** Designed for families and carers of people living with MS, this information kit outlines many beneficial topics for family discussion. *Family Matters* is currently being expanded, with the updated version due for release in June. The current information kit can be found on our website at www.mssociety.org.au/live/family-matters-kit.asp
- **Family Activities.** Our Kids and Teens Days, and our Family Camp programs (currently run in Victoria) have an educational approach, with the aim to provide children and teens with opportunities to meet others who have a parent with MS, have fun, learn more about MS and have their questions answered. Keep checking the 'Events' section in this magazine to see when our next programs are scheduled.
- **Peer Support Program.** This program links people with MS and their family members/carers with others who can relate to their situation. The service is offered via support groups, as well as one-on-one telephone and online support.
- **Respite.** MS Australia – ACT/NSW/VIC has a number of respite services and programs available to clients and their family members, and/or can assist you to find a suitable facility or service in your area.
- **MS Australia – ACT/NSW/VIC Community Teams** provide specialist care for people with MS. Your family member's Community Support Worker will be a key point of contact regarding any questions or concerns you may have around your caring role.

To access any of these services visit www.mssociety.org.au or call MS Connect on 1800 042 138.

Young Carers Respite and Information Services Program

A Commonwealth government initiative, this program provides support to young carers who are at risk of not completing their education due to the demands of their caring role. The program enables young carers to access:

- **Respite services.** These are delivered through the Commonwealth Respite and Carelink Centres. Freecall™ 1800 052 222 or visit the website: www.commcarelink.health.gov.au
- **Information, advice and referral services.** This is delivered through Carers Australia and its respective state and territory bodies. Freecall™ 1800 242 636 or visit the following websites:
 - **Carers Australia:** www.carersaustralia.com.au
 - **Carers Australia, Young Carers website:** www.youngcarers.net.au
 - **Carers NSW:** www.carersnsw.asn.au and www.youngcarersnsw.asn.au
 - **Carers Victoria:** www.carersaustralia.com.au/?/vic/section/3:about-us. Carers Victoria also run an eight-week Peer Support Program specifically for young carers in secondary school.
 - **Carers ACT:** www.carersact.asn.au

Office for Youth

The Commonwealth government's Office for Youth administers a range of programs to help vulnerable young Australians to engage with their families and the community. For example, it facilitates the Transition to Independent Living Allowance (visit www.tila.org.au for more info). The Office for Youth also coordinates National Youth Week (NYW), which is a joint initiative of the Commonwealth, state and territory governments. This year NYW will run from 10 – 18 April. Visit <http://youthweek.com> to find out what celebrations are happening near you.

More information about programs administered by the Office for Youth can be found on the 'Youth' section of the Department of Education, Employment and Workplace Relations website:

www.deewr.gov.au

Financial Assistance

Young carers may be able to access financial assistance under the following initiatives:

- **Carer Payment:** Income support payment for people who are unable to support themselves through participation in the workforce while caring for someone with a disability or severe medical condition.
- **Carer Allowance:** Income supplement to people who, due to their caring role, are unable to support themselves through workforce participation. This may be paid in addition to the Carer Payment or other payments, such as the Age Pension.

Other forms of assistance may also be available. For more information contact your local Centrelink office on 132 717 or visit www.centrelink.gov.au

Home and Community Care (HACC)

This program provides community care services – such as domestic assistance, transport and counselling – to frail-aged and younger people with disabilities, and their carers. HACC is a joint federal, state and territory cost-shared program. For more information call the Aged Care Information Line on 1800 500 853.

Carer Information Pack

Produced by the Aged and Community Care Division of the Department of Health and Ageing, this pack provides practical information to support carers in their caring role. Call 1800 500 853 to request a pack, or download a copy from the Department of Health and Ageing website:

www.health.gov.au

CYCLOPS ACT (Connecting Young Carers to Life Opportunities and Personalised Supports)

This is a service provided by Anglicare Canberra–Goulburn Youth and Family Services and funded by the ACT Government. For more information visit www.cyclopsact.org

Siblings Australia Inc

A national organisation committed to enhancing the wellbeing of siblings of children with disabilities and chronic illness. For more information visit www.siblingsaustralia.org.au

Tips to Looking After 'You'

While carers spend so much of their time thinking about the needs of others, it is especially important for young carers to look after their own needs as well. Below are some useful tips to looking after 'you':

- **Take time out.** Try to allocate some time each week to doing something you most enjoy – whether it's playing sport, listening to music or hanging out with friends, it's important to make time for you. Plan around this and make sure you stick to it each week.
- **Share the care.** Look after yourself by sharing the responsibility of care with someone else – a sibling, aunt/uncle, grandparent or family friend. Also, be sure to access the services and support available, using the information and contact details provided below.
- **Keep in touch.** If, at times, you are feeling angry, frustrated, sad and/or alone in your caring role, it is important to talk to someone you trust, such as a friend, other carers or family members. Alternatively, stay in contact with like-minded people who may be going through the same situation via the MS Australia – ACT/NSW/VIC Peer Support Program (call 1800 042 138) or through Carers Australia (call 1800 242 636).
- **Learn more about the illness/disability of the person you are caring for.** Knowing more about the illness or disability can be helpful in understanding your family member's behaviours and moods. MS Australia – ACT/NSW/VIC has a number of education resources on MS that you may find useful. Contact MS Connect for more information on 1800 042 138.

Source: <http://au.reachout.com>

FlexiRest

FlexiRest provides people with MS, their families and unpaid carers options and choice to help meet their respite needs, particularly where these can't be met by existing community services. In particular, young carers have benefited from the FlexiRest program in the following circumstances:

- Funding has covered the transport and/or accommodation costs for a short, planned family weekend away.
- Transport and camp fees for a teenage boy to attend a scout camp. He is the primary carer for his 44-year-old mum.
- Sport and recreation fees for a family to spend time together at an organised family camp.

FlexiRest is a NSW Government funded program so it is only available to registered clients in NSW. However, there are other respite services and programs available in Victoria and the ACT. Contact MS Connect on 1800 042 138 for more information.

MS COMMUNITY

Rich Rewards

Giving and receiving peer support can be rewarding for all involved. Marie-Louise, an MS Australia – ACT/NSW/VIC Peer Support Volunteer, and Sandra, a Peer Support Receiver, share their experience from either side.

Marie-Louise's Story

I was 26 and seven and a half months pregnant with my second child when I was struck down in the shower, unable to move my right side, walk or talk. A quick diagnosis followed – I had MS. I was distraught and confused, unable to take MS medication until after the pregnancy, and I still had to look after my young family.

I contacted the NSW MS Society (now MS Australia – ACT/NSW/VIC) who referred me to a local MS nurse. She came to see me and put me in touch with other people in my area when I was ready to 'come out'.

Almost four years later I have reached a place where I can deal with things as a normal, happy person. I've returned to work and just landed a promotion as a retail store manager. MS is unpredictable but I get through thanks to treatment, a strong support network, and I have a positive attitude and laughter on my side.

Just over a year ago I received an email from MS Australia – ACT/NSW/VIC calling for expressions of interest from potential Peer Support Volunteers. I didn't think twice. I travelled to Lidcombe (from Northern NSW) to do the training where I was able to meet other people with MS, as well as some carers.

I do all of my peer support over the phone and I can have up to three 'matches' at one time. I've been matched with women around my age who either have or are considering having children, or women who think they can't go back to work... I even work with some matches to set and achieve mini goals, and we talk about their progress each week.

I volunteer for two main reasons: I do it for myself – it makes me feel better knowing that I am able to help other people with MS – and I do it because there is a very great need to have somebody on the phone who can say, 'yeah I know...' or 'I understand'.

Overall, I get an incredible sense of pride, education, personal development and self-worth out of being a Peer Support Volunteer. I love to listen and I get so much in return. It has truly enriched my life.

Sandra's Story

I am a 39-year-old mother of four wonderful children. I was officially diagnosed with MS in September last year, although I believe I was experiencing symptoms for a very long time before that – pins and needles in my legs, feet and hands, and trouble with my eyesight.

Despite finally knowing what was causing these problems, I was terrified. My mother had MS quite badly, although I didn't know a lot about it. I thought I would end up in a wheelchair and die within five years, leaving my children without a mother.

I was quite angry at my neurologist – only because he was the one to deliver the verdict – so I didn't want to talk to him. I took to the internet, which was a big mistake. All it did was frighten me even more!

I called the MS Connect number and, among other things, they referred me to the Peer Support Program. Once enrolled in the program I was contacted by a lovely Peer Support Volunteer who is also a mother. She is down to earth and she gives me hope. I was initially speaking to her every

fortnight and I would save up questions to ask her each time we spoke. I was quite a mess at first but she has helped me through a lot, including how to work through the tiredness and how to explain MS to my children.

Now that I'm correctly educated, I'm no longer scared. I've realised that I can live with MS and still look after my family, as long as I manage it day-to-day.

It's really important to be able to talk to someone in your situation who can understand what you're going through. I've benefited so much from my peer support experience that I would love to think I could also help other people as a Peer Support Volunteer one day.

For all enquiries relating to the Peer Support Program, contact MS Connect on 1800 042 138.

Support Group Profile

Support Group Facilitator Vince Vento offers an insight into the Footscray Peer Support Parents Group, and calls for other parents with MS to get involved.

When and why did you become involved in the Footscray Peer Support Parents Group?

I joined the Peer Support Group as a member about six months ago when a social worker from MS Australia – ACT/NSW/VIC recommended that my wife and I join the group. We have three young boys (aged 12, 10 and 7) and were looking for some advice on how to help the boys understand MS and what I'm going through. Being involved has really helped, especially with the two older ones. I took on the role as the group's Facilitator late last year.

When was the group first established? How many members do you have?

The group was officially formed about a year ago, so it's still only a new, small group. We're certainly looking to expand the group as much as possible this year. Anybody with MS, especially those who are parents, are welcome to be involved.

Where do you meet and when?

We meet on the third Saturday of each month at the MS Australia – ACT/NSW/VIC centre in Footscray, Victoria. We all enjoy a cuppa and talk about our various situations. We are hoping to arrange some guest speakers to come and talk to the group throughout 2010.

What are the benefits to being involved?

The Peer Support Group really helps us to realise that we're not alone. We can ask each other really specific questions about parenting issues and how to communicate with our children to help them better understand MS. It really helps to be able to give each other ideas based on our own experiences.

What would you say makes a successful support group?

It's important for group members to feel comfortable and to be open with one another. I also think it's important for members to come to meetings regularly so that we can form a bond and get the most out of the support group experience.

There are a number of MS support groups operating throughout ACT, NSW and Victoria. To find one near you, contact MS Connect on 1800 042 138.

MS COMMUNITY

MS Ambassador Profile

Louise Burnett shares her experience as an MS Ambassador.

Name: Louise Burnett

Age: 42

Occupation: Pharmaceutical company rep

Family: Married with two young boys

Lives: Illawarra region, NSW

Diagnosed with MS: In 1991 when I was 24

Joined MS Ambassador Program: November 2006

Why did you decide to become an MS Ambassador? I was actually reading an article in *Intouch* a while ago about the first group of people who had trained to become MS Ambassadors. I instantly thought, 'I could do that'. I felt I had a story to tell about my experience with MS. Also, having a background in nursing and sales has given me strong communication skills, which I could use to help others understand what living with MS means. Everyone knows someone with MS but they often don't know much about it.

What was involved in joining the program? I prepared an application and resume, had an interview with the Program Manager and was accepted to become a volunteer MS Ambassador. I then attended a two-day comprehensive training course (where I met other new MS Ambassadors) to gain the knowledge and skills to perform the role.

What are some of the things you have done in your role as an MS Ambassador? I have spoken to fifth-year medical students and a variety of different community organisations and clubs. I have spoken at a pharmacists' conference and at the MS Sydney to the Gong Bike Ride. Most recently I spoke to a personal fitness training group who raised \$30,000 for MS research.

What MS symptoms do you experience and how do you manage these day-to-day? I experience tingling in my legs when I walk a long distance and I am very heat intolerant. This is practically managed by an air-conditioned home and fans. I try to park in shade even if it is further away and I open all the car doors and blast the air conditioning before I get in. I also won't eat large, hot meals, and I wear clothes made of natural fibres so that I don't overheat. I find that if I keep fit by exercising early in the morning when it is cool and have little breaks throughout the day, I am okay. I also have a lot of family support and even the kids know Mummy can get a bit cranky at the end of the day and that I might need some help sometimes.

What motivates you? I set personal goals that I would like to achieve each year and I also have five-year goals. These goals are emotional, physical, financial and spiritual. I want to be as well as I can be so I can enjoy my family and participate in what I want to do.

What is the most rewarding aspect of being an MS Ambassador? I love being able to open up people's minds to MS and demystifying it. I am glad that I can speak for those people that are worse off than me who are held back because of what MS has done to their bodies. I enjoy being able to inspire people to work together and raise money for a cure for MS.

Would you like to become an MS Ambassador, or would you like an MS Ambassador to present at your next event? Contact the MS Ambassador Program Team for more information.

ACT/NSW: Donna Hendry – (02) 9468 8300, ambassadors-nsw@msaustralia.org.au

Victoria: Trish Mifsud – (03) 9845 2700, ambassadors-vic@msaustralia.org.au

HEALTH & WELLNESS

Get Active

How our Health Promotion Team is helping you to stay active.

Heartmoves for MS Program Launched

Following the exciting partnership formed between MS Australia – ACT/NSW/VIC and the Heart Foundation late last year, the first Heartmoves for MS class was launched on 3 February 2010 at Balance Health Club in Mayfield, Newcastle.

While Heart Foundation Heartmoves classes already operate across Australia, the launch in Mayfield is the first of what will be many Heartmoves classes specifically tailored for people with MS.

This fun, social and safe activity program focuses on delivering low-to-moderate intensity exercise incorporating gentle aerobic activity, weight-bearing or resistance exercise and stretching – all of which help to build strength and fitness, and improve balance.

“Physical activity plays an important role in assisting to minimise the symptoms of MS, which is why we are delighted to be working with the Heart Foundation to offer Heartmoves classes to people living with MS,” says Robyn Faine, General Manager Services, MS Australia – ACT/NSW/VIC.

More than 20 people with MS, their family members and carers, along with MS Australia and Heartmoves staff attended the successful launch in February. People with MS enjoyed their first class (pictured above), stayed to socialise afterwards and, by all accounts, are looking forward to the weeks ahead. For more information about Heartmoves at the Balance Health Club in Mayfield, contact Donna Young on (02) 4903 6213.

See below for an update on when more classes are planned, or to find a general Heartmoves class near you, call MS Connect on 1800 042 138.

Upcoming Wellness Days

The following MS Australia – ACT/NSW/VIC wellness days are scheduled for 2010. Come and learn from experts in integrated health, stress management, relaxation, nutrition, and complementary therapy. You will have the opportunity to experience a number of different activities, including strength maximising, tai chi, yoga, qi gong, meditation and more.

ACT/NSW:

- Sydney Metro, 28 March
- Nowra, June
- Central West NSW, November

Victoria:

- Mornington Peninsula, 30 May
- Warrnabool, date TBC

See our Events section on pages 19 – 20 for more details, or contact MS Connect on 1800 042 138.

Expressions of Interest – New Physical Activity Groups

Thanks to the fantastic response from people wanting to get involved in physical activity groups, a number of new groups have been launched to help people with MS improve their health and fitness.

In Victoria, we are excited to launch new Maximising Your Strength groups in Geelong at the St Laurence Healthy Ageing and Wellbeing Centre in Belmont. The classes will run on Tuesdays and Thursdays with a potential to include a Saturday session. The exercise physiologists who will run these classes have received MS-specific training. A new Maximising Your Strength program is also being launched at Brunswick City Baths in March and we are aiming to launch Heartmoves for MS exercise classes in Victoria later in 2010.

In NSW, we launched the first Heartmoves for MS class in Newcastle in February (see above). In the next few months classes are being planned in Maitland (14 April) and Campbelltown in NSW, and Canberra in the ACT.

Working with the Heart Foundation and exercise therapists in the community, we are now calling on expressions of interest for people interested in joining physical activity groups in the following locations:

ACT/NSW: Canberra, Maitland, Campbelltown, Sydney Inner West, Bathurst, Mid South Coast (Nowra and environs), Central West NSW.

Victoria: Frankston, Shepparton and Echuca.

A minimum of 10 people are required for exercise classes to go ahead. Venue, day and time are flexible and will be confirmed. To express your interest or to find an existing physical activity group near you, please contact MS Connect on 1800 042 138.

HEALTH & WELLNESS

Spotlight On: Occupational Therapy

While MS symptoms can often impact a person's ability to participate in everyday activities, occupational therapists can assist you to develop strategies to overcome these barriers.

What is occupational therapy?

The World Federation of Occupational Therapists defines occupational therapy as a profession concerned with promoting health and wellbeing through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Participation can generally be supported or restricted by physical, social, attitudinal and legislative environments. Therefore, occupational therapy may be used to change aspects of one's environment to enhance their participation.

Generally, occupational therapists (OTs) have a broad range of skills and knowledge that enables them to work together with individuals (or groups) who may be impaired in some way due to a health condition, such as MS. Clients are actively involved in the therapeutic process of occupational therapy. Outcomes are driven by the individual and measured in terms of their increase in participation and/or the satisfaction derived from participation.

Occupational therapy is practiced in a wide range of settings, including hospitals, health centres (including MS Australia – ACT/NSW/VIC centres), homes, workplaces, schools and aged-care facilities.

How is occupational therapy beneficial to people with MS?

MS symptoms can impact on a person's ability to participate in their daily occupations. For example, someone who experiences MS fatigue and changes in their thinking and memory may be struggling to cope in the workplace, or as a new parent. OTs can work with that person to jointly identify and address the impact of MS symptoms on their daily life.

OTs provide support, information, resources, skills and opportunities to people with MS, their family members and carers to maintain their potential to participate in the activities of daily living. Taking into account the current needs and future goals of the client, OTs provide a comprehensive assessment of a person's lifestyle and will work with the client (and possibly other allied health professionals) to develop strategies to promote meaningful occupation.

The OT will then support the client to implement and refine these strategies, as well as support clients to learn how to analyse and address the impact of symptoms on their daily lives. This approach arms clients with the basic tools to be able to self-manage their symptoms as they change over time.

The OTs at MS Australia – ACT/NSW/VIC work with clients both individually and in groups to achieve their goals. Examples of group programs led by MS OTs include our Fatigue Management Education sessions (delivered face-to-face and via teleconference) and the Fatigue Self-management Program. See our Events section on pages 19 - 21 for program locations and dates. Our OTs have a specialty scope of practice so when the need for more generic support from an occupational therapist is identified (such as for the prescription of assistive technology or equipment, home modifications or a burst of community rehabilitation), the MS OT can refer clients to appropriate community services. The MS OT can also collaborate and consult with community-based therapists if required.

OTs from MS Australia – ACT/NSW/VIC will also facilitate group education sessions for health professionals to provide best practice information on occupational therapy approaches to help manage the impact of MS symptoms.

How do I access occupational therapy?

OT Australia is the national body of occupational therapists. Its website (www.ausot.com.au) provides general information about occupational therapy as well as state-specific sites that contain registers of private practitioners and their specialty.

MS OTs are based at our various metropolitan centres in the ACT, NSW and Victoria and can provide consultation at the centres or in a client's home. Telephone support is available to all clients and our OTs can also provide support to rural clients through our regional MS community support workers, and through collaboration and consultation with a client's local therapist.

Other MS health professionals, such as a community nurse, physiotherapist, psychologist or social worker can also refer you to one of our OTs. To access the services of MS Australia – ACT/NSW/VIC, call MS Connect on 1800 042 138.

** Special thanks to Robyn Soulsby, Occupational Therapist, MS Australia – ACT/NSW/VIC, for her assistance with this article.*

Community Teams

Occupational therapy is just one of the health services provided by MS Australia – ACT/NSW/VIC. Occupational therapists work alongside the following health professionals in our community teams:

- Clinical Psychologists
- Community Health Nurses
- Community Support Workers
- Exercise Therapists
- Neuropsychologists
- Physiotherapists
- Social Workers

If you would like more information on any of these services, please contact MS Connect on 1800 042 138.

New Self-Management Program

As part of MS Australia's goal to develop and promote symptom self-management strategies for people with MS, MS Australia – ACT/NSW/VIC has been providing advice on the development of a new group self-management program called Moving On.

Moving On has been developed by Arthritis NSW, but it is not just for people with arthritis. If you have any type of chronic condition, including MS, you may find this program helpful. Moving On aims to give participants the skills, knowledge and confidence to proactively manage their own condition and be an active member of their healthcare team. The program covers such things as coping with your chronic illness, healthy eating, physical activity, the importance of leisure time and activities, how to use medicines safely and so on.

As this is a very new program, the University of NSW has been asked to evaluate its effectiveness. This evaluation is currently underway with the program beginning to be rolled out in the Hornsby, Ryde, Blacktown, Hawkesbury, and Hills Shire Council areas of Sydney. If you would like to join the Moving On program, or learn more about the program evaluation, please contact the Senior Project Officer, Eloise Buggy on 1800 332 131 or by emailing movingon@arthritissw.org.au

LIFESTYLE

A Step Ahead

MS can affect people in many different ways. Difficulties with mobility, in particular, can impact on one's quality of life. Our physiotherapists explain how using a walking aid can often help people with MS live a more full and active life.

People with MS often experience a number of symptoms that can cause them to have difficulties with mobility. Leg weakness, loss of balance, poor sensation and fatigue are a few examples of these symptoms. Signs that a person is experiencing these difficulties include, dragging of the feet (especially when tired), or tripping and falling occasionally. Walking long distances or on uneven ground may also become difficult or, a person may start to rely on a wall, furniture, or their partner for support.

If walking does become difficult, people will often start to avoid going out to places such as work or social activities they once enjoyed. However, there are solutions to help manage these symptoms in order to keep active.

Firstly, people with MS who are experiencing mobility problems are encouraged to consult a physiotherapist. Physiotherapists will perform an assessment to reveal the physical reasons why someone may be having difficulty walking, and can suggest strategies to overcome and/or manage these symptoms. Overall, it is important to remember that the best solution will depend on an individual's circumstances.

What are my options?

Orthotic devices, such as an ankle foot orthoses or functional electrical stimulators – which are applied to the nerve and muscle area to help reduce the foot drop often experienced by people with MS – may be all that is required to enable someone to walk further and decrease the risk of tripping and falling. Combined with physiotherapy advice on stretching and exercising, these devices can help to conserve one's energy and increase the ability to walk and function.

A walking aid such as a walking stick or walking frame can also increase stability and reduce the risk of one falling. A walking stick can provide extra stability and allow one to feel safer and more confident when walking on uneven ground or on footpaths. A seated walking frame has the added benefit of allowing the person to stop and rest wherever they are at any given time.

Some people will only need a walking stick occasionally, such as when walking a long distance or late in the day when they are quite tired or fatigued. In these cases, foldable walking sticks are available that can be easily carried for use when needed.

What if I don't want to use a walking aid?

Understandably, many people with MS struggle with the idea of using a walking aid, particularly as they are often still quite young and walking aids are traditionally seen as something that 'old people' use. It is important to remember that a walking aid is just a tool that will enable you to get around and participate in many everyday activities that would otherwise be no longer possible.

The prescription of an appropriate walking aid can help to keep people active and prevent secondary complications caused by inactivity. Walking sticks (including folding sticks) now also come in different colours and patterns to match a person's wardrobe.

Overall, it is important that the person with MS and their family members, friends and colleagues are aware that using a walking aid can enable a person to be more functional, independent and have an improved quality of life.

How do I know which type of walking aid will be best for me?

A physiotherapist will discuss whether an aid is required and give advice on the most appropriate walking aid. Due to the nature of MS and the variability in symptoms, an individual assessment is usually required to determine the most suitable aid. For example, a walking stick may not be the most appropriate aid for someone who has a weak grip. Likewise, walking frames can affect a person's posture in the wrong circumstances.

The options are broad and range from standard, four-legged walkers and front-wheeled walkers to tri- and four-wheeled walkers.

There are a number of walking sticks available and the type chosen is often very individual. Some prefer wooden, some prefer decorated, while others prefer adjustable, fold-up aluminum walking sticks. Again, it is important to consult a physiotherapist about the best solution for your lifestyle and needs. A physiotherapist will also be able to help set up the walking aid correctly (for example, at the right height)

As a general rule, hand grips should be at the height of the wrist bone or crease when the person is standing upright with their arms relaxed at their sides. However, a physiotherapist may adjust the height of a walking aid to tailor it to a person's needs. It is strongly recommended that people have the height of their walking aid checked by a physiotherapist if they have already purchased one before speaking to a therapist.

Due to the unpredictability and progressive nature of MS, regular assessments and reviews of one's ability to walk are important. Some people may only require a walking aid during an exacerbation or some may find their symptoms progress which would require an alternative walking aid.

Physiotherapists with specialist MS knowledge can be located at MS Australia – ACT/NSW/VIC, and throughout various hospitals and community centres. For more information or to access the physiotherapy services of MS Australia – ACT/NSW/VIC, please call MS Connect on 1800 042 138.

** Special thanks to the MS Australia – ACT/NSW/VIC physiotherapists who contributed to this article: Joanne Airey, Dawn Prasad, Robyn Smith and Joanna Elizalde.*

LIFESTYLE

Taking Action on Employment

As a complex and unpredictable disease, MS can have varying effects on a person's ability to work. However, support services are available. As a key focus for MS Australia in 2010, we discuss the current employment situation for people with MS, the services and support available and what is being done to increase opportunities in the future.

MS typically affects a person in their prime employment years, which often raises concerns around one's future career and financial security. However, the value of work for people with MS (as it does for many people) often goes far beyond finances to include a person's identity, social contact and self-esteem.

In Australia the statistics do tell us that employment is a major concern for people with MS. The Australian MS Longitudinal Study (AMSLS)¹ analysed employment changes and reasons for loss of employment in Australians with MS in the four-year period 2003 – 2007. It revealed that there was a pattern of Australians with MS losing their employment, even though this was a period of relative economic prosperity.

By 2007, a total of 56 percent of survey participants with MS had lost their employment and 64 percent were no longer in the paid workforce. This unemployment rate in MS is also much higher than for people with other chronic diseases².

While people with MS can experience a variety of social and physical barriers to employment, a major finding of the AMSLS study was that people with MS were losing their employment mainly because of disabling symptoms of the disease, rather than workplace factors such as inflexibility of working conditions or being asked to leave or being sacked.

Men were significantly more likely than women to lose their employment because of MS, and unemployed people with MS who found new employment did so mainly part-time.

A US study published last year also confirmed that the variables significantly associated with unemployment among working-age people with MS were the severity of disease, difficulties in thinking, gender, increased age and increased duration of MS³. The article stated that, "The combined impact of cognitive changes and overall severity of mobility impairment significantly influenced employment status in the sample". The study also revealed that many people with MS who are unemployed report a desire to return to work.

The good news is that new medical treatments and technologies, better symptom management, legal employment protections, and community resources can all help people with MS remain in the workforce. As such, it is important to become aware of all your rights as an employee, as well as the services and support available.

Growing Opportunities

It is unfortunate that issues continue to occur for people with MS despite the employment programs provided by the Australian government, private agencies and MS Societies. For this reason, MS Australia is taking action.

MS Research Australia (MSRA) hosted a workshop on 17 October 2009 to coincide with its Progress in Research Scientific Conference in Sydney, to examine employment research findings in Australia and the UK and identify how current employment programs could be more effective.

The aims of the workshop were to:

- identify the significant employment issues facing people with MS;
- provide an overview of current employment programs;

- identify the next steps to improving employment support services for people with MS; and
- determine the best way(s) of evaluating Australian employment programs for people with MS.

Stakeholders with varying experience and backgrounds attended the workshop, including people with MS, researchers, MS Australia staff, and representatives from the government and corporate sectors.

There was agreement among attendees that existing services to help people with MS maintain employment do not seem to be working optimally.

There were a diverse range of views on why, including: some people with MS are unaware of the employment services available; many people with MS identify their need for employment support when it is too late for interventions to be effective; MS Societies may not be reaching all who need support; MS Societies may not have employment support policies and programs, or visible promotion of these; employers do not seem to be facilitating the participation of people with MS in the workplace; and negative imagery about MS used in the media may inadvertently affect employers' perceptions and expectations about the capacity of people with MS to participate in the workplace.

At the MSRA workshop, recommendations on the next steps were identified such as, increasing the quality, quantity and accessibility of information on employment support services for people with MS; an evaluation of current employment programs; identifying where access to these is being limited; identifying why people with MS are not engaging early with MS Societies and employment services; and developing a pilot employment support service.

An Employment Research Steering Committee has been established to drive these recommendations and will be coordinated by MSRA and MS Australia – ACT/NSW/VIC.

One of the first activities that the steering group will focus on is the review of current employment resources available for people with MS and their families. The aim is to ensure that these resources incorporate latest research findings and early intervention strategies and are promoted and readily available to people newly diagnosed with MS.

Support provided by MS Australia – ACT/NSW/VIC

- **Advocacy.** A key policy issue for the MS Australia Advocacy team is employment participation. Within the framework of the new National Mental Health and Disability Employment Strategy, the policy team are advocating for a number of key inclusions to increase workplace flexibility and responsiveness to people who acquire disabilities and illness during their working life.
- **Employment services.** From 1 March MS Australia – ACT/ NSW/VIC will commence a new specialist employment service for people with neurological conditions in Victoria. Our organisation has been contracted to the Job Services Australia Program – an initiative of the Department of Education, Employment and Workplace Relations. Through this initiative, we are able to help people with MS in Victoria to prepare for employment, access job opportunities, retain employment, and secure equipment and modifications to assist in the workplace. While this is currently confined to Victoria, we are committed to being a provider of disability employment services and in due course, we will be seeking to tender for service delivery in NSW and ACT. Read more about this in our Advocacy News on page 8.

- **Specialist advice.** Our Community Support Workers and allied health professionals can help you with decisions regarding your employment. For example, they can:
 - explain the advantages and disadvantages of disclosing your MS to an employer;
 - help determine your need for an accessible workplace, and explain how to submit requests to your employer;
 - help you to locate and use employment retention resources; and
 - help you to identify employment options.

Community Support Workers and allied health professionals can also provide advice on managing fatigue at work and strategies to help manage cognitive changes.

At your request, they can also provide education sessions on MS to employers and work colleagues, and can suggest relevant resources and other government and community support available. Face-to-face and telephone support is available for people with MS across NSW, ACT and Victoria.

- **'Working with MS' education sessions.** Run regularly in NSW and Victoria (see Events section for details), this education program provides people with MS, their family members and carers, with information on employment, superannuation and insurance rights, issues around disclosure of MS to work colleagues, strategies for symptom management in the workplace and who to contact regarding work issues. Sessions are led by staff experienced in managing MS in the workplace, as well as a guest speaker from Maurice Blackburn Lawyers.
- **Information resources.** MS Australia – ACT/NSW/VIC has a number of resources available to assist people learn more about working with MS. In particular, our website has an extensive area dedicated to frequently asked questions regarding employment. These have been compiled with the help of Minter Ellison lawyers, and can be found at www.mssociety.org.au/live/employment-faq.asp

For more information, or to access our information resources, please call MS Connect on 1800 042 138. MS Connect can also advise you of other external employment services and support, in your local area, that are relevant to your individual circumstances. Call 1800 042 138.

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**Multiple Sclerosis and Employment Study
Call for Research Participants**

We are looking for volunteers with MS who are currently either working (full- or part-time) or not working at all to take part in a study investigating the reasons why some people with MS cease employment, reduce their working hours and/or change the types of duties performed. As a participant in this study, you will be asked to complete a questionnaire and undertake a brief telephone interview and/or some face-to-face assessment tasks. The questionnaire should take no longer than 1 hour and the assessment tasks no longer than 1.5 hours to complete. This study is being funded by Multiple Sclerosis Research Australia and has been approved by the Human Research Ethics Committee (HREC) of the University of New England. To volunteer or for further information please contact:

Ms Cynthia Honan
PhD Candidate
University of New England
Mobile: 0402 818 147 or
Email: chonan@une.edu.au

NEW RESOURCES

Check out the latest resources, sourced by the MS Library.

Multiple Sclerosis: A Guide for Families

by Kalb, R., Demos Medical Publishing

A diagnosis of MS can affect the entire family. This guide aims to provide family members with the information they need to live comfortably with the disease, and with each other. It acknowledges the confusion and distress that can be experienced by family members and communicates the message that families are not alone.

Chapters are written by well-known experts in each area and include:

- When MS joins the family
- Emotional and cognitive issues
- The family's relationship with the healthcare team
- Fertility, pregnancy and childbirth
- Parenting issues
- Parenting a child with MS
- Adults with MS and their parents
- General health and wellbeing
- Supportive resources for families

Timmy's Journey to Understanding MS

by the US National MS Society www.nationalmssociety.org

This 14-minute animated video shares a little boy's adventure in learning about MS. When Timmy's father comes home from work and is too fatigued to play ball, Timmy gets upset and stomps up to his room. Here, a superhero from a pamphlet about MS, Captain Kip S'myelin, comes to life and takes Timmy on an adventure through the human body.

Timmy learns how MS affects the central nervous system by following a T-cell through the blood brain barrier and into the brain. The importance of asking questions is emphasised as Timmy asks questions about what causes MS, why some symptoms come and go, and why some stay. This DVD was developed for children aged 5 to 12 years and is an excellent resource that can be used to begin discussions about MS, prompting them to ask questions and talk about any fears they may have about MS.

When a Parent has MS: A Teenager's Guide

By the US National MS Society

www.nationalmssociety.org/multimedia-library/brochures/for-children-teenagers/index.aspx

Aimed at teenagers who have a parent with MS, this well-written and easy to read publication from the US National MS Society covers a range of topics, including what you may not know about MS, how your parent's MS can affect you, speaking up for yourself and taking care of yourself.

The booklet also provides teenagers with useful examples of how to start a conversation with their parents about MS and the affect it has on their life. Strategies for dealing with emotions, peers, school work and anger are also discussed.

There is a helpful section on coping strategies and the "good stuff" about having a parent with MS. The publication makes great use of quotes from teenagers, allowing the reader to see that there are other teenagers in the same situation as them.

The Young Person's Guide to MS

By the UK MS Trust

www.mstrust.org.uk/shop/product.jsp?prodid=137

This bright, colourful book is aimed at 10 to 16-year-olds who have a parent with MS. Written in a way that teenagers will enjoy, the book covers a range of topics, including:

- What is MS?
- Symptoms of MS
- How do you get MS?
- Will I get MS?
- How MS might affect me
- Tips for coping
- It's not all bad

Quotes from teenagers highlighting their questions, thoughts and fears about MS are found throughout the book. These answer many of the questions teenagers may have about MS and the way it can impact their life.

To borrow books or for assistance in accessing online resources, please contact the MS Library on (03) 9845 2809 or library@msaustralia.org.au

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