

# MagScene

## Welfare to Work Update

### What will it mean for people with MS?

Following the passage of the Welfare to Work Bills through the Senate Committee, the legislation is now law and will come into effect on 1 July 2006.

This legislation brings significant changes to the welfare system for single parents and people with disabilities and chronic illness. The package is part of the Federal Government's push to increase workforce participation in Australia. Services for job seekers who may need assistance will be increased by \$2 billion over the next four years. The main changes in this package to affect people with chronic illness and disabilities are:

- Reducing the work capacity threshold for Disability Support Pension (DSP) eligibility from 30 to 15 hours per week
- Introducing a new Comprehensive Work

Capacity Assessment (to be called a Job Capacity Assessment) (yet to be released)

- People with disabilities and chronic illness will be subject to the Newstart benefit regime if they are assessed as being capable of working 15 to 29 hours per week
- Increasing the number of job placement places funded by Government for people applying for the DSP after 1 July 2006
- Increasing the Mobility Allowance to \$100 per fortnight for eligible people

Between now and 1 July 2006 the Government will finalise the procedural guidelines for the practical working of the package. At the time of writing we have not seen the assessment tools or the decision making guidelines for this new system. Thus it is difficult to

be certain about how the package will affect people with progressive conditions such as MS.

#### Who will be affected?

These changes will only apply to people applying for the DSP after 1 July 2006. Existing DSP recipients will continue under the old rules and any job seeking will be entirely voluntary. People who have been granted the DSP after 11 May 2005 will be subject to the new rules when they are next reviewed.

Applicants for the DSP will have to undertake a Work Capacity Assessment to determine if they have a work capacity of 15 – 29 hours. This capacity is defined as 'being able to work at award wages independently of a program of support'. If this cannot be established, the person will be deemed to have a 'continuing inability to

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Seeking the Cure.  
Providing the Care.

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work' and is therefore eligible for the DSP. The definition of being fully independent is yet to be finalised by the Government.

If, at assessment, someone is deemed to have the capacity to work, they may start receiving the Newstart Benefit (with all the participation requirements that entails). If their condition worsens or it turns out that services recommended by the assessment do not lead to sustainable work, then they may be eligible for the DSP.

If a person receives Newstart, then they will be bound by the Newstart job search and compliance regime and those working part-time will be subject to the marginal tax rates associated with Newstart.

### **Main issues**

This package is overwhelmingly targeting people who are not working and trying to get them into the workforce – hence the name of the package 'Welfare to Work'. Many people with MS go in the opposite direction (from work to welfare or settling on work AND welfare). The mix of part-time work and a DSP supplement usually works reasonably well for people managing their MS and employment.

This is supported by the Access Economics 2005 findings that people with MS have a one-third greater representation in part-time employment than the general workforce, but receive working-age welfare payments at three times the rate of the general working-age population.

There are still questions about how people who are currently working part-time (but at their full capacity) when they apply for the pension will fare under the new arrangements. If people are streamed onto the Newstart benefit rather than the DSP, they will have a decreased financial outcome due to the high marginal taxation rates with Newstart.

MS Australia gave evidence to the Senate Committee last year about the impacts of the changes on people with MS.

We will continue to work with the Government on the guidelines involving these matters.

Following the Senate Inquiry last year the Government is working to resolve a number of areas of uncertainty in the package relating to people with episodic and progressive conditions. These people will be at particular risk unless the new assessment system takes sustainability of work capacity and workplace suitability into account. As an additional safeguard, the Senate recommended that the guidelines be subject to Parliamentary scrutiny as they are developed.

ACROD, the peak industry body for disability services, reports that the Government will introduce 27 disallowable instruments into Parliament early in 2006, covering important areas of detail in the package. These will be critical in determining how the new compliance rules will apply to people with disabilities assessed as having 'partial work capacity'.

The areas covered by the disallowable instruments will include the kinds of requirements that an activity agreement must not contain (for example, medical treatment); the matters that must be taken into account in deciding whether particular paid work is unsuitable; the meaning of 'special circumstances'; whether a person's excuse for refusing a job or failing a participation requirement is reasonable (for example, lack of accessible, affordable transport).

People who are likely to apply for the DSP after 1 July 2006 are advised to contact the MS Australia (VIC) social workers for advice about the status of the legislation and the processes that will be in place. When the information is released by the Government we will be offering updates.

For more information on this package check the MS Australia website [www.msaustralia.org.au](http://www.msaustralia.org.au) or contact Alan Blackwood on (03) 9845 2713 or [ablackwood@mssociety.com.au](mailto:ablackwood@mssociety.com.au)

See MS Australia's submission to the Senate Inquiry:

[www.aph.gov.au/Senate/committee/clac\\_ctte/welfare\\_to\\_work/submissions/sub40.pdf](http://www.aph.gov.au/Senate/committee/clac_ctte/welfare_to_work/submissions/sub40.pdf)

Read the Senate Community Affairs Committee inquiry's report:

[www.aph.gov.au/Senate/committee/clac\\_ctte/welfare\\_to\\_work/report/index.htm](http://www.aph.gov.au/Senate/committee/clac_ctte/welfare_to_work/report/index.htm)

# CEOs' Corner

Over the summer I re-read Helen Keller's biography "*The World I Live in*".

As readers may recall, Helen Keller was born both deaf and blind. Her achievements were amazing. She travelled worldwide, wrote books and achieved academically. We can greatly admire her story as there are many inspirational qualities that transcend her perceived limitations. One of my favourite quotes is "Through the sense of touch, I knew the faces of friends and the world about me". In reading her memoirs I was also constantly reminded of people with MS who are also inspirational in meeting the daily demands of managing their symptoms and the impact of living with MS. The opportunity to meet our aspirations is certainly a deep desire we all share.

Within the community of MS we are constantly looking for ways we can all achieve our aspirations. Through our skilled staff we can achieve a better understanding of MS and provide information that directly meets your needs. It will continue to be achieved through the new MS community across NSW and Victoria.

From November 2005 the MS Societies of NSW and Victoria have a single Board which is committed to achieving the objectives outlined at our Annual General Meeting. In order to continue to address the needs of individuals with MS, their families and carers we are on a journey of change, driving further efficiencies while remaining locally focused. As we move ahead together you will see changes emerge, for example, a single magazine, improved information and education seminars and programs and a broader range of local health professionals interested in MS.

2006 is also an important year in the life of MS Australia. It represents fifty years since



*Bill Northcote CEO,  
Corporate*



*Lindsay McMillan CEO,  
Mission*

the founders started a small self-help group in Sydney to support families with MS. Reflecting on what has occurred in that time is substantial. Research has advanced and focused on finding a cure and ways to repair and regenerate myelin and minimise the effects of MS. In addition, the specialist services of the MS Societies have become more family oriented and focused on clients remaining healthy and well.

Today the Australian community is better informed about MS. Treatments which assist in reducing the progression of MS were also introduced in 1996.

While a great deal has been achieved, there is still more to be done. We remain vigilant in our efforts to end the devastation of MS. This is a world wide challenge and Australia is a major contributor in achieving this goal. In the meantime, we are totally committed to assist people with MS to live confidently and optimistically.

This CEOs Corner was written by  
**LINDSAY McMILLAN**  
Chief Executive Officer, Mission

# Travelling with MS

## Part 4: Getting About, Accommodation and Toilets



Here is the final part in a series of travel advice articles by Bruce Mumford. Bruce is an example to all of us who are in a wheelchair and feel that we should take the family on that holiday we always talked about but did not think possible. (Ed)

If hiring a car, try to organise this well ahead from Australia. Especially if you want an automatic. To fit the family and my wheelchair we needed a station wagon, which made things even more difficult. It had to be automatic as if my wife couldn't drive in an emergency, I could handle an auto, but never a manual.

We eventually managed to get one for the United Kingdom, but not in France until we got there – and then only just. Hertz provided hand controls free in the UK, but as they were 'add-ons' they were not that easy to use and had to be laboriously detached if someone else wanted to drive.

The first thing to say about your typical tourist site in Europe is that it is not as accessible as one in Australia. You will often be told that the castle/cathedral/minefield was not built with disabled people in mind - but this is really no excuse for not making them accessible now.

At Chambord Chateau just a masonite ramp over a few steps was all that was needed. They had a stair lift at the military museum in York, but it was just a bit short for my scooter and had no room at the bottom to get off, so we spent an awful lot of time trying to manhandle it for what was at best a rather mediocre display and wasn't worth staying at for very long. And then the lift stuck coming back up the stairs...

At the Louvre, they had a special map showing disabled access and toilets, but it was so insanely complicated that I wore my wheelchair's battery out just trying to follow it. You got off the lift at one floor and then had to pack a cut baguette or two before heading off to the other side of the gallery to get the lift down to the next floor.

Unlike accommodation and transport, you probably shouldn't book too many attractions you want to visit before leaving. Because once you get there, you'll often find that entry for disabled visitors is free; and often their carers and sometimes even their children get a discount. Which is just as well really, because at lots of places there isn't a lot you can do once in except sit around and wait for the family to come back!

At Warwick Castle I was given a special sheet for disabled visitors. It informed me that although I would not be able to handle the inside of the castle (lavishly populated by figures by Madame Tussauds who now own the castle) I would be able to view the outdoor events (not actually happening in winter), stroll around the gardens (difficult in rain), visit the fully accessible gift shop (of course) or use the disabled toilets (more sitting around!)

At the very old chateau at Meung-sur-Loire I discovered an embarrassing tendency for my wheelchair to ruck up strips of carpet placed loosely on the floor. As I tried surreptitiously to replace them, I hoped the strips weren't hundreds of years old (although they probably were).

Lots of shops have no disabled access, but only narrow stepped entrances. I went past many that I would have liked to go in, but simply couldn't.

It became very clear to me what Bruce Cameron was on about with 'Accessible Tourism'. There's a lot of tourist dollars being missed out on by those who won't make themselves accessible to disabled people. Against all odds, we sometimes manage to have a little money left to spend while on holiday!

I shouldn't get too negative though. Despite all the difficulties, your trip will be made worthwhile by the help you get from all those strangers. People who prove to you that there really is a streak of goodness at the base of most folk (certain politicians obviously excepted). Like the kind tow-truck driver who pulled over to winch us out of a bog after my wife interpreted my admittedly vague directions of "make a left turn some time soon" as "pull a hard right angle now straight off the road and into that ditch".

Wherever you are, many thanks.

It is important if travelling overseas to book as much of your accommodation as possible before you leave. The MS Society of the United Kingdom was quite helpful and suggested a disabled tourism site on the internet. But at over \$500 a night, the places they recommended looked very nice, but were a bit out of our league.

We stayed at 'Citadines' apartments in London and Paris, which were fairly expensive, but had the advantage of their own kitchen and a helpful front desk, allowing the benefits of both an apartment and a hotel and saving a lot of eating out, which gets quite expensive for a family. Speaking of which, we found food (and wine!) a lot cheaper in France than in the United Kingdom as well as being of much better quality.

Generally apartments and hotel rooms in Europe are very small; but while it does make getting around inside difficult at times, there is the advantage of always having a wall to lean on – or if you miss, not having so far to fall! Check out the layout of the bathroom if you can, because many places have incredibly difficult showers to get into (usually over a bath) and often very slippery tile floors.

You'll get tired out just trying not to do yourself a serious injury in unfamiliar surroundings, so allow time each day to recharge your batteries. Do not make the usual tourist mistake of trying to cram too much in. With MS or any disability, you just can't afford to. You'll tire yourself out, make mistakes (and I made plenty of those without even being tired) and enjoy nothing.

I came to appreciate the luxury of automatic doors and to get very adept at zooming in and backing out of small elevators before the doors closed. One elevator was so tiny I had to send the wheelchair up after me. Très difficile!

I could write a book about toilets in Europe. And when you've got MS, they are a pretty important part of your trip. I remember not really understanding the concerns of some members of our Access Committee about the difficulties of getting up from deeply dished toilet seats. Now I do. And I have also confronted perfectly flat ones that you can't stay on, heated ones and ones that rotate and clean themselves. The best toilet seat was a fully contoured one in a disabled toilet in Belgium. It looked like something from Darth Vader's starcruiser, but worked like a treat!

I found the toilets in the UK hardest to use, where flush buttons don't seem to have been invented yet. Rather you have to use a lever, which often has to be pumped. The easiest to use was one in Japan which flushed itself. I don't want to think about how the sensor worked!

Disabled toilets varied widely, where they were available. Most tourist sites in the United Kingdom have them available, in France they are a little less common, but Germany is well endowed. Like here, you often have to wait for the quite able-bodied to vacate them. Many toilets have attendants sitting outside, whom you pay. As a disabled person however, you are not expected to pay; which in some cases was just as well!

The most unusual experience I had in a disabled toilet was at the castle in Prague, where a lady had set up residence and was just in the process of boiling a cup of tea at a table set with flowers a tablecloth and a radio-cassette player. She was accommodating enough and was happy to let me in, but it felt a bit uncomfortable having a wee in someone's kitchen.

In conclusion, although a lot of my treatise may make it seem it's just too difficult to go overseas with a disability, nothing could be further from the truth. Looking back at the videos, I've realised that things were even better than we thought at the time. When you get back you return with a new self-confidence - as well as a stunned and incredulous look on your face.

And anyway, what's the alternative like? I think it was Mel Brooks who said, "You're dead for a long time . . ."

**BRUCE MUMFORD,**  
Burrawang NSW

# Update on Client Programs



Welcome to 2006! This year marks the **50th anniversary of MS Societies in Australia**. During this time there have been significant advancements in the understanding and management of multiple sclerosis, particularly from the 1980's onwards. And the MS Society has responded accordingly in the development of its programs and services.

Up until the 1980's there were few specialist services for people with MS and MS care tended to be more about crisis intervention – addressing problems as they arose for people. In the mid 1980's, there was recognition that specialist approaches were required for the management of many MS symptoms and that early detection and prevention strategies could lead to better outcomes.

The 1990's saw great advances in understandings about the disease process and new approaches to the medical management of MS. The importance of early diagnosis to maximise treatment options to slow down disease progression saw the MS Society in the 1990's establish a dedicated MS Clinic in partnership with leading Sydney neurologists. The MS Clinic is now located at the new Brain and Mind Institute in Sydney and provides an avenue for timely diagnosis, treatment and clinical research. We are keen to see the establishment of other similar Clinics around the State that will provide specialist neurological and/or multi-disciplinary assessment and intervention services for people with MS.

The MS Society has always strived to be responsive and relevant to people with MS and their families. Over the years we have adjusted our services and programs to reflect research findings and new understandings about MS, and to ensure we address the needs of all people with MS.

Management approaches in the 90's began to recognise the importance of information, education and lifestyle management, particularly for people newly diagnosed. We

began to see a new philosophy – one of empowerment in which the person with MS takes an active role in planning and implementing health care and self-care activities, learning to adapt and change in response to changes brought about by MS.

The MS Society has embraced this philosophy and it underpins all our programs and services. We have developed a range of information and education programs focusing on understanding and managing MS and this year we will be focusing on developing some specific education resources for families and carers. Our Lifestyle Services provide specialist consultation on ways to best manage the challenges of MS and in a way that complements existing health and medical services.

We are clearer about our specialist role and more focused in our service provision. You will see us working more in collaboration with local health service providers, sharing our knowledge to enable them in turn to provide effective support and services closer to where people with MS live.

This year we will be reviewing the way we currently provide programs and services into rural areas. Our aim is to find more efficient and effective ways to do this and in particular ways we can partner more with local health service providers. I have started talking directly with rural people and I welcome suggestions from our rural readers.

Our 50th anniversary celebrations kicked off with the Prevention Possibilities in Multiple Sclerosis (ms06) Conference at the end of March. I enjoyed meeting many of you there and we look forward to bringing highlights to readers in future issues.

**ROBYN FAINE**  
**General Manager Services NSW & VIC**  
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# Developing and Assessing New Therapies for Multiple Sclerosis

Dr Helmut Butzkueven has recently been awarded the prestigious Betty Cuthbert Fellowship, jointly funded by the National Health and Medical Research Council (NH&MRC) and MS Research Australia.

This is to allow him to continue his work – in trying to understand the cause of the underlying disease process of MS and finding a cure. Dr Butzkueven is a member of the MS Group at the Howard Florey Institute, University of Melbourne and a practising neurologist. The following is a summary of Dr Butzkueven's current research.

## Developing and assessing new therapies for multiple sclerosis

In multiple sclerosis (MS), the immune system mistakenly attacks the brain. These attacks destroy myelin, the protective coating around electrical cables in the central nervous system. Current treatments for MS, such as beta-interferon or glatiramer acetate are only partially effective and work by reducing the number and severity of attacks.

However, in the majority of people with MS permanent disability is due to the development of progressive MS. Currently therapies do not reduce this progression and therefore, there is an urgent need to develop new therapies for MS. To this end we aim to further develop the growth factor Leukaemia Inhibitory Factor (LIF).

We have already shown that LIF is made by the body during MS-like inflammation, and that it limits damage from inflammation by directly protecting myelin-producing cells. However, as the body's own LIF production during inflammation is submaximal, myelin protection can be enhanced by giving additional therapeutic LIF. These findings illustrate that LIF could supplement current generation MS treatments by providing "brain protection." Clearly, such a treatment needs to be tested in people with MS, however the way to actually assess this type of drug is not yet established.

We propose to measure the beneficial effect of LIF in an animal model most closely

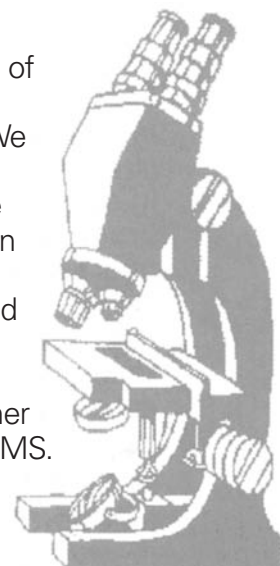
resembling a typical human MS attack of optic neuritis (inflammation of the eye nerve). As the optic nerve is small and very well defined, it is possible to perform accurate assessments of optic neuritis by counting the actual number of cables and myelin-producing cells that have been destroyed.

It is, of course, not possible to examine an optic nerve in a living human in this way. If we can show that LIF reduces myelin/cable damage in mouse optic neuritis, we then propose to measure the effects of LIF by magnetic resonance imaging (MRI). A specific type of MRI known as Diffusion Tensor Imaging (DTI) may be able to determine the extent of demyelination/cable loss, that we have already shown is abnormal in mouse optic neuritis.

We also want to define how LIF works as a neuro-protective drug. We have measured the response to LIF in myelin-producing cells, and have discovered that it stimulates the production of the small protein galanin. We will now assess if galanin itself protects myelin and myelin-producing cells. This will be tested in both isolated cells and whole animal models.

In summary, we propose to obtain "proof of concept" that the growth factor LIF is neuroprotective in mouse optic neuritis. We also wish to understand exactly how LIF reduces myelin damage by examining the effects of galanin, a substance produced in response to LIF in myelin-producing cells. We then aim to develop a new, MRI-based method for testing neuro-protective therapies in mouse MS, in order to establish a method for testing LIF and other neuro-protective therapies in people with MS.

**DR HELMUT BUTZKUEVEN**  
Neurologist, Howard Florey Institute



# MS Research in Australia

## Working together to find the answers...

### Recently diagnosed with MS?

Were you diagnosed with MS later than June 30, 2002? If so, you are automatically eligible to assist with a new nation-wide research initiative that is working to help find treatment for MS and real life solutions for people with MS.

The Australian MS Longitudinal [long term] Study (AMSLS) is an official project of MS Australia, the national umbrella body that promotes the interests of everyone affected by MS and which is responsible for facilitating scientific and applied research into MS. The AMSLS is a groundbreaking study that is designed to expedite new and important multi-disciplinary research about MS, using a large national sample of volunteers who have agreed to assist. The AMSLS will enhance basic knowledge of how MS works, and will also extend our practical knowledge of MS and how to manage its highly variable effects on individuals.

### What does the research need from you?

As a participant in AMSLS, you will periodically be sent confidential, carefully devised questionnaires about many aspects of your MS and how it affects your lifestyle over time. (Internet and hard copy versions of the questionnaires will be available.) For example, you may receive questionnaires on how you are coping financially and, where applicable, how you are managing with your employment and chosen career path. There may also be questions designed to assess your MS in relation to your lifestyle and environment, so that researchers can better determine the 'extrinsic' factors that alter the course of MS. Again, MS is a highly variable condition and you may be invited to take part in rehabilitation studies designed to assess the best treatment methods for individuals with a particular type or course of MS. All such information is greatly needed so that people with MS and their families can make informed decisions about how to achieve the best

lifestyle outcomes for them. Although the AMSLS is a long term project, enrolled volunteers can opt in or out of particular aspects of research, just as they please: by joining up you don't have to answer every questionnaire or participate in all the available research studies that arise.

### My MS isn't affecting me much, so why should I join the AMSLS?

The AMSLS especially needs input from people who are coping well with their MS, along with data from those not so fortunate. To put it bluntly, by enrolling in the AMSLS you'll not only be helping others, you'll be increasing your own information base should you need it in the future. That's a sort of "knowledge insurance"!

### How is my privacy protected?

The AMSLS conforms to Australian Government privacy legislation and has been approved by the ACT Health and Community Care Human Research Ethics Committee, Canberra. No names of participants will be made public for any reason, and as an extra precaution no names or addresses of participants are stored on any computers that even theoretically might be accessed by hackers. (Every participant is given a private code number for all AMSLS data entry and analysis purposes.)

### Where can I get more information?

1. Ask your local State MS Society for an "Information Kit" for the Australian MS Longitudinal Study (AMSLS). The kit consist of an Information Sheet, a Consent Form, and a Reply Paid envelope.
2. Alternatively, if you need more information or would like a kit, please contact:

### DR REX SIMMONS

#### Project Manager

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# Access Economics Report on MS in Australia

Late 2005, **Access Economics**, one of Australia's leading economic consulting firms, released a report on their findings in a wide-ranging study of MS and how it affects, not only those who have it, but Australia as a whole.

## Basic facts about MS in Australia

- Over 16,000 people have MS in Australia.
- Three quarters of people with MS are women.
- 87 per cent of Australians with MS are of working age.
- The age of onset is from 20 to 40, when career and family building are at their peak.
- Prevalence is going to increase by nearly seven per cent in the next five years.

## Comparisons

- In any year MS is more prevalent than breast and bowel cancer and sporting injury.
- MS causes more disability and loss of life than rheumatic heart disease, chronic back pain or mental retardation.

## Total economic costs of MS

- The total financial cost in Australia of MS is over \$600 million a year.
- The value for the loss of healthy life is \$1.3 billion a year.
- Altogether the financial and disease burden cost approaches **\$2 billion a year**.

## Areas of greatest cost

### Loss of productive capacity

- This year 3,200 people with MS will not be able to participate in the workforce.
- The annual lost production cost from reduced hours, early exit from the workforce and temporary absence is \$160 million.
- The number of people with MS who work part-time is disproportionately high.

### Growing informal care costs

- Informal carers provide an average 12.3 hours a week to people with MS.

- The cost of replacement care is \$260 million (43 per cent of the financial cost of MS).
- The disease's increasing severity over time requires increased informal care.

## Areas of greatest challenge

### Work and family

- Using health management, employment policy and responsive welfare to keep people well, working and with their families for as long as possible.
- Providing policy and income support to people who have reduced earning capacity and higher costs because of their MS.

### Support for informal carers is a priority

- The replacement cost of informal carers is a quarter of a billion dollars. The cost of replacement residential care would be 60 per cent higher.

### Medical research

- Government spends less than the national health average on MS research.
- More MS research funds come from the USA than from governments in Australia.
- Last year the PM launched MS Research Australia, which requires \$30 million over four years to deliver better treatments and products.

### Health and long term care

- There are too many young people with MS in nursing homes.
- People with MS use many parts of a health system that requires improved coordination of services.
- People need effective access to some pharmaceuticals currently not PBS-listed for MS.

**Source:** *MS Australia (2005). Fact Sheet: Access Economics Report on MS in Australia.*

# Copping it Sweet

## Who Am I Now Then?

I'm thinking that maybe I need to re-invent myself.

If I am no longer able to work effectively in my previous profession because of MS, then who am I now... please? I don't fancy thinking of myself as an 'ex-designer' for the rest of my life. I suppose all retirees are faced with this sort of quandary when they stop working but I suspect it's even more difficult to find a new direction if you are younger and unexpectedly thrown off the roundabout.

Until I chucked in the towel and opted for the disability pension, I had followed your 'sensible career path' defined by the need to support children, pay a mortgage and those never-ending bills. I guess I was lucky to have always enjoyed my work and I still miss it, but I am now in some kind of limbo. What to do? I like a good read and the other stuff I get up to but there must be something more to my life I reckon.

These days I can think realistically of what I really, really always wanted to do and not have to worry as much about all those damn bills. Maybe there's a useful side to this MS of mine.

I have pondered this a lot recently.

I reckon I could have been an actor but I was hopelessly shy. Then again they say most actors suffer from shyness off the stage. There's a story often told in my family about the time, as a 6-year-old, I was packed into the back seat of our family car with some people unknown to me. I had caught the skin of my elbow in the closing door but I didn't make a sound for miles and miles until my mother noticed the tears flooding down my little red face. Now is that shy or what? I am still struck dumb in front of a group of more than three people although over the years I have learnt the skills to cope... as you do.

Maybe I could do the acting thing now but this wheelchair might limit the available roles a bit and my speech gets a bit garbled at times.

Then again...

I often fancied I should be an artist. I fiddled about at the edges on a few occasions with varying degrees of pleasure. I have enjoyed life drawing, sketching landscapes or various architectural objects but I will always remember once watching a fellow traveller sitting by himself at some exotic location producing quick pen sketches of the passing scene in his tiny sketchbook. I was fascinated and thought then that I would do this some day. I loved the idea of producing very quick 'snapshot' sketches of personal experiences.

That day might have come.

I have been doing some sketching with my special friend Miffy. I have done a few drawings that have shown some promise in a personal satisfaction sort of way.

I now realise that you don't have to maintain accuracy with a bumbling MS hand. It's more to do with feeling. The results can be astonishing.

One of my local coffee house buddies is an artist and retired art teacher. She is soon going to arrange a casual drawing group in her studio nearby. This will be perfect for me. No expectations. No pressure. Just creative pleasure.

Should be perfect, I reckon. I can't wait.

My point here is to suggest that the life changes associated with a disabling disease like MS may be an opportunity for a detour for the better.

MS has turned my life upside down but has given me a chance to look at some of those things I should have done something about years ago.

MS has to be good for something. Surely! Apart from making our lives difficult and keeping those neurologists busy.

**IAN CAMERON**

# New Faces at the Society

**Beverley Jones** joined the MS Society in November as Family Education Project Officer, based in the Lifestyle Services team.

She has only recently come to live in Australia, originally coming from Great Britain, but has spent the last 6 years in New Zealand.

Initially qualified as a Home Economist, Beverley later went into the health and education fields taking a post graduate diploma in Health, Risk and Society.

In her previous positions she has developed educational material, workshops and conferences on a variety of health issues, for both health professionals and teachers.

In this new part time role, Beverley is developing a program for families, support people and carers of people with MS. This will include the development of information resources and education workshops for delivery across New South Wales.



## Peer Support via Telephone Contact

We are in the process of developing a pilot program in the area of peer support. The purpose of this new initiative is to build upon existing efforts, which provide opportunities for people with MS to have access to support from other people with MS.

At some stage you may have found it difficult finding another person who could identify with your experience of living with MS. The aim of developing a new program is to link people with MS who are feeling isolated 'to another person with MS who understands their situation'. The program aims to match eg a mum with young children with a trained Peer Support Worker, who is also a mum with children of similar age.

Peer Support Workers are people with MS who are subject to screening and training requirements before becoming active. Their role is to listen, share their experience and offer support to other people with MS, via telephone contact.

We are currently seeking input from people with MS in relation to the development of the program and would appreciate hearing your comments.

If you feel you would:

- Like to know more about the pilot program
- Have an interest in becoming a Peer Support Worker
- Be interested in completing a questionnaire on your experience of peer support,

please contact

Liz Jewell  
Peer Support Coordinator  
(02) 9411 4522 (Tues, Wed, Thurs)  
or email [ljewell@msnsw.org.au](mailto:ljewell@msnsw.org.au)

### Online Peer Support

Victoria currently offers an online Peer Support facility for people with MS who wish to communicate with other people with MS. This service is now available for people with MS in NSW. My connected community (mc2) is facilitated by trained Peer Support Workers and operates from 8.30pm–10.30pm week nights. The address for those wishing to access the service is <http://mc2.vicnet.net.au/home/mssvpeer/index.html>

# Coming Outdoor Events

On Sunday 4 June you're invited to a very special celebration – the MS Society's 50th birthday. The party starts with the MS Harbourside Walk and Fun Run in Sydney.



**Last year 3,000 people strolled and sprinted into National MS Awareness Week raising a record \$100,000 along the way. In 2006 we're aiming even higher and want 5,000 people to come out and show their support, so get your friends, family and work mates together and let's make this one the biggest yet! Help us take our message to the main streets and put MS on the map for our 50th year.**

Walkers can choose the beautiful stroller and wheelchair-friendly 9km walk, or those feeling a little more energetic can step it out over the 16km course. Either way you'll enjoy breathtaking views, live entertainment and that feeling you get from being a part of something special. Both courses start in Sydney's Hyde Park.

Meanwhile runners will tackle an 8km route through picturesque harbourside streets from Milsons Point to Balls Head Reserve and

return. Up to 1,000 athletes will race down the Luna Park boardwalk towards the finish line under the gaze of the city's most iconic smile. Our fun run is one of Sydney's most scenic and popular but be warned – it's not for the faint-hearted.

If you don't think you've got the puff to participate but still want to be part of the celebrations, why not get a group together and volunteer, or better still fundraise? We have 200 volunteer positions and thousands of dollars to raise so get in touch with us to find out more about the many ways that you can support this annual event.

**For more information contact MS Events on (02) 9413 4166 or email [events@msnsw.org.au](mailto:events@msnsw.org.au)**

**Enter online for the walk and fun run from 18 April at [www.walkforms.org.au](http://www.walkforms.org.au)**

# MS Busibody

This column has appeared in MagScene since 1986 (then monthly), when only 300 photocopies per monthly issue were distributed. Our recently retired editor, Zanna Barron and I compiled, censored and illustrated the little Sydney rag. We soon posted out statewide.

I have shared with you many highs and lows under the disguise of MS Busibody. Regular readers may have noticed my absence in the last two issues. After 20 years, the editorial staff has urged me to 'come out'. So here I am, larger than life.

The second half of 2005 saw huge changes in the MS Society, while personally I was dealing with a dark problem unrelated to MS.

With a bleak diagnosis of lung cancer, MS took second place. I had a biopsy, intense chemotherapy, 12 X-rays & scans, 8 hospital stays, then finally major surgery. I spent Christmas in RPA Hospital. With positive thoughts and support of family and friends, and of course early expert intervention, much to the amazement of my medicos, I'm here to tell the tale. MS Busibody lives on, and it's back to MS matters.

The buzz for the first half of 2006 is the

- ms06 Conference at Star City in Sydney
- MS Australia's 50th Anniversary
- MS NSW and MS Vic merging and working together
- The formation of the Peer Support Program
- Our Central Coast support group is cheering Melinda Giannani who is trekking The Great Wall of China for MS.

## MS BUSIBODY

Aka Katie Booth

# Mr Wisdom's Brain Gain

## Mystery solved!

Beth Watson tells me **TENAMBIT** is a suburb of Maitland, in the Hunter Valley.

Beth survived that dreadful New Year's Day heat in order to forward 1,390 words for the Christmas Challenge of **MUCOPOLYSACCARIDE**.

Watch out Beth, Lorraine Mahe, of Towradgi, (a northern suburb of Wollongong), is closing the gap, submitting 1,221 words.

Well done girls.

Your challenge for this issue is **SYRINGOCYSTADENOMA**; designed to play havoc with your sweat glands.

The usual rules apply.....

- 1 Your listed words must be made up of four or more letters.
- 2 Use only letters from the Challenge Word.
- 3 No letter may be used more often than it appears in the Challenge Word.
- 4 No plurals, place names or proper nouns will be accepted.
- 5 And remember, it's a bigger challenge if you don't use a dictionary.

## MR WISDOM

# Have you got the Rights Stuff?

With acknowledgement of the NSW Ombudsman's publication *The Rights Stuff: Tips for Making Complaints and Solving Problems – A Toolkit for Consumers of Community Services*, 2004. Written by Carolyn Campbell-McLean.

It can be difficult and nerve-wracking to make a complaint. However, there are some things that you can do that might help it be dealt with quickly and efficiently. They will also aid you in the process and improve the results of the complaint.

## **Act sooner rather than later**

Don't leave things too late as they usually get worse and snowball if left. When you think there is a problem with any part of your service it is best to raise the issue straight away and try to resolve it quickly. Preferably, directly with the worker involved or their supervisor – before making a formal complaint.

## **Arm yourself with knowledge**

Ask for information about the issue. Do you have all the facts? Make sure there is not a simple misunderstanding. It is good to find out details of the organisation's policies. You should have been given information when you first started using the service, including information about the process for handling complaints. If you don't have it, request it.

If your concern is about a decision made by the service, you are entitled to ask for 'reasons for decision' in writing. This gives them a chance to explain their decision and why they made it, and also clarifies the situation for you. Don't be afraid to ask questions.

## **Think things through**

Identify the key issues in the complaint. Think about the incidents – what actually happened? When and where did it happen? Clarify the issue – what is it that affects you? What outcome do you want? What do you want to achieve? For example, do you want an apology, change in policy, a change in the decision? Identify some options for resolving your complaint.

## **Keep records**

It is a good idea for you to record information about the issue, and about what you have done to try to sort it out. You need to remember and explain the details of what has happened, so it

is worthwhile to keep a diary. Record notes of phone calls, who you spoke to and the date. Ask someone to help if you need it. Make a folder for all correspondence. The information you record may be very useful in the future.

## **Follow the process**

It is important to discover the process the organisation has for consumers to make complaints. You can ask the organisation about their complaints process at any time. It is always best to try to solve the problem informally with the worker directly involved, before making a formal complaint.

## **Talk to the right person**

Make sure you are talking to the right person. That is, the person whose responsibility it is to address the problem. For example, there is no point in constantly telling the child care worker at your day care centre you need more child care. These decisions are worked out by the centre's coordinator, so you need to raise the issue with them.

## **Makes sure things happen**

When you make a complaint the service provider has a responsibility to deal with it. If raising the issue verbally, you should ask the person you are speaking with to record your complaint. There should be agreement about what should happen next, and timelines for when they will get back to you. They should respond to your complaint and tell you what action they will take.

## **Go to the next level**

If your complaint is not resolved to your satisfaction, or is not dealt with in a reasonable time, you may want to take it further. You can go to:

- the next level of management in the organisation such as the Management Committee
- the internal complaints unit if one exists
- an external complaints body like the Ombudsman, or to the funding body.

## Get support

Complaining about something may be hard work and stressful so it is a good idea if you can have someone to help you by supporting you through the process. This could be a family member or friend who you can talk to about the issues and help you consider your options. It is useful to have someone to think through the issue with you, attend meetings with you, and offer advice. If the issue is serious, if you feel that the service provider is not responding to your concerns, or if you don't have many supports you should ask an advocate to help you with the complaint.

## Stay strong

Making a complaint can be draining. Be persistent – and don't give up! It's your right to make a complaint and have it heard!

### CAROLYN CAMPBELL-MCLEAN

Community Education Officer  
NSW Ombudsman and Chair,  
Muscular Dystrophy Association  
Members Advisory Committee

# Information & Education

## Sessions coming up in your area (April – June 2006)

### Newly Diagnosed Program

These information sessions are aimed at people recently diagnosed with MS and their families and provide an overview of multiple sclerosis and programs offered by the MS Society of NSW.

#### Information Sessions

**When:** Saturday 20 May 2006  
**Time:** 10:00 – 12:00pm  
**Where:** Studdy MS Centre  
Joseph Street, Lidcombe  
**RSVP:** TEL 02 9587 5355 by 17/05/2006

*In addition to the information session, participants are invited to stay for an optional session on health and wellness, including a discussion on immunotherapy (12:00 – 2.00pm)*

**When:** Wednesday 7 June 2006  
**Time:** 6:30 – 8:30pm  
**Where:** St George Leagues Club, Kogarah  
**RSVP:** TEL 02 9587 5355 by 2/06/2006

#### Information Telephone Conference

**When:** Tuesday 27 June 2006  
**Time:** 7:30 - 8:30pm  
**Where:** Telephone link-up for people living in country areas  
**RSVP:** TEL 02 9587 5355 by 16/06/2006

***Please note that although every effort is made to avoid variation, session dates, times and venues may be subject to change.***

## Emotional Expression in MS

You are invited to participate in an exciting research study exploring *the expression of emotion in people with multiple sclerosis* that is being conducted in Sydney by Dr Julie Henry from the School of Psychology, University of New South Wales. Some people experience difficulties functioning as well as they'd like to in their work and social life now that they are living with MS. The aim of this study is to learn more about the possible causes of these difficulties and how they may be prevented. Julie is looking for twenty participants who will be asked to complete a number of questionnaires and short tests.

The questionnaires will ask you about your emotions and how these influence your day-to-day life. The short tests include tasks such as solving puzzles. The whole assessment will take approximately three hours and can take place in a mutually convenient location, such as an MS Society office, the University of NSW in Randwick or in your home. A small monetary incentive is offered in thanks of your contributions and to help cover any travel-related expenses. If you are interested in finding out more about this study, please contact Julie on (02) 9385 3936.

# Behind the Scene

This issue of MagScene for 2006 is a little late in reaching your mailbox because of the recent activities of the Prevention Possibilities in Multiple Sclerosis (ms06) Conference held in Sydney, 29 – 31 March this year.

The ms06 Conference brought together people with MS, families, friends, carers, health professionals, researchers and scientists and delivered a 3-day program addressing a diversity of topics covering the latest in MS research, chronic disease self-management and health and vitality in living with MS.

We were delighted to receive the support of a number of internationally renowned and inspirational speakers, including Prof George Ebers and Ms Lynda Finn from England, Prof Bernd Keiseier from Germany, Dr Jack Burks and Dr Allen Bowling from America, and Mr Fred Steinhaus from Canada.

We were also thrilled to have Australian leaders in their field share their research and clinical insights, including Prof Trevor Kilpatrick, Dr Stephen Kent, Dr Elizabeth McDonald and Dr Helmut Butzkueven from Victoria, Prof Anne-Louise Ponsonby and Dr Rex Simmons from Canberra, and Prof Graeme Stewart, Dr Michael Barnett and Dr Rhonda Brown from New South Wales.

A number of parallel sessions and symposia provided delegates with an opportunity to learn different strategies for self-managing the symptoms of MS and for maintaining general health and well being.

It was fantastic to see so many people with MS, their families, friends and carers attend across the three days. For those readers who were not able to attend the conference, we are planning to bring the

highlights to you in future publications, on our website and via a collection of DVDs. Stay tuned for details of how you can access these highlights over the coming couple of months.

As mentioned in the last issue of MagScene, the merger of the MS Societies in New South Wales and Victoria presents an excellent opportunity to work together on bringing you a joint magazine full of feature articles, personal stories and updates on the MS Society services, programs and fundraising initiatives. Planning has commenced and it is anticipated that we will be able to deliver the benefits in an inaugural issue some time in July or August. Readers will be able to nominate whether they would like to receive this new publication in hard copy by post or whether they would prefer to receive it by email. Readers will also be able to download the publication from the new NSW/VIC website [www.msaustralia.org.au/nswvic](http://www.msaustralia.org.au/nswvic)

As mentioned in MS Busibody's article on page 14, Zanna Barron and Katie Booth started MagScene some 20 years ago. It has grown from a small, in-house, manually-typed, hand illustrated and photocopied publication to what readers have come to know it as today. Although a combined magazine may seem like the end of a long-standing MagScene era, it is hoped that its aims and philosophy will remain strong in a shared magazine for readers in both States. The contributions of Zanna, Katie and Garry over the past years cannot be underestimated and they have left a wonderful legacy on which to base a combined magazine upon in the future.

**ALEX HOPE,**  
Acting Editor

**MS CONNECT™ 1800 042 138**  
**Monday – Friday 9:00am to 4:00pm**

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