

Lifestyle Management

Life just seems to be getting busier, and our lifestyles are becoming more hectic along with it!

Holding down a job, raising kids, keeping up with friends and the housework, keeping fit and having a bit of fun every now and then is quite a challenge.

If you also have to contend with fatigue and the difficulties of being organised and remembering things, as some people with MS have to do, daily life can seem pretty overwhelming!

So, is it possible to keep track of everything, get it all done and still have some energy left at the end of the day?

The Occupational Therapists at the MS Society of NSW have developed a program called 'Lifestyle Management' to help you do just that!

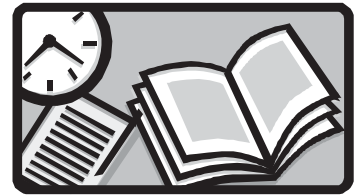
An individual program is designed to specifically meet your needs and includes sections and worksheets that will help you plan and organise your time and activities; use your energy

effectively and keep track of all the important aspects of your life.

The program takes the form of a notebook, organiser or diary.... whatever works best for you!

For example, a program may include:

- * A weekly schedule to help balance and plan your week. This will help you to remember what is on and use your energy effectively.
- * A calendar to plan further ahead for social engagements, appointments etc.
- * A meal planning and shopping list to streamline cooking and shopping tasks.
- * A message page to keep track of telephone calls that need to be followed up
- * A 'notes for myself' page to write down important information.
- * A fitness program to remember prescribed exercises.
- * A projects list and plan for those 'bigger' jobs.
- * A business card holder to keep track of commonly used contacts.
- * A checklist for just about



The above are just a few examples of what people have found helpful.

A Lifestyle Management Program will help you to minimise mental and physical effort, organise helpful routines, include important people in the process and just eliminate all those separate pieces of paper. To make it work however, you do need to be committed and motivated to make positive changes and get into some good habits.

An individual Lifestyle Management Program is created by you, with assistance from a health professional. For more information, contact the MS Society Information Line on 92872929 (1800 042138 for non-metropolitan callers) or the OTs on (02) 96460600 (1800 069159 for non-metropolitan callers).

BEEN THERE!

The following Been There! is from David who has noted that many of the “ads” in Lets Talk are from newly diagnosed PwMS who are quite young. David has “been there” himself and writes to let them know of his experiences of living with MS.

Ed.

APRIL/MAY 2002 Vol.12 No.2

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I am 35 and not newly diagnosed but I was when back in late '87 when I was diagnosed (I was 21). My first couple of years were a bit scary seemingly going from one episode to another. I was sure I was the unlucky recipient of progressive MS even though no one actually ever said I had it. During that time I developed optic neuritis in both eyes, fortunately on separate occasions, numbness in my left arm and the right side of my torso and down my right leg. I had difficulty walking and required a stick at night; running for a while was completely out of the question. After walking any reasonable distance I would end up tripping over my own toes and fatigue, a big factor, would set in.

Now that all sounds rather depressing and glum but I tell this because I was wrong. I didn't have progressive MS and today, 15 yrs later you would have no idea that I have MS. I still probably get more fatigued than most people and I still can lose track of my limbs if I lie down with my eyes shut, particularly if I cross my legs (pretty fun trick to keep yourself amused at times actually). But beyond that I have been trouble free for many years - hell it must be about 6 yrs at least since I saw my Neurologist.

I have no idea what your situation is but I guess being diagnosed for only a matter of months you are probably spinning out a bit and wondering what the future will bring and wanting some definite prognosis, not knowing how to plan your future. I know it is easy to say, but don't panic and don't give up on your plans for the future. You may well find that nothing really changes for you in the long run even if it is a bit crazy right now.

It's little comfort at the moment but don't lose sight of the fact that there are happy endings. So far I am experiencing one and there are no signs that that is going to change in a hurry.

Take care and feel free to get in touch if you want to ask me anything.

David

c/o garrya@msnsw.org.au

or PO 1246, Chatswood, 2057

NEW NATIONAL DATABASE LAUNCHED FOR RESEARCH ON MS

A nation-wide database is being set up by MS Australia to facilitate important research on MS and its effects on our everyday lives.

In the past, the need to locate, recruit and verify suitable subjects (people with MS) for each newly proposed research study has often led to difficulties such as small sample sizes, hesitant support from the nation's research funding bodies, and all-too-brief periods of study. This situation has in turn hampered the acquisition of much vital information about MS in scientific, clinical, socio-economic and quality-of-life areas. Some important, unanswered questions about MS that need longer-term research and/or a large sample size include:

- *What are the environmental risk factors for the development of MS?*
- *What is the relationship between genetic predisposition and the clinical course of MS? (Is MS really one disease?)*
- *What rehabilitation strategies are most appropriate and provide the best outcomes for particular categories of people with MS?*
- *What quality-of-life changes matter most to people with MS and their families, and how might these be countered?*
- *What cognitive, memory and mood changes can a person with a particular course of MS expect to encounter?*
- *What are the effects of menopause and hormone replacement therapy on the*

course of MS?

- *What is the economic impact of MS on people with MS, their families and the community?*

The national database, called the **Australian Multiple Sclerosis Longitudinal Study (AMSLS)** ("Longitudinal" means long term, ie. intended to run over many years – is an officially owned and supervised project of MS Australia, the national umbrella body responsible for strategic planning for MS research in Australia.

Initially, the AMSLS will involve 2,000 Australians with MS who have been confidentially randomly selected by all State and Territory MS Societies. These people will be asked to volunteer to make up a large, statistically representative sample for the commencement of research studies as described above. Commencing July 1st 2002, many newly diagnosed people with MS will be added to the AMSLS, as they respond to information given to them by Australian neurologists and MS Society staff. In ensuing years, as more newly diagnosed people are added, an increasing proportion of Australians with MS will be enrolled on the national database as volunteers for MS research.

Some readers may soon receive an invitation from MS NSW to take part in the AMSLS as a volunteer. If so, your name was confidentially "pulled out of a hat" as a possible participant. All participation is strictly voluntary, anyone can withdraw from part or all of the AMSLS at any time, and privacy of participants is

guaranteed. No personal data on anyone will be released from the database for commercial or other reasons, and, as a strict security precaution, **no information that can personally identify any participant will be stored on any computers.** All participants will be given a secret code, and this will be used instead of their name and address for all research entries on the national database. The AMSLS complies fully with **Federal Government Privacy Legislation** and has been ethically examined and approved by an appropriate governmental Human Research Ethics Committee.

Australian and international experts from numerous fields of MS research and service provision will maintain an ongoing involvement with the AMSLS to ensure that Australia's national database is of maximum use to people with MS. Regular updates on the progress of the AMSLS will be sent to participants and will be available on the **msaustralia.org.au** website. More information about the Australian MS Longitudinal Study can be obtained from the Project Manager, **Dr Rex Simmons** at Canberra Hospital, PO Box 11, Woden, ACT 2606; Phone 02 6244 4228; Email rex.simmons@act.gov.au, or the Chairperson of the AMSLS Supervisory Committee for MS Australia, **Dr Elizabeth McDonald**, 54 Railway Road, Blackburn, Vic 3130 Phone 03 9845 2700; Email emcdonald@mssociety.com.au

THE OPENING OF THE BUNGOONA TRACK IN THE ROYAL NATIONAL PARK

By Kris Darbon

At the beginning of 1989 I commenced working, as a volunteer, on the design and building of the Bungoona Walking Track, just a muddy service track at that time. My job was to advise on the suitability of the gradients and the construction of the footpaths for wheelchairs and for resting spots along the way.



I, as a disabled person, gave advice to park rangers and I agreed with some of their ideas for the track's design. Floods and fires held us up for months at a time and did much to spoil the good work we had done. After these hold-ups the edges had to be rebuilt again to the original levels and the trees and shrubs replanted to stabilize the soil, causing the work to be delayed for a further eighteen months.

When it was all finished I was waiting and hoping that I might receive an invitation to the opening of the track. Then one day, when I was a patient in respite at the MS Society Centre at Lidcombe, I received a phone call inviting me to attend the buffet design night as well as the BIG night to celebrate the



opening which was to be four nights later. I immediately went shopping for a party frock. Back at the Centre I got dressed up as a rehearsal and paraded in front of everyone. I passed! (The men said.)

I had never been to one of those nights before so did not know what to expect. I was looking for someone else in a wheelchair that I might know. Then I saw a



face I knew, one of our councillors. So we sat together right up the front facing the speaker.

In fact, the room seemed to be filled with about twenty or thirty councillors. And finally, our section was invited to go forward to receive a mention for the work we had done on the track.

Between the buffet night and the BIG OPENING night the rains just poured down. The opening had to be delayed until further notice. I was impatient to know what was to happen next and rang the ranger several times so I would not be caught unprepared for the big event. I tried to keep myself busy. I did not want to be thinking all the time about what was to happen next.

Then BINGO! Is this an invitation in the mail? I'm too nervous to open it. Surely this must be about the opening. It is only three days before my

birthday so I'm not expecting any other than birthday mail.

Then, of course, it might be to tell me that its all over for the present and that I would have to wait longer. I opened the envelope and it IS the invitation and then there's a phone call the next day to confirm the invitation. Can I come? someone asks me. CAN I COME!

To calm me down I thought I should have a friend go with me to help me get my thoughts together. We arrived at the entertainment centre at Sutherland just in time for the name tags and a bite to eat.

Finally, after all the other awards, we, the people who



had actually worked on the track, received our awards. The three park rangers received their awards. Later, there was the actual opening of the track itself, on site, and I cut the ribbon. Then everyone saw my efforts.

Author's note to MagScene:

I was in respite for two weeks at the time all this happened. Chris Moor and the two Patricks were living there at the MS Society Centre at Lidcombe, so I am hoping they or one of the nurses or office staff might remember me.

KD

MS SOCIETY CLIENT CENSUS STUDY 2001

Thank you to everyone who participated in the Client Census Study the MS Society conducted last year. The study was a first in Australia.

There were over 2,650 respondents and the information will be very useful for the MS Society to plan better services for you and increase knowledge on people with MS – you!

Your individual responses are only seen by the principal researcher and are not analysed with your name connected to your responses. This is to protect your privacy. The MS Society only receives collective responses to the questionnaire, except where you specifically requested to be contacted.

I wanted to let you know what analysis had been done so far and how the information has already been used.

95% of respondents were interviewed themselves, in 4% of responses the carer was interviewed on behalf of the client and 0.5% of respondents participated by mail.

Who responded?

Only registered clients who gave permission for the MS Society to contact them were invited to participate in the study. Almost 78% of these clients participated. This includes 78% of all female clients, 75% of all male clients, 78% of all rural clients and 71% of all metropolitan clients.

75% of respondents were female.

The average age was 49 years (ranging 8-100 years).

79% of respondents were born in Australia.

The average years since diagnosis was 11 (ranging 0-88 years).

36% of respondents were diagnosed in the last 5 years.

The majority of respondents (66%) lived with a partner or spouse and / or children. This is similar to the proportion of people in NSW who live with a partner or spouse and / or children.

71% of respondents lived in a house they own (or are on their way to owning) or a family house.

The majority of clients (43%) main form of income is through benefits or a pension. A further 17% were employed full time and 16% were employed part time. In comparison to the population of NSW the same proportion were

employed part time, but far fewer were employed full time (43% of the state was employed full time in 2001).

Symptoms reported

The main symptoms reported were fatigue (87%), weakness in legs (71%), temperature tolerance (68%), memory (51%), visual (49%), weakness in arms (44%), numbness (40%), concentration (40%), pins and needles (40%), balance (34%), speech (27%), depression (26%), incontinence (25%), frustration (21%), pain (24%), co-ordination (16%), muscle stiffness (14%), emotional swings (13%), and hot / cold sensations (11%).

Mobility

Most clients (27%) identified with the group with “mild MS symptoms such as sensory problems, mild inco-ordination or weakness and fatigue, but there are no visible problems with walking”.

63% of clients could walk without an aid for at least 16 meters. 17% of clients use a wheelchair for their main form of mobility.

Unmet needs

The main needs that were unmet were employment support, occasional longer breaks from home, frequent short breaks from home, support from other people with MS, financial support, and recreation and leisure.

Immunotherapy

91% of respondents were aware of immunotherapy treatments and 41% were currently injecting one of the types of immunotherapy treatments available.

The choice of immunotherapy treatment was mostly from neurologist advice, however some clients chose their immunotherapy treatment because of other medical advice, GP advice, other people with MS, convenience, side effects of the other options and from information on the internet.

26% of respondents reported finding out about *immunotherapy from MagScene*. Indicating that the magazine is a good source of information for many people with MS. The proportion of the respondents that reported finding out about immunotherapy from MagScene from the rural areas was the same as the metropolitan clients.

Continued page 6

MS Society Contact and Satisfaction

In the 12 months previous to when you participated in the study 60% reported having contact with the MS Society. This proportion was slightly higher for clients living in metropolitan areas of NSW. These people rated their satisfaction with the MS Society as 8.8 out of 10.

The main ways you mentioned would improve your satisfaction was:

Improved quality of service delivery, including:

- Quicker response times
- Better follow through
- Increased availability of staff
- Improved helpfulness of service

More services, including

- Recreation
- Physiotherapy
- Occupational Therapy
- Nursing
- Outreach
- Financial Support

Better access to services, including:

- Time services are provided
- Where services are provided

How the information has been used so far...

The initial analysis of results has been presented at management and board planning days. Plans are also underway to use the information for further research. The MS Society is keen to build on the client census study findings to find out more about the expectation of our clients and how we can best address areas of need for people with MS. To do this we would like to conduct discussion groups and further questionnaires with those of you who would like to be involved.

Future analysis

Over the next few months I will be analysing the responses in great detail. The analysis will be published in professional journals and a report will be stored in the MS Society Library which is available to everyone. I will also keep you updated on findings through MagScene on a regular basis.

Kate Tribe

Tribe Research

Consultant Data Analyst for the MS Society of NSW.

UPCOMING EVENTS

The MS Society of NSW has a full program of events coming up for the remainder of the year. For the benefit of readers here is the program as it currently stands. It is, of course subject to addition and/or change

June: Colonial First State Fun Run/Walk for MS – June 2; MS Awareness Week June 2 – June 8; Sailing Day for MS - June 5; Draw of “Tax Time” Art Union – June 26

July: Launch of “Spring time” Art Union AU 162; Continuation of Awareness Campaign; MTA Race Day for MS – Date to be advised; Friends of MS – Wine & Food, July 20; Robb College University NE Alumni Ball for Alice Coventry – July 20

August: Conclusion of Awareness Campaign; MS READ-a-thon Prize Presentation – Date to be advised

September: Draw of “Spring-time” Art Union – September 25; Holiday on Horseback – Nundle – September 21-28; MTA Industry Dinner – Date to be advised

October: Launch of “Christmas” Art Union AU 163; Friends of MS Luncheon, Parliament House – Oct 24

November: Sydney to ‘Gong Bike Ride for MS – November 3; MS Odyssey “Christmas Party” – Nov 9 (to be confirmed)

December: Draw of “Christmas” Art Union – December 18; Friends of MS – New Years Eve Party

WANTED

VW TRANSPORTER

Or equivalent with

- Wheelchair restraints
- Ramp or Hoist

Contact Gary Ph:(02) 6584 2296 or Email
amuzone@bigpond.com

FOR SALE

POWER WHEELCHAIR

Fortress, working OK, good Batteries, suitable for an adult.

\$1100 ONO

Contact Gary Ph (02) 6584 2296 or email
amuzone@bigpond.com

COUNTRY NEWS

This will be a regular feature for our clients who live in rural NSW, to keep you informed about our service delivery in rural areas. The MS Society is working hard to ensure that our services are accessible to people living in rural areas.

Country Consultation Visits are provided 8 times per year to rural areas. MS Society specialist staff, including a physiotherapist, an occupational therapist and a nurse visits an area in conjunction with the local outreach worker. The aim of the visits is to offer people with MS a specialist consultation where this may not be available locally or where a person is not able to travel to Sydney, or to compliment a service that is available locally. In some cases, the visit is in the form of an education session. A major goal of these visits is to educate local health professionals about the management of MS.

The schedule this year is:

April 9th	Kempsey
May 7th	Wagga Wagga
June 4th	Newcastle
August 13th	Bateman's Bay
September 3rd	Ballina/Lismore
November 12th	Foster
December 3rd	Tamworth

Please note that the schedule may be subject to change.

The S.T.E.P.S to Wellbeing

Information/Education Program is being offered to rural clients via teleconference and some face – to- face sessions. I am pleased to announce that 40% of all education sessions this year will be

delivered for rural clients.

Please refer to the S.T.E.P.S. to Well-being article in this edition of Magscene for further information about topics and dates.

Rural outreach services – As you are aware, the Society has a team of rural based outreach workers in 7 country regions: North Coast; Hunter; Central Coast/New England; Country West/Country Far West, Country South and Illawarra/South Coast regions. Outreach workers spend much of their time developing links with local service providers, so that the needs of people with MS can be addressed locally to where people live. The service offers individuals and their families assessment of their MS related needs and referrals to appropriate services within the Society and in the local community. Please contact the outreach service closest to you if you feel you could benefit from the service.

Rural Support Groups and One-to-One Support:

There are approximately 30 support groups in rural NSW and in June this year we plan to provide training to support group leaders. We are aware that distance and travel can be barriers that prevent people from attending support groups. Peer support can be accessed on a one-to-one telephone link up, and if you would like to join this program, please contact your local outreach worker. In addition, the Let's Talk email program is proving to be a very popular way for people to communicate with each other despite their location!

If you have any suggestions for how the Society can improve its services to people with MS in rural areas, I would be more than pleased to hear from you. You can write, to PO Box 210 Lidcombe NSW 1825, fax, 9643 1486, email, rfaine@msnsw.org.au or phone me on 1800 069 159.

ROBYN FAINE

Manager of Outreach Services, NSW

DEAR EDITOR

In Mid March, three PwMS of mixed gender and disability, a carer and myself took over the MS Respite Centre at Baulkham Hills. The house is a large 5 bedroom brick structure, updated with disabled facilities that proved no problem for a wheelchair or people with limited mobility. We arrived Sunday afternoon and made ourselves at home to be attended to the next morning by Julie. Julie cooked our midday meal and attended to shopping leaving us with supplies to prepare an evening meal plus breakfast. Two of our members travelled to Sydney centre by cab and train leaving the rest of us to socialize on the enclosed back verandah to the company of the birds in the native garden which surrounds the house. Television, video, audio equipment and books are available should anyone require them. I would strongly recommend any MS's wishing respite for themselves or for their carer to think about visiting the house and if you are at all interested contact Jan Anderson at Lidcombe to talk over the possibility. (phone 02 9646 0600)

John G, Singleton.

For eight weeks (2 days a week) with six others I have been attending a pilot study of gentle exercises at MS Society at Lidcombe.

Our "task master" being Katrina Williams. She put up with a bit too much talking and giggling

from us pupils but saw us through our routine. I think everyone benefited from the classes, re-assessment due soon.
Onya Katrina

Lorraine

Caring for a Carer

It is hard enough being the Carer of a PwMS when the Carer is in good health, but when the Carer is in bad health life is very tedious. When he complains of a piercing headache, I think, what are you going on about, as I have suffered with headaches for at least 40 years. When he says my legs won't work, I think well what makes you think my legs are working well, as I gasp and groan with every movement, unloading the car from shopping and looking after a house. So as you can see I want my little bit of sympathy as well and fortunately I receive mine from my partner as he uses his one working hand to endlessly massage my aching brow, sinuses and head. He says this is good exercise for his hand. Between the two of us we manage to keep each other going. This I feel is true love, looking after each other.

Beverley W Carer of Brian

Laughter may or may not activate the endorphins or enhance respiration, as some medical researchers contend. What seems clear, however, is that laughter is an antidote to apprehension and panic.
Norman Cousins

MR WISDOM'S

BRAIN GAIN



Another writing pad of words arrived from Jane Goadey, of Wentworth Falls, totaling a massive 1003 words from the Challenge Word LENTICULOSTRIATE.

Congratulations!

Wendy Sallis of Claymore followed with 936, then Sue Johnston, North Haven with 815 words and Lorraine Mahe of Towradgi with 801. Lorraine tells me she has retired after 27 years with the Health Insurance Commission (Medicare), so she can take up my Challenge seriously.

Your Challenge for this issue is

ACROCEPHALOSYNDACTYLIA

This should drive all you pointy heads crazy.

The usual rules apply.....

Some more cryptic clues for NSW towns,

A MODERN MEDIEVAL PALACE

A SPRITE IN THE FIELD

A ROYAL PRECIPICE

A PRECIOUS METAL ON ADAMS ALE

Answers are on page 20.....

PICTURING MS

The first “pictures” of MS were provided in 1981, with the birth of magnetic resonance imaging (MRI). This technology allowed the best view yet of damage, or lesions, in the brain of individuals living with MS. Since then, MRI has become routine for aiding in the diagnosis of MS and for tracking the course of the disease. Today, new forms of imaging, and new ways of analyzing the results, are providing amazing details on how MS progresses and how treatments affect the disease. Here we explain the basics of imaging, and how these technologies advance the field of MS research.

The Basics of MRI

The MRI machine is a formidable tube that contains a large magnet. “An MRI is basically a picture of water,” explains Nancy Sicotte, MD (University of California, Los Angeles), a Harry Weaver Neuroscience Scholar of the National MS Society. “Protons, found mainly in water in the brain, line up in the magnetic field, and then radio waves are transmitted which disturb the alignment. When the radio waves are stopped, the protons fall back into place. We detect the energy that is released as the protons spin and then line up again.” This energy, captured by computer, generates the cross-sectional pictures seen with MRI.

In this way, MRI detects lesions, areas in the brain or spinal cord where inflammation is occurring or where the myelin coating that insulates nerve fibers has been damaged by the immune attack. To enhance the pictures, people who have MS, or are suspected to have MS, are often injected with gadolinium, a contrast dye that brightens fluid-filled areas.

In MS, gadolinium enhancement brightens areas where the barrier between the blood and the brain has leaked, and the immune system has begun to attack the brain. A lesion that brightens with gadolinium enhancement is considered an active or new lesion. These lesions may come and go, but some develop into more permanent, “non-enhancing” lesions that can be detected without gadolinium.

A Closer Look

Beyond contrast dyes, several techniques are used to enhance the sensitivity of MRI, including magnetization transfer ratio (MTR), which can better quantify tissue damage. This experimental technology involves delivering energy to protons in the brain and then measuring how much is transferred or absorbed. “If the protons are floating in an area where there is no

tissue left, the protons will fail to absorb the energy, and the MTR value will be lower,” says Sicotte. “The lower the MTR value, the more severe is the tissue loss. This method helps to characterize how bad tissue damage is in multiple sclerosis.”

Massimo Filippi, MD, and colleagues (University Ospedale San Raffaele, Milan, Italy) have shown that MTR can pick up on tissue damage in brain tissue that appears normal on MRI (Neurology, January 11, 2000). In a recent study, this group showed that changes may even appear in the “normal” tissue of first-degree relatives of people with MS (Neurology, January 22, 2002).

Following the Flow

Diffusion tensor imaging (DTI) puts a new spin on MRI. “This scan is sensitive to how many protons are moving, and in what direction,” says Sicotte. “This allows us to determine whether myelin has been damaged, because myelin is fat and would [if intact] repel the water.” Recent reports indicate that damage to axons (nerve fibers) underneath the myelin also can affect the flow of water, and thus be detected by DTI.

In a Society-funded pilot project, Sheng-Kwei Song, PhD (Washington University, St. Louis) used DTI in a rodent model

PULL OUT
SUPPLEMENT

ON MULTIPLE SCLEROSIS
SPOTLIGHT

April/May
2002

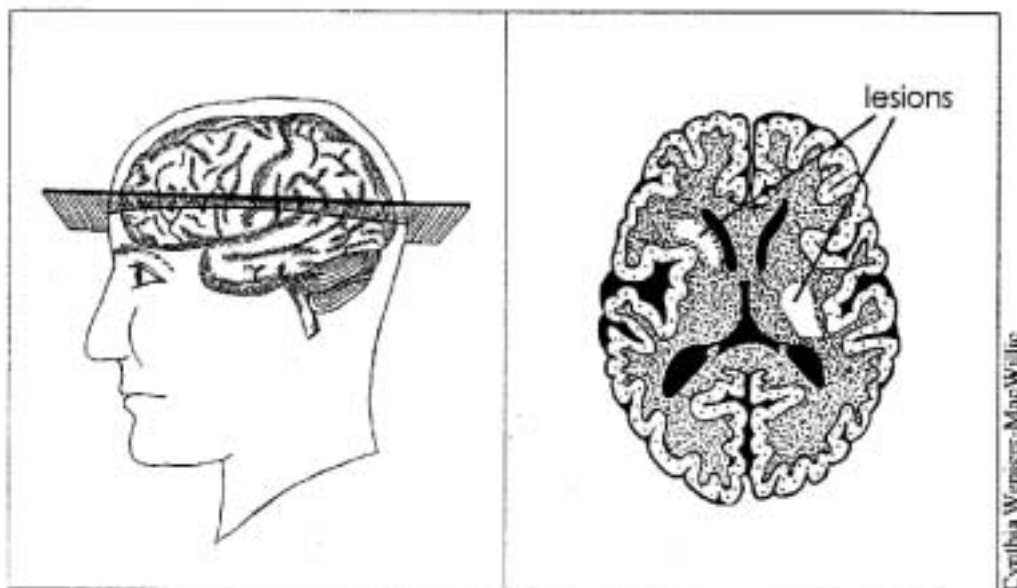


Figure 1. MRI is a picture of protons, found mainly in water in the brain. These particles line up in the magnetic field, and then radio waves are transmitted which disturb the alignment. The energy that is released as the protons spin and then line up again, captured by computer, generates the cross-sectional pictures seen with MRI. In this way, MRI detects lesions, areas in the brain or spinal cord where inflammation is occurring or where the myelin coating that insulates nerve fibers has been damaged by the immune attack.

Cynthia Wenger-MacWaltz

similar to MS that involves damage to myelin but not damage to the axon beneath. By comparing these mice to others with damage to both myelin and axon, Song's team found that water flowed in different directions, depending on whether just myelin was damaged, or both myelin and axons. This imaging technique may be useful in determining the extent of MS damage with greater tissue specificity than MRI.

Spectroscopy Signals

MRS, or magnetic resonance spectroscopy, enables investigators to analyze MRI to detect signals from certain chemicals, such as N-acetyl-aspartate (NAA), and create a graphic display showing the amount of chemical detected. "NAA is a chemical found largely in axons," says Sicotte. "If levels of this chemical are low, axons may be damaged."

Julie Pan, MD, PhD (Albert Einstein College of Medicine, New York) used spectroscopic imaging to study possible chemical differences in persons with different types of MS, in a Society-funded project. Pan recently reported on a collaboration with another Society grantee, Lauren Krupp, MD (State University of New York at Stony Brook), in which they found lower levels of NAA in specific brain areas of people who scored lower on verbal memory tests. This suggests that cognitive dysfunction may be associated with damage to axons (Applied Neuropsychology, September 2001).

Tracking Brain Functions

Standard MRI takes a series of "snap shots" when a person is lying still. Functional MRI (fMRI) looks at the brain "in motion" over a period of time,

detecting changes in the flow of blood in different areas of the brain while the person being examined is undertaking (usually simple) actions or behaviors. "When the brain is active, blood flow increases to the area of activity," explains Sicotte. "Blood contains heme, a magnetic material, so as blood flow increases there are changes in the magnetic field. Functional MRI looks for these changes." In this way, scientists can have a much better sense of exactly which part of the brain might be responsible for specific behaviors or actions.

Heather Wishart, PhD (Dartmouth Medical School, Lebanon, NH) is funded by the Society to study patterns of brain activity related to motor and cognitive function in people with mild relapsing-remitting MS. Using functional MRI, Wishart's group had found that both movement and memory tests

Continued page 11

activated the brains of four people with MS differently than individuals without MS. The results indicate that more areas of the brain were recruited to help with given tasks, even though they did not display obvious signs of memory or movement problems. She is expanding these studies to 40 people and is determining whether the brains of people with MS are activated differently to compensate for areas of tissue damage.

Imaging the Future of MS

In her own Society-funded project, Sicotte is using many of these technologies to determine factors that contribute to the onset of progressive MS. Participants are 40 people with relapsing-remitting MS who show early

signs of secondary-progressive disease. (People with secondary-progressive MS experience an initial period of relapsing-remitting disease followed by a steadily worsening disease course, with or without occasional flare-ups.) “We are using DTI, MRS and other methods to examine the structural changes that may occur, such as damage to myelin and axons,” she says. “We also are using fMRI to determine how brain activation patterns change during this transition.

“If we can identify the structural or functional changes that precede the onset of progressive MS, this increase in understanding may enable us to develop better methods of

evaluating treatments that prevent disease progression,” says Sicotte.

Imaging technology is key to the future development of treatments for MS. “The next generation of therapies for multiple sclerosis will likely focus on the areas of myelin repair and protection of nerve fibers,” concludes Sicotte.

“Determining the targets for these agents, and the proper imaging of responses to treatment must be done so that new therapies can be tested and approved for MS.”

Sara Silberman, National MS Society, USA

<http://www.nationalmssociety.org/Highlights-Imaging.asp>

MANAGEMENT OF SPASTICITY IN MULTIPLE SCLEROSIS

Herndon, RM. *Int. J MS Care*
December 2001;3(4)

Spasticity in multiple sclerosis (MS) can be a blessing or a curse. It is a blessing in that it adds strength to the support muscles that hold us erect against gravity when those muscles have been weakened due to loss of input from the upper motor neurons. When we look at strength in a spastic leg, we find that the weakest muscles are those that pick up the leg (ie, the hip and knee flexors and the ankle dorsiflexors). The strongest muscles are the quadriceps, which extend the knees; the glutei, which extend the hip; and the gastroc-solei, which plantar

flex the ankle. Picking up the leg is typically much more difficult than standing. One aspect of spasticity is loss of the precision of muscle control. It is hard to partially relax a spastic muscle; consequently, going down stairs is typically more difficult for patients than going up stairs. The muscle is strong enough to lift the body's weight, but when an attempt is made to bend the hip and knee, the muscle is likely to give way because the gradations in contraction necessary to hold one's weight with the knee bent cannot be accomplished.

The resulting stiffness and abnormal pull on joints from

spasticity can cause many problems, including abnormal stresses on joints, particularly the knees; muscle pain and soreness; and flexor and extensor spasms. Flexor spasms, in which the knees pull up to the chest periodically or with a minimal stimulus, can be troublesome and make sitting in a chair difficult. Extensor spasms, which cause the body and legs to extend, can push an individual out of his or her chair or cause the individual to tip over backwards. Spasticity in the adductor muscles of the legs makes perineal hygiene difficult, interferes with sexual activity, and can cause pressure problems where the knees rub together.

Management of spasticity can be helpful, but considerable care must be taken. Available medical

treatments include baclofen, dantrolene, and diazepam. All of these are sedating at therapeutic doses, and many patients cannot get adequate muscle relaxation without too much sedation. Additionally, all of these medications cause weakness, so that adequate control of spasticity almost invariably causes some weakness in addition to some sedation. The dose of a muscle relaxant used to manage spasticity is “enough and not too much.” The goal is to reduce spasticity without causing too much weakness.

In those patients who cannot get adequate muscle relaxation without too much sedation,

intrathecal baclofen (see below) may be a useful option. By providing a high local concentration in the lumbar cord with a very low systemic concentration, muscle relaxation can be accomplished without sedation.

Intrathecal Pump

This pump is surgically placed, usually just under the skin of the abdomen. The device is a round metal disk about 1 inch (2.5 cm) thick and 3 inches (7.5 cm) across. It weighs about 6 ounces. Most people report that the pump is not uncomfortable or restrictive and does not interfere with their movement. Depending on your size and

shape, it may not show at all under regular clothes.

Our Library also has available for loan a book on Intrathecal drug therapy for spasticity and pain.

PRACTICAL PATIENT MANAGEMENT by Gianino, Janet M; York, Michelle; Paice, Judith New York: Springer-Verlag New York Inc, 1996.

WB 354 GIA 1996 Bar Code 001234

Those PwMS in NSW who think that an intrathecal baclofen pump may be of assistance in managing their spasticity problem should first contact their doctor ED

The pull-out-and-keep SPOTLIGHT on MS supplement, which will appear in each MagScene, highlights current medical articles on MS in a condensed form.

The NSW Multiple Sclerosis Society is proud to be a source of information about MS. Comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendation or prescription. For specific information and advice, consult your personal physician.

The Multiple Sclerosis Society of NSW or its servants or agents will have no liability in any way arising from material or advice that is contained in this supplement. The statements or opinions that are expressed herein reflect the views of the author(s).

Z Barron: Editor

Dr Garry Pearce: Medical Editorial Consultant, Medical Director MS Society of NSW, Specialist in Rehabilitation Medicine ISSN 1323 4005

“GP Focus on MS” is a newsletter providing information for General Practitioners. It is published twice a year by the Multiple Sclerosis Society of NSW. It is edited by Dr. Garry Pearce, MBBS, FAFRM, FRACGP, Director of Rehabilitation, MS Society of NSW.

For your doctor to receive free regular copies of our GP FOCUS ON MS, please ask your doctor to complete the following.

Dr (Surname).....First Name or Initials.....

Address.....

.....Postcode.....

Doctor’s Signature (required).....

Please post to GP Focus on MS, MS Society of NSW, PO Box 1246, Chatswood, 2057 or fax to (02) 9411 1712

ILLAWARRA/SOUTH COAST AND GOULBURN OFFICE

is now located at 409 Princes
Highway, Corrimal, 2518;
PO Box 1, Fairy Meadow, 2519

Outreach Workers

* Jenny Crofts (Illawarra) ph:
42856407
Email: jcrofts@msnsw.org.au
Works; Tues, Thurs: 8.30-4.00,
Fri: 8.30- 2.00

* Barbara Whitelaw (South
Coast/Goulburn)
ph: 42854702
Works Mon,Tues: 9.00- 4.30,
Wed: 12.00—5.00
Email: bwhitelaw@msnsw.org.au

Macarthur Service

new contact details:
Mail to: PO Box 3133 Narellan
DC 2567
Phone and Fax: 4655 2155
Email: macarthur@msnsw.org.au

Macarthur Region MS Support Groups:

- Glenquarie MS and Other
Disabilities Support Group
- Campbelltown Carers Support
Group
- Narellan MS Support Group
- Tahmoor Social and Support
Group
- Highlands MS Support Group

For further information and
enquiries please call Outreach
Worker:

Marta Hum 4655 2155
Works: Mon/Tues/Wed.

**On Thursday June 6th June
during MS AWARENESS
WEEK (see pages 14 and 15 of
this issue for details of MS
Week) the MS Society, In
conjunction with the Rural Health**

Page . 13 NEWS

Compiled by
Katie Booth

Education Foundation, will
broadcast a program which will
feature Australian MS Research
leaders, Prof. Claude Bernard,
Prof. Graham Stewart, Prof.
John Pollard and Dr Jane Frith

CENTRAL COAST

The fundraising **GOLF DAY** on
Monday 25th March at Toukley
Golf Club raised in excess of
\$900. The sponsors and
competitors were pleased with
the day and hope to make it an
annual event.

MS Awareness Week – first
week in June. The branch is
running a raffle and information
stands at major shopping
centres. Volunteers are needed to
sell tickets. Please ring Sue
Payne on 4332 1273.

READ-a-thon won first prize
for the best stand at the Royal
Easter Show in the Kids World
Pavillion; sponsor Sydney
Sunday Herald. Volunteer
readers dressed in character
gathered 100's of kids around
them as they read stories.
Reading closes for **READ-a-
thon** on 17th May.

Readers are invited to e-mail
contributions for 'Page 13 News'
to the editor of MagScene at:
pwms@msnsw.org.au

...or snail-mail to: MagScene,
PO Box 1246 Chatswood 2057

ILLAWARRA NEWS

Branch members were very busy
during April, with a bus trip for
Berrima for clients, a sausage
sizzle at the Thirroul Seaside
Fair (fund raising) , a fashion
parade of the Shane Rogers
collection at the Corrimal
Bowling Club, and, of course,
ticket sales for the Mothers Day
Raffle.

This is the second fashion
parade we have conducted, and
it is a fun night (compered by
Barbie Rogers of Sale of The
Century fame). The parade
boosted the branch coffers by
\$1,300.

This is an excellent fundraiser,
and the fashions are very
affordable. I encourage any
branch in Sydney and close
environs to contact me for
details (Lorraine Mahe
42834782)

Our big news is the Bulli
Workers Fishing Club has raised
a massive \$18,000 for the
Illawarra client services this
year. This brings their fund
raising contribution to the MS
Society of NSW to over
\$100,000 since they adopted
they adopted us as their
preferred charity. Grateful
thanks from the Illawarra
Branch, the MS Society of
NSW, and from local clients, to
these hard working fisher-
persons (have to be politically
correct).

The next major fundraiser by the
branch will be the Christmas in
July Dinner Dance.

Things are happening in the
Illawarra.

Lorraine B Mahe

KB

PACKED PROGRAM FOR MS WEEK

PACKED PROGRAM FOR MS WEEK

A full program of activities has been planned for MS Awareness Week which this year will run from June 2 to 8 (inclusive).

The week will kick off with the society's annual Colonial First State Fun Run/Walk for MS.

Three time Olympic walker and world record breaker, Kerry Saxby-Junna will show her support for multiple sclerosis as a patron for this year's event as well as a participant on the day.

The Fun Run/Walk will start at Milsons Point, in the shadows of the Sydney Harbour Bridge and take in the beautiful bushland and natural scenery of Sydney Harbour as well as the spectacular man-made icons of the Harbour Bridge and Opera House before winding its way to Watsons Bay.

Karl Kinsella, MS Outdoor Events Manager, said, "This is a great day out for everybody. Whether you are a professional runner, have decided it's time to get fit or just fancy a beautiful walk with some friends. This will be a fabulous chance to see parts of Sydney that you may not have realised existed. From the backstreets of Rushcutters Bay to the native bush of Sydney Harbour Foreshore National Park it really is a spectacular day out"

Participants have the choice of three courses: an 8km fun run from Milsons Point to Balls Head return; a 10km walk around beautiful Sydney Harbour to Double Bay or a more challenging 20km walk to

Watsons Bay.

Over 200 volunteers will be working on the day to ensure participants have a safe and enjoyable day out and also show their support for people with MS.

To date the event has raised over \$560,000 to help people with MS and to fund research into finding both a cause and a cure for this mysterious disease. The MS Society hopes to raise a further \$100,000 this year through fundraisers' efforts.

On Wednesday, June 6, the society will stage its now famous sailing regatta on Sydney Harbour.

Royal Sydney Yacht Squadron



will again host the regatta for more than 90 people with Multiple Sclerosis and their carers and supporters on June 5.

Organised by the Multiple Sclerosis Society of NSW and Sailability North Sydney/Manly, the regatta is designed to give people with MS the opportunity of enjoying the freedom of sailing.

"We are also particularly grateful to the Royal Sydney Yacht Squadron for their great generosity in making their facilities available to the society for the day and thus making it a success," said regatta convenor Leslee Cameron.



The squadron sets a racing course for the yachts and allows participants to use its facilities for an "after race" barbecue.

"The hospitality extended by the squadron makes the day particularly memorable," she added.

It would not be possible to stage the day without the generosity of Ausail Charters, which for the sixth year in succession has donated the Catalina Yachts together with skippers.

"Without the very generous support of Ausail and the skippers who go out of their way to make the day memorable, we would not be able to stage what is rapidly becoming a highlight of the MS calendar," she said.

On Thursday, June 6, the society will stage its second national television broadcast for people with MS, carers, friends and health professionals.

The 90 minute program, to be broadcast over the Rural Health Education Foundation Network throughout Australia will feature researchers, Professor John Pollard, Professor Graeme Stewart, Professor Claude Bernard and Dr Jane Frith.

continued page15

The program will feature Professors Stewart and Bernard discussing research into cause of MS and Professor Pollard and Dr Frith discussing research into the treatment and cure of MS.

Public Relations Manager of the society and producer of the program John Roubicek says: “ a lot of the feedback we get from clients indicates that they want authoritative information on research. They also indicated after last year’s program with Professor Don Paty that they wanted the chance to ask specific questions.

“This year the program will be made in front of a live audience and we are hopeful that this will spark some lively debate.



“Last year more than 1,000 people in NSW saw the program and we are hopeful that in the future we will be able to produce a show that will allow live interaction between our quests and clients throughout the state.

“Satellite time is very expensive and we aren’t able to provide that facility yet, but hopefully in time we will be able to,” he said.

In addition to the “set pieces” MS Awareness week will also see major media activity designed to raise awareness of MS, people with MS and the work of the Multiple Sclerosis Society.

John Roubicek

L.I.S. Library and Information Services

A new initiative for the MS Society of NSW Library (LIS) concerns personal experience books written by or about people who have MS, particularly residents of Australia.

We are quite often approached, especially from overseas - with requests to purchase these types of books. As we have access to a number of other reliable resources we have previously not taken up many of these offers for the following reasons:

- We are not offered the item on a “sale or return” basis, which is our usual method of assessing and purchasing from unknown sources;
- Often the item turns out to contain information relevant to another country and not applicable to Australia;
- The resource often contains inappropriate and incorrect information; sometimes the resource appears to have been written more for personal benefit than with future readers in mind.

None of these factors should deter people from writing about their experiences with MS but they do impinge on what we call the “collection development policy” for the LIS which is based on a range of criteria including the authority of the author, accuracy and of course budgetary constraints.

However, we now feel that there is a place within the collection for these resources which, if carefully proof read and selected, are clearly labelled as being the opinion of the author and not necessarily that of the Society nor the medical profession, could be of use to

other people experiencing a life involved with multiple sclerosis.

We would like to encourage readers to submit their finished products via MagScene to the LIS. The authors should expect constructive criticism and suggestions and I am afraid sometimes rejection.

For your information needs please contact the MS Information Line on 1800 042 138 or the Library by phone, fax, letter, email or call in to 447 Kent Street.

Recent additions to the collection

ADAPTATION, PSYCHOLOGICAL

Russell, Margot. “**When the road turns**”. Inspirational stories by and about people with MS — **Deerfield Beach: Health Communications Inc, 2001.**

BF 335 RUS 2001 MAGNETIC RESONANCE IMAGING

Filippi, Massimo Arnold, Douglas Comi, G. Magnetic resonance spectroscopy in multiple sclerosis — **Italy: Springer-Verlag Italia, 2001.**

WN 185 FILI 2001 POPULAR WORKS

Multiple Sclerosis Australia. Seeking the cure - providing the care — **Victoria: Innographics Multimedia Pty Ltd, 2001.**

WL 360 MSA 2001

CD ROM: RESEARCH Barham, Sue (compiler).

Progress reports in plain language 2001. — **Australia: National Multiple Sclerosis Society of Australia, 2001.**

W 20 PRO 2001

Cate Dawson, LIS Manager

Life is not measured by the number of breaths we take, but by the moments that take our breath away

FAMILY T.I.E.S

Training, Information, Education & Support for Families

MS affects many people - the person diagnosed, partners, families and friends. **FAMILY T.I.E.S aims to provide partners, families and friends with tailored information and support to help meet both their needs and those of the person they support.**

Workshops

The MS Society offers tailored information workshops that address the ways MS may impact on the family. Creative ideas for dealing with the challenges of MS, enhancing family relationships and looking after each and every family member are presented.

Stay tuned for details on upcoming events in your local area, including:

Taking a Break Workshop for partners and families in a caregiving role, May 2002 in Southern Region, Maroubra

Christmas in July Social for people with MS and their families, July 2002 in Western Region, Lidcombe

Managing Confusion Telephone conference group for partners and families in a caregiving role, August 2002 for country areas

Looking After Yourself Workshop for partners and families in a caregiving role, September 2002 in Northern Region, Chatswood

CARERS WEEK October 2002

Taking a Break Telephone conference group for partners and families in a caregiving role, October 2002 for country areas

Melbourne Cup Day Social for people with MS and their families, November 2002

For details of workshops, social activities and telephone conferences in your area, contact Alex Hope on TEL: 9646 0600 or speak to your local outreach worker.

One2One

One2One is a telephone peer support service linking partners and families with other partners and families. You may feel that nobody understands your situation and what it is like to look after someone who has MS. You may like to have contact with other partners and families who are in a similar situation. You may just want to talk to someone who understands. To talk to another family member one-to-one, contact One2One by TEL: 9646 0600 (or toll free 1800 059 169 for country calls) or EMAIL: families@msnsw.org.au

NEWLY DIAGNOSED AND FAMILIES

Information sessions and telephone conferences

These sessions, workshops and telephone conferences are designed for people recently diagnosed or those in their first few years of having MS.

Newly Diagnosed Information Sessions

Wednesday 29 May, 6:30 – 8:30pm at Lidcombe

TEL: 9646 0600 for details and to confirm your interest in attending

Monday 24 June, 6:30 – 8:30pm at Chatswood

Please note that the Northern Region MS Service is commencing major renovations and that session will be held at an alternative venue.

TEL: 9411 4522 for details and to confirm your interest in attending

Wednesday 31 July, 6:30 – 8:30pm at Miranda

TEL: 9540 4544 for details and to confirm your interest in attending

Monday 19 August, 6:30 – 8:30pm at Lidcombe

TEL: 9646 0600 for details and to confirm your interest in attending

Newly Diagnosed Information Telephone Conference Groups

Just like face-to-face, but with everyone linked up by telephone

Remaining telephone conferences planned for this year:

Tuesday 3 September, 7:30 – 8:30pm, for people living in country areas

Wednesday 11 December, 7:30 – 8:30pm, for people living in country areas

TEL: 9646 0600 for details and to confirm your interest in participating

STEPS TO WELLBEING

(look out for the new logo)

Previously known as the **MS & Beyond: Destined for Wellness** series, these sessions, workshops and telephone conferences designed to help increase your knowledge and skills to confidently manage your MS and enhance general health and well being.

Employment & MS Tuesday 7 May, 10:00am – 12:00pm at Corrimal

TEL: 02 4285 6407

Balancing Stress Workshop for people recently diagnosed and their families Monday 13 May, 7:00 – 9:00pm, at Miranda

TEL: 9540 4544 for details and to confirm your attendance

MS AWARENESS WEEK June 2nd – 8th -2002

Immunotherapy Update Telephone conference for people recently diagnosed and living in country areas

Monday 3 June, 7:30 – 8:30pm

TEL: 9646 0600 (or 1800 059 169 toll free) for details

Fitness & Exercise Workshop for people with MS, hosted by local support group

TEL: 9540 4544 for details and to confirm your attendance

Staying on Your Feet Workshop on preventing falls for people with MS

Monday 1 July, 10:00am – 12:00pm in Northern Region (venue to be confirmed)

TEL: 9411 4522 for details and to confirm your attendance

Fighting Fit Workshop for people recently diagnosed and their families

Tuesday 20 August, 7:00 – 9:00pm, at Lidcombe

TEL: 9646 0600 for details and to confirm your attendance

For details of sessions, workshops, and telephone conferences coming up in your area and in the second half of the year, contact Alex Hope on TEL: 9646 0600 or EMAIL: ahope@msnsw.org.au, or speak to your local outreach worker.

LET'S TALK



Latest "ads"
No room to say more!

Coded Reference	473	Female
Lives in	Sydney	
Age	23	
Years with MS	6 months	
Dated	March 2002	

I was diagnosed on 10th October 2001. I had lost all feeling down my left side and thought I was having a stroke. That happened on the 29th September. It was my mother's birthday. I spent 4 months in hospital and regained the use of my left arm and hand, but I still don't have the full feeling back. My left leg still doesn't work so I am in a wheelchair. I was asked out by my fiancé while in hospital and he proposed on February 14th. I would like to get in contact with others my age who have MS.

Coded Reference	474	Female
Lives in	South Coast	
Age	69	
Years with MS	17	
Dated	April 2002	

My symptoms are no balance or co-ordination so I can't walk or write, my focus is not good and I have clumsy hands. I like playing Scrabble, reading mystery novels and the 'Net. I live in a retirement Village and my husband is in a nearby nursing home. I would love a webpal.

Coded Reference	475	Female
Lives in	Sydney	
Age	47	
Years with MS	15	
Dated	March 2002	

I ceased working in 2001 and am on Betaferon. I enjoy being at home and having time to indulge in my hobbies that are sewing and knitting etc. These are however solitary pastimes and I miss contact with the outside world. I am mobile though I have slowed down a bit over the past few years. I participate in Tai Chi and aqua fitness groups weekly.

Coded Reference	476	Male
Lives in	Blue Mountains	
Age	46	
Years with MS	4	
Dated	March 2002	

I am on Betaferon, work full time and am relatively healthy with mild bouts. I get fatigue, spasms, eyesight and balance problems. I am divorced, have no ties and love my life. I like country drives, cruises and movies. Would love to get an understanding webpal.

Garry



My dear friend of forty years recently confided in me that another friend of hers was recently

diagnosed with MS, and would I (as a person with MS) give her some tips to deal with this.

With a very heavy heart, I tried to remember back twenty years.

I told her that It's hard to know where to start. The support from MS Society NSW is very extensive. Information line: 1800 042 138. First step is register as a client. Make contact with MS Outreach Worker. If possible join local support group, look up 'newly diagnosed' meetings.

The web site that I gave her has a wealth of information.

www.msnsw.org.au

And of course MagScene is a lifeline for all PwMS.

I have had MS for 20 years now and it is 'chronic secondary progressive'. I am one of the 30% unlucky ones. Most PwMS have 'remitting / relapsing' which is less debilitating however fatigue is a common symptom.

Over the past few years medications such as Betaferon, Rebif, Avonex & Copaxone have been shown to slow down the disease.

Another thought, maybe just listen. Even talk about anything but; to prove that you are a person with a wide range of interests first – and MS comes

second.

My MS B tips; exercise, physio, healthy, low fat food, lots of water, keep cool, hydrotherapy, rest when needed. Think of all the things you can do. - like grow strawberries on the balcony. Go to the top of the Eiffel tower - in a wheelchair.

MS Busibody

Ms Busibody

My thought for today:

Age doesn't always bring wisdom. Sometimes age comes alone.

FRESH APPLES

It's a warmer than normal, quiet March weekday. Our close friend Ron from around the corner rings with an invitation to join him and Beth, his PwMS wife, for a drive and coffee.

"Thanks but a mate has just called from Sydney. John reckons the Blackheath apples will be ripe about now so he is coming up to get a few. He wants to visit the orchard and plans to pick me up on the way through. He will be here in a few minutes."

So from being another dull lonely morning it has turned into a potentially exciting day. Put the phone down and tidy yourself up. Suddenly SLAP. BANG. A second unconscious perhaps and flat on your face looking at the pantry door. That is not where I was going. Where did that blood come from? A sound at the front door.

"Does anyone live here?" John

arrives and takes control. "That will need a stitch or two"

John is not a professional man thinks I. "Let's ask Ron. He used to be a pharmacist and his opinion would be worth while." "Ron. could you come round please"? I was putting the phone down and slipped"

"You mean that if I hadn't called you wouldn't have had the fall?" I knew of no good answer so just agreed.

Next stop was Katoomba hospital. This was my first visit to the local medical centre and the local newspaper had given me reason to fear somewhat.

This concern was soon dismissed. Everything happened quickly and with the smile one gets used to in the mountains.

The article in the newspaper was way "off beam"

After three stitches John called my wife, who works in Sydney. She was pleased when told we were at the hospital.

From the hospital to Logan Brae Orchard where the fresh apples dismissed all thought of falls.

John bought apple juice and honey for himself but we are close enough to visit frequently so my only need was apples.

The final call was Wentworth Falls for a cup of coffee before returning home. The prospectively quiet day had become an exciting and entertaining day.



Peter, Leura.

MY WAY

Having completed the MS questionnaire (albeit late) and ashamedly answering “no” to the question re had I ever submitted anything for publication, I thought it was perhaps time to rectify this, and so here goes, my very first (and probably last) foray into “amateur” journalism!!

Hi, my name is Gay Frost and I live with my husband of 40 years in Forster on the NSW mid north coast. We have been here nearly 21 years, though both born and bred in Sydney. I have three great “kids” who are married to lovely people and three grandsons “les petite enfants”, Zachary, Lucas and - wait for it - Jack Frost. They certainly keep me on my toes, literally.

I was diagnosed with MS in May 1983 and since then have not really faced too many problems, the most serious symptoms being fatigue, weakness in my arms and legs, forgetfulness plus a myriad of others. Most of the symptoms over the years have been relatively mild though there constantly. However over the past few months I have been experiencing other symptoms and problems, which does scare me a little, so I have made an appointment to see a Neurologist in Sydney.

This all could be a direct result of stress I have had in my life recently. Four years ago my husband suffered a stroke and we nearly “lost” him. His symptoms from the stroke are extreme fatigue and weakness in his legs (we are a good pair), but more seriously it has affected his cognitive abilities

which prevents him from working in our small business, driving a car or doing anything physical very much. So, **I'M IT** - the carer, the driver, messenger, chief cook and bottle washer etc etc. We do have home care help for which I am very grateful.

I am also still trying to keep the business going (otherwise we'd be living in a tent somewhere) and I guess over the past 4 years it has caught up with me. But hey, who's whinging, we are both still here and have lots to be thankful for.

Of late and since the changes in the MS, I have sort of turned into a Dr Jekyll and Mr Hyde. I get unreasonably cross over trivial matters, get exceedingly irate over events, even things over which I have no control and little things upset me now where before they wouldn't have, so on and so on. Is this behaviour “normal” in PwMS??

Prior to my husband's stroke my mother passed away on our eldest son's wedding day poor love (bad timing or what), I lost my beloved brother to cancer and a wonderful cousin, also to cancer, all within a few years. Somehow or other though we do manage to laugh a lot, sometimes through our tears and life goes on. I could write a book - it would be an epic!!

On the “up side” I do have a loving husband and a wonderful family and I do manage to do things for myself. Last years I started to learn French (very slowly) and love it and will continue in 2002. Au revoir.

Gay, Forster

MUSTANGS FOR MULTIPLE SCLEROSIS DAY

On Sunday 26th May 2002. The Mustang Owners Club of Australia (NSW) will be showing off their cars. Every year Kwiktune of 46 Mitchell Rd Brookvale open their workshops where Mustangs can be mechanically inspected for a donation to the MS Society. Last year, between Kwiktune & the Mustang Owners, we raised over \$4500. Forty Mustangs were



inspected and approx 70 Mustangs turned up for the event & Cruise to Avalon. This year we hope to raise more!! Titan Ford is joining us along with several other local businesses such as Strathfield Car Radio, Godfreys of Dee Why, Able Tyres Brookvale & more.

**Phil Wickham Kwiktune
9938 1331**

To those people living on the North Shore they would love to see you! Please drop by, enjoy the barbeque, look at the Mustangs and buy a raffle ticket.

Ed



The Chatswood MS Centre is in a state of nervous excitement!!. The old Federation building is to undergo major refurbishment commencing early

May.

All this means that Garry and I will be temporarily moving into head office at 447 Kent St, Sydney while the Outdoor Event staff, Read-a-thon and Outreach workers will move out into nearby premises for 3-4 months allowing the builders to get on with the job much quicker.

Because of this move our phone number will be 9287 2929 while our postal address and email remain the same.

Meanwhile we will continue to research and prepare MagScene in our new surroundings.

Readers! when you request to have your doctor's address added to the GP Focus on MS mailing list, we now require that you get his signature of authority. (see page 12 of Spotlight)

The MS Outdoor is just back after their 9-day RTA bike ride that was a great success weather wise, fund raising and events wise. They are all happy to be sleeping in their own beds after nine nights in tents.

We remind you that MS Awareness Week starts 2nd June with an array of events. So what can PwMS do to add to the awareness of MS to the public? – talk about it positively to friends, work mates, support your local MS Branch activities!

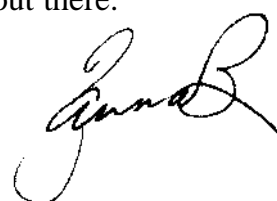
National Volunteers Week

13-17 May. We thank all our volunteers who support

us throughout the year for without their assistance we would not manage to produce MagScene let alone support our many PwMS in the community.

Coming in the July/August issue is our report on the Readership survey, for which we thank you for your input, comments, remarks and assistance.

Meanwhile **Happy Mothers Day** to all mums out there.



Zanna Barron, Editor

The answers to Cryptic place names on page 8 are 1 Newcastle 2 Fairymeadow 3 Queenscliff 4 Silverwater

Deadline for July /August issue is 12th June 2002

MS INFORMATION LINE Freecall 1800 042 138
Mon-Fri 9:00am to 5:00pm. An info line only – Not a crisis line.

MagScene

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