

SPEECH PROBLEMS AND MS

If people are asking you to repeat words; if it's getting harder to carry on conversations because your speech is slurred, slow, or quiet; if you can't talk fast enough to keep up with your thoughts—you may be experiencing a speech or voice disorder.

If you are constantly clearing your throat or coughing when you drink thin liquids like water, you may be experiencing a swallowing disorder.

Both are associated with MS, and both need professional attention.

Dysarthria is a speech disorder. It means speech is slurred or poorly articulated. There may be loss of volume control, unnatural emphasis, and slower rate of speech.

Dysphonia is a voice disorder. It involves changes in vocal quality, such as harshness, hoarseness, breathiness, or a hypernasal sound. In MS, these conditions may result from muscle weakness, spasticity, tremor, or ataxia (lack of muscle coordination).

The organs involved in speech are also needed for swallowing and many people with MS have some swallowing problems or **Dysphagia**. These problems range from an occasional cough or a throat that just can't be cleared to a slowing down of the whole swallowing process.

Chronic swallowing problems can lead

to dehydration or poor nutrition. The most severe problem occurs when food particles or liquids accidentally enter the lungs. This can cause "aspiration" pneumonia, a serious illness.

Help is available

The good news is that most speech and swallowing problems can be managed through an evaluation by a speech/language therapist.

A person with MS may not notice his or her own speech problems. Many times a

As many as 40% of people with MS have speech problems at some time. Specialists believe they are caused by MS lesions (or damaged areas) in the part of the brain responsible for control of the lips, tongue, soft palate, vocal cords, or diaphragm.

family member or physician brings it up. Often people adapt, but when speech problems begin interfering with everyday communication, it's time for an evaluation with a speech therapist. A

speech therapist is more formally known as a speech/language pathologist or SLP.

During an evaluation, the SLP will examine the oral muscles that are necessary for speech—your lips, tongue, and soft palate—and assess how you control their movement with regard to strength, speed, range, accuracy, timing, and coordination. Your teeth and hard palate will also be examined. The SLP will check your breath support and control, how precisely you pronounce words, and how well you are understood by others.

1. Speech Problems & MS
 2. St Vincent's Research
 3. Speech & Swallowing
 4. Readathon • Susan Mees
 5. GI Food
 6. Branch News • For Sale
 7. Gawler Foundation • Kathie Ross
 8. Nic Jools Story
 9. Michael Page
 10. RTA Big Ride • Society Staff Changes
- Pages 11 – 14 Pull out supplement**
- What to believe
15. Newly Diagnosed Information
 16. Show your carer you care
 17. Betaferon storage • Reflections
 18. Central Coast anniversary
 19. Carers Newsletter
 20. MS Busybody • LIS
 21. Mr Wisdom
 22. Client Census Study
 23. Lets Talk
 24. Behind the Scene

Sydney, Jan 21, 2003

St Vincent's Researchers Conduct World-First MS Research

Director of Neurology and Neurosciences at St Vincent's Hospital, Professor Bruce Brew has announced that a team under his direction has been able to differentiate adult stem cells into particular brain cells as a potential means of eliminating some of the effects of Multiple Sclerosis and other similar illnesses.

The premise of this NH&MRC funded research is to take stem cells from the bone marrow of mice as well as bone marrow from humans and insert these cells into the brains of mice which have a disease that resembles multiple sclerosis.

The brain contains several different kinds of cells in addition to neurones. One of these cell types is the oligodendrocyte. This cell produces a substance called myelin which surrounds the neurones and makes electrical conduction along the neurones more efficient.

People with multiple sclerosis and a number of other diseases produce less myelin which causes poor

electrical conduction and therefore poor neurological function. One of the reasons for this diminished myelin production appears to be a loss of oligodendrocytes.

One solution to this myelin shortage would be to transplant oligodendrocytes into the brain of a patient with multiple sclerosis to reverse the myelin deficit. However, this would involve donation of human brain cells, which aside from the impracticality would create problems with rejection.

Another possible solution however is the use of adult stem cells. All cells in the body have exactly the same genes, the only thing that distinguished one type of cell from another - such as muscle cell in one's leg from a brain cell - is that different genes were turned on during their development.

A stem cell is a primitive cell with all the genes of the rest of the body, but in which none of the genes that cause differentiation into a specific type of cell (ie brain or muscle) have not yet turned up.

For the first time, St Vincent's researchers are using adult stem cells derived from the bone marrow to differentiate them into brain cells. Preliminary data have now shown that some of these cells can be induced to differentiate into oligodendrocytes. This development has the potential to reverse the deficiency of myelin that is associated with many of the disabilities in multiple sclerosis and other illnesses.

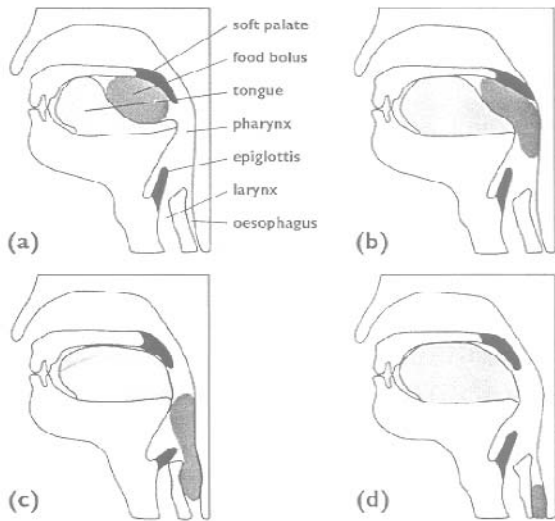
Professor Brew says "while we are still some years away from a human application, the fact that we are able to use adult stem cells in this way is extremely important in the development of effective therapies against a variety of brain ases."



The Chairman of the MS Research Advisory Board, has commented on the announcement of an apparent research breakthrough on MS.

He said: "The announcement of this preliminary research result is an exciting development. It is especially exciting because it obviates the need for embryonic stem cells and appears to herald the possibility of autologous stem cell repair. The realistic goal to repairing myelin injury due to multiple sclerosis has always been to harness the body's own reparative mechanism.

"The news that a bone marrow derived adult stem cell appears to be capable of becoming a specialised oligodendrocyte (the myelin-producing and supporting cell in the brain and spinal cord) and commencing this repair is a major development. It is likely however that considerable work will have to be undertaken in the animal model of multiple sclerosis to determine how effective and extensive this repair is."



The therapist may then offer strategies and exercises for specific problems. Some exercises can strengthen and improve the muscles involved in speech production. There are techniques for slowing down, over-articulating, phrasing, and pausing.

Active listening and self-monitoring skills are also essential. Listening to yourself on a tape recorder can help you hear and learn to correct your speech. Some people practice new speaking skills in group therapy.

Medications that relieve other MS symptoms can sometimes help dysphonia. For example, baclofen/lioresal which relieves spasticity, may improve a harsh, strained voice quality. In some cases, injections of small amounts of Botox into affected muscles can relieve spasms and improve dysphonia. There are also exercises to promote relaxation and improve breath support.

People with severe speech problems may need to use voice amplification devices, electronic aids, or computer-assisted alternative communication systems. Again, an SLP can make an evaluation to determine which technology is most appropriate, and teach the best use of aids that substitute for or augment speech. Family and friends should be trained in these communication techniques, as well.

The art of the swallow

To evaluate a swallowing problem, an SLP will want to observe the action. You will probably be asked to swallow a barium liquid while your mouth and throat are x-rayed and filmed. When

the film is viewed, the barium reveals the details so the SLP can diagnose the problem exactly. The SLP will usually suggest specific exercises to improve muscle strength or coordination. A change in the position of your head or certain head movements may also improve swallowing and reduce coughing for some people.

Swallowing (see diagram)

- a. The bolus is propelled towards the pharynx by the tongue
- b. The soft palate is elevated and closes off the entrance to the nasal passages
- c. The epiglottis reflects back over the entrance to the larynx
- d. The bolus is propelled down the oesophagus by peristalsis

The following food safety rules may help those with swallowing problems avoid dehydration, poor nutrition, or the risk of aspiration pneumonia.

- Sit upright or lean slightly forward when eating or drinking.
- Keep the chin parallel with the table or slightly tucked down.
- Begin a meal with something icy, eg: a sherbet shake, or a fruit or vegetable smoothie.
- Take one small bite or sip at a time. Never try consecutive swallowing.
- Never wash food down with a liquid. Instead, add moisture to the food.
- Choose soft, moist foods and thick, icy liquids first, as they are the easiest to swallow. Dry solids and thin liquids are more difficult, and require closer attention to safe swallowing.
- Avoid thin liquids altogether when fatigued. A good rule is: consume thin things in the morning and thick things in the evening.
- If you feel yourself slowing down during a meal, pause and switch to something icy.
- Quiet yourself and your surroundings during a meal. It's always a good idea to make mealtimes a calm and social part of the

Continued page 18

BECOME A MAIN CHARACTER IN THE MS READATHON STORY...

The MS Readathon has begun turning the pages on the 2003 campaign to encourage children to read and help raise money for people with MS. This year is a new chapter in this historic program which will see the different MS states united on an inaugural National campaign.

In NSW last year, the MS Readathon attracted over 10,000 participants who read 270,545 books and raised \$692,282 for people with MS. On a national level, this year's campaign is hoping to reach between 50,000 to 80,000 students around Australia to support our cause.

MS Readathon Coordinators visited about 800 NSW schools throughout last year in order to encourage students to become involved in the MS Readathon. In some cases these presentations were attended by a person with MS. Feedback indicated that students were more eager to **become involved in the ms** Readathon having met a person with MS.

In keeping with school requests we are seeking the involvement of more people with MS to accompany the Coordinators on school visits in 2003. Visits will be taking place in 29 different regions of NSW throughout the month of May and part of June. As a participant in these information sessions you would

be discussing the issues surrounding Multiple Sclerosis and answering questions. Wheel chair access is generally available at most schools.

Your contribution would provide a truly valuable educational experience for NSW school students but you will be rewarded ten times over with the enthusiasm and interest of the students. This is also a fantastic opportunity to become involved in the fundraising activities of the Society on a flexible basis.

For more information please do not hesitate to contact Carolyn Weir on 02 9411 7811 or via email: cweir@msnsw.org.au

FREEDOM TO MOVE

My name is Susan Mees I was diagnosed with MS in 1992.

After the birth of my daughter Penelope in 1996, my mobility gradually got worse. I went from one stick to two, then to a walker and a wheelchair. I put on weight, and found it harder to exercise. I became very conscious of my weight, and found it very tiring to even walk, let alone exercise.

In October last year while my daughter was having swimming lessons I was itching to get in the water with her. Not being a swimmer myself, and being a little frightened I was worried. I did however pluck up the courage with a little bit of encouragement. It was from that moment on my life changed and I've never looked back.

At present I swim at least 4 times a week. I started off floating and regaining my confidence in the water, (considering I haven't swum since I was a child). I started to swim the breaststroke without any effort; it felt great just looking like every body else in the pool.

I gradually found my self-increasing my speed and not even feeling tired, the main thing I noticed almost straight away was that my bladder was working more efficiently. For me that was great. In between swimming I was doing some leg exercises without any problem and I found I could stand on my own, balance upright without hardly any effort and even when I'm not in the water my balance has become much better. I even get out of the chair with much more stability and balance, I've found my body has become a bit more flexible and I've also lost weight off my arms and legs.

I have talked about my physical benefits, but I feel there are some psychological benefits like being perceived like anyone else and not feeling any different also achieving something I thought I'd never do again.

The other thing I've learnt through this is not to take myself too seriously and look at life differently.

I say to myself don't say you can't, say you can....

Susan Mees, Bawley Point

GI FOOD Part Two

Reproduced with kind permission from
Sanitarium's publication "Good Food News"
March 2002

Factors influencing the GI of a food

There are many things that can affect the rate at which a carbohydrate is broken down into glucose and then absorbed into the blood. The following factors can have an impact on the GI of foods:

- The physical form of the food e.g. beans and seeds have a fibrous coating that can slow down their digestion and therefore lower the GI.
- Processing methods such as milling, grinding and extruding often make foods easier to digest and have been connected with a higher GI e.g. wholemeal bread has a higher GI than multigrain bread which contains intact grains.
- The presence of soluble fibre or fat in foods can slow their digestion and therefore lower the GI.
- The type of starch in the food. There are two different types of starch in foods - amylose and amylopectin. If a food contains a greater amount of amylose starch it will have a lower GI.
- The amount and type of sugar in the food. Low GI fruits such as apples and pears are high in fructose (fruit sugar) which has a lower GI than sucrose and glucose.

Applying the GI to your eating plan

The first step in adopting the GI into your current diet is to try to have one low GI food at each meal. It is certainly not necessary to have only low GI carbohydrates in your diet. Adding one low GI food to your meal will lower the overall GI of the meal. There is definitely room for high and moderate GI foods in a healthy diet and many of these foods can provide important sources of nutrients.

Low GI food ideas:

- Eat breakfast foods based on wheat bran, oats and barley.
- Adding most fresh fruits as well as milk to breakfast cereal will help lower the overall GI of a breakfast meal.
- Choose grainy, dense breads with whole seeds for toast and sandwiches.
- Include in your main meal pasta, noodles, sweet potato, legumes, Basmati or Doongara rice as a variation on potatoes.
- Add legumes, barley or macaroni to soups and casseroles.
- Look for biscuits, slices, cakes and muffins made with dried fruit, oats, other wholegrains - or better still, make some of your own!



Limitations Of GI

While it seems that the use of GI when selecting foods may lead to health benefits, we should keep in mind some limitations of GI.

GI is only one nutritional aspect of a food. There is a wide range of nutritional factors that we need to consider when deciding whether or not a food is a good choice. When choosing a food it is important to check the total and saturated fat, fibre, sodium and sugar content. For example, toasted muesli has a lower GI than untoasted muesli, yet often toasted mueslis are much higher in fat due to added oils.

The GI of a food is not predictable without proper testing. Since there are a number of factors in foods that can influence GI, sometimes the GI of a food is quite different from what we might expect. An example of this is wholemeal bread, which has a GI of 69. Even though wholemeal bread is more nutritious than regular white bread, mainly due to the fibre and

Continued next page

phytochemical (natural protectants found in plant foods) content, these two breads have a similar GI. Food preparation can also effect GI of foods. Well-cooked pasta tends to have a higher GI than firm, just-cooked (al dente) pasta.



A Final Word

It is important to remember that, when making your food choices, the GI should not be used in isolation from other nutrition principles. Be sure to check the nutrition contents of products and choose items that are only moderate in fat and sugar, low in saturated fat and salt, and are a source of fibre. In addition, the correct use of the GI, is to compare the same types of food eg white rice vs brown rice. Finally, make sure you enjoy a wide variety of foods every day.

If you would like more information about how to read food labels, you can request a copy of Sanitarium's 'Food Labels' leaflet.

The main story was prepared by Melinda Ramsay (B Med Sci. M Nutr & Diet).

This article has been reviewed by Mr Alan Barclay, Research and Development Manager, Diabetes Australia - NSW.

CENTRAL COAST BRANCH NEWS

THE MS GOLF DAY will be held at Toukley Golf Club on 24th March. All golfers are invited to join in and help boost MS funds. 4 Person Ambrose Start. Hit off 8:00am. \$30each includes lunch and prizes. Phone Sue or Clem Payne on 4334 1273

The 10th Anniversary of the formation of the Central Coast Branch was celebrated at the Christmas Lunch at The Central Coast Leagues Club. A large cake was cut by two of the original committee members, Rita Thwaites and Katie Booth. The branch was thanked and applauded for their work over the years.



A group of enthusiastic golfers in Leura recently had a lunch at which they discussed ideas for fundraising for PwMS. They hit upon holding a golf day at the **Leura Golf Club** and have settled on May 8th, 2003.

Anyone interested in playing for a good cause can contact Peter Aboud via email on pama@pnc.com.au or Tel 4784 3699.

FOR SALE

QUICKIE F55S ELECTRIC WHEELCHAIR

- Power tilt
- Power recline
- Seat belt
- Swing-away tray
- Adjustable headrest
- Puncture proof tyres
- Dynamic Dx4 controller
- 2x73 amp batteries
- 6amp charger

Used for only 5 months

Original purchase price \$14,200

Selling price \$5,000 ono

Contact: Grimaldi Ph 9682 3282 or 4577 4229

FOR SALE

PRO-MED ELECTRIC HOIST

which allows a carer to safely care for a PwMS at home. Includes medium size sling with head support and battery charger

Easy to fit a patient in bed or a chair, provides upper body and head support. Recommended for lifting from the floor and general lifting of a less secure patient.

\$1200 ono

Phone Deidre 4658 1773



THE GAWLER FOUNDATION OFFERS A NEW HEALING OPTION FOR PEOPLE WITH MS

The Gawler Foundation is well known for its work with people dealing with cancer. Thousands of people with cancer have had more fulfilling and enriched lives after attending live-in retreats at the Foundation's Yarra Valley Living Centre in peaceful Yarra Junction, a little over an hour out of Melbourne. Now Dr Ian Gawler has teamed with Professor George Jelinek, author of 'Taking Control of Multiple Sclerosis', to offer the world's first live-in retreats for people with MS, using similar principles to the cancer retreats. To date, two of the weeklong retreats have been completed in 2002, and four will be offered in 2003.

Ian Gawler, himself a survivor of advanced bone cancer, describes the residential programs as 'revolutionary'. Course participants from the first two retreats have found them enormously positive and life changing. Apart from covering the scientific basis and practical application of therapies, there is a strong focus on mind-body medicine and the broader goal of genuine healing. Participants learn to meditate or deepen existing meditation, and to explore their feelings about the disease and life issues in general, in a nurturing group environment.

For more information, contact the Gawler Foundation on 03 5967 1730 or visit the website at www.gawler.org.

Letter to the Editor

Dear Zanna

I always look forward to receiving my MagScene and really enjoyed your Christmas edition. The articles about the first Christmas Cards (page 1), creation of the modern day Santa (page 6), and 'Purely Australian' (page 8) were simply delightful and the MS information is always invaluable. In response to your question on page 20, as to how we PwMS coped over the festive season, I'd like to share the following item.

A PURELY AUSTRALIAN CHRISTMAS

I grew up in WA, where summer temperatures were often 45°C Christmas was wonderful, with beautiful fresh salads and mouthwatering cold meat platters! However, it just wasn't Christmas without my Mother's (and Nanna's before her) jellied beetroot, served covered with crushed pineapple, on a bed of shredded lettuce, with grated carrots on the side. To me, nothing said Christmas quite like it and I adopted and adapted the recipe when I left home.

About 11 years ago I divorced; moved to NSW and was diagnosed with MS 4 years ago. I remarried three years ago, but the first Christmas I spent with my husband's family did not go quite to plan. Proudly, I presented my husband's family with my own special creation of beetroot, carrot and pineapple in a light jelly mold design - and they were horrified! I hadn't realised that theirs' was a traditional, baked Christmas dinner - no salads please! That was the last time I made jellied beetroot and I guess it may sound silly, but Christmas just hasn't felt complete.

This year I was invited to a pre-Christmas dinner with friends and guess what was on the menu? Lots of fresh salads and jellied beetroot! I was so excited and even though we didn't have it at the family Christmas, this year actually felt like Christmas again.

Kathie Ross

(If you would like a copy of Kathie's Jellied Beetroot recipe, send a stamped self-addressed envelope to MagScene and we will mail it to you. Ed)

THE STORY OF MY FRACTURED LEFT HIP

I have been asked by MagScene editors to write about my experiences of having MS, Osteoporosis and a hip fracture. I specialize in osteoporosis and in my self-diagnosis I realized that I fulfilled all the risk factors for a possible fracture except for one, I was not a female

In 20 seconds, three and a half years ago, my life changed when I became a paraplegic. Initially I had some response from intravenous Prednisone for my MS but this was very short lived. (I had been given oral prednisone some years earlier when I developed a left optic neuritis)

A few days after I became a paraplegic, my paraplegia changed to a complete flaccidity with no muscle tone at all. In spite of initial exercise programs, despite the almost unsurmountable, depressing and massive difficulty in getting adequate physiotherapy I did gain some movement in both lower limbs over a 15 month period. Sadly my recovery has been complicated by severe Neuropathic pain that has been impossible to treat in spite of innumerable attempts from the fantastic team at the RNSH Pain Clinic.

Because of the pain last year I developed severe clonus. Both of my lower limbs were jumping up and down without any rhyme, rhythm or reason. My wheelchair got caught on a loose rug - I fell to the tile floor and landed on my left hip. At this time I was alone in the house, stupidly had left my hands free phone on a table which I could not reach from the floor. So over a period of

time - it seemed like eternity, I crawled some 25 feet to the nearest phone and with the aid of a pencil dialled 000. As usual the Ambulance Services were marvellous and were here within minutes. They lifted me into my wheelchair and checked me out. All seemed well but my left hip was painful. At the bottom of my heart I knew I needed to have an X-ray.

However, on the Thursday morning of the same week I had a very important engagement at the Sydney Adventist Hospital. I was trialling a new drug for the treatment of osteoporosis - Zometa; I planned to have the X-ray done on the Thursday morning when I was at the hospital.

Tuesday night was a very difficult, sleepless night; Wednesday was a painful unforgettable day. By midnight on Wednesday I developed a severe spasm in my left leg. Once again my wife called the Ambulance. As usual they were marvellous. They gave me some intravenous Morphine and soon I was in the RNSH Emergency Department having an X-ray. The rest of that night was completely blurred except for a vague recollection of a surgeon (Dr R. - a real gentleman) telling me that I was about to have an operation and possibly a hip replacement. Some hours later I was in recovery ward. As I was able to give myself analgesia when needed by a PSA (self administered analgesia). Therefore the post operative pain was minimal. Dr R had pinned and plated a fracture in

my L Hip or more precisely the neck of the Femur. Those four days in hospital passed quickly. On Monday morning I came home. To my surprise however for the next 12 weeks or longer, the pain persisted. Any attempt to move my left leg or rotate in either direction was agony.

I had learned a valuable lesson. Hip fractures are far more painful than any other fractures I have ever endured. I have had a few others I must admit -- I did play rugby union when I was a lot younger! To add to my miseries a few weeks later I fell again from my wheelchair and fractured a rib once again on the left-hand side.

Since fracturing my pelvis [neck of the Femur] I have become aware of a product called hip protectors. I now wear these every day, even in the shower. I would strongly recommend to anybody with multiple sclerosis, particularly if they are unable to weight bear, that they should consider doing likewise. Weight bearing and calcium are the basic ways of preventing osteoporosis combined of course with change in lifestyle.

Since my own experience I have become very interested in the prevention of hip fractures. The hip protectors work by distributing the impact of the fall so the bone does not break. The biggest problem of course is the patient has to comply. They are of no use sitting in a drawer.

I have done a lot of reading on this subject and would like to give you a few relevant statistics:

Continued next page

Few people think of hip fractures as a killer. Yet, one quarter of people who fracture their hip will die within 12 months as a result of the fracture and its complications. More than a third will die within two years. The surviving 40% will lose their ability to perform simple activities independently such as walking, moving and climbing stairs⁽¹⁾.

In fact, a 50-year-old woman's lifetime risk of dying from hip fracture is equal to her risk of dying from breast cancer and greater than the risk of her dying from endometrial cancer. Yet, few governments think of the prevention of hip fractures in the same light as the need for breast cancer screening⁽²⁾.

The reason hip fractures are so prevalent in the world in both men and women - there were 1.6 million fractures in 1990 and the number is projected to rise to 6.2 million by 2050 - is a combination of factors led by low bone density caused by osteoporosis and some medications, diseases such as Hypertension (high blood pressure) and other conditions which often develop in ageing populations⁽³⁾.

Most governments in Australia have falls prevention programs which aim to curb the growing number of hip fractures among at-risk individuals. However, the effectiveness of these programs in reducing the incidence of fractures has recently been questioned⁽⁴⁾.

(1) Martoli et al, Journal of American Geriatrics Society 1992-40

(2) Cummings et al, Arch International Med 1989. 149:2445-8

(3) www.oesteofound.org/advocacy_policy/

roundtable_2002/pdf/presentation_delmas

- (4) An Analysis of Research on Preventing Falls and Falls injury in Older People, a report by the National Ageing Research Institute (Australia), April 2000

Nic Jools, FRCOG
FRANZCOG Osteoporosis Specialist, Sydney Adventist Hospital

Hip Protectors are made by ABENA_SANICARE, ph:1800 655 152. www.sanicare.com.au

MICHAEL RECEIVES AUSTRALIA DAY HONOUR

Recognised for his outstanding service to the community, 61-year-old Blaxland man, Michael Page has been awarded an Order of Australia Medal (OAM) in the 2003 Australia Day Honours List.

While the Australia Day honour came as a shock to Michael, "At first I thought this must be a mistake", those who know him weren't surprised.

Since being diagnosed with MS in 1988, Michael has refused to slow down and actively seeks involvement in community services. "I'm there to help them and help myself", he said of his local neighborhood centre where he has volunteered for 10 years.

Michael is seen as a valuable member of not only the Lower Mountains Neighborhood Centre, but also the Blue Mountains Soccer Club and Lower Mountains MS Support Group.

He started work at the front desk

of the Lower Mountains Neighborhood Centre in 1993. He has also acted as volunteer bookkeeper, paymaster and Community Management Committee Member and was voted Team Member of the Year in 1997.

Since the early 1990's Michael has been the contact member in the Lower Mountains MS Support Group which, he says "has been such a grand group of people to be involved with". As a contact person in the group, Michael is seen as an exemplary and dependable member of the group. "Each month we get together and have a good yarn and exchange views...it's been a great experience being involved with them".

Upon receiving the Australia Day honour, Michael said he "felt very honoured".

While the shock of the medal receded and "reality began to set in," for Michael, he now looks forward to the formal presentation due to take place in a few months time at Government House, Sydney.

The MS Society and the Council of People with MS congratulate Michael on his exceptional achievement.



THE RTA BIG RIDE



The MS Society has been the benefiting charity of the RTA Big Ride since it began, raising 2.2 million over the past 12 years to help people with multiple sclerosis. Most of this money was raised through the hard work of volunteers who choose to be fundraisers seeking sponsorship from work colleagues, organizations, families and friends.

Bike riders on the 2003 RTA Big Ride March 15 - 23 discover, at a leisurely pace, some of NSW's significant historical towns and finest rural country

The 2003 ride left Warragamba, Sydney on Saturday 15 March and travels south west via Camden, Bowral, Bundanoon, Goulburn, Bungendore, Yass and Harden and finishes at the Riverina town of Cootamundra, home of the popular Cootamundra Wattle and birthplace of Sir Donald Bradman

Highlights of the 2003 ride include visits to the Bradman Museum, spectacular walks that follow the path of explorers Hume and Hovell, and a visit to a didgeridoo manufacturer.



Organised by not for profit group Bicycle NSW and sponsored by the Roads and Traffic Authority, the event promotes recreational cycling. Now in its 13th year the 2002 ride raised \$250, 000 for the Multiple Sclerosis Society.

SOCIETY STAFF CHANGES

There have been a number of changes within the Society over the last few months but I will only mention those that have happened next to us here in Chatswood where we prepare MagScene.

Anne-marie Keleher, former manager of Readathon has moved to Queensland where she is now Readathon manager for that state. She was replaced by **Donna Hendry**, Donna's précised interesting CV follows.

- * Returned to Sydney from Riyadh, Saudi Arabia after living there for four and a half years.
- * During this time in Riyadh, she was offered the position of Head of the Physical Education Department of the Multinational School, an internationally recognised Australian curriculum school, accredited by Education Victoria, where she worked for over 3 years until she returned to Sydney.
- * Studied Marketing 1990-1992, Married with 8 yr old daughter, Interests -competitive swimmer for 8 years at State level, qualified for the Nationals, traveling, camping, reading, music, started at MS Readathon on 20 January - Working at MS Readathon will be a rewarding and challenging experience. She is looking forward to being involved in the 2003 MS Readathon and raising funds for PwMS.

Carolyn Wier who recently worked as a volunteer in Outdoor events is now working in Readathon.

We wish them a successful Readathon for 2003

Ed



Living on Earth is expensive, but it does include a free trip around the sun every year.

Birthdays are good for you; the more you have, the longer you live.

Happiness comes through doors you didn't even know you left open.

HOW CAN YOU BELIEVE WHAT YOU READ ABOUT MS?

(A USER'S GUIDE TO UNDERSTANDING RESEARCH ARTICLES)

Dr Gary Fulcher

Senior Clinical Psychologist / Research Development Officer

MS Society of NSW



SPOTLIGHT ON MULTIPLE SCLEROSIS

There are articles about MS, its causes and its treatments everywhere these days - in scientific journals, in popular magazines, and in a variety of Internet web sites. How do you know what to believe? I have listed the most important details you need to consider whenever you read pieces on medical, scientific or therapeutic aspects of MS (or any other condition).

Author qualifications:

People who write about any medical conditions should be properly qualified to do so. Unless you are a scientist or health professional yourself it can be tough to work out who is appropriately qualified and who isn't. (It can sometimes be a bit tricky for scientists and health professionals as well.)

In MS, you can feel safer to trust what is written if the writer is a medical practitioner or scientist, such as:

- Neurologists, the universal standards for which are: BSc, MD, FRAN.
- Psychiatrists with credentials including: BSc, FRACP.
- General practitioners with

credentials of BSc.

- Immunologists and geneticists. These are scientists rather than medical practitioners and their credentials are: BSc, FIM or FGEN.

The other frequent group of writers are commonly referred to as "allied health professionals". While many excellent practitioners do not have a PhD, people who write in their field should have a minimum of a Masters degree, with the PhD being a higher standard of scientific qualification.

Included among this set of writers are:

- Clinical psychologists with credentials of: BSc or BA, MA and/or MPsycho, PhD and/or DPsych.
- Neuropsychologists with credentials of: BSc or BA, MA and/or MPsycho, PhD and/or DPsych.
- Occupational Therapists with credentials of: BHSc, and/or MHSc, and/or PhD.
- Physiotherapists with credentials of: BHSc, and/or MHSc, and/or

PhD.

- Dieticians with credentials of: BHSc, and/or MHSc, and/or PhD.

Now, it has to be said that the qualifications alone do not guarantee the quality of the writing or the reliability of the information written. Hints for how to figure that out are given in the next section. At this stage, another group of writers needs to be mentioned.

Beyond the professionals with clearly appropriate qualifications, there are others who regularly publish articles in a variety of media that have either more dubious or less universally valid sanction. These writers include:

- Naturopaths that have, at best, a diploma rather than a degree. These practitioners are not registered with the Health Department to practice and can more easily have charlatans representing what is a potentially very helpful vocation.
- Reflexologists that have at best a diploma. These practitioners are also not registered and the discipline has no

established scientific basis or tradition to its practise.

- Iridologists, again with only a diploma and no established scientific basis.
- A range of other practitioners or advocates of alternative ideas and therapies.

These people often give advice that appears to be logical, sound and intelligent. They regularly quote cases where their treatment has produced almost miraculous effects. The media frequently displays these cases, particularly on television. The evidence of benefit seems obvious and absolute. So why am I writing this article that recommends that you do not immediately accept such "plain proof" of benefit?

The problem is about that "proof". While single cases are compelling evidence for the benefits of certain therapies, they are not proof. How can this be so? The following section will (hopefully) explain this and other concerns about articles in the public domain that need to be read with wisdom and caution. My easy job is to issue the caution; my challenging job is to try to provide the wisdom.

What is reasonable proof?

Proof of an effect in human illness is very hard to produce. Why? - mainly because of the human elements that produce very powerful individual differences that must be factored into any decisions about accepting evidence. There are three main areas in research to understand before we accept "evidence" as "proof". They are: placebo, significance and statistics.



1. **Placebo:** A very important factor in human response to treatment is the "placebo" effect. This refers to the fact that humans respond not just to the treatment provided but also to the social situation in which the treatment is given. People feel better partly because of the care and kindness of therapists, whether the therapy they provide works or not. In an experiment I once did on treatments for relieving chronic headache, I created a sham treatment. Some of the subjects that were allocated to the sham treatment reported a reduction in headache frequency, intensity and duration equal to those on the "real" treatments, and these effects lasted for up to a year after treatment stopped.

Were these people fools? Not at all! What this group provided was the benchmark against which the effect of the real treatments had to be judged. If the real treatment is not significantly better than the placebo effects, then it cannot be claimed to be any more effective than a "pretend" treatment, or just being kind and caring. This is why research should include a comparison group - either a placebo group or a group waiting for treatment. The effects of the real treatment on people can then be compared to

people who have received no treatment or people who received a pretend treatment. In drug trials, the most common form of placebo is a "sugar pill".

2. **Significance:** You will read and hear about a treatment making a "significant"

difference, or one treatment being "significantly" better than placebo or another treatment. What does this actually mean? Well, that's a complicated question that I will try to answer clearly.

A sound research experiment on people, such as a drug trial, should have at least two groups of "subjects": the experimental group (who receive the "real" treatment) and a control group (who receive a pretend treatment). This strategy makes the experiment a "controlled" study.

Before anyone is allocated to one of these groups, they should undergo a series of tests and examinations by an independent examiner (not part of the experiment team) to establish their health prior to treatment. The results of these assessments become the baseline against which the effects of the treatment can be tested.

Once these assessments have been completed, the participants in the trial are then allocated to one of the groups - the control group or one of maybe several experimental groups. Drug trials often have two or more treatment groups such as: high dose, medium dose, low dose.

To avoid the possibility that the researcher might allocate the potentially better subjects to the experimental group and put the potentially unresponsive subjects in the control group, this allocation process is done randomly. This is a bit like pulling names out of a hat, although there are more sophisticated ways to do it, such as by using special computer allocation techniques. An

important part of the allocation process is that subjects do not know which group they are in. Some people might be annoyed if they discovered they were in the placebo group and not cooperate in the experiment, while others who discovered they were in the high dose group might feel so elated that they had a false level of positive response. So, subjects need to be "blind" to the kind of treatment they are getting. Once subjects have been allocated, treatment can commence.

The aim then is to see if, and by how much, the subjects get better compared to what they were like before receiving the treatment. Or, in the case of some of the much longer experiments of immunotherapy in MS, to see if subjects get no worse from the beginning of treatment to some point in the future. The baseline assessments are many and there might be a series of assessment points after treatment begins - for example, each year for 5 years.

These assessments should be carried out by assessors who do not know which group the subjects belong to, otherwise they might be tempted to report higher or lower effects according to what treatment they were receiving. So, assessors also need to be "blind" to the kind of treatment subjects are getting, and this makes the experiment a "double-blind, controlled" study. In scientific terms, this is the best kind of study possible because it reduces the chances of bias and tests the treatment against a true yardstick.

But "What about significance?" I hear you asking. Well, significance is about how much

improvement is enough or how different the scores between the experimental and control need to be to be a "real" difference? In relapsing/ remitting MS, for instance, we know that the number of relapses varies in the one person over time and between people all the time. Let's say that you had 4 relapses in 1995, 1 in 1996, 6 in 1997, 3 in 1998, and 3 in 1999. If you started immunotherapy in 2000 and had 4 relapses that year, what would you say about the impact of the medication? And, if you had 2 relapses in 2001, what would you think? And, if you had 3 relapses in 2002, what would you conclude? How significant do you think the impact of the medication was on your MS? I suspect your answer is: "I don't know", and that would be right.

In MS, the course of the condition is too erratic, and too individual to be able to make precise sense out of numbers like these. This is because you don't know how many relapses you could have expected, so you don't know if the number of relapses you had were more, less, or the same as you could have expected without immunotherapy. What is needed in MS are experiments with lots of people in the experimental groups and lots of people in the control group so that a comparison between treatment and no treatment (or pretend treatment) can be made over a long period of time on lots of people. Using group information, or data, means that you are now looking at averages rather than individual scores.

Now, if you look back at the variability of the five relapse scores for the individual from 1995-1999, and multiply that by the variability among, say, 1,000 subjects, you can see that scores are going to be very wide ranging. This variability needs to be taken into consideration when comparing scores.

Otherwise, you might compare the experimental group in a year when they all had their highest exacerbation rate (average of 6) with the control group when they all had their lowest exacerbation rate (average of 1) and conclude that the medication did not work. If, however, you took into consideration the group variability over time, you would reduce the chances of making this error of concluding that a treatment did not work, when, in fact, it might have. This is where statistics and statistical procedures become very important.

3. Statistics: Using statistics allows the researcher to avoid coming to conclusions based on variability of scores rather than real effects. There are two kinds of errors to avoid:

- a. **Type 1 error:** Concluding that a treatment worked when it actually didn't.
- b. **Type 2 error:** Concluding that a treatment didn't work when it actually did.

In medical research, the worst kind of error is considered to be Type 1 as this would mean that people would be given false hope about a treatment that, in fact, did not work. While a Type 2 error may prevent an effective treatment from being revealed

that is thought to be better than a non-effective treatment being continued.

"What about significance?" I hear you asking again. Well, significance is one of the main ways of avoiding Type 1 errors. You see, with all those measures that are taken and all the variability among all the subjects, the chances of a result are very high. Remember that the number of assessments taken prior to treatments is usually very high, as experimenters want to know the full range of effects their treatment will have. These assessments are repeated at every checkpoint over the experiment, such as every year for 5 years. If there were 10 or more original measures (e.g. blood pressure, heart rate, muscle tension, pain rating, anxiety, depression, number of doctor visits per month, number of analgesics per day, number of days off work per month, plus a range of blood tests), there will be at least 60 measures for every subject at the end of the experiment.

Chance alone could result in an error as shown in the earlier MS example when the experimental group happened to all have a bad year of exacerbations and the control group had a very good year. So, you have to eliminate chance and statistics helps to do that.

When you compare two sets of scores (between groups or within one group over time) you are comparing both the averages and the variability of groups. Special statistical procedures do this automatically and then give a figure for how confident you can be that the difference between the scores did not occur by chance. These figures are usually p values or F values and are always a decimal score lower than 1. The accepted value of p or F is 0.05. This translates into a score of 5/100 and means that there is only a 5% chance that the difference between the scores happened by chance. Anything less than that is acceptable. So, if the value were 0.01, it would mean that there

was only a 1% of the difference occurring by chance. The smaller the p or F value, the more confident you can be in the results.

Invitation:

Next time you read an article on MS, try using the guides in this paper to help you sort out whether to accept or believe what the authors have written. As you read the article think about:

- Were the author qualifications appropriate?
- Were there a control and experimental group, and were they were correctly selected and used?
- Were the subjects and the researchers "blind" to the treatments or other experimental conditions?
- Were the results significant, and, if so, how confident can you be that the results are real and relevant?

Good reading and reviewing!

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.

Please print

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

NEWLY DIAGNOSED & FAMILIES

NEWLY DIAGNOSED INFORMATION SESSIONS

When: Monday 24 March, 6:30 - 8:30pm
Where: Southern Region MS Service
Suite 1, 28-30 Urunga Parade, Miranda
RSVP: on TEL 9540 4544 by 16/03/2003

When: Monday 19 May, 6:30 - 8:30pm
Where: The Studdy MS Centre
Joseph Street, Lidcombe
RSVP: on TEL 9646 0600 by 14/05/2003

NEWLY DIAGNOSED INFORMATION TELEPHONE CONFERENCE

When: Thursday 3 April, 7:30 - 8:30PM
Where: Telephone link-up for people living in
country areas.
RSVP: on TEL 02 9411 4522 by 21/03/2003

MS & Beyond: BALANCING STRESS

Although stress is a normal part of life, many factors associated with adjusting to a diagnosis of MS may be particularly stressful. The purpose of the session is to increase your understanding of how stress affects you and to explore strategies for balancing the effects of stress.

When: Monday 31 March, 7:00 - 9:00PM
Where: Studdy MS Centre
Joseph Street, Lidcombe.
RSVP: on TEL 9411 4522 by 26/03/2003

MS & Beyond: TIPS FOR STAYING POSITIVE

Coming to terms with a diagnosis of MS is not always easy. The process of ongoing adjustment to diagnosis is explored and enlightening and practical tips for staying positive and living with MS are presented.

When: Wednesday 21 May, 7:00 - 9:00PM
Where: Ryde/Eastwood Leagues Club
117 Ryedale Road, West Ryde
RSVP: on TEL 9411 4522 by 16/05/2003

FAMILY T.I.E.S

Training, Information, Education, Support
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 with MS whom they support.

Would your partner or family member like to be included on a mailing list to receive updates on upcoming sessions and workshops for families, friends and carers of people with MS?

Contact Alex Hope:

TEL: (02) 9411 4522
FAX: (02) 9411 1712
EMAIL: families@msnsw.org.au

TELEPHONE SUPPORT GROUPS FOR FAMILIES AND CARERS

Distance, lack of time, family, work and other commitments can make it difficult to access information and to share ideas with other families and carers.

Telephone groups are like being part of a face-to-face group, but with the added benefit of being able to take part in the comfort and privacy of your own home, wherever you live. They are a great way to learn more about supporting someone with MS, accessing community resources and taking care of you.

The MS Society is offering 4-week telephone groups for families and carers and is seeking expressions of interest.

Contact Alex Hope

TEL: (02) 9411 4522
EMAIL: families@msnsw.org.au

Care to Listen

Care to Listen is a telephone peer support service linking partners and families with other partners and families. You may like to have contact with another family member or carer who shares the experience of supporting a family member who has MS. You may just want to talk to someone who understands. *See page 19 for more details*

For more information, contact Alex Hope:

TEL: (02) 9411 4522
EMAIL: families@msnsw.org.au

SHOW YOUR CARER THAT YOU CARE

MagScene has acquired a unique gift offer from the leading SWISS GRAND HOTEL BONDI BEACH of one nights accommodation for two in the Ocean View suite including buffet breakfast, undercover parking, use of the indoor and outdoor pool and sauna.

The Swiss-Grand Hotel offers full size suites, each with a bedroom, separate lounge and bathroom. Not to mention a private balcony with sweeping views of either the beach or cosmopolitan Bondi. Each suite is comprehensively appointed, with a king-size bed (or over-sized twins), two televisions, three telephones, a cocktail bar, tea and coffee making facilities and individually controlled air-conditioning. It's accommodation on a grand scale, more like a small apartment than a hotel room.

Overlooking Australia's most famous stretch of sand and surf, the magnificent Swiss-Grand Hotel Bondi Beach is located just 15 minutes from the heart of Sydney. Some of Australia's greatest sports and entertainment venues are even closer, including the Sydney Cricket Ground, the Sydney Football Stadium, the Sydney Showground and Randwick Racecourse.



This gift certificate must be taken by 25th May 2003 (it must be used prior to 25th May).

All you have to do is write in 30 words or less why your carer deserves a special night away at the Swiss Grand. Send your entry by either email (pwms@msnsw.org.au) or snail mail (MagScene, PO 1246, CHATSWOOD, NSW, 2057). Also please send your phone number with your entry so we can contact you quickly if you win. Entries close 4th April 2003 and our selection will be final. The winner will be announced in the next MagScene.

IMPORTANT BETAFERON STORAGE INFORMATION FOR USERS

- A new formulation Betaferon that can be stored in conditions up to 25°C (normal room temperature) will be available shortly
- You will not need to keep it in the fridge unless temperature is consistently above 25°C
- The active ingredient has not changed and Betaferon will work exactly as before.
- It is likely that your next script will be dispensed with new formulation.
- When you collect your new Betaferon, which will be in a simple carry bag, check that you also receive the Administration kit and customer leaflets.
- Your pharmacist is being advised of this change.

REFLECTIONS BY PETER

It seems that in each country we have made our own God unhappy". All around the world we have managed to introduce our own disasters. For each of us it seems to be a sign of great skill. In Australia we have too much heat and lack of water. There was too much rain, now too much snow in Europe. In Arabia the Muslims have most of the world's oil and cannot manage a civilized trading relationship with the major Christian traders who are in the United States. In South America there are too many civil wars and the traders there have great skill with drugs such as cocaine which they trade in the US and the rest of the world.

The Chinese and the Russians are very skillful to their own benefit and manage the well being of their huge populations. These benefits seem to be achieved without the complications of democracy. The wellbeing of Africa confuses me. The politician for whom the World owes most respect at present I believe is Mr. Nelson Mandela. In so many countries we see so much power in the hands of evil persons, or maybe just those seeking control over others and wealth and more power. But our vision need only be limited to the Lower Blue Mountains to find a very special run of the mill sort of person with MS.

Peter, Leura

Any views expressed in the above article are those of the individual writer

We could learn a lot from crayons: some are sharp, some are pretty, some are dull, some have weird names, and all are different coloursbut they all exist very nicely in the same box.

STATE ELECTION

Remember March 22nd is election day and before this you should have made your representations to candidates to ensure they pay attention to your local issues and represent us as PwMS when considering disability issues.

To assist you in finding your local candidates please refer to:

<http://www.parliament.nsw.gov.au/prod/web/phweb.nsf/frames/members>

If you want to get a list of all members in spreadsheet form go to:

<http://www.parliament.nsw.gov.au/prod/parlment/members.nsf/reports/ContactSpreadsheetAll.csv>

Garry & Zanna

Continued from page 3

the day and to save discussion of "hot" topics for times when no one is trying to eat.

- With solids, swallow at least two times per mouthful-the first time to send the food down, followed by a dry swallow to catch any residual particles.
- With liquids, especially hot thin liquids, swallow; then clear the throat; then swallow again before taking more liquid.

A note about dry mouth

Some speech or swallowing difficulties might stem from dry mouth, a common side effect of some drugs used to treat other MS symptoms, especially bladder problems. Dry mouth contributes to tooth decay and gum disease, as well as discomfort, and it should be discussed with your healthcare provider. The medication causing the problem may be adjusted or you may be advised to use mouthwashes, artificial saliva, or other approaches to protect your teeth and increase your comfort.

We offer an excellent pamphlet on Swallowing and Speech difficulties. Compiled by Anika Hobbs, Kristen Stack, Penny Mogg and Beth King in collaboration with Nicole Whitten, Speech Pathologist - St Joseph's Hospital, Auburn NSW. Available by sending a stamped, self addressed business size envelope to MagScene, PO Box 1246, Chatswood, NSW, 2057.

<http://www.nationalmssociety.org/Brochures-Overcoming.asp>

CENTRAL COAST TENTH ANNIVERSARY

Dear Zanna

I just wanted to write you a short note to let you know that the Maitland multiple Sclerosis Support Group celebrated its tenth anniversary on 21st June 2002. I founded the group on Friday 19th June 1992. Six local MS ladies attended. We met at the Lower Hunter Community Health Centre, East Maitland, back in '92. We have monthly meetings and second monthly guest speakers. For our 10th birthday on 21st June this year, we had Robyn Adams - Outreach worker for Hunter area and Ros Chapman - Outreach worker for Central Coast/New England join us. It was a very special meeting and we celebrated with a Caramel continental Cake (and more).

We now meet at the Church of Christ, East Maitland. On Friday 15th November 2002, we all went out to lunch together.

Our end of year luncheon was held at the Endeavour motel/restaurant, at Maitland, Robyn Adams joined us once again. It was also the 10th year that we had been to the same restaurant. Very good indeed. Many thanks, Greetings to all
Ruth Richards



We made a mistake!! regarding the Volunteer Function mentioned on page 6 of the last MagScene in that we only mentioned Northern Region when it should have read 70 volunteers from **All Regions** received a special "Thank you Award"

Reminder

Each region has its own Volunteer Coordinator
Northern Region, Leslee Cameron, 9411 4522
Western Region, Sue Bell, 9646 0600
Residential Unit, Kerri-Ann Barlow, 9646 0600

We welcome any new Volunteers

Leslee Cameron

Southern Region, Patricia Smith, 9450 4544
Nursing Home Volunteers, Hazel New, 9646 0600

CARE TO LISTEN

PEER SUPPORT FOR FAMILIES & CARERS

The **CARE TO LISTEN** program is an innovative program funded through the NSW Department of Health and coordinated by the MS Society of New South Wales to meet the needs of family and friends supporting or caring for someone with a chronic illness.

Celebrating Carers



Caring for someone with a chronic illness can be very isolating. Work, family and caregiving responsibilities, distance, transportation difficulties and fatigue can become major obstacles in seeking social and emotional support.

Care to Listen is a pilot program aiming to provide peer support by telephone and/or visits to families and carers of people with MS and other chronic illnesses.

If you are a Partner, Parent, Child or Significant Other and would like to talk and share your experiences with another person. We have trained peer support volunteers available to assist you.

We will endeavour to match you with a carer with similar circumstances and interest to you. They can validate your needs and how you are feeling, or help identify valuable resources within you and in your local community.

Sometimes it is good to know that you are not alone and doing the best you can and that your efforts are very much appreciated.

Are you a Carer and in need of some care yourself?

Feeling overwhelmed, tired and needing to talk with someone who understands you and your situation?

We may have just the right person for you to ease your load and talk through some of those issues that seem to be weighing you down in your caring role.

We have seven caring peer support volunteers, recently trained in our 5 weeks telegroup training, to provide you with telephone support and the occasional visit or social contact.

The benefits of sharing with someone who understands are invaluable.

If you are interested, contact Alex, Marta or Sharon on 9646 0600 (or toll free for country callers on 1800 069 159)



FROM THE DESK OF MS BUSIBODY

Congratulations to all of us who have made it to 2003! It is a milestone for me because 20 years ago, at just over forty, I joined the

MS Society. 1983 was the same year that young Bill Northcote joined the society as an accountant. I have so much to thank the society for. I can still remember the warm friendly voice of Robbie Gallen, the receptionist at Bryson Street Centre (then head office). Now she is at Lidcombe. In those days Chatswood Centre at Mowbray Road was a friendly activity centre and consulting place. It was there that I first met Zanna, (before I changed my name) when she was running the art class as a volunteer.

Garry Anderson who joined the society in 1982 was working at Bryson St and it was together with Bill and Robbie that they arranged for the first computer in the society that was capable of word processing. Garry and Robbie spent many hours teaching themselves the first Microsoft Word program. This was well before Windows and the mouse.

Of the physiotherapy team, I can recall Gisela Alhers working on my silly foot.

I saw the opening of Lidcombe Centre in 1987; MagScene in '86; Hydrotherapy Pool around '89 and later Kent Street H.O.

Recently I read some advice; Look at life through the windscreen rather than the rear vision mirror. I can agree to a point, but no matter how you race through the highs and lows of life, you'll miss some of the signposts. My advice is - keep a journal of events and write dates on photos. There is potential for at least one book on every life.

Ms Busibody

Points to ponder.

Hindsight is an exact science

I intend to live forever, so far so good

L.I.S. Library and Information Services

A great deal of background work is taking place within the LIS to support our current MS Information Line and the future Response Team.

Now that the intranet (PAD OUT) is available for all Staff to access from anywhere in NSW (or in fact the world) we need to change most of our in-house hardcopy resources to electronic, in order to make full use of this technology.

The resources to which I refer are additional to our book, audiovisual and pamphlet collections and the Suggested Readings List and provide easy access to, for example, community and government services information.

Our recent purchases have also been more in the technical rather than the general information area.

However client services Staff need to be well up to date in all areas of multiple sclerosis and the management options and services available to people with MS, so whilst this LIS work is "invisible" to you our clients nevertheless it is most important.

For any enquiries please contact the MS Information Line on 1800 042 138

Cate Dawson, Manager, LIS

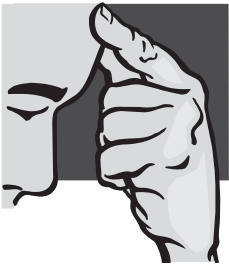
NEEDED URGENTLY SECURE GARAGE

- Pensioner needs storage for personal effects e.g. toys, clothes, household items
- For up to 3 months maximum
- For peppercorn rent (low as possible)
- Close to North Ryde area if possible

**CONTACT: Catherine Ph: 9888 117 or
email: catherinecpc@idx.com.au**



BRAIN GAIN



I hope you all had a joyful Christmas and a restful holiday. Not so Janet Goadby, who had to

evacuate (along with Rufus and Cooper) because of the bushfires! So they all spent their Christmas with a rather large German Shepherd and friends. Sounds like the dogs got a chicken dinner, I hope the adults did too! Casey and Phoebe spent a quiet day inspecting the contents of their stockings. Phoebe (fox-terrier) promptly devoured hers. Casey, being a well mannered Bichon, saved his for Phoebe to have later. I hope we have seen the last of the bushfires and that all PwMS came through them unscathed.

Wendy Sallis of Claymore managed to use all her grey cells to find 1340 words from the challenge

VISCEROPERITONEAL, congratulations Wendy. Wendy also sent me some anagrams to solve. I am becoming rather fatigued trying to solve them Wendy, perhaps if you could also send some cryptic clues to go with them. What do readers think? Let me know if they would also like some anagrams to solve and perhaps Wendy can construct them for us..

Elizabeth Watson of Tenambit submitted a grand total of 1270 words. Congratulations Elizabeth. Janice Goadby of Wentworth Falls followed with

1209, Lorraine Mahe of Towradgi had 1010 and Doreen Willis of Eastwood 473.

Your next challenge is **PITHECANTHROPUS**. You are sure to go 'ape' over this. 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 must 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.

I have listed some more cryptic town names for you to solve, I have had to venture inter-state. Answers on p24

- 1) *She bounces up from Wonderland*
- 2) *The Roman God of Wine will end up in the swamp
It's all Greek to me.*
- 3) *Have a little gossip before the copse.*
- 4) *The clone loses it's tail to end up in a hot stew.*
- 5) *Is it a hat or a horserace?*

Dear Mr Wisdom,

Herewith the next challenge Word entry, managed 1209 this time, good fun.

Rufus and Copper had a quiet Christmas, after having had the excitement (?) of having to evacuate the house due to the proximity of a large bushfire. All we wanted was peace, quiet and rain, which we got thank

goodness. We were lucky that we were able to go to a friend wMS and stop with them but they have a German Shepherd which is very friendly, but rather large for two Griffons. The Shepherd wanted to play but Rufus just rolled over and Copper backed off (hard to play with something you can walk underneath). We were all glad to get back home, however the emergency bags are still packed for both dogs and human. It sure alters your priorities, again!! Not a nice feeling to leave your 'material' things behind, but they can be replaced and you discover once again the value of friends. They are irreplaceable.

Well thank you for the challenge, will go back to trying to do the Herald cryptic and ordinary crosswords, trying being the operative word with the cryptic one. The nine letter word one is usually good, but I think the person who compiles the crossword has a very devious mind.

May 2003 be peaceful for all.

Regards

Janet Goadby

ARE YOU ARTISTIC?

Would you like information to extend your artistic skills? We are currently putting together some information we would like to share with you.



If you are interested we would be very pleased to hear from you . Don't be shy. Contact: Leslee Cameron 9411 4522 or MagScene: for details.

CLIENT CENSUS STUDY - UPDATE NO. 3

As promised in the previous edition of MagScene, here is the next update in the series on the findings from the MS Society of NSW 2001 Client Census Study.

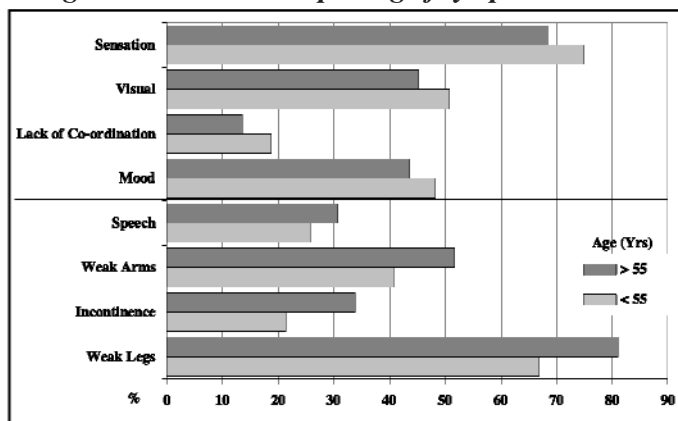
In this edition we bring you a focus on PwMS over 55 years of age, of which there were 778 who participated in the Client Census Study.

Not surprisingly those who were older than 55 had been diagnosed for a longer period (17 years average) than those who were younger (8 yrs average). They had also been diagnosed at an older age (47 yrs v 35 yrs) which may be indicative that the time from the first sign of symptoms to diagnosis is less now than it used to be.

The majority of over 55s live independently at home (88%). Almost half live with a partner or spouse and a further 13% live with a partner and children. A fifth live alone and 7% live with another family member.

PwMS reported similar numbers of symptoms regardless of whether they were younger or older, however, the types of symptoms they reported varied. A greater proportion of the younger group reported sensation symptoms, visual problems, lack of co-ordination and mood swings than the older group. While a greater proportion of the older group reported problems with speech, weak arms, weak legs, and continence problems. See figure below:

Younger & older PwMS reporting of symptoms



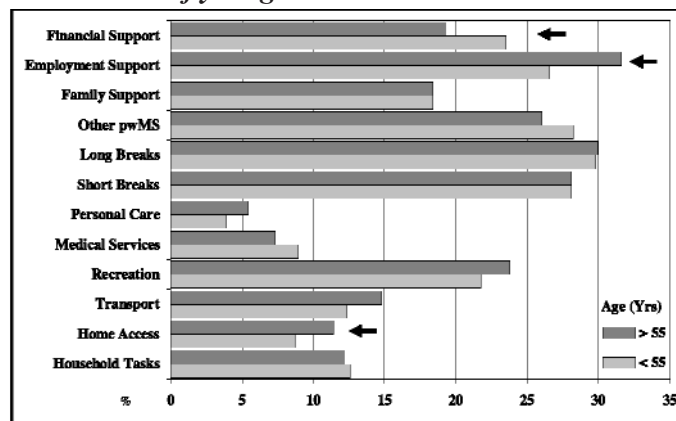
Although the older PwMS group reported less mobility than the younger group, two of the group had turned 90 years old and a quarter of the group still walked unaided.

A higher proportion of respondents over 55 reported an unmet need in relation to physical access to or within their home than those younger than 55 years (11.4% v 8.7%). This was also true for employment support (31.6% v 26.6%), however, a lower proportion of pwMS over 55 years reported financial support as an unmet need than those younger than 55 (19.2% v 23.5%). See the figure following.

Older PwMS reported that more contact from the MS Society of NSW and more services provided by the Society would increase their satisfaction with the Society. The Society recognizes that in the context of the general

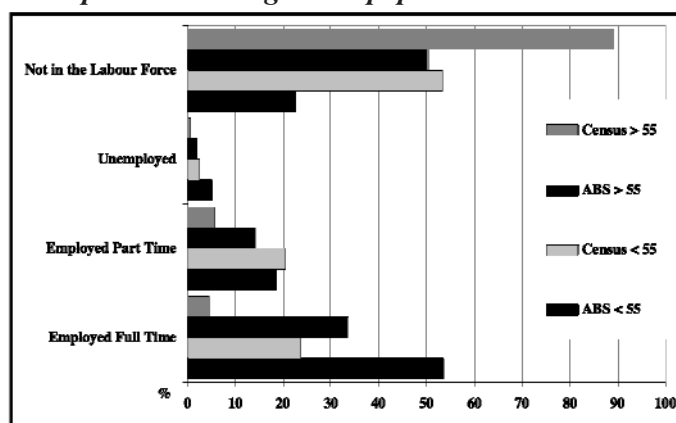
population getting older, there is a need to broaden its focus on issues such as healthy ageing, independence & self-provision, lifestyle and community support for this group.

Unmet needs of younger & older PwMS



A difference was found between the proportion of PwMS over 55 who were not employed or seeking work when compared to the general NSW population, than younger PwMS and the general NSW population. This difference was mainly found from the variation in part time employment in the two age groups. Although, slightly more, younger PwMS were employed part time than the general NSW population, a lower proportion of the over 55s were employed part time than the general NSW population.

Employment status of younger and older PwMS with a comparison to the general population in NSW



I hope you found the update interesting. The next update will look at the census findings in regard to immunotherapy.

Kate Tribe, Tribe Research Pty Ltd

Consultant Data Analyst for the MS Society of NSW

On behalf of the MS Society NSW Census Study Team: Robyn Faine, Wendy Longley, Gary Fulcher, Liz Henderson, Garry Pearce, Bill Northcote, Alex Hope, Lily Blagus



LETS TALK

Speech and Swallowing as the theme for this latest MagScene has come direct from a number of PwMS with this problem. They had contacted both Outreach Workers and MagScene requesting help and information regarding this often frustrating but sometimes overlooked symptom of MS. We say overlooked because many people, often GPs, think that little can be done to help. This is not true because Speech Pathologists, with new technology, are learning more about the mechanisms of speech and swallowing and the nerves that control it every day.

Because face to face and telephone communication can be very difficult for those PwMS who have a speech problem email is a logical answer and one which Lets Talk hopes to promote. The following is an excerpt from an email which I received from someone who has quite a severe speech problem but as you will see is very "with it".

If you would like to communicate with #477 please email me and I will let you know her email address.

<i>Coded Reference</i>	477	<i>Female</i>
<i>Lives in</i>		<i>Blue Mountains</i>
<i>Age</i>	57	
<i>Years with MS</i>	1	
<i>Dated</i>		<i>December 2002</i>

I contact you in connection with a request that I had brought to the attention of an Outreach Worker. She thought you might be interested in running it as an inclusion in MagScene.

My concern results from having lost the use of a vocal cord through MS. Having to deal with the social and psychological implications of this I sought help from the MS Society. I wondered if they could put me in touch with anyone else who had suffered speech impediment through MS and might be asking similar questions and facing similar issues to my own.

There is little data available - hence this email to you now.

It seems to me that people with speech disability differ in some respects from those with other physical symptoms i.e. the prospect of the usual support group setup sounds like a nightmare: being with all those other people and you can't make yourself understood! The difficulty of meeting someone new and trying to sound like a 'personality' instead of a Darth Vader clone! The

temptation to isolate oneself rather than wheeze or select one of a thousand different ways to express a feeling without words!

I thought that perhaps in writing something about this specific manifestation you might be able to invite anyone interested to have email contact with other similar souls like me. Face to face/voice to voice contact would not be necessary, but an email or even snail mail link might be the way to go. You may of course have done all this before or feel it is impracticable. I will look forward to hearing your reaction, whatever it may be.

Myself? Well, 57, 1 husband, 2 children, 1 dog; a NZer; always been involved in teaching something to someone (usually Latin) and in NZ was involved in counselling as a hospital chaplain with the Anglican Church; MS diagnosed this year and am just about to start Betaferon; passions include music from blues to classical, things botanical, and most anything life has to offer!

I am told I can wheeze quite comprehensibly over the phone, so please phone or email me, whichever suits you best.

With thanks.

About 3 yrs ago I was doing a course through TAFE as a PwMS for 8yrs. I was having trouble with my hands typing assignments. My teacher suggested getting Voice Recognition Software and giving it a try. After looking around I finally settled on ViaVoice Office 98, by IBM. It took quite a while for the program to recognise my voice, as with MS sometimes the voice goes a little funny. Eventually I got there and the software worked very well, albeit a little American in its set up. There was quite a bit of mouse input which I found at the time OK, and managed to get my assignments done, and very neatly too. You must be prepared to spend a great deal of time voice training the software, so it picks up all the nuances in your voice, from being tired, to cranky, bored or whatever.

Now nearly 3 yrs later, I don't use the software anymore. I have been on Interferon now for nearly 3 yrs and have regained nearly full use of my hands. If I limit my typing to 30 minutes at a time, I can manage to still do my assignments, as I am still doing a course through TAFE.

K.E.

Mittagong

GARRY

behind the scene

This twenty four page issue is brimming with informative articles prepared with our MagScene readers in mind.

Great excitement in our office when we were invited to attend the NSW Premier's Forum to hear Christopher Reeve speak. It was a very emotional address with Christopher asking "Why is it that human nature has first to experience the suffering before providing help". This is why he feels ethically bound to be a spokesperson for Spinal Cord Injury. He asked everyone to 'imagine' what it is like before making decisions about legislation against stem cell research. He talked of the importance of hope, best care and optimal outcomes. His main message was never give up hope for a cure - never destroy hope.

The NSW State Election takes place on Saturday 22 March 2003. You can help over the next few weeks to raise the profile of issues of interest to people with disabilities.

If elected to the State Parliament what would your candidate do about the provision of equipment, personal support and assistance services, transport, access to buildings?

Write letters about these topics to every candidate putting their name forward in your electorate. Ask questions of candidates at meetings. Write to your local newspaper. Get on the phone to talkback radio presenters and ask them to question candidates about what they will be doing regarding these issues if elected.

On page 17 we provide some relevant website addresses for you to contact your local candidate to ask about local issues.

On page 16 we have a very special gift

offer that you can win for your carer. We need to know why **YOUR CARER** is just so appreciated. We look forward to reading your entries.

You may have noticed that this back page is different from previous issues. This is as a result of Garry starting to use a new Desk Top Publishing program which allows much more versatility than MS Word.

Lastly we say Goodbye to three special staff: Carolyn Ball, Southern Region manager who has been with the MS Society for 8 years and will be sadly missed along with Jenny Croft and Barbara Whitelaw. We thank them on behalf of MagScene readers for their dedication and loyal service to PwMS.



Stop Press

A sad note; for those who knew physiotherapist, Gisela Ahlers, she died after a long, brave battle from cancer on 28th February. We express our deepest sympathy to her son Jan.

Until April May issue, keep smiling

Answers to place names from page 21:

- 1) Alice Springs
- 2) Baccus March
- 3) Chatswood
- 4) Cloncurry
- 5) Derby

**Deadline for April/May
issue is
4th April 2003**



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