

FATIGUE IN FOCUS

Fatigue is one of the invisible symptoms of MS.

What is fatigue?

MS fatigue is different for everyone; for some it causes overwhelming tiredness, whilst in others it worsens symptoms such as visual disturbance, difficulties with concentration, memory, mobility and muscle spasms. Fatigue may make it more difficult to deal with everyday activities.

Primary fatigue

Primary fatigue is experienced as a direct result of damage to the central nervous system. This damage slows down nerve reactions causing fatigue.

People with MS experience different types of fatigue including:

- **Lassitude:** an overwhelming tiredness not directly related to participation in activity or exercise.
- **'Short-circuiting'** fatigue: occurs in specific muscle groups; for example, the hand after writing for a short time.
- **Heat sensitivity fatigue:** a rise in body temperature can cause fatigue. This kind of fatigue can occur due to the seasonal changes in the weather but may also be triggered by other things; for example, taking a hot bath or eating hot meals.

Secondary fatigue

Fatigue can be experienced as a result of other factors that are not necessarily directly related to your MS. These can include:

- **Sleep disturbance:** this is often due to symptoms that can be alleviated or lessened; for example, spasms, pain, urinary urgency at night, depression or anxiety.

- **Infection:** may cause a number of symptoms that could bring on specific MS fatigue; for example, having a cold or flu may raise your body temperature.



- **Exertion:** the increased effort required by the body, if mobility or coordination is affected, can cause fatigue.

- **Medication:** there are many medications that may cause tiredness or drowsiness as a side effect. It is important to be aware of this. If you notice that there is a correlation between a change in fatigue levels and a change in medication, tell your doctor.
- **Depression:** may be due to nerve damage or because of the emotional impact of adjusting to MS.
- **Local environment:** the lighting and temperature within a work area is crucial, as poor lighting increases visual effort and heat frequently exacerbates fatigue.

Continued page 2&3

Fatigue management

Fatigue requires a coordinated approach that involves active participation and involvement from family and colleagues, as well as health professionals. You may feel that your personal relationships are affected because people do not understand how fatigue affects you. If you would like to talk about the difficulties you are experiencing coping with fatigue, it may be worth talking to a trained counsellor. Your local MS society will be able to advise you on where to find counselling, or may even offer such a service itself.

Drug Treatments

Primary fatigue management will probably involve the use of drugs. It may take several attempts to find the most suitable drug and dose for you. Because MS fatigue is caused by damage to the nerves, standard fatigue medications are not effective.

It is common for someone with MS fatigue to be treated with drugs that are also used in the treatment of Parkinson's disease, flu or narcolepsy (excessive daytime sleepiness). This is because they have been shown to have an effect on MS fatigue, not because your doctor thinks you have any of these conditions. Drugs for fatigue include:

- Amantadine: Side effects experienced may include dizziness, headache and difficulty sleeping.
- Modafinil: This is a new treatment still undergoing clinical trials. Small-scale studies have supported its use for MS fatigue. Side effects can include headaches, weakness and nausea.

Occupational therapy and physiotherapy

The occupational therapist's role is to adapt tasks and incorporate strategies that allow daily activities to be carried out in an efficient, energy effective way. Physiotherapists help strengthen, stretch and relax muscles. This increases joint movements and improves circulation. They can structure an aerobic exercise

programme for you.

Areas to consider when examining your daily routine should include:

Rest and relaxation

If there is regular pattern to your fatigue, it is ideal to take the rest before it is at its worst, as this enables the body to recuperate more quickly. Relaxation techniques are available on compact discs or audiotape, and are an effective method of complete relaxation. The relaxation method used must not require active contracting and relaxing of muscles, as this can increase muscle spasm.

Prioritisation of daily activities

If you make a list of your regular habits and routines, some activities will be an obvious priority. Others can be shared, altered or even eliminated. Some changes will require the cooperation of others; it is important that everyone understands why the changes need to be made and the benefits they will have to you.

Planning and adapting daily activities

Daily activities demand varying levels of physical and mental effort. It is important to balance these tasks, rather than rushing to complete everything in one go. Activities are ideally planned around regular rest periods. It is best to complete essential tasks when fatigue is at its minimum, and also break tasks down into manageable stages.

Organisation

You can ensure energy efficiency and effectiveness during a task, for example by keeping frequently used items within easy reach. Gadgets such as food processors, remote controls and headset telephones also limit the effort required in completing activities. Key areas where this can help are the kitchen and work place. Your local MS society may be able to recommend sources of equipment and adaptations in order to conserve energy.

Good posture and positioning

Sitting rather than standing is desirable in maintaining a good

Continued page 3

Continued from page 2

posture and saves energy during lengthy tasks. It is important to consider your technique when handling or lifting objects. This helps prevent injury and uses energy effectively.

Healthy balanced diet

A low fat diet, avoiding heavy hot meals, may be effective in limiting fatigue. Excessive alcohol and smoking may also have a negative impact on the level of fatigue you experience.

Appropriate exercise

Gentle aerobic exercise is a positive approach to managing fatigue. It promotes muscle efficiency and strength, as well as increasing stamina. It is important to consult a health professional before starting any exercise regime.

International MS Society Journal, Issue 1 Feb 2003

<http://www.msif.org/docs/msinfofocusjan02en.pdf>

also see **Neurology & Neurosurgery 5(2), 2003**

You may be able to save a child's life on a hot day!



Every day in Australia children are left in cars whilst parents go shopping.

The smaller the child the greater the risk. A young child will quickly dehydrate, lapse into unconsciousness and may never fully recover.

- * If the car is unlocked, and it is safe to do so, remove and place the child out of the sun.
- * If the child appears distressed or listless, call for an ambulance immediately by telephoning 000.
- * Check the child's airway, breathing and circulation, and assist if necessary.
- * Sponge the child's skin with cool water until ambulance officers arrive.

Important: A listless child showing little distress might be more dangerously ill or closer to death than a child screaming for attention.

- * If the car is locked, call police immediately and request urgent assistance.

www.kidsafe.com.au carries a fact sheet for parents on hot cars which can be printed out and distributed at preschools, day care centres etc

Especially during the summer months you should pass this important information onto any family or friends with young children.

Editor

INTERNATIONAL MS CONFERENCE BERLIN

I was lucky enough to attend the International MS Conference held in Berlin in late September 2003. Many of us remember the previous international conference, the very successful event held in Melbourne in 2001.

Other Australians were there in an official capacity, including Lindsay McMillan, Chief Executive of the Victorian Society, and Bill Northcote, CEO of the NSW MS Society.

Lindsay gave a paper outlining an international comparison of the financial impact of MS on families.

For me, a person with progressive MS in a wheelchair, the most interesting sessions were those presented by medical researchers outlining the progress they had made.

The usual awards were made, including that by the Australian-born head of the World Bank, James Wolfensohn. The theme of the conference, and attendance from many countries, from India and Iran to the United States, Australia and most European countries, showed how widespread are the problems associated with MS and also the determination to make progress in dealing with them.

Dr. Claire Clark, Sydney

POWERED SCOOTERS AND WHEELCHAIRS:

Your Rights and Responsibilities



These days, it's not unusual to see people using powered scooters or powered wheelchairs in the community, on the footpaths and in shopping centres. They are becoming a popular solution for travelling longer distances as an alternative or complement to using cars or public transport. They are also known as electric wheel-chairs, motorised scooters or battery operated scooters and wheelchairs.

Powered scooters can be three or four wheeled, and are usually operated with both hands gripping a handlebar type arrangement; powered wheelchairs are four or six wheeled, have a more compact base and are usually operated with one hand using a joystick.

Using a motorised scooter/ wheelchair.

You do not need a licence to use a motorised scooter/ wheelchair. However, you are responsible for operating the motorised scooter wheelchair safely.

To do this, there are skills and abilities essential for the safe operation of the

equipment. These include co-ordination and strength, balance and endurance, adequate vision, perception, clear thought processes, memory and judgement. As you do not need a licence, there is no formal organisation that can assess your driving skills. However, your GP or an occupational therapist may be able to assist in the assessment of these essential skills (Council on the Ageing (ACT) Inc and Able Access, 2002).

Under the Australian Road Rules, when you are driving a powered scooter/ wheelchair, you are classified as a pedestrian and must follow the same rules as pedestrians. The maximum speed you can travel is 10 km per hour. It is an offence to use the powered scooter/ wheelchair when your blood alcohol level is above .05 (Australian Road Rules 1999).

Registration and Insurance

You are not legally required to register your motorised scooter/ wheelchair.

In NSW, the Nominal Defendant Scheme

Continued page 5

Continued from page 4

provides Compulsory Third Party cover only in road related areas, not in shopping malls (other states vary).

Additional insurance is therefore recommended to cover public liability (damage done by you to others and their property), house and contents and personal effects (theft or damage), and personal accident.

Sometimes motorised scooters/ wheelchairs can be included in house and contents policies, however it is essential to have this clarified by the insurer (Council on the Ageing (ACT) Inc and Able Access, 2002).

Some useful questions to ask your insurer include:

- Do you cover motorised wheelchairs for loss or damage?
- Can you cover me for damage my motorised wheelchair may cause others, including personal and property damage?
- Does the cover extend outside the home and what are the limits?



- Are there any exemptions?

Driving Safely

If you already have a powered scooter/

wheelchair, you are entitled to use the same areas as pedestrians: footpaths, dual use paths, bicycle paths and most shopping malls. You may not use a road if a "No Pedestrians" sign is displayed (usually on a freeway). Planning your journey, avoiding busy intersections and ensuring there are kerbs or driveways for safe road crossings are crucial points to consider. Make sure you are visible by wearing bright clothes, or having a tall flag on the motorised scooter/ wheelchair. Carry a mobile phone for emergencies. The NRMA (131 111) provides a free emergency road service for tyre punctures/ problems only; they cannot assist with electronics or flat batteries.

If you are considering a powered mobility aid, it is recommended you seek advice on the type that would be suitable for you, as well as the skills you require for its safe operation. Contact your local occupational therapist, or for supplier information contact the Independent Living Centre on 9808 2233.

For access to the Scooter Safe Guide in its entirety, visit

http://www.mynrma.com.au/member_centre/community/safety/scooter_safe.shtml

Or contact NRMA:

John Brown , Policy Advisor,
Mobility Safety on (02) 8222 2162
john.brown@mynrma.com.au

References

Council on the Ageing-ACT Inc & Able Access (2002). *Scooter Safe Guide* (A project funded by the NRMA-ACT Road Safety Trust)

Australian Road Rules 1999,
<http://www.rta.nsw.gov.au>

Our thanks go to the MS Society OT Department for their support in the preparation of this article. Ed

WHAT INSURANCE OPTIONS ARE AVAILABLE FOR PWMS?

This is an often-asked question. So let us go through some of the types of insurance.

Income protection insurance and Total Disability insurance are not available to a PwMS as the chance of making a claim in the future are just too high.

Trauma cover is insurance which pays out if a person suffers a medical crisis, such as heart attack or cancer. One of the conditions is MS, so this type of insurance is simply not available to a PwMS.

The big one is life insurance. This is usually available to PwMS. Let us examine this.

If a completely healthy person applies for life insurance they are set a price (or premium) which is based on age, smoking status and sex. If a person's health is not standard they will attract a loading, which increases the premium. It may be based on something such as high cholesterol and may then attract a 50% loading, which increases the premium by 50%.

A PwMS who is otherwise healthy will attract a 100% or 150% loading as a starting point (depending on the severity of their MS), and may then have other conditions added to this, such as high cholesterol, which may lead to a 200% loading in total.

Some people have so many conditions that they can't get life cover at all, because the loaded premium would be too expensive to make it worthwhile, or the life company decides that it won't issue a policy

Insurance is a very important aspect of securing a financial position. The area often overlooked is that of the partner of the person with MS and this should be considered.

Often the person not affected by MS is the major breadwinner, and hence their income is very valuable to the financial well being of the couple (and/or family). If this person is unable to work for health reasons

things can get very serious very quickly. Hence this person should ensure they are fully insured.

Please note that I can assist with insurance through AMP, ING, MLC, Citicorp and similar companies.

Todd Cameron is an authorised representative of AMP Financial Planning Pty. Limited, ABN 89 051 208 327, AFS Licence No. 232706

Todd can be contacted on 02 9890 8300 or todd.cameron@ampfp.com.au

EXTENDING THE SHELF LIFE OF FRUIT



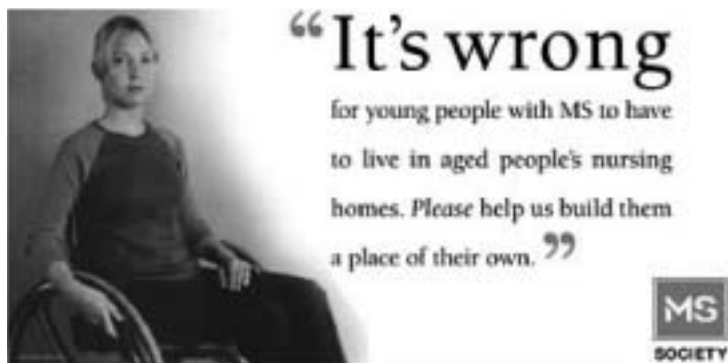
"The contents of your fruit bowl could soon stay fresh a lot longer—thanks to a substance hailed as one of the health-giving components of red wine," reports New

Scientist. "Dipping apples in a solution of trans-resveratrol, an antioxidant found in grapes, extended their shelf life from two weeks to three months. Similarly dipped grapes fared less well, but their shelf life still doubled to two weeks." The researchers found that only small amounts of the antioxidant were needed to prevent tissue damage and ward off the yeasts and moulds that wilt many fruits. "In subsequent work, the team has protected other produce, including tomatoes, avocados and green peppers," the magazine said. "They are now looking into cheaper methods of producing resveratrol."

We know some people who just drink the wine, to hell with apples!

Ed.

YOUNG PEOPLE IN NURSING HOMES



Many young people with disabilities including brain injury, MS and other neurological conditions are currently living in aged care nursing homes.

The decision to place a young person into a facility for the care of the frail elderly can be devastating. Across Australia there are **6000** people under the age of 65 who are permanent residents in nursing homes.

1100 of these are **under 50** years of age. **30** are under **25** years of age.

The long-standing issue of young people in nursing homes is a crisis in its own right, but it is a key part of the current crisis in aged care. MS Australia has called on all political parties to make a commitment to getting younger people out of nursing homes and creating appropriate accommodation services across the nation.

In 2002, a group of more than 180 participants attended a National Summit for Young People In Nursing Homes in Melbourne, and a **National Young People In Nursing Homes Advocacy Alliance** was formed. This Alliance will coordinate lobbying efforts, develop partnerships with and across health and community service sectors and ensure that action is taken on the agreed strategies that will be developed by the National Alliance.

At this meeting it was also decided that

Commonwealth and State Governments should establish a National Body for Young People In Nursing Homes

Who are the younger residents of nursing homes?

People with MS/neurological conditions.
People with acquired brain injury.
People with physical and/or sensory disability.

The problems

While nursing homes generally serve the needs of the frail elderly, they create lifestyle and care problems for younger people. The main problems with nursing home for younger people are:

- Nursing home staff not trained to meet the needs of younger residents
- The environment is to manage the end of life not the living of life
- Little peer support: isolated by age from the predominant resident group
- Few opportunities to participate in community life
- Care service revolves around personal care only

Costs of Care can be high

Little or no access to required therapy services contributing to upstream bed blockages in acute hospitals

Distress and depression experienced by residents and families

Nursing home environments do not lend themselves to visits by the friends of younger people, increasing the effects of social isolation

THE FUNDING TRAP

Nursing Homes

Nursing homes are funded by the Aged Care Branch of the Federal Department of Health and Aged Care. They

Continued page 8

Continued from page 7

administer funds and standards for aged care services throughout the country (www.health.gov.au/acc/rescare).

Aged care services are designed for people over 65 years of age. Young people are not supposed to take up places in this system, although people under 65 comprise 4.5% of all nursing home residents.

People with Disabilities

The funding responsibility for services for younger people with a disability is defined in the Commonwealth State Disability Agreement (CSDA). The CSDA in each state/Territory defines the services to be provided by each party, and includes the level of additional growth money provided in the agreement to fund additional services to be managed by the States.

The State Governments have responsibility for accommodation services, as well as therapy, recreation and equipment, among others.

The Commonwealth has primary responsibility for disability employment services, advocacy and research.

The CSDA is the instrument that governs the funding of all disability services. For alternative accommodation places to be developed for younger people as alternatives to nursing home places, they must be done under the auspice of the CSDA by the State Governments.

Nursing homes are not part of the CSDA and younger residents cannot access many of the community services available to other people with disabilities.

They are caught in a bureaucratic and political **funding trap**.

THE FUNDING TRAP IS:

Different departments, different jurisdictions, someone else's problem.

The Commonwealth has responsibility for aged care, the states have responsibility for accommodation for young people with disabilities.

The major barrier that has been identified to fixing this tragic problem and creating alternative services is the need to transfer the funding for the younger nursing home residents to the States.

They need to seriously negotiate a solution to this problem and resolve how alternative services can be developed.

The States want to develop new services, but without the cooperation from the Commonwealth in the form of policy and dollars, this cannot be done effectively.

We need a national solution.

It is important to ensure that aged care places are kept for aged Australians.

The Commonwealth must show leadership on this matter. The pressure on aged care services across the country demonstrates that older people need these beds, and many young people want something more appropriate.

NB

2004 is an election year. In future issues of MagScene we may ask readers to assist in some way.

Have you had an experience relevant to this article that we could use to make our representations powerfully personal? We would not quote your name only suburb.

Write or email me confidentially.
zbarron@msnsw.org.au

Editor

THE STEM CELL STORY

by Martha King, "Inside MS", (USA) Oct 2003

The following story was first published in the October, 2003 USA MS Society journal "Inside MS". Although it is very oriented to the situation in America the situation in Australia is not too dissimilar. Refer to "Stem Cell Research in Australia" at the end of Spotlight. Editor

Almost every week, the media bring up the topic of stem cell research. We hear stem cells trumpeted as the source of relief for Alzheimer's, Parkinson's, or paralysis following spinal cord injury. Almost inevitably, reporters include multiple sclerosis among the conditions likely to benefit. On the other hand, the air is full of warnings about the ethical and social implications of stem cell research, a technique called therapeutic cloning. What's really going on?

We'll try to answer some basic questions about stem cells-and to examine how controversies seem to follow the source of stem cells, not stem cells in themselves. It would be wonderful if we could give an overview of what stem cell therapies might mean to MS, but the field is too new. No one actually knows very much yet-and only research, which is going on now-can change that.

One thing is certain

Stem cells are a possible source for repair or replacement strategies in MS. Indeed, whether the target is Parkinson's, spinal cord injury, or MS, hope is based on being able to replace dead or damaged tissues with tissue that functions normally. In MS there are still huge unknowns about the process that damages the tissues-the myelin on nerve fibers and the fibers themselves-in the central nervous system. Until there are therapies that can stop MS from

doing damage, repair therapies are probably doomed to failure.

Stem cells and stem cells and stem cells

As soon as the term "stem cell" is used, confusion begins.

There are different kinds of stem cells, appearing at different phases of development and possessing different capabilities. Three main types-embryonic, fetal, and adult-all have potential for tissue repair. All can be thought of as seeds for more specialized cells that develop from them.

A great deal is known about the journey of a single fertilized egg cell-which is the original stem cell-to an adult with billions of highly specialized cells. Many of the factors that guide cell growth and differentiation have been identified. And, in the course of questioning why the body makes new muscle, skin, bone, or blood after injury but fails to repair many other kinds of damage, medical scientists have learned that remnant stem cells, here and there in the body, are the starting points for new supplies of many cell types.

Adult stem cells

Until recently, scientists believed that stem cells in adults were nonexistent. They were thought to disappear before birth or in early childhood. Now, research has uncovered various kinds of stem cells in the adult body.

Not so long ago, the MS research community was electrified to learn that large numbers of "progenitor" neural stem cells are lurking in the adult human brain. Some of these are precursors of the oligodendrocytes, the cells that make myelin.

Once damaged, mature oligodendrocytes don't replicate. Their working days are over. So



MS investigators quickly began exploring ways to prod these oligodendrocyte precursor cells to wake up from their dormant state and start dividing. This, they hope, will ultimately create new mature myelin-makers able to effect repairs. Researchers, many funded by the National (USA) MS Society, are probing ways to make this happen within the brain, using growth factors and other approaches.

MS investigators are also thinking of creating more myelin-makers by transplanting a fresh population of stem cells into the central nervous system from elsewhere. Some scientists have even speculated about treating stem cells with gene therapy to endow them with MS-fighting properties before transplanting them.

Limitations of adult stem cells

Adult stem cells appear to have tight limits on the types of cells they can generate. Adult neural stem cells generally develop into cells specialized for the central nervous system only. They don't have the flexibility to become anything else. This issue of flexibility, or potential, will come up again.

So will the important question of access. Human adult neural stem cells are highly diffused, somewhere among millions of other cells, in brain tissue. They are not easy to harvest. Research has produced some hints that they might be found in more accessible tissues, such as skin or bone marrow. Until more is known, they remain fiendishly difficult to locate-but the hunt is on.

If it were possible to harvest and treat adult stem cells that have the capability of becoming neural cells and then return them to the patient's body, the technique would solve a major obstacle blocking almost all possible stem cell therapies: compatibility. Stem cells, just like donated organs, must be genetically compatible with the recipient or they and all their more developed offspring will be rejected, attacked, and destroyed by the recipient's immune system.

Restrictions on human adult stem cells in research

There are many ethical, governmental,

and institutional restrictions guiding research on human tissues in general. Research on human adult stem cells that conforms to these restrictions is being conducted in the United States. Some of it is funded by the National (USA) MS Society. Human brain cells for research can be procured, for example, from surgical procedures performed on people with epilepsy.

Fetal stem cells

After eight weeks of development, a human embryo has become a fetus. Stem cells in a fetus have apparently already made many "decisions" to produce cells of specific systems only. Cardiac stem cells, for example, will make heart muscle cells only. But other fetal stem cells still possess a flexibility that might mean they could be coaxed to produce much more specialized cells in a laboratory.

Fetal stem cells can be harvested from umbilical cord blood at delivery, or from the placenta expelled after birth, and parents may choose to donate this resource for medical science. The National (USA) MS Society is currently funding research on the potential of umbilical cord blood as a source of stem cells that could become oligodendrocyte precursors, and then transplanted for MS repair.

Fetal stem cells can also be harvested from fetuses that have been terminated. Fetuses with genetic defects would usually not be considered as a source of stem cells for transplant purposes, although they might contribute to other kinds of studies.

Concerns about fetal stem cells

Research using any material from aborted fetuses is a highly emotional issue. Abortion opponents fear that any research use justifies a procedure they find repugnant. Research advocates believe that great benefits to society might be forthcoming in fields as diverse as organ replacement and prevention of birth defects. They also point to possible gains in understanding fundamentals. With so much still to learn, research might open unexpected pathways to tissue repair.

Research using fetal tissues is highly

regulated but is not forbidden by U.S. government regulations. Some states have passed regulations that make it difficult to conduct such research. A few states have made it impossible. Other states have encouraged fetal tissue research.

Embryonic stem cells

"Universal" stem cells-which seem to have the greatest potential to develop into any kind of cell or tissue over time-are found only in the earliest developmental stages of an organism, the "blastocyst" stage. In human beings, this six- to eight-day period starts at fertilization and ends when cell differentiation increases dramatically and major organs start to form. Blastocysts contain embryonic stem cells that carry, in theory, the potential for all the cell types of an adult, just as an acorn contains a complete oak-roots, bark, wood, leaves.

Concerns about embryonic stem cell sources

Embryonic stem cells can be harvested from the excess fertilized eggs that have been created for infertile couples. Clinics that treat infertility with "in vitro" fertilization (or IVF) routinely fertilize many more eggs than the parents-to-be will need. They do this because the process is so complex and unpredictable.

The parents have the right to offer their unused fertilized eggs to other couples or to donate them for research. The Coalition for the Advancement of Medical Research estimates that 100,000 embryonic cells are currently stored in clinic freezers. Most will eventually be discarded.

Very early "universal" stem cells can also be obtained using a technique that offers a possible solution to the dark specter of immune rejection. The technique is called Somatic Cell Nuclear Transfer, or SCNT. The resulting embryonic stem cells match the DNA of a potential recipient of stem cell therapy. Subsequent use of cells or tissue from this initiating procedure is called therapeutic cloning.

Whether the stem cells are obtained from IVF storage freezers or cloned, creating stem cell lines involves separating the blastocyst, a hollow ball-like cluster of cells, and growing

individual cells into populations called cell lines. Successful cell lines can be maintained for many years and produce ample supplies of these otherwise rare cells. But, like many other lab procedures, establishing a successful cell line is not as easy to do as it may sound. Consequently, one of the controversies in this field has to do with the availability of the stem cell lines "approved" by the U.S. government.

Embryonic stem cell research is legal in the U.S., provided the work is not taking place in a state that has specifically prohibited it (as a few have). However, there are federal limits. Federal funds may support research using only embryonic stem cell lines that were established before August 9, 2001. This restriction does not apply to research funded with private, nonprofit, or foundation dollars at this time.

Prospects ahead

While exploration of stem cells for MS therapy is in its infancy, the field has received an encouraging boost from a multidisciplinary research team in Italy. (See "Transplanted cells repair MS-like nerve damage in mice" in News section.)

The research showed that mice recovered from an MS model disease when they were injected with adult mouse neural stem cells. The cells migrated from the bloodstream into the brain, and homed in on the many damaged areas. There, they generated mature myelin-making cells, which began to function. The mice regained their former ability to move normally.

Inbred laboratory mice do not have the rejection problems of human beings, but this study, if successfully repeated, shows that some stem cells "know" where to go and seemingly respond to specific repair needs.

Problems ahead

Human stem cell therapies face many vexing problems. What is the best source of stem cells for effective therapies? How can stem cell therapies be safely tested in people with MS? Can rejection be limited or circumvented - or would such therapies always need to be tailor-made for an individual patient? And what might happen to MS research if the federal government passed

legislation that prevented exploration of this field?

Where does the National (USA) MS Society stand?

The Society supports research, done in the highest ethical fashion and within the bounds of federal, state, and local regulations, using all human cell types that might further the development of treatments and a cure for MS. Thus the Society - along with the American Medical Association, other voluntary health organizations, and many scientific societies - opposes regulations that would limit the full exploration of this important area.

<http://www.nationalmssociety.org/IMSOct03-StemCell.asp>

Stem Cell Research in Australia

In December 2002, Australia passed two pieces of federal legislation to regulate cloning and embryonic stem cell research. The first, Prohibition of Human Cloning Act 2002, outlawed any form of human cloning, whether it be to generate tissues (therapeutic cloning) or a new human being (reproductive cloning). The second, Research Involving Human Embryos Act 2002, allows researchers to access surplus human embryos, under strict conditions.

A major objection to stem cell research, from both religious and non-religious groups, is that it devalues human life because it uses embryos as 'a means to an end'. For that reason Australia's legislation ensures that embryos cannot be created for the sole purpose of harvesting their stem cells. The only embryos that can be used are surplus embryos that were available at the time the legislation was drafted in April 2002. These can only be used if the embryo donors give their consent.

Researchers who want to use such embryos are legally required to obtain a government licence. To get such a licence they must show that their research will lead to new knowledge that can't be obtained by other means. Applications must first be approved by the in-house ethics committee of a researcher's institution, and then by a National Health and Medical Research Council Committee made up of scientists, lawyers and ethicists.

<http://www.science.org.au/nova/079/079box01.htm>

MARIJUANA AND MS

The National MS Society in the USA has reported on the findings of a large UK trial on the use of Marijuana to treat symptoms of MS. Those interested can read the complete article on

<http://www.nationalmssociety.org/pdf/research/Research-2003Nov6.pdf>

Below are the conclusions of the above report.

Editor

Conclusions: These results provide the first carefully gathered – and largest yet – sample of data on the effects of marijuana extracts for treatment of MS-associated symptoms. These long-awaited results show that these oral derivatives of marijuana do not provide objectively measured improvement in the spasticity experienced by persons with MS. On the other hand, they confirm prior suggestions that patients using marijuana felt better in ways that could not be measured by their physicians. It is important to note that this study does not provide information related to the use of smoked marijuana, the most commonly reported anecdotal use for MS and all other diseases for which it has been suggested.

In the view of the National MS Society's Chief Medical Officer, Aaron Miller, MD (Maimonides Medical Center, Brooklyn, NY), "Oral cannabis oil or synthetic THC appears to have significant benefits on pain and on patient perceptions of spasticity, but not on objective measurement of spasticity. Whether the positive effects that patients reported resulted from a specific chemical effect of cannabinoids or a heightened placebo effect cannot be determined from this study, because unpleasant side effects allowed more than three-quarters of patients to recognize that they were taking the active drug. Also, the study provided no quantitative information about the extent of pain relief, so it is unclear whether patients perceived the benefits of cannabinoids to outweigh side effects.

The long-term effects of orally administered cannabinoids are not known and their use in most states remains illegal. Smoking marijuana is unwise because the toxic effects appear to exceed those associated with tobacco smoking." "These data will be useful in the ongoing debate on the value of marijuana derivatives for symptomatic treatment of MS, a part of the larger debate about the use of medical marijuana more broadly.

Individuals interested in the use of marijuana derivatives for symptoms of multiple sclerosis should consult their personal physicians.

L.I.S. Library and Information Services

Occasionally the LIS is asked if we sell books, videos and other resources. Recently feedback from the MS Connect Customer Satisfaction Survey suggested that being able to purchase these commercially produced resources from the Society would improve our information and support program. The following explains why LIS **does not do this**.

As a Society our paper based in-house publications provide professional, evidenced based information on a range of topics associated with MS, using our many years of experience. Currently these are provided free of charge if a single or small number of copies are requested - though if large numbers are requested eg for a class of students - we charge replacement costs plus postage and packing. Often these resources are also available to be printed free from our website.

At present we also manage to provide free access to more expensive in-house resources such as books and videos. This gives me the opportunity here to announce a new publication called **"Employment, Employers and People with Multiple Sclerosis"** (see abstract below). This resource is produced on compact disc, (free on request), but also available in VHS format, 10 copies available for loan.

Commercially produced information resources are completely different scenarios as they are already available from well-established booksellers.

New resources are always being assessed by the LIS - these often include suggestions from readers of MagScene - and if we feel that an item would be of use to our users we purchase an appropriate number of copies and make them available on loan.

If the LIS sold these resources we would only become an additional "step" in the ordering process between the purchaser and original supplier, probably leading to an increase in the price.

What the LIS **does** offer you however is complete & **exact** details of a resource to make purchasing that elusive book or video easier, just ask!

The abstract for the new CD / video follows:

This resource provides information for people with MS and their current and potential employers. It emphasizes that with some adjustment in the work place - generally assessed at under \$500 - a pwMS will remain or become a valuable employee. Paid employment is important for everyone as it provides quality of life and a role function and identity. The role the Society can play in advising about disclosure of a diagnosis with MS, advocacy and advice on work adjustments for all parties is described.

Please contact the LIS on library@msnsw.org.au or 9646 0600 to request any of our resources

Cate Dawson

Manager Information resources



CAN YOU HELP?

Our family is going on a trip to Europe and the United Kingdom later this year. We decided that despite

our usual lack of funds, it was better to go now, while I was at least partially mobile. With MS, leaving things 'til later', is not really an option.

After many phone calls and Internet hours I am still pretty lacking on info for accessible accommodation and travel overseas. NICAN only does travel in Australia. The UK MS Society referred me to an accessible holidays site that had places to stay for \$900A a night. Obviously they don't have the financially disabled in mind! Funnily enough, physical and financial disability seem to go together as everything you do when physically disabled involves more cost - and yet we have less ability to earn income (I am waiting however, for my offer of appointment as CEO to a major corporation to come through once my exceptional abilities are recognised).

I am hoping some of our readers have some info on accessible travel and accommodation overseas that they could pass on. While adverts can be quite informative, there's nothing like real experience!

Bruce Mumford, 1 Station Rd,
Burrawang, 2577

(02) 4886 4276, or
mumford@ispdr.net.au

NEWLY DIAGNOSED PROGRAM 2004

Dates for your diaries....

Newly Diagnosed Information Sessions

These sessions aim to provide you with accurate information about MS and MS Society services. They are a great way of having your questions answered, speaking with a rehabilitation specialist and outreach worker, and talking with other people who have MS and their families.

When: Saturday 28 February 2004

Time: 10:00am – 12:00pm

Where: Studdy MS Centre
Joseph Street, Lidcombe

RSVP: TEL 9646 0600 by 20/01/2004

When: Wednesday 10 March 2004

Time: 6:30 – 8:30pm

Where: Phillips MS Centre
293 Mowbray Road, Chatswood

RSVP: TEL 9411 4522 by 3/03/2004

When: Monday 22 March 2004

Time: 6:30 – 8:30pm

Where: Southern Region MS Service
Suite 1, 28-30 Urunga Parade,
Miranda

RSVP: TEL 9540 4544 by 15/03/2004

Newly Diagnosed Information Telephone Conference

These information telephone groups are offered to people newly diagnosed and living in country areas. Similar to the face-to-face sessions, the one-hour telephone conference provides an opportunity to speak with a rehabilitation specialist, an outreach worker and other people with MS.

When: Thursday 1 April 2004

Time: 7:30 - 8:30pm

Where: Telephone link-up for people
living in country areas

RSVP: TEL 9646 0600 by 15/03/2004

MS & BEYOND: Fighting Fit (Telephone Conference)

Fitness is important for general health and well being, restoring mental alertness and

reducing fatigue. The relevance of exercise in MS, guidelines for getting started, motivation techniques and ways to minimise body temperature while exercising will be explored.

When: Tuesday 9 March 2004

Time: 7:30 – 8:30pm

Where: Telephone link-up for people
living in country areas

RSVP: TEL 9646 0600 by 20/02/2004

MS & BEYOND: Tackling Fatigue

Fatigue is a common symptom of MS. The session will explore ideas for banking, budgeting and spending your energy. You will become aware of your rest needs and energy efficient ways to use your body and environment.

When: Tuesday 24 February 2004

Time: 7:00 – 9:00pm

Where: Phillips MS Centre
293 Mowbray Road, Chatswood

RSVP: TEL 9411 4522 by 21/11/2003

The Bungawalbin Wetlands

Come with me, if you care

Discover the treasures, of Bungawalbin
wetlands

It is a piece of land, oh so lush and rare
Discover the treasures of these wetlands,

Certainly it is worth a mention

With nests of broilgas hidden within

Of stopping there, I had no intention

Until something caught my eye

Just a flicker of a hawk swooping

And the sound of a heron cry

With tortured paper barks, boughs looping

So come with me, if you care

Discover the treasures, of Bungawalbin
wetlands

Copyright ©2003 Maree Martin

**Can anybody tell me where the
Bungawalbin wetlands are? Maree is not
allowed to answer.**

More poems from Maree next issue, Ed

WOULD YOU ASK THIS QUESTION

Question I am having a very hard time falling asleep and staying asleep at night. Is this a problem typical to people with MS and do you have any recommendations?

Answer Unfortunately, you are not alone with your sleep difficulties. An estimated 60% of American adults suffer from sleep disorders and the numbers are even higher for people with MS. For most, "not sleeping well" means that the time spent in bed trying to sleep is substantially greater than the total time they actually sleep.

This kind of reduced sleep efficiency often results from an increase in the number of awakenings during the night, as well as difficulty in falling asleep initially.

The following are some strategies for helping you fall asleep and stay asleep so you can get the rest you need:



- Create a bedtime routine (e.g., warm bath, reading for 15 minutes, lights out) to set the stage for falling asleep and staying asleep. Try to stick to a set bedtime each night.
- Exercise daily. It's better to do a little exercise each day than to skip days and overdo it in between.
- Experiment with relaxation techniques, such as repetitive mental exercise (e.g., counting backwards slowly from 100 or slowly repeating a mantra, like the word "ohm" or "peace"); visualization (imagining yourself in a tranquil place like the beach or woods); or progressive relaxation (mentally "putting to sleep" each part of the body, starting with the toes and progressing upwards).
- Limit your intake of caffeinated beverages, alcohol and tobacco.
- Avoid long daytime naps (try 15- to 20- minute "power naps" several times a day instead).
- If sleep is still elusive after about 10 minutes, find something quietly active

to do, like reading, writing, knitting, or puzzles to make yourself sleepy.

However, the best sleep habits and behavioral strategies will not be helpful to you if sleep disruptions are caused by physical problems such as nocturia (the need to make frequent trips to the bathroom at night), pain, sleep apnea (temporary pauses in breathing accompanied by momentary gasping or snoring), or periodic limb movements (PLMs). PLMs are more common in people with MS than in the general population. Although PLMs are often very slight movements (a flexion of the big toe, for example), they alter the quality of the person's sleep. Therefore, people with MS can have PLMs that interrupt or disturb sleep without even being aware of them.

Anxiety and depression are among the psychological symptoms that can disturb sleep.

A variety of medications and other behavioral strategies are available to manage sleep disturbances. In order to determine which interventions would be most helpful for you, it is necessary to identify the source(s) of your sleep problems. Talk to your doctor, being as specific as possible about your sleep schedule and habits.

Your sleep partner may also be able to provide valuable information about your sleep behavior during the night. The doctor may refer you to a sleep specialist (usually a physician or psychologist with specific training in this area) if the specific causes of your sleep disturbance are not readily apparent. The sleep specialist will use a variety of techniques to identify the source(s) of your problems and recommend a treatment regimen. It is important to address any sleep problems you are having because they can contribute significantly to your day-to-day fatigue.

**By Marion Brandis, MA, RN, BSN,
Clinical Services Nurse, New York
Chapter, MS Society**

http://www.nationalmssociety.org/NYN/event/event_detail.asp?e=7201

COPPING IT SWEET

Driving with MS

Driving is pretty important to me. I live by myself and can't always rely on friends to move me around. I don't do



'house-bound' easily and I enjoy getting out to shop or visit people at will.

With the progression of MS, my legs were becoming less reliable in moving about easily when and where they were asked. The probable

impact on my driving was obvious. The rest of me was and is still fairly good.

I bit the biscuit and decided to refer myself for a driving assessment.

This is not difficult, just time consuming and perhaps a little scary for someone of my age and condition. Your vehicle may then require some modification and you might need to suffer an RTA driving test.

It was recommended that I receive lessons in driving with hand controls and undergo RTA testing for a licence to drive with these modifications.

At this point my old licence was downgraded to a learners permit until completing the test.

I made several formidable trips on the bus to the driving centre for my lessons and became proficient in a dual controlled car set up with the driver's hand controls.

My driving was OK but blimey, the road rules have moved on a bit since 1965.

Over-the-shoulder checks. Use of left indicator when leaving a small roundabout. When you can cross an edge line and so on. A bewildering variety of speed limits to trick the unwary.

I failed my first RTA test. I made a fatal

error in not allowing sufficient distance between myself and a very large bus approaching at speed as I turned onto a very busy road. I had been waiting at the intersection for some time knowing that it was also bad form to delay traffic unnecessarily. It was Hobson's Choice for me but I should have waited rather than risk the fatal error.

I booked a repeat test at the earliest possible moment. This was not going to beat me. No Sir-ee! I thought feebly.

Test 2 came around and I set off marginally more confident than I had for Test 1.

Things were going well I thought and I started to feel vaguely infallible.

Then it started to rain.

Not a gentle flurry but a deluge of biblical proportion.

The windscreen quickly became unworkable.

I must have missed the lesson on coping with the Deluge. I knew I mustn't take my right hand off the brake/accelerator lever or my left hand off the steering wheel spinner knob.

How then, for pity's sake, do you turn the wipers on?

My brain engaged overdrive as I tried to work out what the correct procedure might be. The RTA was blithely jotting notes on his official clipboard, ignoring my plight. I decided, fortunately, that I should tell him I was going to pull over and stop to turn on the wipers.

I had somehow avoided sleight-of-hand and satisfied the rigorous requirements of the RTA.

There was, however, more to come!

Halfway through this ordeal I noticed that the car was trying to go faster regardless of my pressing on the brake lever.

Continued page 17

Continued from page 16

Oh! Lordy Me!

“Turn right at the next intersection please”.

Indicators. Mirror checks. Over-the-shoulder checks. Engine internally haemorrhaging. Stress levels off the scale.

This was not fair.

“I think there’s something wrong with the car” I whimpered.

“I need to pull over here Mr Clipboard ... Sir”.

Indicators. Mirror checks. Over-the-shoulder checks.

Thoughts of yet another test appointment.

We stopped safely.

He looked at me. I looked at him.

I felt helpless.

I engaged my practical brain and wondered what could be causing this nightmare.

Then, in a parting of the clouds, I realised what had happened

My very kind and helpful occupational therapist had forgotten to fold away the surplus accelerator pedal after driving me to the RTA for my test. My right foot had moved slightly during the test and was now pressing lightly on this accelerator pedal.

Mr RTA became Mr Quite Nice. He came around my side of the car to help stow the accelerator pedal.

I completed the driving test somehow without further incident.

Mr Quite Nice retreated to his bulletproof lair to consider his verdict.

After what seemed like an age he approached the counter with a totally neutral expression.

My heart sank lower.

... ‘Congratulations’

I could have kissed him! But he was safely behind his battlements.

I could have kissed my OT. She was mortified about the accelerator pedal incident and offered to drive me all the way home instead.

I was driving again and relieved not to be always thinking of my feet.

I have just completed my first annual driving re-assessment with my friends at the driving centre. This was easy and we laughed a lot about my previous visit.

I would not like anyone to suspect my RTA adventures were typical for this important course of action. I sometimes do complications in spades. This was one such occasion.

It is recommended that drivers with MS carefully monitor their driving ability, especially in unexpected situations requiring quick or unusual responses.

If you have any doubts, you should consider a driving assessment.

There are several organisations providing official assessments, recommendations and driving lessons for those with special driving needs.

The occupational therapists and the specialised driving instructors are eager to assist people with special needs to continue driving.

After various off-road tests of eyesight, speed and accuracy in comprehending traffic situations and observation of on-road physical driving abilities, you are assessed. You may be fit to continue driving with or without modification to your vehicle.

Ian Cameron

ANNOUNCING A NEW MS ADVISORY COUNCIL

Staying in close touch with the needs and interests of people living with MS and their families and carers is a vital priority of the Board of the MS Society of NSW. Although the Board gets feedback from its many sources (directors with MS and carers, management advice etc), it has recently set up the MS Advisory Council as an additional more formal consultative forum.

The MS Advisory Council is made up of both people with MS and family members, who closely fit the broad profile of people living with MS in NSW (as confirmed by the Society's 2001 census results). They will meet with the Society's Board and Management representatives up to 3 times per year.

The purpose of the MS Advisory Council is to provide the Board and Management of the MS Society with a perspective from people with MS and family members, on activities, projects and initiatives that impact on people with MS. Acting as a sounding board, it will contribute to the planning and review of Society services and other programs and issues. The Board of the Society remains the governing body of the organization.

The inaugural chair of this Council will be Jim Conway, a person with MS and an ex-director (13 years) of the MS Society. Jim is a renowned musician of both national and international recognition, and is well known to many of you. Current PwMS NSW Council representatives have been invited to sit on the MS Advisory Council, which will now absorb the advisory role that the PwMS Council in NSW has had over the years. Seven (7) of the 14 Council

members include people with MS and family members from rural NSW, ensuring a perspective on the needs of people with MS living in rural NSW.

The MS Advisory Council will hold its first meeting in March 2004 and we look forward to giving you feedback.

Paul Murnane

President, MS Society NSW

HOW TO MAKE THE MOST OF A NAP

A nap is any quiet rest period—not necessarily sleep—during daylight hours when you'd normally be awake. An occupational therapist can help you determine whether your nap schedule is helpful for your situation. Naps are helpful only if they don't interfere with your night-time sleep.

Where: a sofa, recliner, a bed (on top of, not under, the bed covers). You can even nap with your head down on a desk.

How often: one to three times per day (daylight hours), when you'd normally be active.

How long: 10–30 minutes, as often as three times per day; 1–2 hours, not more than once per day.



Helpful hints:

- Turn TV and music off or go to a quiet environment.
- Loosen tight clothes (don't put on sleepwear).
- Dim the lights; if you can't do that, face a corner or use an eye mask.
- Close curtains or blinds.
- Use light covers or sweater or jacket to avoid getting chilled or overheated.

FROM THE DESK OF

MS Busibody

The disadvantage of being wheelchair dependant is the absence, or lack of standard vertical hugs. Hug deficiency disorder is very common with wheelchair users.

Regular quality hugging rates pretty high, on the scale of well-being, second only to a good belly laugh. The traditional hug usually requires each hugger to have both feet on the ground, and at least one arm around each other's neck or torso and preferably cheek to cheek. Two or more huggers can partake, front-to-front or even front to back, but never back to back. The only hugging I can hope for is someone sitting on my knee. Or most unlikely a horizontal hug, which is by the way, off limits.

Our neighborhood New Years Eve's party raged until just after 9.30. Two spinsters, a widow, me, two jovial singing nuns and two young families all enjoyed the fireworks over the lake. Classical guitar and five young nymphs dancing Swan Lake in the moonlight entertained us.

Seeing no hugging opportunities to end 2003 I quietly wheeled back to my empty home to find my faithful life-size bear willing to accept my bear hug and eager to help me devour the rest of my chocolates.

Don't miss your chance to hug someone you know today!!

Ms Busibody ©



Mr Wisdom's Brain Gain

I hope everyone is enjoying the holidays and standing up to the heat.

Madam Editor has moved the deadline forward, so unfortunately I have received

no entries for the last Challenge **CYSTOVESTICULOGRAPHY**, so thank you to all who did it. I apologise that your names and scores are not presented.

Having mentioned holidays, I must tell you about Noddy's most recent trip to the Gold Coast. He was staying in a fancy hotel (Palace Versaise), and on the first night, just as he was getting into bed, the door burst open and a beautiful young blonde burst in.

She took one look at him and said "Sorry, wrong room!"

"Not only that," replied Noddy, but you're also 30 years too late!"

(The joke included is only a joke ... I can't afford a holiday at a Gold Coast hotel!)

Your Challenge for this issue is **PACHYDERMOPERIOSTOSIS**.

You have to be thick skinned to have a go at this.

The usual rules apply.

INDEX

- 1-3. Fatigue in Focus
- 4-5. Powered Scooters and Wheelchairs
- 6. What Insurance options are available for PWMS?
- 7-8. Young people in nursing homes
- Pages 9-12 Pull out supplement**
 - The Stem Cell Story
- 13. LIS • Can you help
- 14. Newly Diagnosed PROGRAM 2004
- 15. Would you ask this question
- 16-17. Driving with MS
- 18. Announcing a new MS advisory council • How to make the most of a nap
- 19. From The Desk of MS Busibody • Mr Wisdom's Brain Gain
- 20. Behind the Scene

behind the scene

Sadly, this will be the last time Garry and I will work together on MagScene at Chatswood office. We've worked at Lidcombe and Kent Street, but always together.

Let me reassure you that MagScene will continue to be produced by us but at "arm's length" - Garry in Nowra, me at Chatswood/Belrose.

I'm all set up in my study at home; equipped with all the latest necessary electronics, eg colour printer, scanner, laptop, fax and copier. Garry and I will be linked electronically via the MS Society. The same editorial policy will be maintained:

- *Is it informative, quotable or memorable?*
- *Is it within the framework of most readers' interest and conversation?*
- *Does it touch the individual's own concern?*
- *Is it humorous?*

For new readers, Garry, Katie Booth and I started MagScene in 1986 and since then it has continued to grow in readability, information on living with MS, and professionalism.

We are certain that there will be new hurdles to get over: I have to become computer literate and to feel confident in preparing our copy under the new regime.

As Zanna has already mentioned I will be moving into a

retirement village in Nowra at the end of February. My youngest daughter, Robyn, with 3 young boys, lives in Nowra Hill - quite close to my village which is in the centre of Nowra.

My 3 bedroom Unit in Richmond Ave, Dee Why is for sale. Ground floor, set up for wheelchair, within wheeling distance Dee Why RSL club, shopping centre and Dee Why beach. Anyone interested can contact Christian Ryals, LJ Hooker, Dee Why, tel 9971 2877.

I am still going to work on MagScene and will do so via the Internet. Both Zanna and I will be connected to the MS Society by a Virtual Private Network (VPN). With this we can use our computers anywhere. So the current Magscene team will continue including our volunteers.

We can both be contacted via email to:
magscene@msnsw.org.au

Until April, enjoy!!
Zanna and Garry

**Deadline for April/May
issue is
April 4th 2004**



MagScene

ISSN 1323-4005

Publisher: MS Society of NSW

ACN 000 320- 632

Printer: Printwarehouse

Designer: SCANDIA

For People with MS NSW, PO Box 1246

Chatswood 2057

Phone: (02) 9411 4522

Fax: (02) 9411 1742

Editor:

Zanna Barron
magscene@msnsw.org.au

Technical/Consultant:

Garry Anderson
magscene@msnsw.org.au

Proof Reader:

Wal Simmonds

DTP:

Doris Blairs
Elizabeth Way

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