

Network



Stress and MS	10
CCSVI update	12
SA medical cooling electricity rebate campaign	14
Peer support update	16
Education seminars 2011	17
A lazy person's guide to exercise	21
Introducing Maggie Beer	22
Employment Solutions	24
Acupuncture and traditional Chinese medicine in MS	26
Yoga and other mind-body therapies and MS	28
Fundraising and events	29

In this issue

CEO report.....3
 News.....4
 Stress and MS.....10
 CCSVI update.....12
 SA medical cooling electricity rebate campaign.....14
 Peer support update.....16
 Education seminars 2011.....17
 A lazy person's guide to exercise.....21
 Introducing Maggie Beer.....22
 Employment Solutions.....24
 Acupuncture and traditional Chinese medicine in MS.....26
 Yoga and other mind-body therapies and MS.....28
 Fundraising and events.....29
 Order 2011/2012 Entertainment™ Book.....35
 Locations.....36

MS Head Office
 PO Box 525, Modbury SA 5092
 P (08) 8396 0044
 Toll Free 1800 812 311
 F (08) 8396 0184
 E ms@ms.asn.au

MS Northern Territory
 PO Box 867, Nightcliff, NT 0814
 P (08) 8948 5300
 F (08) 8948 5344
 E ms.nt@bigpond.net.au

www.ms.asn.au

MS Society Privacy Policy: The MS Society of SA & NT is committed to the protection of private information. A full copy of the MS Society Privacy Policy is available by phone: 8396 0044 or online at www.ms.asn.au

Disclaimer: Material published in Network may not be reproduced in any form without permission from the MS Society. Any views expressed are not necessarily the views of the MS Society. All reasonable efforts have been taken to ensure the accuracy of any content but no responsibility can be taken for any error or error by-omission.



10



12



16



17



22



24



28



29

CEO report

14



21



26



36



Welcome to our first edition of **Network** magazine for 2011.

In this addition we have lots of information re some new and exciting services that we are in the process of developing including our new peer support program and our ever expanding education sessions. We also have some fantastic and inspiring stories from our clients including 'A lazy person's guide to exercise' on page 21 and Jayne's employment journey on page 24.

Our Keeping Cool concessions is developing momentum with an alliance of a number of disability organisations getting together to lobby government to fund these concessions. Further information including a sample letter is provided on page 15.

In February we held our annual Megaswim event which was a resounding success with over 400 swimmers participating and a staggering \$90,000 raised.

Thank you to everyone who supported and participated in the event and made it such a success. Further details are on page 29.

CCSVI (Chronic Cerebrospinal Venous Insufficiency) continues to be a hot topic and we have provided some updated information re this treatment including a story from Mark Taplin who discusses his CCSVI journey on page 13.

Under the theme of health and wellness we have a number of exciting articles including yoga and acupuncture, how to deal with stress and we are excited to have the support of Maggie Beer a highly recognised and credited chef who has created some wonderful recipes especially for **Network** on page 22.

This edition is jam packed with information and I hope that you find it both useful and informative.

James Bardsley

Chief Executive Officer
MS Society of SA & NT Inc

News

Personal training program for people with MS

The MS Society together with Tafe SA Diploma of Fitness students are looking for volunteers to take part in small group personal training programs.

The focus is on strength and endurance training which has been shown to be beneficial for people with MS. The program is likely to be run twice a week for 6–8 weeks at Regency Tafe (137 Days Road, Regency Park) utilising state of the art gym equipment. All exercises can be modified to suit a variety of mobility levels. It doesn't matter if you are a new or current exerciser. No previous experience is required.

If you are interested or would like more information please contact Margot Strelan on mstrelan@ms.asn.au or phone **(08)8360 0800**.



Australia Day Awards

Congratulations to Australian of the Year Simon McKeon.

Simon was the founding chair of MS Research Australia, and a long time advocate and champion of our cause. As a person with MS, he personified what people living with this disease can achieve and we thank him for his contributions and support.

Annual General Meeting

The MS Society of SA & NT's annual general meeting (AGM) is now locked in for Wednesday the 19th October 2011 commencing at 10:30am.

This year, as previously discussed, we will be taking the AGM to the southern suburbs and have secured the South Australian Learning Centre located at Minda Incorporated, King George Avenue, Brighton 5048 as the venue. We are in the process of putting the agenda together for the AGM and hope to have some exciting guest speakers this year.

Further information will be provided in the Winter edition of **Network**.

Consumer Participation Committee vacancy

The MS Society utilises consumer information and input to assist us in developing our strategic and service directions.

We capture this information through surveys, projects, emails and client contact. Vacancies now exist however for our People with MS Consumer Participation Committee. This committee meets on the first Tuesday of the month at our Smart Road Modbury office. The meetings are held over lunch time and usually last around an hour and a half. To date, the Consumer Participation Committee has reviewed projects and adopted recommendations, created resources, and has made general comments on the services provided by the Society. The committee is looking for people with MS who are available and interested in providing input and overseeing projects around service delivery, policy development, resource allocation, and raising an awareness of the issues facing people with MS and their carers.

If you would like to be part of the consumer participation committee, please contact Nigel Cooper (Manager Services) on **(08)8203 6600** or ncooper@ms.asn.au for further information and for a copy of the committee's terms of reference. You do not need to have committee experience to be part of the committee.



Community Solutions

Multiple Solutions (an initiative of the MS Society) is currently developing a new and exciting service for people with a disability including people with MS.

The new service will incorporate three service streams as identified in the diagram below.

These services will provide some new and exciting options for our clients and we look forward to providing you with more information about how these services can be accessed in the future.

Community Connect

Social Inclusion

Supported group activities designed to encourage participation and develop social networks for individuals within their local community. Activities and events that enhance social interactions for individuals, based on common interests.

Active Living

Providing group activities which assist individuals improve their health and wellbeing such as Movement and Fitness, Nutrition and Healthy Minds.

Skill Development

Exposure to activities such as Photography, Mechanics, and IT to develop new interests and skills.

Community Coaching

Training and/or Employment Support

Providing assistance to individuals to support their success in education and employment.

Support may include: Transport Training, Budgeting Assistance, Onsite Support and Personal Mentoring.

Behaviour Support

Guidance in interpersonal communication, understanding self and others and developing negotiation and conflict resolution skills.

Leadership Program

Providing mentoring to individuals to assist them in achieving their long term goals, and contributing to their community.

Community Care

In Home Support

Providing domestic assistance and garden maintenance services to individuals in the community.

Respite Services

Providing in home respite support to clients who are being cared for by family or household members, by giving carers a short term break from their usual support routine.

News continued

Information Services

One of the common themes that is invariably raised by clients is that you want to be able to access information that is clear, concise and timely. You have also indicated that you would like to be able to contact us more readily when you have questions or problems and be able to have access to a friendly voice.

The Society is exploring how we can best provide you with better services in this area and are planning to pilot a new program in the new financial year to achieve this aim.

Further information on this pilot program will be provided in the Winter edition of **Network**.



Regional Services

Services in regional areas are also under development and we hope to be able to commence some new and exciting pilot programs in key regional areas in the new financial year.

These programs would include providing locally based support services to enhance existing support networks for people with MS, and be able to better integrate into other local community services.

Office Locations

We are beginning to see an uptake in services offered in our new service centres across the metro area.

We now have sites across all metropolitan regions (locations are indicated on the back page of this edition).

If you are still having issues accessing our services or would like to provide any feedback on the services in your area please email: feedback@ms.asn.au.

Membership Update

Just a small reminder that at the last Annual General Meeting the Society changed the membership structure to include new membership categories.

As a client of the MS Society, membership is no longer compulsory. If you choose not to join or renew your membership you will still be able to access all of the services previously provided and receive your regular copies of Network magazine.

Membership is still a valuable way of contributing to the direction of the organisation and also has some fantastic entitlements so we encourage people to apply/renew.

If you have any questions on membership with the Society please contact our membership services at membership@ms.asn.au or call **(08) 8396 0044**.

Looking for Board Members

The MS Society of SA & NT is looking for expressions of interest from suitably qualified candidates for non-executive Board of Directors positions.

The Board comprises of ten (10) directors who are nominated from the membership of the organisation. The current vacancies will commence as casual vacancies and then be eligible for a three year appointment at the next AGM.

The Board is responsible for the strategic direction and corporate governance of the organisation in conjunction with the CEO.

An expression of interest form is available to download on the MS Society's website at www.ms.asn.au and should be completed and forwarded, with a copy of your resume to:

Executive Assistant

MS Society of SA & NT Inc
PO Box 525, Modbury SA 5092

Interested applicants should outline skills and experience in at least two of the following:

- Strategic planning;
- Interaction with government;
- Business acumen and effective networking;
- Corporate governance;
- Leadership in a service orientated environment;
- Knowledge and/or experience within the disability and not for profit sectors;
- Fundraising and not for profit marketing



Please note Board positions are not remunerated.

Please contact the Executive Assistant for further information.

Telephone **(08) 8396 0044** or email jcasey@ms.asn.au

National Disability Insurance Scheme

In June 2009 the Federal Government commissioned a report by the Productivity Commission into a long-term disability care and support scheme.

Amongst other things, the Productivity Commission has examined:

- how a scheme should be designed and funded to better meet the long-term needs of people with disability, their families and carers
- how to determine those people most in need of support, the services that should be available to them, and service delivery arrangements
- the costs, benefits, feasibility and funding options of alternative schemes

- how the scheme will interact with the health, aged care, informal care, income support and injury insurance systems
- its impacts on the workforce
- how any scheme should be introduced and governed
- what protections and safeguards should be part of the scheme.

In February 2011 the Productivity Commissioner released a draft report into this review, which identified and recommended a significant overhaul of the disability sector.

The Society welcomes any review of the existing disability services system and the findings of the report are being reviewed and a submission is being prepared by the Society to government.

The Society would welcome any feedback you have around this matter so please email feedback@ms.asn.au if you have any comments.

Information and copies of this report including detail re public hearings can be found at:

<http://www.pc.gov.au/projects/inquiry/disability-support>

News continued

Report from the south/east

The MS Society recently completed a review of our services and looked at the areas where people with MS live. This has formed part of our decentralisation program and has seen the development of new service offices across the metropolitan area.

In looking at regional areas, the Society is attempting to strengthen our relationship with local health and community services. An example of this relationship is our work in Naracoorte with the local physiotherapy clinic. The Society supported the Clinic in accessing a grant from the Department of Recreation and Sports' Inclusive Recreation Inclusive Sport program. The Clinic has now, with the help of the Naracoorte MS Auxiliary and the local Rotary Club, purchased a Motomed to assist people with MS in exercising. Research clearly shows the benefits of exercise on general health and wellbeing. The MS Society appreciates the support of local service clubs and especially the commitment and dedication of our volunteers (Naracoorte Auxiliary) who are determined to make a difference for people with MS.



Repatriation Rehabilitation Service

Rehabilitation is a fantastic way to improve your overall health and general conditioning. It ensures that you feel and function at your best in both the home and work settings. Attending rehabilitation doesn't always mean staying in hospital – in fact it is commonly provided via out-patient services at various facilities.

An expert MS Rehabilitation Assessment Service exists at the Repatriation General Hospital, which includes a rehab physician, physiotherapist, MS nurse, continence nurse, speech therapist and dietician, just to name a few services.

If you feel that a general overview of your health and wellbeing in relation to your MS would be helpful or if you have any specific issues that you would like addressed by any of these specialties, the MS Assessment Clinic at the Repatriation General Hospital is available for you to access. A GP referral is all that is required. Alternatively, contact one of the MS Society client services staff on **(08) 8396 0044**.

Direct enquiries can also be made to:

Sharon Barlow
MS Clinical Practice Consultant
on **(08) 8204 6611** or via email:
sharon.barlow@health.sa.gov.au

If you would like to learn more about what is involved with MS Rehabilitation and its benefits, come along to the seminar on Friday, 3rd June from 10am–1pm at the Payneham Library Complex. RSVP's to this seminar can be made on **(08) 8396 0044** or email: **educationseminar@ms.asn.au**

Multiple Sclerosis rehabilitation research at Flinders University and the Repatriation General Hospital

We have 2 exciting research projects investigating:

Fatigue, Balance, Falls and Mobility in MS

The Effect of Functional Electrical Stimulation on Mobility and Fatigue in MS

We are looking to recruit people diagnosed with MS who:

- Have problems when walking due to fatigue
- Experience drop foot when walking

For more information or to register your interest in participating in any of these trials, contact:

James McLoughlin
James.McLoughlin@health.sa.gov.au

Chris Barr
Chris.Barr@health.sa.gov.au

Or call the South Australian Movement Analysis Centre
(08) 8275 2852

MS Medications Snap Shot

The landscape of managing and treating MS is continually changing. New medications, theories and treatments are appearing on a regular basis as our understanding of the disease improves. In 1996 – 2001 we saw the release of the first Immunomodulatory therapies Betaferon, Avonex, Copaxone and Rebif. These were considered ground breaking in their approach to treating MS and assisting in the reduction of relapses for people with Relapsing Remitting MS. These medications are still considered effective and form the basis of MS treatments.

In 2007 an infusible therapy Tysabri was approved for treatment and once again demonstrated a reduction in relapse rates.

Now in 2011 we have 2 oral therapies Movectro and Gilenya, which have been approved by the Therapeutic Goods Administration (TGA). Currently they are not available on the PBS but this may change in the near future. These treatments are indicated for people with Relapsing Remitting MS, and as with other treatments for MS they can only be prescribed by a Neurologist.

Movectro acts by reducing Lymphocytes in the immune system and reduces inflammation in the nervous system. It is a short course treatment with long lasting effects.

Gilenya appears to prevent some potentially damaging T cells (types of white blood cells called T-lymphocytes) from leaving the lymph nodes. The result is that there are fewer T cells travelling into the central nervous system (CNS – the brain and spinal cord) to attack the myelin sheath. Gilenya is taken daily.

Both of these medications require preliminary health checks and screening, which are fairly standard.

The MS Society welcomes new therapies, which give people choice and alternatives. We cannot recommend any particular treatment, and suggest given the diversity of current treatments that consultation with your Neurologist is worthwhile. For further information visit the MS Society Website.



Stress and MS

Living with multiple sclerosis can be distressing, but evidence shows that alleviating stress has surprising benefits for people with MS, reports Alexandra Clarke.

A diagnosis of MS can add unforeseen stress to your life, but who would have thought that facing life's everyday challenges could also make living with MS more difficult? Research has shown that stressful life events such as illness, death, job stress, minor surgery, relationship problems and even going on holiday, can trigger MS exacerbations. In one study it was shown that just one stressful event over a four-week period doubled the likelihood of an exacerbation. The good news is that research also shows that minimising the impact of day-to-day and ongoing stress may delay or prevent an episode.

Stress is the strain we feel with a change in circumstance that causes us physical pain and emotional tension. It has been shown that chronic stress (experienced over a long period of time) is most taxing on the immune system.

'Research has shown stress can trigger MS exacerbations.' For people with MS both acute and chronic stress can be an issue.

'Uncertainty is one of the biggest predictors of stress and anxiety in people generally,' says Megan Varlow, Clinical and Health Psychologist for MS Australia (ACT/NSW/VIC).

'So, living with a disease that's unpredictable just increases the chance that you're going to feel stressed and anxious.'

Understanding that stress can be self-perpetuating will help you identify where it starts and how to avoid falling into the stress cycle. 'What happens is you're stressed by something, then you start to anticipate something else is going to be stressful,' Varlow says. 'So the stress tends to feed off itself.'

This is true for all people, and those with MS have more reason to be stressed. Regular injections, having to visit your doctor more frequently, having an MRI scan, or any of the medical interventions associated with MS can create added stress.

Taking a random approach to stress relief isn't going to work here. You need to try to manage the triggers and recognise things that make you feel stressed.

'A lot of stress management programs talk about stress like it's a 'boogie man'— something that you can't really see,' Varlow says. Making the stress tangible, however, is key to combating it. 'You need to identify the causes of stress, then act on them,' she says. 'It could be that you're worried about the uncertainty related to the disease; telling your employers that you have MS, or you might have a needle phobia.'

Once identified, stress can be tackled. For instance, if you're struggling with the decision to tell the people at work, getting advice from a lawyer on your options will give you practical strategies. The same goes for injections, or decisions about your medical choices. You may need to see an MS clinical nurse, or a counselor. Just talking to a nurse can help, because you realise you're not alone.

'When you feel stressed, your heart rate and breathing increases. Then you get muscle tension' Varlow says. 'So it's important that you do something to reduce the physical response and the possible consequences that come with it.'

That's where psychologists and counselors can help. They can teach you different stress management strategies. Breathing techniques, relaxation exercises, and mindfulness meditation, can all help control your body's response to stress.

When we're feeling stressed, we tend to think that the problem is bigger than it actually is. Try to identify negative thinking, and challenge yourself to think in a more constructive way. Instead of saying: 'This is terrible; I can't cope,' you might say: 'This is really difficult; I will take it one step at a time.'

'So, living with a disease that's unpredictable just increases the chance that you're going to feel stressed and anxious.'

A sense of humour is also beneficial. If you can see the funny side of something that's bothering you, it can help you to think about it in a different way. Making a joke about something unrelated, or laughing when the chips are down, can help change your mood and your focus.

You can't totally remove all stress. After all life goes on, but if you're able to reduce your own physical level of stress, you will feel better, and those around you will as well. This is particularly true when dealing with children. According to Varlow it's normal to get frustrated and stressed with your children, and think 'I can't cope with this. They're too fast for me and it's only going to get worse'. She cites the case of a young mum whose balance was affected by MS, making it difficult for her to keep up with her small children. With practice, she'd take a couple of deep breaths before she did anything, and remind herself: 'It's not a disaster. This is something I can cope with; I am not a terrible mother.'

The breathing gave her the space in her head to be able to change her thinking, and then her behaviour.

Ways to ease the stress

Putting MS in perspective can help you regain a sense of power, says Registered Nurse and MS Society Counselor, Pamela Klaer.

Being fit improves your mood, sleep pattern and general coping skills. Klaer recommends finding an MS Society physiotherapist in your state to help with your exercise regime.

Find a counselor you can trust, and keep talking. 'Just sitting with people and letting them talk about things they don't want to worry their families with, helps contain their worries' she says.

Keep a diary 'Often people will do this in conjunction with their medication,' says Klaer, 'but I suggest people also write down what they're feeling on a

day-to-day basis, because when they're feeling better, it's useful to look back on difficult times and say, 'Yeah, I remember I felt like that then, but I got through it'.

Klaer says it helps her clients to make more sense of their condition if they imagine their life as a coffee cup and MS as a tennis ball.

'When you're diagnosed with MS the tennis ball fills the whole coffee cup. Every waking moment is consumed with the thought of MS,' she says. 'But as time goes by, you're managing your medication, you're feeling better and not talking about it as much.' The MS hasn't gone anywhere, but people probably think it has, because your life gets bigger around it. It's your life that changes, not your MS.

Reprinted with permission from Bayer Health Care



CCSVI update

Chronic Cerebrospinal Venous Insufficiency (CCSVI) continues to be an area of major interest for people with MS, the MS Society and medical experts around the world. A clinical trial has now been funded in Australia, supported by MS Research Australia (MSRA) at the Austin Hospital. Associate Professor Brian Chambers, the lead researcher, is looking for suitable volunteers as well as age matched, same sex, controls. If you are interested in volunteering, or have further questions about this project, contact Heather Cameron, Research Nurse, by email heth_cam@tpg.com.au



The funding of clinical trials is great news for CCSVI. These trials are essential in gathering much needed clinical evidence on the role CCSVI has in MS and the subsequent treatment recommendations. As many people with MS would be aware, treating CCSVI has worked extremely well in some people and had limited effect in others. The reason for this is not yet clear. Evidence gained from this and other trials will help inform the MS community on whether treating CCSVI should become a recognised and suggested treatment option.

The MS Society is open to any treatment that is proven to have a positive effect on the MS disease process and the quality of life for people with MS. It is fair to say that there are some doubts around the world on the role CCSVI plays in the MS disease course, but clinical research will address this one way or the other. It is important however that these trials occur quickly and results published promptly, to meet the huge interest within the MS community.

The MS community has spoken clearly and loudly on their interest in CCSVI and the need for treatment and further research. This momentum has certainly had an impact on the research world and is accelerating the need for these trials. Considering medication development and subsequent trials take many years, the response to CCSVI research is a clear indicator that people with MS do have a voice, and that this voice is heard.



There is no doubt that CCSVI research has been accelerated with trials happening in the US and Europe as well.

In line with keeping people informed, MS Australia supported a public forum on CCSVI in Melbourne on the 2nd April. The forum was held at the Blackburn office of the MS Society and streamed to locations in Sydney and Canberra. We hope to have access to the forum on our website shortly.

In other news, Kenneth Mandato, M.D., an interventional radiologist at Albany Medical Centre in Albany, N.Y. has commented on a retrospective study involving 231 patients. These patients all had MS and underwent treatment of the Internal Jugular and Azygos veins with or without placement of a stent (a tiny mesh tube).

Dr Mandato commented that 'our results show that such treatment is safe when performed in the hospital or on an outpatient basis – with 97% treated without incident. Our study, while not specifically evaluating the outcomes of this endovascular treatment, has shown that it can be safely performed, with only a minimal risk of significant complication.'

Personal View Point on CCSVI by Mark Taplin

I have had MS for about 10 years, and have had a family history of MS, and autoimmune diseases. I am currently trialing the medication FTY-720, and became aware of Dr Zamboni and his procedure of CCSVI. As a candidate for the Save the RAH political party, I met a Doctor who had access to an ultrasound, and out of interest, I had my jugular veins scanned. It found I had a virtually flat right vein, so I then researched Australia for someone who could give a high definition Doppler ultrasound that would measure blood flows in my brain.

I came up with a Dr in Newcastle, and his diagnosis showed stenosis (blockage) of both jugulars, the right one only working at 8%, and the left, 21% of average. He referred me to St Vincents in Sydney, where I was lucky to be the last person to have the CCSVI operation done. The simple outpatient procedure opened up the veins, by balloon angioplasty, to allow normal blood flows to occur in my brain. A follow up scan showed my cerebral flow increased from 555 ml/minute to 1410.

Within 10 days my dropfoot, fatigue, and brain fog all but disappeared. Now 6 weeks on, I still feel improvement happening. My neurological tests at the QEH show my EDSS disability score has dropped from 3 to 2.

I do not believe this is the cure for MS, but the symptomatic improvement cannot be denied. The sad thing about it all is that the hospitals have had to stop this treatment, because this is deemed 'experimental'.

I have become very active with CCSVI Australia facebook, a forum for people with MS online and I am working closely with the medical profession on my personal experience with MS and CCSVI. There are so many issues to deal with, such as, are MS symptoms a result of vascular disorder or neurological?

The S.A. MS Society has sponsored me to attend a conference in Melbourne, where Dr Zamboni is the guest. MSA is convening a meeting of MS Research Australia, people with MS, surgeons, radiographers, and CCSVI patients to work through the issues and perceived barriers. Maybe CCSVI will become a standard Medicare procedure in the future? I would like to think so.

We will post the results of that meeting on our website, but in the meantime, please contact me if you would like to know more.

Mark Taplin
0438 542 858

SA medical cooling electricity rebate campaign



Tips for writing letters to your local MP

Now is the perfect time to write to your local MP in regard to our cooling concession rebate campaign. The MS Society is lobbying hard and working with the South Australian Government to introduce a rebate for people who need to keep cool during summer for health reasons. MS is a perfect example of this. Below are some helpful hints to assist you in writing your letter. When we all work together we can make a difference!

As someone with a medical need to keep cool, or as a person caring for someone with a medical need to keep cool, you can have a lot of political impact through the simple act of writing a letter to your local political representative.

The most effective communications with your local Member or relevant Minister should:

1. Be as short and to the point as possible.
2. State the problem clearly (best to address just one problem at a time).
3. End the letter with a something like: 'I look forward to hearing back from you soon' – it is important that you make it clear that you expect them to respond. You don't have to cover all of these points, but some things you might want to address in your letter are:

- Explain what happens to you if you get too hot, why this happens and what you have to do to keep cool. Examples of what happens to your electricity bills in the summer with actual dollar amounts can help them understand. Do you have problems when the outside temperature is 25°, 30°, or 35°C? What about humidity? Do you just live in the room with the air conditioner when it is hot outside?
- Make sure they understand that this is not just about your 'comfort' – it is about being able to function and to have a life. How does it affect your life, family, and/or work if you can't keep cool?
- Tell them how some additional financial help is really needed to help you pay for the running costs of your air conditioner in the summer. If they have some idea of how much it costs you to run your air conditioner, or how much you need to run it, this would help them to understand that some substantial assistance is required.

If you would like some help in writing letters or would like more information on the cooling campaign, contact David Winderlich on **0408 984 980** or email **keepingcool@msaustralia.org.au**

An example of a letter/email

Address details

Date

Subject: *Electricity Rebate for medical needs*

Dear Minister,

I am writing to you to ask for your help in considering a review of the State's Electricity Concession.

I am a 51 year old person with Multiple Sclerosis. My MS is Primary Progressive, which means it just progressively gets worse with no remission. I am in a wheelchair and suffer very painful muscle spasms and fatigue that increase during summer due to the heat and humidity. I do not leave home unless I know where I'm going has air conditioning. We must have ours on a lot even after bed time so I can get a decent rest.

People with MS need air conditioning not just for comfort but to be able to function. My husband is also my Carer and when I'm hot and bothered, it makes his job looking after me a lot harder to do. Anything from transferring me in and out of the wheelchair to dressing me.

This summer we have had to use the air conditioner as early as 1st October. That same week, I heard that Electricity Charges were going to be increased. We now will be paying more, and there is talk of paying more still to make the country greener.

Please consider an allowance to MS people on the basis of their medical condition, such as allowed for dialysis patients. Not all MS patients would be eligible as I wouldn't have 20 years ago. Now it is an essential medical support for maintaining my health. I simply cannot cope physically without the air conditioning.

I do hope you can be of assistance and look forward to hearing your views on this matter.

If you would like any additional information, on me or my circumstances, please contact me on xxxx xxxx, via email (address above), or even via old fashioned 'snail mail' (address above).

Yours faithfully,

Signature

Name

Peer support update

The MS Society's Peer Support program is well underway. Evidence clearly shows the benefits of peer support programs and our members and clients have been keen for their development. Several groups in the metropolitan area have started, with several others still in the planning phase.

What is a Peer Support Group?

A Peer Support Group is a gathering of people with MS. The purpose of the group is to provide support to each other and to share information by:

- Learning more about MS
- Sharing feelings and experiences
- Obtaining accurate information
- Providing an opportunity to talk through problems or choices being faced
- Listening to others who share similar feelings and experiences
- Helping others through the sharing of ideas and information
- Knowing they are not alone.

If you'd like to attend any of the groups below, or start another group, please give me (Katherine) a call. There are people on waiting lists that are unable to attend the times below and would love to join a more convenient group.



All groups are free or at minimal cost. I'd love to hear from people in the Eastern or Northern areas of Adelaide who would like to be involved in a group. We have had initial meetings in these areas but we need more members to keep the groups going and to provide more support to people with MS in these areas.

I will be focussing on regional groups later in 2011. This will include visits to outer regions, but more detail will follow in the coming months.

I am currently trying to establish interest for a young people with MS support group in Adelaide. If you are under 30 years of age and would like to meet other young people with MS,

I'd like to arrange a gathering in 2011. This is likely to be an informal meal at a cafe. Please contact me to register your interest – it'd be great to hear from you.

Also if you're interested in becoming a Peer Leader or if you have been recently diagnosed with MS and are interested in gaining group or one on one support, please contact me for more information.

If you have any questions, would like to join a group or volunteer your time to support others or promote community knowledge about Multiple Sclerosis, please contact me on **(08) 8203 6600** or **0433 534 482** or email **kathrinec@ms.asn.au**

Current group meetings

Gawler	2nd Monday of each month	10am–12pm	Gawler Neighbourhood House
Adelaide Hills	3rd Wednesday of each month	11am–1pm	Stirling Coventry Library
Inner South	1st Monday of each month	10am–12pm	Glandore Community Centre
Western	1st Monday of each month	6pm–8pm	Rotated at group member's houses

Education seminars 2011

I am excited to include the remaining education seminars and workshops for the rest of 2011 in this edition of Network. The education series are designed to help promote and maintain health and wellbeing as well as to provide the latest MS information and research available to people with MS, their families and friends.

We hope to make some of these seminars available via our website in the near future so that those clients located rurally can also hear the expert information provided.

Due to unforeseen circumstances, the 'Nutrition & Lifestyle' Seminar with Professor Peter Clifton has had to be rescheduled. This seminar will now occur on the 17th of September 2011 and will also include Neurologist, Dr Mark Slee, as an additional guest speaker to discuss recent research and treatments in MS.

For those people who have provided their RSVP for this seminar, your name will automatically be added to the rescheduled seminar list and you will be contacted regarding confirmation of this date.

Confirmation letters for all seminars and workshops are provided approximately one week in advance of the event. If you do not receive this letter/email confirmation for a session you had planned to attend, please notify the office on **(08) 8396 0044** before the relevant date.

I hope that you find various topics in the program for 2011 of interest. I look forward to meeting many of you soon!

Any future suggestions for topics can be emailed to **educationseminar@ms.asn.au** for consideration in next year's education series.

Warm Regards
Emma Christian
 MS Nurse/Education Coordinator

Managing an MS bladder PLUS 'Rehabilitation' – What's it all about?

Friday 3rd June, 10am–1pm
 (morning tea provided)

This seminar will provide you with great information about a couple of different topics. Firstly, how MS can affect the bladder and the various treatment options available. Dr Samantha Pillay, an Adelaide-based urologist, has a wealth of experience in this area and will provide her expert knowledge in this forum about the bladder and how best to manage any issues. There will also be an opportunity to ask questions.

Rosalie Donhardt, a continence nurse from the Continence Resource Centre, will discuss topics such as what practical support is available for people with continence issues, products, and how to access funding support.

Finally, the topic of 'Rehabilitation' will also be discussed in this seminar as it is an education and treatment approach that is designed to promote good health and general conditioning, one of great value in MS. Rehabilitation can help reduce fatigue, assist with mobility problems and personal care, overall fitness, and even thinking and memory. Rehabilitation ensures that you feel and function at your best, both at home and work.

Dr Kirrily Holton, a rehabilitation doctor, will present the benefits and goals of rehabilitation, the different types available and how and when to access it if required. Come along to this informative seminar and enhance your knowledge on ways to manage MS.

Where: Payneham Library Complex and Community Facilities, 2 Turner Street, Felixstow (corner O.G. Road)

RSVP: Monday 2nd May
 Ph. **(08) 8396 0044** or email:
educationseminar@ms.asn.au

Cost: \$5 per person

Fatigue Management Course

6 consecutive weeks from Friday 29th July until 2nd September, 10am–12pm

Fatigue is a major issue for many people with MS. This course covers various strategies and techniques to help minimise and manage fatigue utilising work simplification and energy conservation principles.

Where: MS Society, 31–33 Smart Road, Modbury

RSVP: Monday 25th July
 Ph. **(08) 8396 0044** or email:
educationseminar@ms.asn.au

Cost: \$20 for 6 sessions

Education seminars 2011 continued

Newly Diagnosed Seminar

Tuesday 2nd August, 6:30-8:30pm

Have you, or someone close to you been diagnosed with MS in the last 12 months? Then this evening is for you.

Come along for a relaxed evening of open discussion and have the opportunity to ask your own questions of the experts. Topics covered include:

- An overview of MS, latest research and treatments by neurologist, Dr Andrew Lee and neuro-ophthalmologist, Dr Celia Chen
- A Physiotherapist talking about the importance of fitness and exercise with MS
- A Multiple Solutions Employment Consultant discussing your rights with regard to employment, disclosure issues and available workplace support.

Where: The Box Factory, 59 Regent Street South, Adelaide City (street parking available in Halifax and Carrington Streets)

RSVP: Monday 25th July
Ph. **(08) 8396 0044** or email:
educationseminar@ms.asn.au

Cost: Free

Latest MS Research & Treatments, Nutrition & Lifestyle Seminar

(NB: this seminar replaces the previously advertised 'Nutrition & Lifestyle' Seminar)

Saturday 17th September, 9:30am-12:30pm

(tea, coffee & biscuits provided)

Join us for a fantastic morning of information and inspiration with three guest speakers: Dr Mark Slee, Professor Peter Clifton and Mr Nigel Cooper.

Dr Slee is a neurologist who practices at Flinders Medical Centre where he heads the MS Clinic. He will be discussing the latest research, evidence & treatments in MS, including oral medications, CCSVI and stem cells.

Professor Clifton is the laboratory head of Nutritional Interventions at Baker IDI Heart and Diabetes Institute and is a co-author of The CSIRO Total Wellbeing Diet books, which provide scientifically tested and nutritionally balanced ways of achieving a long-term healthy eating plan. Peter is also Professor of Medicine at the University of Adelaide and practises as an endocrinologist at the Royal Adelaide Hospital and Flinders Medical Centre. Peter is widely published in the areas of diet, functional foods and heart health and a frequent and sought-after speaker at national and international conferences.

Finally, Nigel Cooper, Registered Nurse and Manager of Services at the MS Society of SA & NT will be presenting an update on 'hot off the press' information from an international MS conference in Montreal, Canada at the start of June. He will also be discussing 'lifestyle choices with MS' and how to make positive decisions and treatment choices in the context of future directions of MS research. Tips that help to maintain motivation for a healthy lifestyle will also inspire you to make changes and stick to it!

Where: The Venue at Richmond, Sturt Pea Function Room, West Adelaide Football Club, 57 Milner Road, Richmond

RSVP: Wednesday 17th August
Ph. **(08) 8396 0044** or email:
educationseminar@ms.asn.au

Cost: \$5 per person

'Let's Talk Fitness'

Tuesday 18th October, 6:30-8:30pm

Research shows that maintaining even a simple exercise program improves overall health and wellbeing. Need some ideas and motivation?

Join us for an action-packed evening with the Physiotherapist Team. Topics that will be discussed include:

- The importance of keeping fit and how it benefits your MS
- Types of exercise such as aerobic, weight training, water exercises, yoga and pilates



- How to choose the right exercise program
- How to keep cool and avoid dehydration
- When and how do I find time to exercise in the business of life?
- PLUS a live demonstration of various low impact exercises you can do from your own home

Where: MS Society Elizabeth South Office, Unit 6, 183 Phillip Highway, Elizabeth South

RSVP: Tuesday 11th October
Ph. **(08) 8396 0044** or email:
educationseminar@ms.asn.au

Cost: \$5 per person

Fitness Workshop Series

3 consecutive Tuesdays 25th October, 1st & 8th November, 7pm–8pm

The Fitness Workshop Series follows on from the popular 'Let's Talk Fitness' Seminar. The importance of developing and maintaining an exercise program is well-established in research literature. This set of 3 workshops will be practical in nature and based on a different form of exercise each week. You will be exposed to a wide variety of ways to continue your own fitness sessions from home. Standing and seated options will be provided.

Week 1 Therabands/Strength Exercises

Week 2 Yoga & Tai Chi Exercises

Week 3 Combination of Exercises including a Wii Fit Demonstration

Attendance at the 'Let's Talk Fitness' seminar is not required before participating in classes, however class sizes are limited, so be quick to secure your place.

Where: MS Society Elizabeth South Office, Unit 6, 183 Phillip Highway, Elizabeth South

RSVP: Friday 7th October
Ph. **(08) 8396 0044** or email:
educationseminar@ms.asn.au

Cost: \$15 per person (for series)

Education seminars 2011 continued

'Come & try water exercise'

**Monday 14th & 21st November,
7pm–8pm**

If you have an interest in swimming (or even if you don't!) these two practical classes are a great opportunity to explore and reap the benefits of exercising in water. Come along and try these classes to gain insight into the power of water exercise and swimming for fitness. For those who are lacking in motivation to start their water exercise regime for summer, these classes are for you...don't forget your bathers! Limited number of places available.

Week 1 Water exercise class

Week 2 'Swim for Fitness'

Where: MS Society pool venue,
274 North East Road, Klemzig

RSVP: Tuesday 1st November
Ph. **(08) 8396 0044** or email:
educationseminar@ms.asn.au

Cost: \$5 per person

'Make a Change' – Lifestyle Planning Workshop

**Wednesday 28th September,
10am–12pm**

**Follow up session:
Wednesday 26th October,
10am–12pm**

Do you need some help and motivation with keeping on track with your personal goals? The reality of life can often mean that we put off making good lifestyle choices, even when we know a change would improve our overall health and wellbeing. Having some guidance from an expert can be of great value. Whether it is starting an exercise regime, losing weight or reducing stress levels, this small practical workshop will help you to identify and achieve a personal lifestyle goal. Our social worker, Kathrine Cock, will provide you with the motivational tools, advice and support to design your own health plan to reach an individual goal. As a result, you will leave the workshop feeling motivated and encouraged to implement change in your life!

Where: MS Society,
31–33 Smart Road, Modbury

RSVP: Wednesday 21st Sept
Ph. **(08) 8203 6600** or email:
educationseminar@ms.asn.au

Cost: \$5 per person

Moving towards Wellness

This is a Chronic Condition Self-Management course which is run by the Arthritis Foundation of South Australia but open to anyone living with a long-term condition, including MS. The program is conducted once a week for 2.5 hours per week for 6 consecutive weeks. An MS specific module is available on a 7th week at the end of the 6 week course. Upcoming courses are as follows:

- Friday 6th May – Friday
10th June, 10am–12:30pm** at the Gawler Hospital Day Centre, Gawler Health Service, Hutchinson Road, Gawler East
- Saturday 30th July – Saturday
3rd September, 10am–12:30pm** at The Arthritis Foundation, 118 Richmond Road, Marlestone

Cost for this course is \$80 per person for all sessions (\$10 per accompanying person).

For further information and registration, please call **(08) 8396 0044** or email **educationseminar@ms.asn.au**

RSVP: Monday 25th April and Monday 18th July respectively

Contact details

The Multiple Sclerosis Society of South Australia & Northern Territory Inc.
31–33 Smart Road Modbury
PO Box 525 Modbury SA 5092
P **(08) 8203 6600**
F **(08) 8203 6699**
Toll Free **1800 812 311**
Email **ms@ms.asn.au**
Web **www.ms.asn.au**

A lazy person's guide to exercise

My name is Karen Dawe. I have had MS for over 11 years. I get tired easily, dislike the heat, have wobbly legs and walk with a distinct limp. When I get too hot or too tired my speech becomes slurred and I can hardly hold myself up, let alone walk.

I have a dip in my sofa from where I sit too much and a fat dog in the garden begging for walks. By my own admission I am the laziest person when it comes to exercise. I hate it with a passion!

It took me 6 years after being diagnosed to start exercising. I had every excuse but my main one was 'I've got MS! How could I possibly exercise and do what others do?' My head was dominated by negative thoughts that made me fear my MS and how others would treat me if they found out.

When I was first diagnosed I attended a newly diagnosed session then didn't return to the MS Society for 6 years. A great social worker from the MS Society helped me reconnect and 'tricked' me into starting an exercise program for 'research purposes'. This was my first introduction to whole body vibration therapy and much to my surprise I am still going 5 years later. I have a session once a week where I stand on a noisy, vibrating platform and do strengthening and stretching exercises. Pleasant but nagging voices from the physio team demand that I 'pull in my stomach', 'keep my chest up', 'keep my elbows in' and 'keep breathing'. They have trained me so well that every time I see one of them I automatically pull my shoulders back and brace my tummy muscles.

After I use this machine I feel exhausted but once I rest I feel very energised. After a few days the muscle soreness starts but this tells me I worked hard!

I have never been able to set aside time at home to exercise (I have 4 children and 2 still live at home) so I try and incorporate simple exercises into my every day activities. Eg. When I'm standing at the sink to wash the dishes I do calf raises and lunges. I bend forwards when I'm sitting on the toilet to stretch my back (being careful not to fall off). I brush my teeth and stretch the backs of my legs at the same time. I do bicep curls with my full shopping bags at the shops. I only hold onto solid things because of my balance. Even when I broke 2 toes (I rolled over my foot whilst sitting on a computer chair) I still exercised when I could.

'I have a dip in my sofa from where I sit too much and a fat dog in the garden begging for walks.'

As a result of regular exercise I have noticed that the strength & balance in my legs and around my feet has improved. This has meant that I can actually wear feminine slip on shoes (ballet slippers) instead of lace up sneakers! I have also lost 10cm around my waist. As well as lazy I am also vain so this was great! I think eating healthy helped – I have also eaten fairly healthily but I do try to incorporate more fruit and vegetables into my diet and avoid junk food when I can.



Not so long ago I realised I needed good trunk control and arm strength to continue driving my car with hand controls. I started 'pumping iron'. Well, using little hand weights. Initially I started with 0.5 kg and only 5 repetitions, now I lift 1.5 kg weights and complete 20 repetitions with each exercise. Recently I have started with 2kg weights and hold them over my head for much longer periods than I ever imagined. My arms don't hurt anymore when I drive and the wobbly bits are less wobbly!

A lot of things have changed because of MS but I am still the same person inside. I have learnt to take responsibility for my own health and realise that a change in attitude has helped me the most. It has taken me many years to learn that if I am persistent and patient, change will happen (but not overnight!). I don't like to fail so I start with small goals that I can achieve and then gradually increase my goals over time. Finally, I realise that I could not have done it on my own. Working with those at the MS Society who understand my MS has been crucial to understanding my body and overcoming my limitations.

By Karen Dawe

Introducing Maggie Beer

The MS Society of SA and NT is excited to welcome Maggie Beer to our magazine. As all South Australians (and most of Australia) would know, Maggie is a highly recognised and credited chef. Last year she appeared on Master Chef, and we are pleased that she has agreed to support the MS Society and people with MS. Below is a recipe that Maggie has created especially for our clients. For this edition, Maggie has chosen crisp skin salmon with pea salsa, with a beautiful accompaniment of broccoli with almonds and lemon butter. Please try the recipe out, and let us know what you think!

Crisp-skin Salmon with Pea Salsa

Serves 4

This is definitely my idea of fast food. I keep salmon fillets with the skin-on wrapped separately in the freezer for those days when I've not organised anything for dinner in advance. The fat content in salmon means it freezes well – I've even roasted it in the oven straight from the freezer if I've forgotten to take it out to thaw. Of course, you need to use super-fresh fillets which you are sure haven't already been frozen to start with so that they still taste fresh after thawing. Given my hectic schedule these days, there are times when Colin and I will eat this for dinner at least once, if not more, every week.

For a quick mid-week meal, I often do nothing more than pan-fry salmon fillets, skin side-down and with a good dose of sea salt, until almost cooked, then serve it with a drizzle of extra virgin olive oil, squeeze of lemon juice or splash of verjuice and a grinding of freshly ground black pepper, with zucchini freshly picked from my garden during summer or a salad at any time of the year (I just vary the leaves depending on what is in season).

The pea salsa is another one of those fantastic kitchen standbys I can prepare at the drop of a hat when I haven't planned on making anything else.

4 × 140 g salmon steaks, skin-on
sea salt
extra virgin olive oil, for drizzling
10 g unsalted butter
juice of 1 lemon
chervil sprigs and lemon wedges,
to serve

Frozen Pea Salsa

30 g unsalted butter
extra virgin olive oil, for cooking
2 golden shallots, finely chopped
¾ cup chicken stock
1 ½ cups frozen peas
1 sprig chervil
sea salt and freshly ground black
pepper

For the frozen pea salsa, melt butter in a frying pan with a little olive oil over medium heat, then add the shallots and sauté for 10 minutes or until translucent.

Meanwhile, bring chicken stock to the boil in another saucepan. Add peas and chervil to the shallots, then, when the peas have thawed, add the hot chicken stock and bring to the boil.

Remove from the heat and leave to cool slightly. Purée the pea mixture in a blender (or use a mouli if you have one), then season with salt and pepper if you like.

'Given my hectic schedule these days, there are times when Colin and I will eat this for dinner at least once, if not more, every week.'

Heat a large frying pan over medium heat. Season the skin-sides of the salmon steaks with salt. Add a splash of olive oil to the hot pan, then cook the salmon steaks, skin-sides down, for 2 minutes or until the skin is crisp and you can see from the side that they are cooked at least halfway through.

Season the other side of the fish with salt, then quickly wipe the pan with paper towel, drop in the butter, and, when melted, gently turn the salmon over, using either a palette knife or spatula. Immediately remove the pan from the heat, then leave salmon steaks to sit in the hot pan for 5 minutes. The centre of the fish should be just set or a little rare.

Place a salmon steak on each plate, then top each with a spoonful of pea salsa. Squeeze over the lemon juice, sprinkle with chervil and drizzle with a little olive oil, then serve with lemon wedges to the side.

Broccoli with Almonds and lemon Butter

Serves 4 as an Accompaniment

Preheat fan-forced oven to 180°C (350°F). Place almond flakes on a baking tray and roast for 5 minutes or until golden, then set aside to cool.

Blanch broccoli in a saucepan of boiling salted water. Meanwhile, melt butter with a splash of olive oil in a frying pan over medium – high heat. Add almond flakes and toss, then drain broccoli and immediately add to the pan. Deglaze pan with lemon juice, then transfer to a serving plate and serve immediately, seasoned with salt and pepper.

50 g almond flakes
1 head broccoli, cut into florets
100 g unsalted butter, chopped
extra virgin olive oil, for cooking
juice of 1 lemon
sea salt and freshly ground black pepper



Employment Solutions

How we can help you to stay at work longer

I was diagnosed with Multiple Sclerosis in 1995 and originally became a client of Multiple Solutions as a Job Seeker about 7 years ago. After receiving assistance with resume development and interview techniques, I managed to find a suitable position independently as a Customer Service Representative. As soon as my employment was considered stable and I no longer needed assistance from Multiple Solutions, I was able to exit the program.

As my health situation changed, I needed to contact Multiple Solutions again to seek assistance through the 'Job in Jeopardy' Program. My case manager arranged a government funded Worksite Assessment so that an Occupational Therapist could ensure my work station was suitable and recommend any equipment that may be beneficial. As a result, I was fortunate to be provided with a suitable computer mouse and arms for my office chair.

Whilst these items helped me continue to work as a Customer Service Representative, my health changed again 6 months later. At this time mobility became very difficult and I was unable to walk.

As this prevented me from attending work I once again contacted Multiple Solutions to ask for help. I felt anxious and terrified about losing the function in my legs and possibly my job. Knowing that this would be a very traumatic experience, I was hesitant about picking up the phone. However, after making just one phone call, my case manager was at my front door within a day and was able to arrange another work site assessment. Within 4 weeks I received a loan electric wheelchair which meant I was able to return to work whilst waiting for my custom made chair. I received my own chair soon after and I haven't looked back since. It is the best thing that has happened to me since I was diagnosed with MS.

Receiving support from this program and the people who were involved has made such a difference to my life. It's fantastic to now be treated as a 'normal' team member with no 'special' needs. I no longer need more time to get to meetings or other special allowances put in place. It does mean though that I can visit the cafeteria to get my morning tea now, which is not so good! Others have said I look great and less tired now, which must be because it is not such a struggle for me to mobilise since using an electric wheelchair. The experience of having to use an electric wheelchair was not as traumatic as I thought it would be and my employer and work colleagues have been great through this transition. I am so happy to know that I can continue working 15 hours per week for many years to come.

Jayne



*Jayne's story is an excellent example of the positive difference we can make to your working life. Don't be afraid to pick up the phone and talk to us about any aspect of your work and how MS might be affecting you. You will be surprised at what is available and best of all, it won't cost you anything! As well as physical aids, we can provide mentoring support, help you to negotiate reduced working hours or perhaps changes to your duties depending on how your symptoms are affecting your work. So if you think you, or someone you know, might benefit from this service please contact our Workplace Support Coordinator, Mary-Anne Edge, on **(08) 8396 0044** or **0430 197 890** for more information.*



‘Receiving support from this program and the people who were involved has made such a difference to my life. It’s fantastic to now be treated as a ‘normal’ team member with no ‘special’ needs.’

Thank you



Jesse Frick Thank you so much

Jesse Frick living with MS for 5 years

‘Thank you so much for your kind donations. The donations that are received really do make a difference. Without these donations people like me, living with Multiple Sclerosis would not receive the support that we need.

Again I truly thank you, not only from myself but on behalf of all people with MS.’

To our valuable supporters of the MS Society of SA & NT, The Society would like to thank you for your support with our Jesse’s Story appeal, but more importantly your help continues to provide services to people living with MS .

Jesse’s Story Appeal donations so far has raised an amazing total of

\$81,918.00

Thank you very much for your donations

‘Again I truly thank you, not only from myself but on behalf of all people with MS.’



Acupuncture and traditional Chinese medicine in MS

Jingduan Yang MD, Director, Acupuncture & Oriental Medicine Program, Jefferson Myrna Brind Center of Integrative Medicine, Thomas Jefferson University, Philadelphia, Pennsylvania, USA

Traditional Chinese Medicine (TCM) as practised today developed from a body of knowledge of an ancient healing system that first appeared in China in written form around 100 B.C.

This system describes human physiology and psychology in a similar manner to modern medicine. However, it also depicts the body and its function in terms of life energy called qi (pronounced 'chee') and the pathways along which the qi moves within the body, called meridians. TCM holds that the fundamental causes of illness are the blockage of meridians and imbalance of qi.

The TCM practitioner will first identify the meridians involved in the illness process and the nature of qi imbalance, based on the symptoms, then develop and implement a treatment plan, which often includes acupuncture and Chinese herbal medicine.

Qi

Qi is an essential concept in Chinese medicine. When used with the name of an organ or system, qi means the life energy that supports all the functions of that organ. For example, the heart qi keeps blood circulating throughout the body, and the blood qi is the nourishment the circulatory system provides to the body.

Qi is also used to describe emotions, such as anger qi, or joyful qi. 'Symptoms' of qi imbalances include deficiency, stagnation, rebellion, and collapse. According to TCM, MS symptoms such as visual disturbance, dizziness, muscle twitches, and migrating pain are often due to liver blood deficiency. Memory loss, insomnia, lower back pain, incontinence and erectile dysfunction are believed to be caused by kidney qi and essence deficiency. Muscle weakness and atrophy, fatigue, indigestion, lack of mental clarity and bruising easily are thought to indicate spleen qi deficiency.

The nature of qi is also categorised as Yin or Yang. Yin qualities include cold, stillness, and physiologic processes involved in nutritional support, while Yang qualities include heat, moving and physiologic processes involved in function. In the normal state of health, Yin and Yang are in balance with each other.

A TCM practitioner would interpret MS symptoms such as restlessness and involuntary movement of muscles and extremities as signs of Yang qi, which may be the result of too much Yang qi or too little Yin qi in the system. For the TCM practitioner, it is critical to differentiate these two conditions to tailor the most appropriate treatment.

We can see parallels to Yin and Yang in modern medicine, such as excitatory and inhibitory neurotransmitters in the neurologic system and suppressing and stimulating cytokines in the immune system. Restoring the balance is the goal of acupuncture and Chinese medicine.

Diagnosis and treatment

Each person must be thoroughly evaluated by a well-trained and experienced TCM practitioner, who applies the comprehensive theoretical foundations and techniques of ancient Chinese medicine in the diagnostic and therapeutic process. According to Chinese medicine, people who have the same MS subtype may have a different qi imbalance and therefore require individualised treatment.

Acupuncture

Acupuncture is a tool to balance Yin and Yang, open meridian channels that are blocked, remove qi stagnation, redirect rebellious qi and facilitate qi circulations to produce an effective therapy.

In treatment, the acupuncturist inserts sterile, disposable, fine needles on the surface of the skin at the point (often called acupoint) that is connected with particular meridians. Some people may feel a minimal sensation when the needle is inserted, while others experience a brief but sharp pain. After inserting the needle, the acupuncturist needs to touch and manipulate the qi, which will generate sensations such as dull aching, pressure, tingling and numbness that may also radiate along the meridians and may sometimes linger hours after the treatment. Side effects associated with acupuncture are extremely low. Minor adverse reactions include bruising at acupuncture sites, fatigue, needle pain, and bleeding. Serious complications are rarely seen and are often caused by negligent or poorly trained acupuncturists.

Using a clean needle technique, avoiding vessels when inserting the needle and performing the treatment with the person in a relaxed position can reduce side effects.

Chinese herbal medicine

Chinese herbal remedies are an essential component of the healing process in TCM. Unlike many synthetic medications or vitamins, these remedies do not have specific biochemical targets from an isolated compound. While a herb may have many chemical agents, they are chosen based on the energy output of the whole. The treatments are selected based on the practitioner's evaluation of qi energy, yin and yang balance and other components of the diagnostic portion of the visit.

Chinese herbs should be used by an experienced practitioner and not indiscriminately because, according to TCM, the body's life system changes over time. Prolonged use should be evaluated at regular intervals to ensure that the treatment is continuing to promote harmony and balance. The qualities of herbal remedies vary with manufacturers and people should always consult a practitioner with experience in using these products.

Research and clinical studies

A review of the available studies on acupuncture commissioned by the National Institutes of Health in 1997 concluded there was 'clear evidence' that acupuncture was beneficial for relieving pain and certain other symptoms, and stated that the evidence was as strong as it is 'for many accepted Western medical therapies'.



The panel found that acupuncture was 'remarkably safe with fewer side effects than many well-established therapies'. It is important to keep in mind that these were not studies on MS.

There are few studies on acupuncture and MS specifically. These have shown mild, short-term benefits. One suggested there might be improvement in MS-related bladder difficulties and others have shown conflicting results on spasticity. A large-scale survey reported that around two-thirds of MS patients benefited from acupuncture, with improvements in pain, bowel and bladder problems, spasticity, weakness, coordination, tingling, and sleep disorders. However, subjects also reported increased fatigue, spasticity and dizziness.

There are limited well-designed studies on acupuncture or herbal medicine in treatment of MS. Due to the deficiency of modern research methodology and inconsistent and inadequate treatment intervention, the conclusion from clinical studies needs to be interpreted with caution.

Editor's note: There have been no well conducted studies to evaluate the safety or effectiveness of Chinese herbs in MS. Some Chinese herbs do contain compounds with immune-stimulating activity. Thus, on a theoretical basis, these herbs could worsen MS or antagonise the effects of disease-modifying medications.

Thank you to the Multiple Sclerosis International Foundation for allowing us to reproduce this article from MS in focus – Issue 15 – © MSIF 2010. All rights reserved. www.msif.org

Yoga and other mind-body therapies and MS

Eve L. Klein, Neurology Resident, and Barry S. Oken, Professor of Neurology and Behavioral Neuroscience, Oregon Health & Science University, Portland, Oregon, US

Mind-body therapies are practices that focus on the relationship between awareness, behaviour and the physical body. They constitute a physical practice form of CAM. Relaxation is usually an important component of mind-body therapies. As psychological stress often plays a role in disease processes, mind-body therapies may be helpful in treating disease. Mind-body therapies include such practices as yoga, hypnosis, meditation, biofeedback, tai chi, visual imagery, and qigong.

Yoga is a mind-body practice that incorporates components of both meditation, including awareness and breathing techniques, and physical activity or body postures. There are many varieties of yoga.

Research has shown that psychological stress may impact the immune system and susceptibility to disease. Additionally, mind-body therapies have been associated with alterations in brain and immune function in diseases including MS. Thus it is logical to suspect that stress-reducing practices such as yoga and other mind-body interventions may be beneficial in a disease of immune dysregulation such as MS. However, Bikram yoga, a type of yoga practiced in hot temperatures, may exacerbate MS. From this framework of suggestions stems the need to study directly the impact of yoga and other mind-body therapies on MS.

Despite this rationale, there have been only a limited number of studies directly examining the effect of mind-body therapy on people with MS.

A nonrandomised, noncontrolled study of 19 people with MS found that following an eight-week t'ai chi programme, subjects experienced improvement in walking speed, flexibility, energy and mental health. Another nonrandomised controlled study examined the effect of a course of "mindfulness of movement" on MS. This study found that people who participated in the mindfulness of movement course experienced improvement in many of their symptoms as well as their balance as compared to controls. A single randomised controlled trial of 69 people with MS found that six months of either yoga practice or exercise with a stationary bicycle was associated with an improvement in energy level and fatigue as compared to a wait-list control.

Many patients with MS suffer from chronic pain and headaches. Although not specifically studied in patients with MS, a ten-week programme in mindfulness meditation was associated with improved pain scores in people with MS with chronic pain. There is also evidence suggesting that relaxation techniques, hypnosis and biofeedback may be effective in treating chronic pain. Trials for chronic headache have demonstrated that relaxation training, biofeedback, and t'ai chi are associated with improvements. Relaxation therapy and thermal biofeedback are considered to have the highest level of evidence for the prevention of migraine by the American Academy of Neurology.



In general, mind-body therapies are associated with low physical and emotional risk and relatively low cost. Thus these treatments are popular, not prohibitively expensive, and supported by some promising if preliminary evidence.

Mindfulness is the development of the ability to pay deliberate attention to one's experience from moment to moment, to what is going on in one's mind, body and life, and to do this without judgment.

Biofeedback is a process that involves measuring bodily functions such as blood pressure, heart rate, skin temperature, sweat gland activity and muscle tension, conveying the information to the person in real-time. This raises the person's awareness and therefore the possibility of conscious control of those functions.

Thank you to the Multiple Sclerosis International Foundation for allowing us to reproduce this article from MS in focus – Issue 15 – © MSIF 2010. All rights reserved. www.msif.org

Fundraising and events



MS 24 Hour Mega Swim

The 6th Adelaide MS 24 Hour Mega Swim was held on February 12–13 at the picturesque Unley Swimming Centre. It was another outstandingly successful event with 21 Teams including over 400 swimmers braving cool conditions to raise a record amount of over \$90,000!

Furthermore, this achievement is enhanced, as Megaswim also won the 2011 Unley Council Australia Day Community Event of the Year Award.

This year we had 7 more teams than in previous years with over 120 more swimmers – this made for a great atmosphere and some very healthy competition between teams to both swim the most laps and raise the most money.

Final Results saw all new teams taking out the major awards:

Overall winner

Aviation Rescue Fire Fighting,

Highest Fundraiser

Team Hughsie

Longest Swim Distance

FLO (Fleurieu Swimming Club)

Judges Award for ongoing support

Swim Ninjas and Swim 4 Life

Highest Individual Fundraiser

Claire Gordon

The MS Society entered 2 Teams – one of staff and friends and the other, TEAM MS, mostly comprising of clients and their families. The fundraising efforts of these teams were amazing, raising over \$15,000 between them.

We must particularly acknowledge one of our MS clients, Claire, who raised over \$6,000 on her own. This was Claire's first Mega Swim and unsure about her swimming abilities she started weekly training sessions with Team MS coach Elly. When the day arrived Claire had drummed up many sponsors and had the confidence and ability to swim 2 kms. Excellent work Claire!

MS Client, Chris and her Mum Rita swam again this year – despite Rita's recent knee replacement surgery. Genevieve won a Go for Gold Scholarship last year and along with son Luke was keen to support the Mega Swim, so that others could benefit as she did. 9 year old Caleb, who has cerebral palsy, was keen to better his record from last year. Big brother Andrew was in attendance to make sure he was OK, 25 laps later he was looking rather tired as he tried to keep up with his little brother.

Christina swam for 6 hours non stop, doing at least 8 km. We asked after her well-being and she said she wouldn't be able to move if she got out – so she just kept going! Daughter Andrea and son Matthew made it a family affair. Lesley again swam about 8km and ex MS Society worker Erica came back once again with her daughter Annika and nieces Shantay, Bonney and Monique. They were all swimming most of the 24 hours and slept overnight. Thanks girls!



Neville came with his carer, Julius. They both swam and then Neville went on the exercise bike and did more work. Jessica put in another legendary performance swimming 1 km every hour for the first 12 hours and then cycled 14 kms – what an effort.

Special mention must also go to Fred, a post polio client who turned 80 last year and whose daughter has MS. Despite very serious health problems leading up to the swim he turned up on Sunday morning and swam for an hour. Weaker souls would have stayed in bed but Fred did not want to let down his many sponsors. Thanks Fred – you are a legend. Special thanks also to Sarah and Chris, Jonathan, Jack and Elly for doing some of the 'graveyard' shift in the middle of the night and Gerald for the early morning shift when it was freeeeeeezing.

I must again particularly acknowledge the huge effort put in by Ruth Ziegeler and her team of helpers from Atlantis Masters Swimming Club, the great service offered by Nathan and the staff of the Unley Swimming Centre, and the helpers from Hyde Park Rotary Club.

Fundraising and events continued



Thanks also to Monique Williams and Maxine Brooks who put in so much time and effort from the MS Society perspective, Sarah Hueppauff and Sandy Andrews for Team MS organisation and the many staff and friends who volunteered on the day.

The funds raised from the Mega Swim support the Go for Gold Scholarship program which gives people with MS the opportunity to apply for up to \$2000 to pursue a dream. These applications are currently being assessed. The Mega Swim also funds the MS Society's physiotherapy Keep Active Program which includes 15 classes per week of land-based exercise, hydrotherapy, yoga, vibrogym and passive/active exercise bikes in a number of locations across the metropolitan area. Over 100 clients per week are enrolled in these classes.

Put the 11-12 February 2012 in your diary and let's make the 2012 MS 24 hour Megaswim even more successful than this year's amazing event. Thanks everyone for sponsoring, donating and attending. We really are making a difference to the lives of people with MS.

Lee O'Connell

Captain TEAM MS



MS Readathon

Take part in the 2011 MS Readathon and help Australians living with multiple sclerosis.

It's so simple!

1. Register online
2. Read for 30 days
3. Collect sponsorship
4. Be rewarded for your reading

New to 2011...
CHOOSE YOUR OWN READING REWARDS
Find out more at
www.msreadathon.org.au



the **novel** challenge

For the Over 18's

The MS Readathon, the iconic children's reading-based fundraiser, is now calling for literary-minded adults to get involved and raise much-needed funds for multiple sclerosis.

Visit www.thenovelchallenge.org.au

On behalf of the 20,000 Australians living with MS, thank you!

Fundraising and events continued



OT for MS A NIGHT TO RAISE

A fundraising ball to promote Occupational Therapy and raise funds for the Multiple Sclerosis Society of SA and NT

when Saturday 25th June 2011

where Donato's Function Centre 62 Humphries Terrace, Kilkenny, SA

time 6:30pm start 12:00 finish

dine 3 course meal

drink beer, wine and champagne

live entertainment (Lucky Seven, DJ and Dancers)

cost \$750 for a table of 10 or \$80 each.



For ticket sales and enquiries please contact Lisa or Jess
0402626671 liseruiz86@gmail.com or
0422174775 jessicacicarello@y7mail.com



CASH BONANZA LOTTERY



MS \$10 Cash Bonanza Lottery

- 1st prize \$30,000 cash
 - 2nd prize \$15,000 cash
 - 3rd prize \$5,000 cash
 - 4th-5th prize \$2,000 cash
 - 6th-10th prize \$1,000 cash
 - 11th-20th prize \$500 cash
 - 21th-30th prize \$100 cash
 - VIP winners Gold \$2,000 cash
Silver \$1,000 cash
 - Credit card draw \$2,000 cash[†]
- Buy 10 receive 1 bonus ticket**

35,000 tickets @ \$10 per ticket
 Lottery opens: 7th March 2011
 Lottery closes: 8th June 2011
 Lottery drawn: 2pm,
 15th June 2011
 19 Fosters Road
 Greenacres SA 5086
 Results: Public Notice Section
 of The Advertiser, Saturday
 18th June 2011
 Lotteries Hotline: (08) 8360 0888
 Fax: (08) 8360 0899
 Email: lotteries@ms.asn.au
 Website: www.ms.asn.au
 PO Box 198, Greenacres SA 5086
All winners will be notified.
[†] To be eligible for credit card
 draw you must use credit card
 at time of purchase.
 Lottery conducted by The Multiple
 Sclerosis Society of SA & NT Inc
 Proceeds for Research and Client Care
 ABN: 85 662 359 859
 SA Licence no: M 12199

MS CASH BONANZA LOTTERY

5 WAYS TO ORDER YOUR TICKET

Phone our lotteries hotline: 1800 812 311 or 08 8360 0888 or Fax to: 08 8360 0899
 Post to: PO Box 198 Greenacres SA 5086 Email: lotteries@ms.asn.au Online: www.ms.asn.au

1 ticket \$10 5 tickets \$50 10 tickets \$100 + 1 bonus ticket Other _____ @ \$10 ea \$ _____

Mr/Mrs/Ms/Dr: _____

Address: _____

Telephone No. work _____ home _____ Email _____

Cheque/money order made out to: Multiple Sclerosis of SA & NT or Cash
 Debit my credit card Amex Visacard Mastercard

Card holder name _____ exp ____ / ____

Signature _____

Fundraising and events continued

Fundraising Calendar 2011

Month	Date	Event/Fundraising Activities
May	8	■ Mothers' Day High Tea – Sunnybrae Function Centre
	25	■ World MS Day
	30–3	■ MS Awareness Week
June MS Month	1	■ MS Readathon – Read for 30 Days
	6	■ MS Cash for a Cause Lottery – Tickets on Sale
	7	■ 'Crazy For You' Therry Dramatic Performance, Arts Theatre, Angas Street, Adelaide
	8	■ MS Cash Bonanza Lottery – Sales Close
	10	■ Badge Day – Rundle Mall & Adelaide Central Market
	15	■ MS Cash Bonanza Lottery – Lottery Drawn
	17	■ Badge Day – Unley Shopping Centre & Burnside Library
	25	■ OT For MS A night to Raise – Donato Centre, 62 Humphries Tce, Kilkenny
TBA	■ Ansett Down to Earth Club Movie Night – Trak Cinema, 8pm	
July	13	■ MS Cash A Thon Lottery – Sales Close
	18	■ MS Mega Money Lottery – Tickets on Sale
	20	■ MS Cash A Thon Lottery – Lottery Drawn
	29	■ MS Quiz Night – Sicilia Social & Sports Club Inc
	31	■ Stop reading MS Readathon
August	30	■ MS Readathon Money Due Date
	31	■ MS Cash for a Cause Lottery – Sales Close
September	4	■ Fathers' Day Raffle
	6	■ 'The Mousetrap' Therry Dramatic Performance, Arts Theatre, Angas Street, Adelaide
	7	■ MS Cash for a Cause Lottery – Lottery Drawn
	10	■ MS Christmas Cracker Lottery – Tickets on Sale
	18	■ Sunday Mail City to Bay Fun Run
	28	■ MS Mega Money Lottery – Sales Close
October	5	■ MS Mega Money Lottery – Lottery Drawn
	24	■ MS Red Hot Summer Lottery – Tickets on Sale
November	1	■ Melbourne Cup Luncheon
	8	■ 'The Cemetery Club' Therry Dramatic Performance, Arts Theatre, Angas Street, Adelaide
	TBA	■ Movie Night Fundraiser – Twilight 'Breaking Dawn' Hoyts Cinema, Norwood
December	7	■ MS Christmas Cracker Lottery – Sales Close
	14	■ MS Christmas Cracker Lottery – Lottery Drawn
	TBA	■ Family Christmas Movie Night Under The Stars

■ Lottery/Raffle ■ Mega Swim ■ Therry Dramatic Performance ■ Event ■ Movie Night ■ Awareness/information event

The new 2011 | 2012 Entertainment™ Book... discover why it's the best deal of all!



Purchase your new 2011 | 2012 Entertainment™ Book now for just \$65 and you'll receive over \$15,000 in valuable offers you can use all year. Choose what you want to do and when you want to do it with valuable 50% off, 25% off and 2-for-1 offers, valid from now until June 1st, 2012.

For only \$65 you'll receive over \$15,000 worth of valuable offers!

Entertainment™ Books feature the best restaurants, attractions, cinemas, sports, hotel accommodation and much more. Purchase a Book and at the same time, you will also be helping community fund-raising!

The new Adelaide Entertainment™ Book features many of the most popular businesses in the area like...



Fine and Contemporary Dining

- Magill Estate
- Lencoehead Restaurant
- Joleys Boatouse Restaurant
- The Lion Hotel
- Victory Hotel
- Kitchen Door at Perry's Hill
- Etonic Garden Restaurant
- Enoteca
- Evos Ozoni
- Evos Restaurant
- Rigoni's Bistro
- Zucca Greek Mezza
- Aris Bar & Ristorante
- Maxilian's
- The Marse
- Sparrow
- Slemers Indian Restaurant
- The Kamil
- Silver's of Clarendon
and many more...

Casual Restaurant and Family Dining

- Red Rock Noodle Bar
- Victoria Hotel
- Cafe Paradiso
- Montezuma's Restaurant
- Hotel Croam
- Spargo's
- Follies
- Alisa Hotel
- Cafe Mondali
- Jones the Grocer
- The Stonehouse Bar & Grill
- Bocca North Adelaide
- The British Hotel
- Large Pier Hotel
- The Olden Central
- Ramgate Hotel
- The Esplanade Hotel
- Marcelina
- The General Hawlock
- Brighton Metro Charles Diner
- Outback Jacks Bar & Grill
- Hog's Breath Cafe
and many more...

Informal Dining and Takeaway

- Hungry Jack's
- KFC
- McCafé
- McDonald's
- Noodle Box
- Wokinbox
- Brumby's
- Cherry Blossom
- Hubsons Coffee
- Dorset King
- Red Rock Express
- Wendy's
- Arcana Cafe
- Qporto
- The Coffee Club
- Andersen's of Denmark
- Gelatissimo
- Pretzel Marie
- bb's cafe
- The Yoghurt Shop
and many more...

Arts, Sports and Attractions

- The Beachouse
- Cleland Wildlife Park
- South Australian Jockey Club
- Event Cinemas
- Adelaide Symphony Orchestra
- Adelaide Jagers
- Adelaide United F.C.
- Fort Adelaide Football Club
- Adelaide Cosmos Football Club
- Palace Nova East End Cinemas
- Wells Cinemas
- Kangaroo Stealnik
- Greenhills Adventure Park
and many more...

Retail, Travel, Leisure and Accommodation

- Hayman
- Haralton Island
- Bridges Hotels and Resorts
- Croam
- Dreamworld
- Warner Bros. Movie World
- Gourmet Traveller
- Fantasy Cruises
and many more...

To see a complete list of participants in the 2011 | 2012 Entertainment™ Book, visit www.entertainmentbook.com.au
To purchase your new Entertainment™ Book, please contact:

Order 2011/2012 Entertainment™ Book

To order your book, please contact Emily Polomka on (08) 8360 0821 or post order form to PO Box 198, Greenacres SA 5086

I will collect book/s **OR** I have included \$8.50 per book for postage and handling

Title: First name: Family name:

Address:

City: State: Postcode: Phone:

I enclose a cheque/money order payable to the Multiple Sclerosis Society of SA & NT **or**

Please debit my credit card Mastercard Visa AMEX

Card number: - - - Expiry date: -

Card holder's name: Card holder's signature:

Number of Adelaide books purchased: x \$65 each (GST included) = \$ (+ \$8.50 p/h)

Total enclosed \$

\$13 from each book sold goes directly to Multiple Sclerosis Society of SA & NT Inc.



Multiple Sclerosis Society
of SA & NT



Locations

Head Office/Modbury

110 Reservoir Road
Modbury SA 5092
PO Box 525
Modbury SA 5092

P (08) 8396 0044
F (08) 8396 0184

Brighton

7A Sturt Road
Brighton SA 5048
PO Box 275
Brighton SA 5048

P (08) 8377 0911
F (08) 8377 0711

Christies Beach

Level 1, 111 Beach Road
Christies Beach SA 5165
PO Box 885
Noarlunga Centre SA 5168

P (08) 8392 0100
F (08) 8392 0199

Darwin

Nightcliff Community Centre
11/18 Bauhinia Street
Nightcliff NT 0814
PO Box 867
Nightcliff NT 0814

P (08) 8948 5300
F (08) 8948 5344

Elizabeth South

Shop 6, 183 Philip Highway
Elizabeth South SA 5112
PO Box 4104
Elizabeth South SA 5112

P (08) 8256 3700
F (08) 8255 5796

Greenacres

19 Fosters Road
Greenacres SA 5086
PO Box 198
Greenacres SA 5086

P 1800 812 311
F (08) 8360 0899

Modbury

31–33 Smart Road
Modbury SA 5092
PO Box 525
Modbury SA 5092

P (08) 8203 6600
F (08) 8203 6699

Woodville

63 Woodville Road
Woodville SA 5011
PO Box 16
Woodville SA 5011

P (08) 8345 8700
F (08) 8268 4224

