## Momentum

New Zealand

The Otago Multiple Sclerosis Society Newsletter

Otago Multiple Sclerosis Society www.msotago.org.nz Phone: (03) 455 5894

(0508 67 68 246)

Multiple Sclerosis

Otago



8 Baker Street Caversham Dunedin 9012

Manager
Tania McGregor
021 1659 440
tania@msotage.org.pz

Field Officer
Jo Smith
027 296 5254
jo@msotago.org.nz

Health Support Officer
Pam Macdonald

Patron
Dr John Mottershead

## EXPLAINING AND MANAGING FATIGUE

Fatigue is one of the most common and frustrating symptoms of MS and something that many of our clients have challenges with. Fatigue can be felt in many areas or a person daily life. Fatigue can be an invisible aspect of MS which means some people have trouble understanding the problems and what it can cause.

Unlike other types of tiredness due to excessive exercise, activity or lack of sleep, MS fatigue doesn't subside or can be solved by resting. It is however possible to take a proactive approach to your condition and improve your quality of life.

## **Understanding fatigue:**

Fatigue affects people differently and to varying degrees. It can be very hard to describe fatigue, but most people define it as a feeling of overwhelming weariness that has an impact on their ability to do things.

People with MS who experience fatigue may do so because of it direct effect on the nervous system, or because of other factors. The various factors can co-exist, requiring multiple management strategies. People with MS may also experience fatigue because of something entirely unrelated to their condition, such as unknown infection. Thus it is important to discuss any substantial increase in fatigue with your doctor.

## **Explaining fatigue to others:**

It is difficult to explain fatigue to others. Because it is invisible, people can misunderstand what you are experiencing and may think you are really just depressed or lazy. It can be hard to gain support and understanding when this happens, but reassure yourself that you are doing the best you can to cope with fatigue and describe its effects to others. Ultimately, you are not responsible for what others think.

In these circumstances, some people with fatigue find it too hard or too



Inside this issue:	
Atlas of MS 2013 6	;
The sun and MS7	,

Boosting Vitamin D ..... 12

Masters Games 2014 ..... 8

The Southern Trust

tiring to explain how it feels and instead make other excuses for their difficulties — such as being short of sleep or feeling sore. However, it can be better in the long run to take the time to explain fatigue, so that the nature of your difficulty is understood and supported.

## Fatigue due to an overactive immune system:

When the immune system detects infection, such as influenza, it increases white blood cells (lymphocytes) and special proteins (cytokines) to fight the virus. It is presumed that the production of these substances is what causes the tiredness which people tend to associate with "having the flu". When the immune system attacks the nervous system (as it does in MS) it secretes the same substances, bringing on the fatigue and tiredness the same way as when fighting an infection.

Whatever the actual mechanism, this type of fatigue usually occurs in the early to mid-afternoon with an improvement by the evening. It mirrors the daily temperature variation of the bod which peaks mid-afternoon. It is not known if there is a direct link.

#### **Treatment:**

Steroids supress the immune system response and this may be effective in reducing fatigue as well as speeding up a recovery from a relapse. However steroids can be prescribed only sparingly for this type of treatment. There are other types of non-MS medications that may be helpful in treating this type if fatigue. You could discuss this with either your neurologist or GP to see whether these medications would be likely to benefit you.

## Fatigue due to increasing body temperature:

When the body's temperature is raided through exercise, heat, change in climate or infection, the signs and symptoms of MS can become more obvious and weakness can be increased. Just a small increase of one quarter of a degree in body temperature can affect a demyelinated nerve's ability to conduct the electrical impulses that make up the nervous system messages.

So, when the change in body temperature prevents the nerve fibres from sending messages through the body, thus causes fatigue in the fibres themselves and contributes to limitations in activities.

#### **Treatment:**

Minimising the amount of heat to which the body is exposed to will reduce the likihood of fatigue, so air-conditioning, cooling vests and cool showers can all help. Consider exercising in cool environments, such as swimming and aqua jogging.

## Fatigue due to medication:

Many of the medicines commonly used to treat MS symptoms can cause or worsen fatigue as a side-effect. Particular medications to note include interferons, steroids (especially on withdrawal from a high dose), antidepressants and medications for spasticity or pain.

#### **Treatment:**

Because the range of medications that may aggravate fatigue is wide, it is important to talk to your GP or Neurologist if you have concerns about any medication you are on.

Note: Drugs that assist with sleep may cause sedation and drowsiness during waking hours, which can be confused with fatigue. If you have any concerns, talk to your GP or Neurologist.

## Fatigue caused by disability:

MS can cause problems with mobility and muscle control. Compensating for these disabilities requires energy and effort than would otherwise be necessary to perform daily tasks. When some muscles cannot perform certain tasks other muscles are used instead and the extra work load can tire these muscles, leading to additional fatigue.

### **Treatment:**

Neurophysiotherapists and physiotherapists can demonstrate exercises to strengthen and main body functioning and there is a range of equipment available to help converse energy and reduce stress on muscles and joints.

Occupational therapists can suggest modifications to your home or workplace to improve your efficiency and reduce the effort involved in daily tasks.

MS Society Field Officers, friends, family members and other people with MS can be useful sources of practical advice on ways to reduce energy needs.

## Fatigue due to interrupted sleep:

MS causes a variety of symptoms that disrupt sleep. Muscle spasms, pain, bladder problems and

**DISCLAIMER:** The information in this newsletter is for the purpose of informing people about multiple sclerosis, events and interesting reading. The contents of this newsletter neither indicate nor reflect the views of the Otago MS Society. You should not rely on any information produced in this newsletter in place of a visit, consultation or advice of a doctor or other qualified health provider.

breathing difficulties can all affect sleeping patters.

#### **Treatment:**

The solution to this type of fatigue lies with identifying why the sleep is being disrupted and treating the underlying problem. Your GP or Neurologist can help with this.

## **Fatigue and depression and stress:**

While depression and stress don't technically cause fatigue, they can affect energy levels in a similar way, in part by disrupting sleep.

#### **Treatment:**

Stress and depression are brought about when we have difficulty coping with the various challenges we face. Try to reduce the problematic aspects of life wherever possible and seek help from others. Support and information is available from GP's counsellors and help lines. An MS Society Field Officer is also available for one-on-one discussion and can provide a referral to services in your community.

## Fatigue due to poor nutrition:

Poor diet and dehydration can contribute to fatigue, as the body does not have the necessary nutrients to provide energy.

#### **Treatment:**

Foods that combat fatigue include complex carbohydrates and foods rich in potassium, iron and vitamins B and C. You should also maintain an adequate intake of liquids.

A dietician can provide specialist advice on nutritional needs. This is particularly important of you also have bowel problems.

## Fatigue and well-being:

Coping with fatigue can be draining. Thus, feelings or tiredness and exhaustion can lead to more feelings of tiredness and exhaustion. However, maintaining a healthy lifestyle can help you cope better with fatigue.

Keeping physically fit is very helpful and it is possible to develop a balanced programme of activity that takes account of any limitations. A physiotherapist can help with specific exercises, but they must be aware of the potential limitations MS imposes.

(Remember to monitor your body temperature in case this increases fatigue.)

Managing time and energy and minimising stress is also important. Whether at work, home or elsewhere, conserving energy and taking periodic breaks will make a big difference to how much can be done each day. It may be useful to plan each week's work, social and late night activities in advance so that the most important activities take priority.

Maintaining a healthy and balanced diet is important for everyone, but especially for people with MS. Be aware that excessive alcohol can increase fatigue and toxins like nicotine should be avoided.

Each day's activities should include opportunities for relaxation (such as gentle exercise, yoga or meditation) and moments of high energy should be balanced with adequate rest periods.

## Final thoughts:

While coping with ongoing fatigue can be very draining, there are good approaches available for lessening its impact on your life. These strategies apply to anyone, whether their fatigue is MS-related or not.

It is important to be aware of the causes of fatigue and to avoid as many of those triggers as possible. This means staying healthy, minimising stress, maximising rest and avoiding other illnesses.

Without minimising the difficulties that fatigue can bring, it can provide positive outcomes as well. Firstly, Fatigue requires people to take a stock of their lives and identify the real priorities. This can make life more purposeful and, thus potentially more satisfying.

Secondly, the need to slow down and rest more can provide an opportunity for contemplation and relaxation that not everyone has.

Some people with MS will not be able to avoid fatigue and it can be a frustrating problem. However, a proactive and positive approach to coping with fatigue can provide you with more control and confidence.



## Who are our Southern District Health Board Neurologist's?

### **Dr John Mottershead**

Dr John Mottershead studied at Oxford University and carried out research on MRI scanning and multiple sclerosis at the Institute of Neurology in London. He trained in clinical neurology before taking up a post as consultant neurologist at the Greater Manchester Neurosciences Centre in 2002 where he worked as a neurologist with a sub specialty clinic in MS, largely dealing with disease modifying treatments. In 2009, he moved to Dunedin and he is a consultant neurologist at Dunedin School of Medicine with a special interest in multiple sclerosis (Mottershead, 2013). Dr Mottershead is also the Patron of our MS Society Otago.

## Dr Alan Wright

Dr Alan Wright (2013) has undertaken subspecialty fellowships in a variety of areas of neurology including movement disorders, cognitive neurology and neuromuscular disease. His expertise encompasses the broad range of neurological diseases with interest in headache, epilepsy, multiple sclerosis, stroke, Parkinson's disease etc. (Wright, 2013).

### **Dr Nick Cutfield**

Dr Nick Cutfield is clinical lead and consultant neurologist at Dunedin Hospital. Dr Cutfield is the Clinical Director of the Brain Health Research Centre www.bhrc.otago.ac.nz, as well as Clinical Senior Lecturer at the Department of Medicine, University of Otago. He is on the Neurological Foundation of New Zealand Scientific Advisory Committee. He trained in Otago, Auckland and London before returning to Dunedin, and has a wide variety of clinical and research interests.

### **Professor Graeme Hammond-Tooke**

Prof. Hammond-Tooke is a clinical neurologist with particular interest in neuromuscular diseases, psychogenic disorders and transcranial magnetic stimulation (TMS). He is an Associate Professor at Dunedin School of Medicine and member of the Neurological Association of New Zealand; Australia and New Zealand Association of Neurologists; Australasian Neuromuscular Network (Hammond-Tooke, 2013).

### References

Cutfield, N. (2013). Health Science staff profile. Retrieved August 26, 2013, from University of Otago: http://www.otago.ac.nz/healthsciences/expertise/profile/?id=846

Hammond-Tooke, G. (2013). Health Science staff profile. Retrieved August 26, 2013, from University of Otago: http://www.otago.ac.nz/dsm/people/expertise/profile/index.html?id=671

Mottershead, J. (2013). Brain Health Research Centre. Retrieved August 26, 2013, from University of Otago: http://www.otago.ac.nz/bhrc/staff/otago040568.html

Wright, A. (2013). Dr Alan Wright. Retrieved August 26, 2013, from Mercy Hospital: http://www.merceyhospital.org.nz/specialists/dr-alan-wright

## Lest We Forget

It is with great sadness that we acknowledge the passing of Heather McDonald who was a member of our Society; our thoughts are with her family and friends during this time.



## Who are our Southern District Health Board Neurology Nurses?

## Sharon Stevenson-Hall CNS/BN/MSCN (MS Certified Nurse) Rachel McLay-Barnes CNS/MSCN (MS Certified Nurse)

We are pleased to have the opportunity to introduce ourselves to those of you we have not met.

We are both currently employed by the Southern District Health Board (SDHB) holding hospital based positions as Clinical Nurse Specialists in Neurology with an expert interest in Multiple Sclerosis. We are located in the Frederick Street Outpatient Department at Dunedin Hospital and we work alongside the Neurologists who are also based at the hospital.

We have both been working with people with Multiple Sclerosis for the past 13 years.

Sharon has had the opportunity to develop her interest in MS through her association with the MSNA Inc (Multiple Sclerosis Nurses Australasia), becoming a delegate member representing the South Island of New Zealand in 2003, and as an affiliated member of the IOMSN (International Organization of MS Nurses). In the same year both Sharon and Rachel achieved a postgraduate level paper with the focus on MS, from the Queensland University and in 2004 both achieved the qualification of International Multiple Sclerosis Nurse Certification and are still currently certified.

We accept referrals to see people who live within North and South Otago, Otago, and Central Otago areas. We can be the patient's point of reference regarding information, treatment, clinical studies, advice and locally available resources.

As MS Nurses we have an important role in patient care, empowering people with MS through the provision of accurate information, encouraging realistic and positive expectations and supporting a sense of control over the disease

Being correctly informed is vital when people are initially diagnosed as it sets sensible expectations and when the experience matches the expectation the outcome is more likely to be positive.

Practical things we can help with are:

- Recognition and management of a relapse and what is a relapse?
- Exacerbation, event, attack, or "flare up".
- Not associated with a high temperature or any illness/infection.
- A new symptom or deterioration in an existing symptom lasting more than 48hrs.
- Caused by inflammation on the myelin sheath.
- After a relapse the inflammation subsides and repair commences.
- When this occurs the symptoms reduce in severity and may disappear, this can take up to 3 months.

## What should you do?

- Important that you visit your GP to eliminate any other underlying cause and the event is documented.
- Encourage GP to inform your Neurologist of event it is not necessary that you are seen by your Neurologist.

### What you can do

- Rest- include rest periods into your daily activities.
- Diet- maintaining a good well balanced diet is important, avoid missing meals.
- Sleep discuss with your GP issues that interfere with good sleep.
- Stress be active about reducing things that stress you.
- Stop smoking.
- Education programme for self-administration of Beta Interferon, Copaxone and Avonex
- Referrals to other health professionals
- Education and advice about medication and symptom management

The position of an MS Nurse is constantly evolving; we enjoy the ongoing challenge of working within this area with the ultimate aim of continued improvement of the service delivery to people with MS and their families hopefully enhancing their quality of life.

Both Sharon and Rachel can be contacted at the Neuroscience Outpatient Clinic, Dunedin Hospital (03) 470 9286 ext 9286.

# Atlas of MS 2013 launched with staggering global statistics on the condition



Global statistics released about Multiple Sclerosis which affects 2.3 million people worldwide highlights the improvements that New Zealand must make in the access to high cost medicine use in MS.

The Multiple Sclerosis International Federation launched the 'Atlas of MS 2013: Mapping Multiple Sclerosis around the World' at the 2013 European Committee for Treatment and Research In Multiple Sclerosis (ECTRIMS) in Copenhagen on 2nd October.

"MS is one of the world's most common neurological disorders and the leading cause of non-traumatic disability in young adults," comments Professor Alan J Thompson, Chairman of the MSIF International Medical and Scientific Board and Peer Baneke, MSIF Chief Executive in the published report. The Atlas of MS 2013 enables MS Organisations around the globe to provide policy makers, governments and health professionals with "Reliable data concerning the worldwide distribution of MS provides useful insights about the disease... to campaign for better support and quality of life for people with MS."

"We are extremely excited to receive this report and to have been a part of it," commented Multiple Sclerosis Society of New Zealand National Coordinator Amanda Keefe. "With the results from the National Incidence Study that is taking place across the New Zealand at present we hope to use the findings, due to be released early next year, alongside these global statistics to be able to lobby PHARMAC and Government for both better funding for more high cost medicine use, many of which are available and often fully funded in other countries and receive better funding for research."

Over 3000 New Zealander's are diagnosed with MS which is one of the most common neurological conditions in the country with women three times more likely than men to be diagnosed.

## Atlas of MS 2013 Stats

## **Global Key Findings**

- The estimated number of people with MS globally has increased from 2.1 million in 2008 to 2.3 million in 2013
- MS is found in every region of the world
- The 2:1 ration of women to men with MS has not changed significantly since 2008. (In NZ the ratio is 3:1, higher than the global average)
- Support and healthcare services have improved but substantial global inequalities remain.
- There are substantial inequalities in the availability of and access to disease modifying therapies
- The number of MRI machines in emerging countries has doubled in five years with a global statistic of 0.31 increased to 0.46 per 100,000) and an increase in the number of neurologists around the world from 1.01 in 2008 to 1.32 per 100,000 in 2013.
- High income countries have 100 times more neurologists per head than low income ones
- One in five countries has no organisation providing support to people with MS
- More research is needed in relation to quality of life and experiences of people with MS
- More research is needed to measure indirect costs of MS
- 8 out of 10 people who are diagnoses with relapsing-remitting MS develop secondary progressive MS
- The average age of MS onset is 30 years
- Physiotherapy is available is almost all (99%) of the 100 countries that provided data on rehabilitation services.
- Cognitive rehabilitation was the least available of the rehabilitation services worldwide, being available in only 48% of countries, even though cognitive problems can affect 40-70% of people with MS.
- The most common presenting symptoms were found to be sensory (40%) and motor (39%), and least common were pain (15%) and cognitive issues (10%).

## The sun And MS

People living at higher latitudes have a greater chance of developing multiple sclerosis. Now a long-awaited study aims to find out whether a lack of sunlight could be the problem.

Strange but true; the further you live from the equator, the greater your risk of developing multiple sclerosis (MS). This is thought to be as a result of the lack of sunlight – or more precisely, lack of vitamin D, which we synthesise from sunlight. Does this mean those living above a certain latitude should take vitamin D supplements?

Researchers in New Zealand and Australia have joined forces to try to find out, and are now recruiting for the first large, placebo-controlled, randomised study designed to investigate whether taking daily vitamin D supplements affects those at risk of developing the disease. "This is the leading-edge hot topic in MS research," says Deborah Mason, the Christchurch-based neurologist leading the New Zealand arm. "It's the trial that everybody has been waiting for."

MS is a disorder in which the immune system starts to attack the myelin that coats the nerve fibres, interfering with communication between the brain, spine and other parts of the body. There are many different types of MS, but it's typically characterised by intermittent episodes of demyelination, or attacks, causing symptoms including visual disturbances and limb weakness that may worsen over time.

Vitamin D receptors are found throughout the body – in the bones, brain, heart, for example, and where there is a receptor, vitamin D affects function. In recent years low vitamin D levels have been implicated in numerous health problems including bone disease, colds and flu, tuberculosis and even Alzheimer's. And in the development and severity of MS.

For some decades it has been known that populations living at higher latitudes have greater rates of the disease – it's significantly more common in countries such as New Zealand and Canada than in the Mediterranean countries or Central America, and it's three times more common in Southland than it is in northern regions of New Zealand. This geographic relationship "has been shown worldwide", says Mason.

"There are much higher rates in Hobart than in the Gold Coast and northern parts of Australia, for instance."

The theory that this could be a result of reduced sunlight exposure and lower levels of vitamin D was mooted early on, and gained traction as researchers found that people with MS seem to have lower vitamin D levels than those who didn't. Also, that genetic changes that affect vitamin D regulation were more common among people with MS.

Which might be enough to persuade most people with MS to take it, but it's not enough for a clinician to recommend it, says Mason.



"This is still an association—nobody knows the mechanism by which it might work, or even if it's the answer."

The study will involve more than 300 people from New Zealand and Australia who have had a single episode of demyelination, but haven't been diagnosed with MS. Participants will take vitamin D supplements of one of two strengths, or a placebo, and be observed for three years.

As the evidence of a link is so strong, some researchers have questioned whether it is ethical to withhold vitamin D in the placebo patient groups. However, Mason says they simply don't know if vitamin D supplementation is effective, or even safe, and they need to find out. After all, it wasn't that long ago women were told to take calcium supplements, because there was good reason to believe it would build bone density – before New Zealand researchers discovered that taking calcium supplements increased the risk of heart attacks.

It's not entirely clear what constitutes an optimal level of vitamin D, but New Zealanders are showing low levels of it compared with people in the United Kingdom and the US.

This could be the result of cultural factors – our fear of the sun, or less fortification of vitamin D in our food. "But one of the problems is that in winter sunlight across southern parts of New Zealand there isn't enough of the right UVB wavelength to make vitamin D – even if it's a sunny day, unless you're sitting on top of a mountain, you're not getting the right amount of sunlight to make vitamin D."

Mason says she has no idea what results the trial will produce, but of course it would be nice to find out supplementation makes a difference.

"If we could prevent just 10% of people getting this disease just by increasing their vitamin D, that would be amazing."

"In winter sunlight across southern parts of New Zealand there isn't enough of the right UVB wave length to make vitamin D."

## **The Southern Trust Masters Games**

On Wednesday 5th February 2014 at 6.00 pm, the MS Otago team which consisted of staff, members, volunteers and supporters with Multiple Sclerosis or other neurological conditions lined up to compete in the NZ Masters Games 5km walk. Appearing in our "bright orange" t-shirts with it stamped on the back "I survived the NZ Masters Games 5km walk".

It was great to see the enthusiasm between the team members, and all were excited and eager to get to the start line and begin!

We had some members in wheelchairs with their support crew close by, Bernie on her motorised red racer with Ross at the ready just in case Bernie turned up the speed dial a little too far and went "off course", and some with a stick or two "just in case" and a couple of extra chairs for Jo and myself!!

We received amazing support by all the competitors participating in the walk, not to mention the wonderful volunteers who were involved with the Masters Games.

Jo and I were overwhelmed by the courage, spirit and determination shown by the team, and we are extremely proud that we all completed the challenge, whilst we may not have been on the top of the podium, it was about being part of this event, and that we did as a team.

We know that there were some tired people and the end of the 5KM, and I think most of us were grateful that it was Waitangi Day the next day, as it gave use the opportunity to rest, relax and it was great to have amazing weather.

On behalf of myself and Jo thank you all for being part of our MS Otago Masters Team for 2014, and I hope that we will have more of you join us in 2016, when the Masters Games returns here to Dunedin.



## MS sufferer tired of being labelled a drunk

MISUNDERSTOOD: Former America's Cup sailor Rick Dodson, 54, has multiple sclerosis and says he is often mistaken for being drunk.

A former America's Cup sailor is fed up with being refused alcohol because his illness makes him appear drunk.

Mairangi Bay father of two Rick Dodson, 54, says bar and liquor shop staff need to understand the symptoms of multiple sclerosis (MS) before making snap judgments.

"I went to a wine shop in Parnell the other week and asked for a six pack of beers because I was going to a friend's place for dinner.

"The guy behind the counter said, 'no I can't serve you because you're drunk'."

Dodson says the staff member continued to refuse him a sale even after he explained that his slurred speech and unsteadiness on his feet were symptoms of MS.

"I showed him my MS card, but he said, 'no I can't, I still think you're drunk'."

MS Auckland, a support organisation for those with the condition, provides members with wallet-sized cards explaining the symptoms.

Slurred speech, shaky hands and affected balance are symptoms that have been causing problems when people with MS attempt to drive or purchase alcohol. Others may experience fatigue, numbness, spasticity and bladder problems.

"Everyone with MS has this story. It's happened to me in bars as well," Dodson says.

MS Auckland general manager Therese Russel says no two people exhibit the same symptoms which

makes it difficult for people to recognise the disease.

"To other people they are all signs that someone is

drunk." She says another member had her keys taken off her in the car park as she went to drive home. Dodson says he is frustrated with uneducated people denying him the freedoms he is entitled to.

"I respect them for doing the right thing and saying, 'look no you're drunk', but as soon as I pull out the card that should be the end of it." MS Auckland is now looking to produce a new identification card to prevent any further disputes.

"The issue we have is how do we make it more recognisable? Maybe something with a photo on it, our website, symptoms and a phone number to call?"

Dodson says his team mate David Barnes, who also suffers from MS, does not drink but has still had to contend with ignorance from retail workers. "Dave got stopped outside the supermarket, the police showed up in the car park after the checkout girl said something." His daughter was with him at the time and said, 'no its OK Dad's got MS'."

Both are members of the Kiwi Gold Sailing crew vying for a spot in the Rio de Janeiro 2016 Paralympics.

Dodson was the Team NZ on-board strategist during both the 1995 and 2000 America's Cup victories. He was diagnosed about 15 years ago but continued to sail with Team NZ in the early stages of the disease. He has since undergone speech therapy and continues to live a full and active life.

Article written by Maryke Penman - North Shore Times.

## **Room Hire Available**

The Day Room which is located at 8 Baker Street, Caversham, DUNEDIN is available to hire for your next board meeting, training session, group meetings, or function.

This versatile inviting room can be set up in a variety of individual needs; seating is currently available for a maximum of 50 people.

Our venue is completely wheelchair friendly including the ablution area which also has a disabled friendly shower unit.

Our heat pumps provide a warm and inviting atmosphere

on cold days, and on hot days our sliding windows provide some much needed cooler airflow.

Our premises are located in a quiet suburban neighbourhood, near main bus routes, street parking, and also off street parking is available.

Bookings are available during some weekdays, most weekends and evenings. Should you wish to view our venue please contact Tania on (03) 4555 894 ext 2 to arrange a time to visit.

The hiring fee contributes towards the continued work of the Otago Multiple Sclerosis Society in the community.

## 10 Tips for managing day-to-day life with Multiple Sclerosis

Multiple Sclerosis the disease is often unpredictable. Because symptoms can vary from day to day (you may be feeling too fatigued to even walk out of the house one day, but completely fine the next), living with this progressive autoimmune disorder can be particularly challenging.

But if you rely on a few simple strategies (along with your treatment plan), you can take charge of your MS. Below are some suggestions that can help you manage your MS more effectively.

1. Prepare for the Worst, Hope for the Best. Have a backup plan. Whether your to-do list includes work responsibilities, taking care of your family, or both, always have a contingency plan in case your symptoms flare up. Make



arrangements with a neighbour, family friend, or family member who can pick your child/ children up from school, or depending on your job it may be possible to arrange a number of days when you can work from home in the event that you're unable to make it to your place of work.

2. Have the Right Tools at Hand. If mobility is sometimes a concern for you, have assistive devices, including a stick or a wheelchair, at the ready, either in a hallway or in the boot of your car. Most of us today use assistive devices such as



PDAs or computers, using a mobility device isn't giving in to the MS it's a way of taking charge of it and using the tools you need to get the job done.

3. Pace Yourself. People who live with MS tend to cram everything in when they have a good day because they don't know what the next day will bring, but at times that can backfire. Balance activity with rest, and listen to your body.



Stop before you become exhausted and hit a wall; otherwise, you may experience payback the next day. Remember pushing yourself too hard can leave you exhausted, so don't take on more than you can comfortably handle.

4. Focus on Health.

While managing your MS is important, make sure you don't ignore other aspects of your health. Getting enough rest, eating a healthy diet (one that's high in fibre and low in fat), and exercising regularly are all



important to staying well. After all, having MS doesn't mean you're immune to other illnesses. Taking steps to stay healthier overall will also help you cope better with your MS symptoms.

## 5. Recognise stressors and deal with them

Whether you listen to music, read a book, exercise, engaging in something you find enjoyable and relaxing can help you cut down on stress, which may exacerbate MS symptoms. While there's no definitive research linking stress to the worsening of MS symptoms, experts say that too much stress can certainly cause unpleasant physical symptoms including upset stomachs and knotted necks and tense muscles. Because people living with MS are affected by stress in different ways you may find it stressful to cut back on work, while someone else may find having a full-time job too stressful - doctors advise that you determine how your body reacts to stress and work with your doctor to find effective ways to relax.

#### 6. Make Time for Exercise.

Research shows that exercise can help ease symptoms for many people with MS. In a study conducted by researchers at the University of Utah (in the United States), both high-intensity



resistance training and standard exercise programs were shown to significantly lessen fatigue in people with moderate to severe MS.

It has been suggested that moderate aerobic exercise, which may improve muscle strength and bladder and bowel function, as well as stretching exercises to relieve stiffness and improve flexibility and mobility. Just be sure to take some basic precautions based on your symptoms; if you're having problems with balance, for instance, consider swimming or riding a stationary bike. Take regular breaks and drink plenty of water so that you don't become overheated, which has been shown in some people to temporarily aggravate MS symptoms.

- 7. Get Help Early. Whether it's managing financial setbacks or handling problems related to mood or well-being, it's especially important for people with multiple sclerosis to make sure they don't wait until they're in a really bad place before asking for assistance. Once you're in a crisis, it can be tougher to get your life back on track. Get a support team in place and ask for help in finding treatment and solutions at the first signs of trouble, no matter what problem you face.
- 8. Know the Signs of Depression.

  Depression is so common among people living with MS, at least 50 percent of people who have multiple sclerosis experience depression. If you experience symptoms of depression such



as a loss of interest in daily activities; changes in appetite, sleep patterns, or mood; feelings of worthlessness or guilt; or even persistent thoughts of death or suicide consult a doctor immediately. Depression is treatable; living with MS is hard enough without having to deal with it while you're depressed.

9. Plan for the Long Term. Early career and financial planning for the future can go a long way toward making your life easier. Just as you don't know how you're going to feel tomorrow, you won't be able to predict how your MS

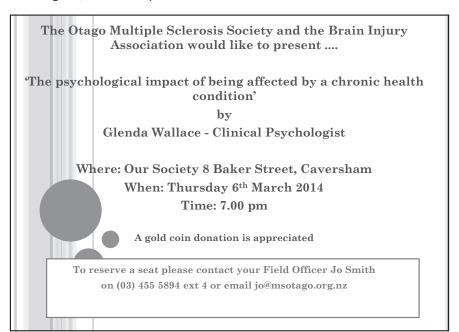


will affect you in the years ahead. Ask yourself questions such as "What kind of work might I do if I'm unable to continue the career path I'm on now?" and "Am I prepared for a period of unemployment?" "Taking steps to prepare for the future can help people feel less stressed and give them a sense of control over their situation.

**10. Create an Efficient Home and Workstation.** Even if your MS symptoms are minor and you experience only occasional fatigue, it's a good idea to take a look at and organise your surroundings so you use less energy to get



things done. For example, putting frequently used items within easy reach is a simple way to make your life a bit easier. Think of it as having a certain amount of energy each day, do you want to use all your energy getting somewhere, or do you want to conserve that energy as much as possible so that you can enjoy whatever you plan to do once you get there?



## Boosting vitamin D could slow progression, reduce severity of multiple sclerosis

For patients in the early stages of multiple sclerosis (MS), low levels of vitamin D were found to strongly predict disease severity and hasten its progression, according to a new study led by Harvard School of Public Health (HSPH) investigators in collaboration with Bayer HealthCare. The findings suggest that patients in the early stages of MS could stave off disease symptoms by increasing their vitamin D intake. "Because low vitamin D levels are common and can be easily and safely increased by oral supplementation, these findings may contribute to better outcomes for many MS patients," said lead author Alberto Ascherio, professor of epidemiology and nutrition at HSPH.

The study will appear online January 20, 2014 in *JAMA Neurology*. MS is a central nervous system disease that causes problems with muscle control and strength, vision, balance, feeling, and thinking. It's estimated by the World Health Organization that roughly 2.5 million people in the world have MS.

Previous research indicated a connection between low levels of vitamin D and risk of developing MS or having MS symptoms worsen, but those studies included patients with longstanding MS whose vitamin D levels could partly be a consequence, not a predictor, of disease severity. The new study looked at vitamin D levels among patients at the time of their first symptoms of the disease

Researchers analysed data from 465 MS patients from 18 European countries, Israel, and Canada who enrolled in 2002 and 2003 in the BENEFIT (Betaseron in Newly Emerging Multiple Sclerosis for Initial Treatment) trial, which was aimed at comparing the effectiveness of early versus late interferon beta-1b in treating the disease. The scientists looked at how the patients' vitamin D levels which were measured at the onset of their symptoms and at regular intervals over a 24-month period correlated with their disease symptoms and progression over a period of five years.

They found that early-stage MS patients who had adequate levels of vitamin D had a 57% lower rate of new brain lesions, a 57% lower relapse rate, and a 25% lower yearly increase in lesion volume than those with lower levels of vitamin D. Loss in brain volume, which is an important predictor of disability, was also lower among patients with adequate vitamin D levels. The results suggest that vitamin D has a strong protective effect on the disease process underlying MS, and underscore the importance of correcting vitamin D insufficiency, which is widespread in Europe and the U.S., the researchers said.

"The benefits of vitamin D appeared to be additive to those of interferon beta-1b, a drug that is very effective in reducing MS activity. The findings of our study indicate that identifying and correcting vitamin D insufficiency should become part of the standard of care for newly diagnosed MS patients," said Ascherio.

**Source:** Harvard School of Public Health Published: Wednesday, January 22, 2014.



Everyone using a health or disability service has the protection of a Code of Rights. An independent Commissioner promotes and protects these rights under a New Zealand Law called the Health and Disability Commissioner Act 1994.

Your rights when receiving a health or disability service:

- 1. To be treated with respect.
- 2. To be treated fairly without pressure or discrimination.
- 3. The right to dignity and independence.
- 4. To receive a quality service and to be treated with care and skill.
- 5. To be given information that you can understand in a way that helps you communicate with the person providing the service.
- 6. To be given the information you need to know about your health or disability; the service being provided and the names and roles of the staff; as well as information about any tests and procedures you need and any test results. In New Zealand, people are encouraged to ask questions and to ask for more information to help them understand what is going on.
- 7. To make your own decision about your care, and to change your mind.
- 8. To have a support person with you at most times.
- To have all these rights apply if you are asked to take part in a research study or teaching session for training staff.
- 10. The right to complain and have your complaint taken seriously.

## FUNDRAISING ITEMS AVAILABLE FOR OUR SOCIETY

## 2014 DIARY PENS (with a pull out calendar)

A number of our members have purchased these for gifts already, and some have them available to pass onto others. Please note that these pens are inexpensive at only \$2.00 per pen.

We have had professionally made display boxes to hold our pens, and you may know of a business that would be happy to support our Society by having one of these on their premises, if you do then please contact Tania on (03) 4555 894 ext 2.



## MS OTAGO DESIGNER EARRINGS

Many of you have seen the lovely MS Otago earrings that some of us wear. As we had a number of very positive comments made about these earrings we asked Kismet Jewellery if they would have some more made



especially for our Society. We thought it was an excellent opportunity to raise awareness of MS, raise the profile of our Society, and to generate some income.

To those of you who have purchased a pair of earrings thank you!, and we now only have 12 pairs available so we have reduced the cost of these earrings to \$ 15.00 a pair!!!!

These would make a lovely gift for someone. If you wish to purchase a pair please contact Tania on (03) 4555 894 ext 2.

## **BULK TOILETPAPER STILL AVAILABLE**

Thank you to all of those who have already purchased some toilet paper. Stock supplies of toilet paper are literally walking out the door! Be in quick and order yours now. They are \$20.00 per pack which include 45 rolls. If you wish to purchase a pack please contact Tania on (03) 4555 894 ext 2 to arrange a time to collect yours.

Please note that all the above fundraising is part of the Otago Multiple Sclerosis Society Fundraising Programme.



## Multiple Sclerosis Researchers Celebrate Breakthrough Gene Discovery

A milestone has been reached on the path to finding a cure for multiple sclerosis, researchers believe.

A group of international scientists, including an Australian contingent, has discovered 48 previously unknown genes that influence the risk of developing the disease.

MS, which attacks the central nervous system and can have an impact on mobility, balance and sensation, affects 23,000 Australians.

The discovery is a big step towards finding a cure and further treatment for the debilitating condition, according to University of Sydney associate professor David Booth, who led the Australian and New Zealand component of the study.

"The exciting thing about this is we have doubled the number of genes that we now know are associated with MS," he said. "What that means is every one of those new genes is potentially providing us with a new way to understand the disease and to come up with new therapies for the disease."

Researchers believe the findings underline the central role the immune system plays in the development of MS.

The results also show an overlap with genes found to

be linked to other autoimmune diseases, including inflammatory bowel disease and coeliac disease.

The findings of the team of scientists, working under the umbrella of the International Multiple Sclerosis Genetics Consortium, were published in medical journal Nature Genetics on Monday.

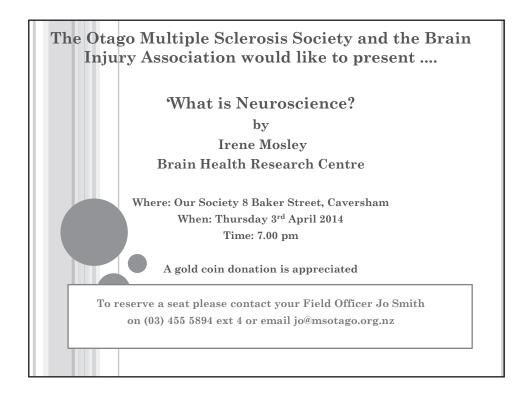
As part of the study, the largest investigation of MS genetics to date, DNA from blood samples from 80,000 people with and without the condition were examined, including 1800 from Australia and New Zealand.

Booth said the "milestone" provided specific research targets. "So going forward we will try and find out why all of these genes affect MS," he said. "And particularly finding which processes are tagged by groups of genes and that will give us specific information on immune processes that are not functioning as they should."

As a result of the findings, there are now 110 genetic variants linked to MS.

MS Research Australia's chief executive, Matthew Miles, said the work was a huge contribution to understanding MS.

Source: The Guardian, 30 September 2013





## **Otago Multiple Sclerosis Society AGM**

When: Monday 17th March 2014

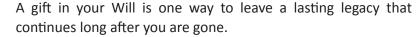
Time: 1.00 pm

Where: 8 Baker Street, Caversham, DUNEDIN

Please support the Society by attending this event

## A LASTING LEGACY

We all have a different way we want to leave our mark on the world. As little as 1% of your estate will make a lasting difference to the Otago Multiple Sclerosis Society, which will enable us to continue supporting, providing services and education to people with Multiple Sclerosis and other neurological illnesses.





## **HOW DO I MAKE A BEQUEST?**

A bequest is made through your Will. If you already have a Will, all you need to do is add a codicil (supplement), which amends part of the Will. You are able to place conditions on any bequest, but since your bequest is likely to be received far into the future, it is more beneficial if its terms are as general as possible. We recommend that you seek legal advice from your Solicitor when adding a bequest to your will.

## **SAMPLE BEQUEST**

I give \$\_\_\_\_\_ or \_\_\_\_\_ % of my estate to the Otago Multiple Sclerosis Society (Inc) to be applied for its general purposes. A receipt taken by my trustees as being given on behalf of the beneficiary will be a complete discharge to my trustees for this legacy.

## **DunedinPrint**

Inspiration | Design | Innovation

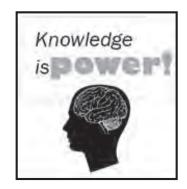
**Proud to sponsor MS Otago** 



For all your print requirements please contact:

P: 477 8213 E: print@dunedinprint.co.nz 297 Vogel St, Dunedin 9016

# Knowledge is Power Series for Newly Diagnosed



This is a free at-home educational series for people newly diagnosed with multiple sclerosis, their families and support network.

Knowledge is Power was first developed in the USA. It has been written by highly regarded professionals who know about MS and the effect it can have on your life and the lives of those around you.

The programme has been reviewed and adapted by MS Australia and used there. MSNZ has reviewed this programme and it is now available here.

Being newly diagnosed with a condition like MS can be difficult and stressful time for all those affected. You, your family, friends and colleagues may know very little about the disease, or may know enough to be overwhelmed and frightened by this new development in your life. There is a lot of information to take in.

Knowledge is Power makes it easy for you to learn about MS and how it can affect your life and the lives of those around you.

We have divided the information into 10 easy-toread modules. Over time we have found that most

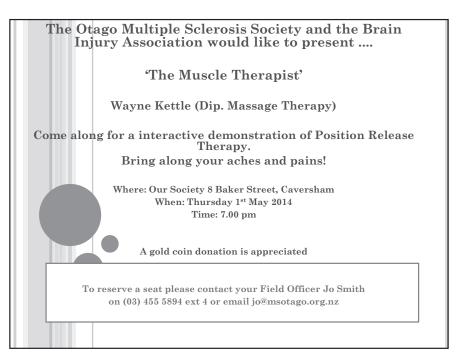
newly diagnosed clients share a common feeling of being totally overwhelmed and dealing with one of the greatest challenges that MS presents-the unpredictability and uncertainty of what might happen in the future. We believe that passing on a couple of modules at any one time allows you to read and learn at your own pace, and it's possible that not all of the modules will be relevant to your situation.

Currently the series is available through our National Society, and here in Otago. The modules can be posted directly to you, or a home visit can be arranged with Jo to discuss the modules available in more detail. We are hoping that in the very near future these modules will also be available via email.

The modules that are currently produced are:

- What Multiple Sclerosis is
- Dealing with your diagnosis
- Disclosing your diagnosis
- Managing your MS
- Disease modifying drugs for MS
- Working with your doctor
- The impact of MS on your family
- Maximising your employment options
- Building and maintaining intimate relationships
- Parenting issues for people with MS

If you wish to receive any of these modules, or should you have any further queries please do not hesitate to contact our Field Officer Jo Smith on (03) 4555 894 ext 4 or via email jo@msotago.org.nz



## **MS** in Family Members

There are very substantial risks of developing MS in family members and children of people with MS. Children of a parent with MS have about a 30-40 times higher risk than the rest of the population. This may be even higher if they smoke and are female. But there are now good data on reducing MS risk with adequate sun exposure and/or vitamin D supplements. I believe it is now a clear responsibility for doctors managing people with MS to advise them of this important avenue through which to potentially protect their children and other relatives from developing the disease.

The evidence for this risk reduction with sun exposure or vitamin D supplements or both is now clear. The 2003 Tasmanian study showed a major reduction in risk of MS for those who get adequate sun exposure, particularly in childhood in winter.1 For those who live in areas where getting adequate sunlight is a problem, or for those who wish to avoid the sun for other health reasons, the US Nurses Health Study has clearly shown that MS risk can be nearly halved by taking a small supplement of vitamin D (in that study anything over 400IU).2 From our knowledge of vitamin D effects on the body and immune system, it is likely that a higher dose would have even more significant protective effects.

My recommendation for close relatives of people with MS would be a supplement of 5 000IU a day in winter and in summer on days when there is limited access to sun, reduced proportionately for children. The aim is to keep the level of vitamin D in blood at above 100nmol/L (40ng/mL in the USA). This is the level above which a number of studies have shown a protective effect against developing MS.

So to calculate the dose for children, using 50kg as the adult dose equivalent, a 25kg child would need half this dosage, and similarly a 10kg child one fifth of the dose. This can be omitted on days when there is adequate sun exposure. It has been suggested that on a population basis, in areas of high MS prevalence, supplementing with vitamin D during pregnancy and early childhood could prevent a great proportion of the MS in the world.3 The author suggests that, like folic acid, vitamin D supplementation should be routinely recommended in pregnancy. This is supported by a large epidemiological study showing that babies born at the end of winter were more likely to get MS later in life than those born at the end of summer.4 Children are never too young to begin vitamin D supplements; indeed they should ideally start while in the womb.

The evidence in relation to dietary change is not so clear cut. While I am a strong advocate for people

with MS following a plant-based wholefood diet that is very low in saturated fat, as



detailed on this website, the question of whether to put family members on the same diet to reduce their risk has not been so clearly answered. Professor Swank points out in his book The Multiple Sclerosis Diet Book that he placed all family members on the same diet. Further in his experience of over 3,500 patients with MS, not one of their relatives on the diet developed the disease, to his knowledge. This is pretty extraordinary, given the statistics we have seen of the high risk in relatives. In Canada, around 1 in 500 people gets MS, and that risk is raised 30-40 fold in first degree relatives of people with MS. So in the 3,500 families Swank treated, we would have expected to see many hundreds of new cases of MS. To have not documented a single case is quite remarkable; given that Swank was the neurologist looking after these people, any such cases would almost certainly have come to his attention. So many people with MS will opt to use all avenues to protect their children and modify their diets as well as supplement with vitamin

### Overview

Overall, the evidence is compelling. People with MS can, on the basis of the evidence presented here, reasonably expect to be able to reduce the risk of MS developing in our relatives. This will be very reassuring for those of us naturally very concerned about the health of our children and close relatives who are at greatly increased risk of developing this disease. It is good to finally see the MS societies starting to recommend vitamin D supplementation during pregnancy and for children where a parent has MS.

#### References

- 1. van der Mei IA, Ponsonby AL, Dwyer T, et al. Past exposure to sun, skin phenotype, and risk of multiple sclerosis: case-control study. BMJ 2003; 327:316.
- 2. Munger KL, Zhang SM, O'Reilly E, et al. Vitamin D intake and incidence of multiple sclerosis. Neurology 2004; 62:60-65.
- 3. Chaudhuri A. Why we should offer routine vitamin D supplementation in pregnancy and childhood to prevent multiple sclerosis. Med Hypotheses 2005; 64:608-618
- 4. Willer CJ, Dyment DA, Sadovnick AD, et al. Timing of birth and risk of multiple sclerosis: population based study. BMJ 2005; 330:120

Page last updated:01-Oct-2013

## **Staff News**

Hello to you all. I hope that you all had an enjoyable and relaxing holiday break, and that you managed to spend time with family and friends.

The first 2 months of 2014 have simply flown by, and most of us have settled back into work mode, and those with children the daily school routine.

It has been pleasing to see the sun recently as this gives me the opportunity to escape outside into my garden, weeding has become the number one priority, following closely behind, finishing off a couple of outside projects that were started a number of months ago.

During the holiday break we didn't travel to Nelson, instead we opted to stay at home; we took the odd day trip here and there particularly when the weather permitted. Nana and Grandad from Nelson are due for a visit in April which the girls are looking forward to, but the biggest news is that my younger sister and her 3 children have moved to Dunedin, so Hannah and Katelin are getting to spend lots of time with their Aunty and younger cousins, and Pete and I get to play "Aunty Tarn and Uncle Pete" which is interesting when all 5 kids are together, you can imagine the noise and mess the children can make!

Hannah and Katelin have settled into the new

school year, the nightly homework is met with the odd moan or two, the weekly sporting activities are due to start, and Katelin is off to camp for a week, there is just not enough hours in the day to get everything done.

Jo enjoyed her time away travelling back to the UK with her family, and as promised she is well and truly back on deck!



Tania McGregor Manager

We entered a team in The Southern Trust Masters Games 5KM walk, it was wonderful to have past members participate again, but it was great to have new members being involved, both Jo and I were extremely proud of the way our team completed the challenge and the biggest achievement was all of the team finished!!!

As always Jo and I are looking forward to implementing new initiatives and ideas during the coming year, and we are both looking forward to what 2014 may bring.

It is good to have all our members back to the groups. I hope you all enjoyed time with your families during the Christmas period. Congratulations to all who took part in The Southern Trust Masters Games walk for 2014, this was a really good turnout of members and supporters, and the greatest achievement was everyone finished the 5 kilometres.

I am always looking to try to new recipe ideas so if you have a favourite food or there is something you would like us to try, please feel free to come and speak with me about it.

I am looking forward to another wonderful year with you all.



Pam Macdonald Health Officer



"The University of Otago Human Nutrition department is seeking people with Multiple Sclerosis to share attitudes and beliefs towards nutrition and where you seek your dietary information from. This involves a 15 minute online questionnaire about your current dietary beliefs dietary intakes in the form of agreement or disagreement with various statements.

If you are interested in completing the questionnaire, please email Natasha Bourke at bouna016@student.otago.ac.nz or contact Jo Smith (Field Officer) for the email link to complete the questionnaire online.

Happy New Year, Christmas and New Year seems like a distant memory now as it is March already and Christmas is only 9 months away! My family and I had a wonderful time back in the UK and I even brought back some interesting literature regarding MS in the UK for which I hope to share with you over the coming months.

Tania and I have been recently updating some of our brochures. This has been an exercise that has prompted us to consider the ways in which the Society is able to support our people. This includes whether it's for a person with Multiple Sclerosis (MS), their caregivers, their family & friends and also not to forget the employers and colleagues of someone with MS. As a Society we are here to support everyone involved in the care of a person with MS including other health care professionals.

### So, as your Field Officer what can I do for you?

Firstly and most importantly I am here to listen. My qualification is in Counselling therefore I have highly developed interpersonal skills. I believe in the importance of developing positive collaborative relationships with both clients and external healthcare agencies to be able to better support our clients.

I am able to visit you in your home or it may be that we meet at another place that you feel comfortable. I can provide you with information about MS, to those established and newly diagnosed clients and answer any questions that you may have. A recently visited client said that things didn't seem so scary when you have support and someone to help you through all the information, then you are able to take control of your MS.

Other than being another source of support I am able to help in practical ways. I can refer you to counselling, physiotherapists, occupational therapists, nutritionists, social workers, continence nurses, speech language therapists and the list goes on. The Society works closely with Access Ability so that we can refer to them if you need home help or personal carers, respite at McGlynn etc.

I am happy to advocate for you especially for such things as work place issues, visiting Government Departments, hospitals and other health care providers. I can assist and support you in applying for lottery grants for mobility equipment whether that's a mobility scooter or a modified vehicle. We also provide applications for Total Mobility taxi vouchers which allows you ½ price taxi fares.

You are welcome to become part of our Social Groups which I facilitate in



Jo Smith Field Officer

all Otago regions. These groups are informative, educational, supportive and most of all fun! We also have 'Guest Speaker Evenings' once a month here in Dunedin in which we provide quality speakers on a range of topics associated with living alongside a chronic illness such as MS.

I would like to note that if you have something you wish to discuss, I am able to be contacted by a number of ways. I am available from 9am – 3pm Monday to Friday, you are more than welcome to visit me at my office located at 8 Baker Street, Caversham, Dunedin, you may choose to email me jo@msotago.org.nz or ring me directly (03) 455 5894 ext 4. I welcome your calls but if I am away from my desk please leave a message and I will get back to you upon my return.

Here's to you wishing you a wonderful 2014 and I look forward to what this year has to bring. Take care and please don't hesitate to contact me if you have something you wish to discuss. My 'door' is always open!

Always tell someone how you feel, because opportunities are lost in the blink of an eye but regrets can last for a lifetime.

## Vitamins, minerals, and supplements

To find out whether a supplement will provide specific benefits, it is necessary to understand how the immune system works in MS and how a specific vitamin or mineral will impact the immune system. As MS is an autoimmune disease in which the immune system appears to be attacking the body and causing damage to the CNS, any supplement that claims to boost or improve the immune system should be avoided. Additionally, in evaluating vitamins and minerals for use as potential symptomatic and/or disease-modifying treatments, it is important to look at evidence for the effectiveness and safety of these substances.

Dosing is an important factor with vitamin or mineral supplements. Vitamins or minerals taken at a certain dose may be beneficial. However, taken at a higher dose, the same vitamin or mineral may be harmful. So, it is very important to work with your doctor and other members of your care team to determine which supplements you should take and what the proper dose should be.

#### Basics about vitamins and minerals

Vitamins are chemicals that our bodies need to maintain health. Except for vitamin D, which is a hormone produced in the skin when exposed to sun, we typically get our daily requirement of vitamins from dietary sources (foods and drinks). Vitamin D can also be obtained from some foods.

Minerals are inorganic substances. Like vitamins, our bodies need certain minerals to stay healthy and

we can get these from dietary sources. The Food and Nutrition Board of the National Academy of Sciences has defined the recommended daily allowance (RDA) of different vitamins and minerals that we need to consume on a daily basis. There is general agreement that we should get the RDA of basic vitamins and minerals to stay healthy. There is controversy, however, about whether we should take more than the RDA of certain vitamins and minerals. It is understood that getting too much of some vitamins and minerals may be dangerous to health. This is why it's important to talk to your doctor before you take any vitamin or mineral supplement (or any other type of supplement).

#### Vitamins and minerals in MS

A variety of vitamins, minerals, and other related supplements have been evaluated for use as symptomatic and disease-modifying treatments for people with MS. The most important of these include vitamin D and vitamins and minerals with antioxidant effects, such as vitamins C and E and selenium.

#### Vitamin D

Vitamin D supplements are potentially important for people with MS from both the perspective of symptom management and disease-modifying effects. Vitamin D is recognized as an important factor in maintaining bone density and people with MS are at increased risk for bone loss (osteopenia and osteoporosis) for many reasons, including corticosteroid use, decreased sun exposure, and loss of mobility.

Results from several studies suggest that increased blood levels of vitamin D (as well as high intake of the vitamin) may be associated with a decreased likelihood of developing MS and a decreased risk of exacerbations and disability progression in people with MS. More studies are needed to determine a clear relationship between vitamin D and MS and for more definitive evidence as to whether vitamin D supplementation truly has disease-modifying effects. Albeit, people

with MS may choose to take vitamin D supplements at modest amounts of 1,000 to 2,000 international units (IU) daily. The generally accepted safe upper limit for daily vitamin D intake is 4,000 IU, however higher amounts may be recommended based on your specific circumstances.. If you would like to use vitamin D supplements, talk to your doctor first. Your doctor can give you a blood test to find out your blood level of vitamin D and, if it's below normal, your doctor may suggest a daily supplement amount to bring your levels



up to normal.

## **Antioxidant vitamins**

The idea behind taking antioxidant vitamins, which include vitamin A (usually taken as beta-carotene, which is a safer form of the vitamin), and vitamins C and E, is that these vitamins reduce damage caused by free radicals. A free radical (also called an oxidant) is a molecule in the body that has an unpaired electron. These molecules are very unstable because they are constantly trying to pair their unpaired electron. This causes them to react with other substances in the body, resulting in oxidative damage. The RDA of antioxidant vitamins can be obtained by eating 3 to 4 servings of vegetables and 2 to 4 servings of fruits every day. The safety of taking antioxidant vitamin supplements in amounts exceeding the RDA has not been established in people with MS and there is a theoretical risk that these vitamins may stimulate the immune system,

which is already overactive in MS.

Vitamins C and E, in combination with selenium, have been tested in a small study conducted in people with MS. Although the combination was well tolerated, the study was too small to make any determination about effectiveness.

It is also thought that vitamin C may be useful in helping prevent urinary tract infections, which can occur commonly in people with MS. The idea behind this is that vitamin C may help to make urine more acidic, which in turn makes it more difficult for bacteria to colonize the urinary tract. However, evidence indicates that vitamin C does not acidify urine. Therefore, there is some controversy about whether intake of high amounts of vitamin C is beneficial for a person with MS. Evidence does support the use of cranberry (in

pill or juice form) to acidify urine and protect against urinary tract infections. Vitamin E, which is available in vegetables, nuts, meats, vegetable oils, and fruits, prevents oxidative damage in the body. If you are taking polyunsaturated fatty acid (PUFA) supplements or consume a diet high in PUFA, which is thought to be beneficial in MS, your requirements for vitamin E

will go up. Before you start increasing PUFA intake, talk to your doctor about how this will increase your need for vitamin E.

Vitamin A is an important vitamin for eye health as well as normal cell growth throughout the body. Sources of vitamin A include liver, eggs, and cod liver oil. Vitamin A is a fat soluble vitamin which is stored in the body and may accumulate over time. Therefore, you should avoid taking too much of this vitamin. The RDA for men and women ranges from 2,300 to 3,000 international units (IU) and daily intake should not exceed 10,000 IU. If you are pregnant, you should not consume high amounts of vitamin A because intake of excessive amounts of this vitamin may result in birth defects. Pregnant women should limit vitamin A intake to the safer form of the vitamin found in fruits and vegetables called beta-carotene.

## Vitamin B6

B complex vitamins, which contain vitamin B6 (pyridoxine), are taken to increase energy. Natural sources of vitamin B6 include many different foods, such as fish (salmon and tuna), vegetables, chicken and pork, beans, and bananas. The RDA for vitamin B6 is 1.3 milligrams for adults ages 19-50 years and high amounts of the vitamin (such as 1,000 milligrams) can cause numbness, tingling, or pain. These symptoms are reversible once supplementation is decreased.

#### Vitamin B12

Claims have been made that vitamin B12 (cobalamin)

is an effective treatment for MS. However, there is little evidence to support these claims. Deficiencies in vitamin B12, which can lead to MS-like neurological symptoms, are typically found in only a small number of people with MS. In patients who have low levels of vitamin B12, a supplement should be used. Natural sources for vitamin B12 include meat, poultry, shellfish, eggs, and dairy products.

#### Selenium

Vitamin B Folic acid Vitamin Vitamin

Vitamin Vitamin

The mineral selenium has antioxidant effects and sources include legumes, seafood, whole grains, lean meats, and dairy products. Supplementation of the mineral selenium is potentially useful in MS because of the antioxidant properties of this substance. Selenium is contained in antioxidant enzymes (thioredoxin reductase and glutathione peroxidase) which are active

in reducing certain oxidized molecules in the body. Selenium (in combination with vitamins C and E) was tested in a small study conducted in people with MS. Although the combination was well tolerated, the study was too small to make any determination about effectiveness.

#### Calcium

Adequate intake of calcium, which is the most abundant mineral in the body, is important to maintain the health of bones and teeth, and the regulation of vital body processes. An old hypothesis that high calcium intake (consumption of large amounts of milk or other dairy products) during childhood, with a sudden decrease in consumption at adolescence, can cause MS is not supported by much evidence. Dietary sources of calcium include dairy products, leafy vegetables, and eggs. People with MS are at increased risk for bone loss, so adequate calcium intake is crucial (RDA for adults: 1,000 to 1,200 milligrams). Calcium taken in excess amounts may result in toxic effects. To avoid this risk, calcium intake should not exceed 2,000 milligrams per day for those over 50 years of age and 2,500 milligrams for those 19 to 50 years of age.

#### Zinc

Zinc is used in many different processes in the body (RDA for men: 11 mg; women: 8 mg). There have been few systematic studies of zinc in MS. Results from some studies have shown that people with MS have low levels of zinc, while other studies have shown the opposite. These latter studies have suggested that zinc may work to activate the immune system and that zinc supplementation may worsen MS. High intake of zinc can result in copper deficiency, which may result in MS-like neurologic symptoms.

Article sourced at: http://multiplesclerosis.net/ natural-remedies/vitamins-supplements The Neurological Foundation and the University of Otago present

## Brain Day 2014 DUNEDIN FREE PUBLIC EVENT Saturday 15 March | 10am - 3pm

Brain Day Dunedin is a FREE public event brought you by the Neurological Foundation of New Zealand and the University of Otago's Brain Health Research Centre as part of Brain Awareness Week. This is a unique opportunity to enjoy a programme of presentations from leading international and New Zealand neuroscientists and clinicians who provide updates of their incredible research work in the laboratory and clinic.

Please join us for an exciting line-up of key speakers, a panel discussion and lectures (see schedule below) on Saturday 15 March!

**NEW VENUE: OTAGO MUSEUM** 

#### **KEY SPEAKERS**

10:00-11:15am

## Changing our minds and boosting our brains

**Dr Helena Popovic** Medical doctor and author

Dr Helena Popovic is a medical doctor, author, international speaker and one of Australia's foremost authorities on how to maintain brain function. Her book *In Search of My Father*, which was showcased to a capacity audience at the 2013 Auckland Writers and Readers Festival, is an uplifting story of caring for her dementia-stricken father and taking charge of brain health.

Dr Popovic is visiting New Zealand in March 2014 to support the Neurological Foundation's Brain Awareness Week programme. In this FREE public lecture, she will talk about the many things that we can all do to optimise our brain function and reduce the risk of dementia. As a doctor involved with the ongoing care of her father, she has applied the same principles to his everyday care. Dr Popovic says the three main things that we can all do are physical exercise, meaningful social connection and mental stimulation. She says "The latest research shows that participating in exercise and social stimulation greatly decreases the chance of getting dementia. For the brain to stay healthy and operate at its best, we also need the right nutrition, rest, stimulation, challenge and reward."

## Displays and information

Various community support groups and the Neurological Foundation will have staff present at information stands during the day – feel free to chat with staff before and after lectures.

## 11:30am-1:00pm

#### **PANEL DISCUSSION:**

## The neuroscience of tinnitus

Featuring Neurological Foundation Chair of Neurosurgery Professor Dirk De Ridder, Professor Deborah Hall (Nottingham) and Dr Grant Searchfield (University of Auckland)

Chaired by local journalist, author and filmmaker **Allan Baddock** 

Following on from the week's international Tinnitus Research Initiative conference in Auckland, our three panellists will answer Allan's clinical and scientific questions regarding the latest research, progress and treatment prospects for this debilitating condition.

Make the most of the opportunity to hear three world-class tinnitus researchers in one event – question and answer time will follow the panel discussion.

## 1:30-3:00pm

## Stem cell transplants for Parkinson's disease

**Arnar Astradsson** Neurosurgeon

Parkinson's disease (PD) is a debilitating neurodegenerative disorder characterised by the loss of dopaminergic neurons in a specific area of the brain. As an alternative therapeutic strategy to drug therapies or high-frequency deep brain electrical stimulation (DBS) for patients with PD, stem cell-based therapies are being developed. Although obtaining and delivering the appropriate cell types to patients is challenging, the potential therapeutic benefit of this option is considerable.

Visiting from Denmark's leading hospital, Copenhagen's Righospitalet (comprising 76 operating theatres), neurosurgeon Arnar Astradsson will discuss recent advances in the field of stem cell therapy for Parkinson disease. It is hoped these advances will create a viable, long-term treatment option for synaptic repair for this debilitating disease.

## -1:00-1:30pm | BREAK-

The Museum café will be open. Order a delicious coffee then wander through the community groups stand area and view the plastinated brain display.

#### Check out the University of Otago School of Physio stand area:

- Practice a simple balance test and receive feedback on your performance
- Try the Equitest balance machine from the School of Phsylo clinic
- Watch a dvd of the Parkinson's group dance class
- Speak to the physio team and observe their collection of clinic resources in action

No bookings required to attend lectures | Please arrive early to secure your seating – our key speakers have attracted large numbers at past events | For further information, go to www.brainweek.co.nz or phone 0508 BRAINS (0508 272 467)







BRAIN DAY DUNEDIN | OTAGO MUSEUM | 419 GREAT KING ST, NORTH DUNEDIN

## The Otago Multiple Sclerosis Society gratefully acknowledges the generous support of

















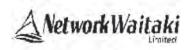






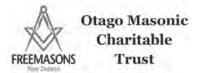
St Kilda **Community Sports** Society





The Marsh Family **Trust** 





ANZ STAFF **FOUNDATION** 















March 2014						
monday	tuesday	wednesday	thursday	friday	saturday	sunday
31					1	2
3	4	5	6	7	8	9
Social Group	Games Group		Guest Speaker @ 7pm			
10	11	12	13	14	15	16
	Games Group	Mosgiel Group	Men's Group			
17	18	19	20	21	22	23
AGM 1pm	Games Group					
Social Group						
24 Otago Anniversary	25	26	27 Social Evening @7pm	28	29	30

April 2014						
monday	tuesday	wednesday	thursday	friday	saturday	sunday
	1	2	3	4	5	6
	Games Group		Guest Speaker @ 7pm			
7	8	9	10	11	12	13
Social Group	Games Group	Mosgiel Group	Men's Group	Oamaru		
14	15	16	17	18	19	20
	Games Group	Balclutha	Central Otago	Good Friday		
21	22	23	24	25	26	27
Easter Monday	Games Group	Social Evening @7pm		Anzac Day		
28	29	30				
	Games Group					

May 2014						
monday	tuesday	wednesday	thursday	friday	saturday	sunday
			1 Guest Speaker @ 7pm	2	3	4
5	6	7	8	9	10	11
Social Group	Games Group		Men's Group			
12	13 Games Group	14 Mosgiel Group	15	16	17	18
19 Social Group	20 Games Group	21	22	23	24	25
26	27 Games Group	28	29	30	31	