

Momentum

NEW ZEALAND

The Otago Multiple Sclerosis Society Newsletter | ISSUE 1 - SPRING - SUMMER 2017

Hi Members and Clients of Otago MS

Spring has sprung at last and good to see the leaves and flowers appear on the trees and in the garden.

I would first like to thank everyone that supported David the executive committee and myself throughout what has been a difficult time as we continue to work together to breathe positivity into the Society and repair the many misunderstandings that have been created throughout the Otago MS network. Rest assured we are all here to support People with MS and associated conditions and the families involved with that support.

Please note all the executive committee work hard and for many hours and freely give their time and do not receive any payment for these efforts.

This is the week where the National MS society is celebrating 50 years as an organisation and I would like to take a moment to acknowledge the effort that has gone into creating and running a National society so effectively for 50 years.

National was formed by several pioneering regions including Otago 50 years ago and is now run by the 18 regional societies.

At its origin was the concept of advocating for PWMS nationally and it continues to be the most effective tool that the MS community has.

During my husband's time (David) on the national board (1997-2003) they achieved access to funding for Interferons and this was entirely due to the National society and Helen Clark and the newly formed labour government in 1999.

It is interesting that political pressure is constantly required to influence New Zealand health care and national advocating is a prime goal of the National society.

Even today there are currently three life members of the National and one is Anne McAuley who is an ex-president of the Otago Society. Anne was an exceptional Otago President and Dunedin Physiotherapist who retired to Cromwell to start a new life in wine at her own Packspur winery ridge <http://www.packspur.co.nz/about.html> and now her and husband make award winning Pinot Noir.

The Otago society had its own 50 year celebrations in 2015 and this event was celebrated in several ways but in particular by the planting of a tree in the Botanic gardens which is a reminder of all the effort that past society member's executive committee members and employees have put into living with MS and supporting MS over the years.

ms.
Multiple Sclerosis
Otago

INSIDE THIS ISSUE:

Information gathered - page 2

Financial update - page 2

Introducing - page 2

Incidence study - page 4

Regional support - page 4

MS awareness week - page 5

The Dorothy Award - page 8

Breathing to relieve fatigue and increase vitality - page 9

10 tips for managing day-to-day life with multiple sclerosis - page 10

How to prepare for an appointment with your neurologist - page 9

Who are our southern district health board neurologist's? - page 13

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

8 Baker St Street, Caversham
Dunedin 9012

Patron
Dr Catherine Smith
PHD Dip Phyt

Executive Committee
President: Beverly Glenn
Treasurer: David Glenn
Gavin Meed
Peter Roy
Michelle Smith



Cont from page 1.

I myself first came in to contact with MS in 1984 and as it was then it still is now a most complex and debilitating illness.

Well done to President Malcolm Rickerby and Vice president Neil Woodhams and the national team for their continued good work at National.

Currently we are considering the newsletter format and would be grateful if in the future we could send

out an electronic version to people to reduce costs and speed up information to members. If you could email your email address to 8 Baker St office so we can correlate the addresses and send the newsletter out to you.

Please email to your email details if you can receive the newsletter electronically to info@msotago.org.nz.

Kind Regards

Beverly Glenn

INFORMATION GATHERED AND HELD BY THE SOCIETY.

Several members have asked me about the collection of information by the Otago MS society and how it manages or controls that information.

In my years with the society I consider we have controlled the information in line with the requirements of the 1993 Privacy act as we are required to.

Confidentiality is a standard requirement in staff Individual employment contracts and is managed by the obligation of being an employee of the society.

As the executive committee is the employer and the entity that deals with complaints and issues that can be sensitive it's important that confidence in holding this information be established by the society.

For executive committee members though who then become the employer and holder of confidential information on members and volunteers this is slightly different. There is an expectation that executive committee members will sign the society executive committee confidentiality form. This will be a requirement to be observed by every executive committee member.

In my opinion it should form part of the obligation and responsibility of all executive committee members in joining the society and being involved in the handling of what can be personal and private information.

It is commonly expected by all other MS societies in NZ.

David Glenn

FINANCIAL UPDATE FOR THE OTAGO SOCIETY AS AT THE END OF SEPTEMBER.

The society continues to trade well with income from rent at 6 Baker Street and 503 Hillside Road consolidating well. Bequest have been forthcoming with further bequests being signalled we are very grateful for this support.

We have been delighted to be working with the Otago regional council to extract the society from the mobility funding subsidy that they provide. The society has never benefitted from being part of the exchange of money around this and it is good to see that technology has finally caught up with this and the funds are being managed directly with the ORC via a swipe card. It was an onerous task managing the funds between taxis and the ORC and an evitable wait on the repayment of funds. This sum has often been between 10 and 20 thousand dollars. The shop revenue is a highlight with income of 32,000 for the YTD ahead of budget and supporting cash flow as well. We have been delighted to negotiate with the open polytechnic to rent our rooms to them to provide a regular venue for the Horticulture course they are delivering to the community at large.

Given we did not have the services of an administrator/organiser of the Street appeal the executive committee felt it prudent to postpone this till next year when support and an organiser is in place.

We are working with Graham McGregor to sign off previous funding applications and get further funding applications in place.

INTRODUCING.

The Otago MS Society would like to introduce two new staff Dr Graham McGregor as Executive director and Serena Cox as Society administrator. Serena started as a temporary administrator on 26 September 2017 to take care of the day-to-day activities of the Society. She comes from a strong administrative background and, as members and visitors may have already discovered, has a bright, warm and welcoming personality. Earlier in the year, Graham assisted with various Grant Applications for the Society, on a voluntary basis. He is pleased to report that three out of four of these Applications were successful. Graham

has offered to continue working for the Society on a voluntary basis to ensure it continues to do the very best it can to fulfil its Constitutional Aim:

"... to stimulate the development and co-ordination of therapeutic, rehabilitative and social services for those persons with Multiple Sclerosis and their families."

Serena and Graham are operating out of the front office and would be pleased to meet individuals as convenient and invite you to drop in for a brew and a chat as the need arises.

Currently the executive committee are interviewing for a Field officer.

OCRELIZUMAB

This report has been developed to update New Zealand Regional Societies about the progress and developments of MSNZ's advocacy work in relation to Ocrevus (Ocrelizumab) for people with MS (PwMS).

In March 2017 the FDA in America approved Ocrelizumab as a treatment for RRMS and PPMS. MSNZ has reviewed the positive research and been in discussions with the pharmaceutical company Roche regarding the treatment since 2016. In August 2016 Roche submitted Ocrelizumab for Medsafe approval which can take over 12 months in most cases. This is still under review and we hope to receive further information by October 2017.

What is Ocrelizumab?

<http://www.roche.com/media/store/releases/med-cor-2017-03-29.htm>

OCREVUS is a humanised monoclonal antibody designed to selectively target CD20-positive B cells, a specific type of immune cell thought to be a key contributor to myelin (nerve cell insulation and support) and axonal (nerve cell) damage. This nerve cell damage can lead to disability in people with MS. Based on preclinical studies, OCREVUS binds to CD20 cell surface proteins expressed on certain B cells, but not on stem cells or plasma cells, and therefore important functions of the immune system may be preserved.

How is Ocrelizumab Administered?

OCREVUS is administered by intravenous infusion:

First & second infusions (day 1 and day 15):

Pre-medications 30-60 mins before infusion

Infusion 2.5 hours

Observe for at least one hour after infusion

Subsequent infusions

Pre-medications 30-60 mins before infusion

Infusion 3.5 hours

Observe for at least one hour after infusion

Side effects

Patients most commonly experienced mild to moderate infusion reactions and upper respiratory tract infections. There were also slight increased risks of oral herpes reactivation and neoplasms which should be considered when assessing treatment appropriateness.

Read more: Safety of Ocrelizumab in Multiple Sclerosis: Updated Analysis in Patients with Relapsing and Primary Progressive Multiple Sclerosis - poster presented at the 69th American Academy of Neurology (AAN) Annual Meeting; April 22-28, 2017; Boston, MA, USA

No cases of Progressive multifocal leukoencephalopathy (PML), a rare and potentially fatal viral brain disease were found during the trials. Since then one case in Germany has been found in an Ocrelizumab patient however causality has been assigned to the earlier use of Natalizumab (Tysabri). Read more here about switching patients at high risk of PML.

More Information about Ocrelizumab

For more information about Ocrelizumab visit: <http://www.roche.com/media/store/releases/med-cor-2017-03-29.htm>



The Otago Multiple Sclerosis Society

www.msotago.org.nz

ROOM HIRE AVAILABLE TO THE PUBLIC

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

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

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

President - Malcolm Rickerby
 Vice President - Neil Woodhams
 National Executive Committee Members
 - Mark Etheridge
 - Jane Heywood
 - Jeff Silvester
 - Ian Chadburn
 - Tony Kerr

National Manager - Amanda Rose
 Communications and Administration Coordinator
 - Emily Smith
 Phone 0800 67 54 63
 Email info@msnz.org.nz
 Website www.msnz.org.nz

INCIDENCE STUDY

This year we made our final payment for the MS Incidence Study with the receipt of the final report, see Page 11. We continue to engage with the researchers about plans to continue to a five-year review to understand participants progress post-diagnosis. The findings have helped guide and support our advocacy work regarding the need for increased funding for neurology services and the importance of early interventions. The study reported the average age of first symptom development was 37.8 years. This is older than the average age recorded in previous studies and notably those with Primary Progressive are diagnosed at a later age. The mean age at diagnosis was 42.2 years indicating that there is a significant delay, almost 4 and a half years, between the onset of first symptoms and diagnosis. Improvements must be made to ensure that symptoms are reported and diagnosis made earlier to enable the initiation of treatment to prevent further accumulation of disability and disease progression.

REGIONAL SUPPORT.

Between July 2016 and June 2017 MSNZ distributed 3,318 information and educational resources to the public and our Regional Societies. MSNZ endeavours to provide nationally consistent and evidence-based resources available free of charge.

Every 6 months our Regions report their statistics for MOH reporting. During this year the statistics clearly showed that there is a continued demand nationally for information and support by MS organisations with:

10,667 email requests for information

5241 face-to-face meetings for information

8733 telephone requests for information

MSNZ continues to deliver our annual Field Worker Training that is progressive and supports PwMS to self-manage their lives. We are also increasing the circulation of relevant, evidence-based and up-to-date information on MS to our Regions to support their clients.

MS New Zealand's mission is to advocate for people with MS(PwMS) in NZ to have access to first world treatments, resources and services to improve their well-being and quality of life and to reduce the burden of MS on those diagnosed, their carers and

families.

PHARMAC provided us with statistics based on an Official Information Act request (18 April 2017) regarding the uptake of the treatments advocated for in recent years. The data clearly demonstrates the success and demand of DMTs and we hope our current advocacy work will continue to increase access for those who research shows would benefit. In the 28 months since the first treatments became available there have been:

901 applications for Fingolimod (Gilenya®), Natalizumab (Tysabri®), dimethyl fumarate (Tecfidera®) and teriflunomide (Aubagio®), or where treatment has not been decided

865 successful applications

889 individuals have claimed their treatment

25 pending applications

8 deferred applications

11 declined applications

A breakdown of data by treatment shows the following.

Fingolimod (Gilenya®): there have been **431** applications, **417** approved **9** pending and **5** declined

Natalizumab (Tysabri®): there have been **261** applications, **250** approved **7** pending and **4** declined

Dimethyl fumarate (Tecfidera®): there have been **188** applications, **177** approved **9** pending and **2** declined

Teriflunomide (Aubagio®): there have been **21** applications, all have been approved

16 applications were declined where no treatment was specified

14 applications were initially declined and then subsequently approved

4 applications for renewal were declined, **2** were subsequently approved

Auckland	82	Auckland
Bay of Plenty	29	Bay of Plenty
Canterbury	129	Canterbury
Capital & Coast	91	Wellington

Counties Manukau	48	Auckland
Hawkes Bay	23	Hawkes Bay
Hutt Valley	44	Wellington
Lakes	19	Rotorua
MidCentral	43	Central
Nelson Marlborough	28	Nelson & Marlborough
Northland	21	Northland
South Canterbury	19	South Canterbury
Southern	102	Southland & Otago
Tairāwhiti	0-5	Gisborne
Taranaki	23	Taranaki
Waikato	64	Waikato
Wairarapa	9	Wellington
Waitematā	118	Auckland
West Coast	6	West Coast
Whanganui	13	Wanganui



CHRISTMAS LUNCH DATES WEEK 2017

Christmas lunch dates.

The Dunedin Christmas lunch is set for Sunday the 3rd of December at 11.30 for 12 Lunch at the Leisure Lodge North Dunedin

The Mosgiel Christmas Lunch date is set for the Thursday the 7th of December at 11.45 for 12.00 at the Mosgiel RSA.

Numbers required to be given to Serena for both events.

MS AWARENESS WEEK 2016

The 2016 Multiple Sclerosis Awareness Week took place across the country between 29 August and 4 September. With funding from Pub Charity Limited, three videos, plus a 30 second silent short of video 1, were created using Attitude TV as the producers. MSNZ, MS Auckland and Attitude TV all worked together to develop the themes and intentions of the videos. They were all designed to be true, honest, from the words of people with MS and while they discuss the fact that MS is life-long and life-changing, these people do not let MS define or stop them living their lives, and supports help to achieve that.

Video One showed four people with MS from different demographics talking about what life with MS is like for them, how they first experienced MS, how they live their lives with it and the importance of support.

Video Two provided key facts about what MS is from those who live with the condition in New Zealand. It followed the same four people with MS but was more factual and direct to the viewer. This video addressed the fact that there are so many myths and unknowns about MS. Many have heard of the name multiple sclerosis, or MS, but do not know what it means, what are some of the symptoms and how it impacts the lives of those diagnosed.

Video Three followed Julie, a young Tongan woman with MS living in Auckland. Her experiences with her first symptoms, how she manages her life and condition and how the support that her family and MS Field Worker provide help. Julie also discussed how MS does not define her nor will it stop her achieving her dreams.

The three videos reached over 70,000 people on Facebook and were viewed over 17,000 times on Facebook, Youtube and on websites.

MSNZ was also able to support our 18 Regional Societies in raising much-needed funds with Street Appeal resources. Around \$164,377 was collected in the 2016 Street Appeals, a 17.4% increase from 2015.

Thank you to everyone who donated their time and money to support our Regions with their MS Street Appeals. With our organisations having to raise the majority of funds direct from the community, each and every person's support is greatly valued.

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 indicates or reflects 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 healthcare provider.



Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

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.
9. 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.

GREEN JUICE RECIPE AND PREPARATION

Ingredients:

Dark green lettuces – ¼ to ½ of a head (depending on the size of the lettuce): red and green leaf lettuces, romaine, endives.

Iceberg is useless and do not use

Escarole – 2 or 3 leaves
Beet tops (young inner leaves) – 2 to 3 leaves
Watercress – 5 or 6 leaves
Red cabbage – 2 or 3 leaves
Green bell pepper – ¼
Swiss chard – little
Green apple – 1

Preparation:

Greens should be washed taking care to rinse off sand or soil that is often present at the base of the leaves. Shake off water or put in salad spinner to remove excess moisture. Cut off bottom portion of stems of chard or any other fibrous leaves. Chop up because it is quite stringy and hard to pulp. This avoids raising temperature of pulp and killing enzymes.

Using a two-step (grinder/press) juicer, grind and collect pulp in a bowl. When all produce has been ground stir thoroughly, but not so much as to introduce unnecessary air into the pulp.

If you're using an electric press raise the juice part slowly to avoid having pulp squirt out of cloth and onto the juice person.

Using multiple juicing cloths you can prepare the second cloth while the first one is pressing. Also, some people will fold over the squashed cloth/pulp package and press it again to get a little more juice out of the pulp. Wash juicer after every green juice.

After pressing, the remaining pulp, conveniently packaged in the juice cloth, can be discarded.

The green juice is much more active than the carrot or carrot/apple juices and should be consumed immediately. Dr. Gerson did not recommend storage of the green juice for any length of time before consumption as it deteriorates rapidly.

Helpful Numbers

If you, or anyone you know, may need to talk to someone Lifeline New Zealand have a counselling line operating 24 hours, 7 days. The number is 0800 543 354.

Do you have difficulty hearing or talking on the phone? Register now for the 111 TXT service so you can contact Fire, Ambulance or Police in an emergency.

To register visit www.police.govt.nz/111-txt.

Healthline 0800 611 116





MARSHA MARSHALL - CHIEF EXECUTIVE OFFICER

Hello everyone,

This month the Government released a paper around the next steps for transforming New Zealand's disability support system. The transformation is based on the Enabling Good Lives (EGL) principles, which gives disabled people and their families greater choice and control over their supports and lives. The roll-out of the transformation will begin in the mid-Central region (Palmerston North) and will also include a new social investment approach. There will be a co-design process within the sector between March and June 2017. You can read more about this and get a copy of the Cabinet paper from the Office of Disability Issues website here: [https://www.odl.govt.nz/nz-](https://www.odl.govt.nz/nz-disability-strategy/other-initiatives/transforming-the-disability-support-system/)

[disability-strategy/other-initiatives/transforming-the-disability-support-system/](https://www.odl.govt.nz/nz-disability-strategy/other-initiatives/transforming-the-disability-support-system/).

We would also like to tell you about a new resource available to Manawanui clients called Engaging Your Own Support Workers. It provides advice on how to engage support workers, from the preparation of a budget and weekly plan, through the process of advertising and interviewing, to inducting and managing a new employee. The advice presented is tailored to Individualised Funding. There are downloadable and editable templates for a job description, job application forms and other documents that support the recruitment process. While the resource is primarily for people looking to engage support workers as employees, it will also be useful for those engaging workers as contractors (self-employed) or domestic workers (IR56 Taxpayers). The downloadable resource and templates are available here: <http://www.incharge.org.nz/employing-staff/>.

CAN YOU HELP?

**Do you have any preloved item
we can recycle and sell?**

Donate these today! Clothing, Household Items, Books, Bric A Brac, Toys, Tools, Camping etc

Please donate to:

The Otago Multiple Sclerosis Society POSH Op Shop

DROP OFF: 8 BARKER ST, CAVERSHAM OR WE ARE HAPPY TO PICK UP

**Thank you for your kind donations all proceeds go to Otago MS Society.
And stays in Otago**

**PEOPLE COMING TOGETHER AS A COMMUNITY CAN MAKE THINGS HAPPEN!
AND MS OTAGO IS PROUD TO BE PART OF THIS VIBRANT COMMUNITY**

ms.

Multiple Sclerosis
Otago

CONTACT US VIA, Ph 03 455 5894 | info@msotago.org.nz | www.msotago.org.nz

THE DOROTHY AWARD

The Dorothy L Newman Scholarship supports people with MS who, as a result of their condition, are unable to continue in their present employment. Recipients are provided with financial support, to undergo a course of retraining in order to gain new employment.

In November 2016, MSNZ awarded Scholarships to three worthy recipients. One recipient unfortunately did not begin her course; however, two successful applicants, and a third continuing from a previous year, rose to the challenge with great success.

The Selection Panel were particularly inspired by those who showed a strong commitment to their future employment, and understood the practicalities of managing a career and their chronic health condition.

Thank you to Sue Clothier and the Dorothy L Newman Trust for financially supporting half of the Scholarships.

Annual Report 2016–

Alinker #keepmoving

In May 2017 MSNZ was advised we are to be the recipients of generous donation of a new and innovative mobility device called “The Alinker”. The donation is thanks to the Li Ka Shing Foundation. 40 Alinkers will be available in NZ, 10 allocated to selected rehabilitation centres and 30 to MSNZ to allocate to our Regions. Later in 2017 MSNZ we will be developing the #keepmoving programme to be implemented across the country. The programme aims to provide people with the opportunity to try an Alinker to see how it can benefit their lives in terms of social engagement, mobility and overall health.

Since her award Christine O’Sullivan has become the NZ Alinker Ambassador and helped spread the word about staying positive, active and engaged in the community with a disability, like MS.



About the Alinker

The Alinker is a non-motorized walking-bike without pedals designed in the Netherlands. It is for everyone who wants to maintain an active life regardless of their movement abilities/disabilities. It is designed to be so cool that it overcomes the uneasiness towards disabilities that is felt by mainstream society. When you are using the Alinker you are the person with that cool bike rather than someone who is overlooked or ignored. The Alinker is challenging assumptions about people with disabilities and is striving to build a more inclusive community.

We look forward to receiving this donation, seeing how it can improve the lives of PwMS and reporting on the outcomes next year. 16

BREATHING TO RELIEVE FATIGUE AND INCREASE VITALITY

I am a meditation teacher. And meditation teachers are, stereotypically, all about breathing. I am also a person with MS. I was diagnosed in 1994 when there was no medication and I have had no medication since. I have experienced the power that bringing good breathing to our condition can reap.

I used to be a bad breather. I remember before I even had a name and a diagnosis for my disease, describing to people how I found it "exhausting to breathe." In fact, that was a dominant symptom.

I remember returning home from work completely spent and, when my husband asked me a question, wondering whether I had the breath to answer it or whether I should save that energy that it would take to speak for the actual act of breathing itself.

Fast forward a couple of decades and I have added breathing to the power-pack of internal resources I have activated, cultivated and use to keep on top of this challenging condition.

Why does breathing matter?

The way we breathe affects our energy levels, our alertness, our moods and our digestion. It has also been strongly implicated, by robust science, in the levels of inflammation in our bodies.

When I am hit by the life-denying creature that is fatigue, I rapidly experience brain fog, muscle weakness, low mood and a sense of 'fading out' of my immediate surroundings. The bed-fellow of low mood and weakness is panic – panic in the form of questions. How will I cope if this continues? Will I get home safely and in time for the collapse to come. Who will I have to cancel on and therefore disappoint? How long will this episode last? What will I have to sacrifice if it doesn't clear up quickly?

To understand how vital our breathing is, it helps to be aware of a couple of things someone with MS might do when they begin to feel the onset of fatigue. The first – and most natural – is to feel increased stress. Something that happens when we are stressed is that we immediately change our breathing pattern from slow and deep to rapid and shallow.

We breathe from the upper half of our body only – a phenomenon known as 'chest breathing' – and only use half the apparatus of our diaphragm. The instant effect of this is that our nervous systems get the message we are under threat and they must channel all their energy into getting ready to run from this threat. In MS, this overloads an already over-active nervous system and the enemy of the rest and repair state that our bodies are really asking for.

The second thing that tends to happen when we feel fatigued is that we reflexively slouch. There is a slump to our posture, as we surrender to the feeling that the effort of holding ourselves up is too fatiguing. This is, again, very natural and understandable, and yet again, exacerbates the problem. When we slouch and crumple into ourselves, we constrict the

very area we need for charging ourselves with vital breath. We are essentially suffocating ourselves.

So two things are crucial. Making room for breath and breathing a full, whole breath that can flow freely, reassure and soothe our nervous system that all is okay (and thus reduce inflammation) reach all the organs that need oxygen to improve their function – our muscles, our organs, our digestions and our brains in ways that make us feel better emotionally – and charge us with vitality.

Our breathing involves musculature – the muscles of our diaphragm. Everyone with MS is familiar with the phrase "Use it or lose it" and that goes for toning the muscles of the diaphragm itself. These muscles start in our core, our belly. Regularly practicing deep breathing – from low down in your belly way all the way up into your chest, collar bones and throat – is a great exercise for toning these most important and life giving muscles of all.

Sit in a chair or up in bed or lie on the floor. If you are in a chair, make sure your bum is pressed back against the back of your seat – you will feel instantly how that makes you more upright. If you are in bed, prop yourself up with pillows or have someone stack pillows for you, for the same effect. If you are lying on the floor, for instance on a yoga mat, I recommend placing a folding blanket underneath your shoulder girdle so that you get a lift in your heart and with your hands lying along the floor at your sides, making sure your palms are open to the ceiling, which in turn opens your shoulders and your chest so that it has plenty of room for breath. Your guiding thought should always be "am I making the maximum room in my body for my breath?"

Breathe deep and low. With your spine long like this, make your belly soft so that it can easily fill with breath. Taking your attention to your belly will help you know how deeply to breathe. You want to feel it puff up with air. Take that breath in a leisurely, almost luxurious way, all the way up to your chest, collarbones and throat. And now – here's the big tip – when you release that breathe as an exhale, make it even longer (if only a little bit) than your inhale was. Recent science has discovered that this kind of breathing – making your exhale longer than your inhale – has a kind of magical effect on your nervous system, phenomenally reducing stress hormones and inflammation.

It's a great practice to do a regular check-in. Where is your breathing coming from? Is coming from it low down or high up? Does it feel rapid, scattered and shallow? Or like a good massage on the inside – strong, tender and delicious?

Don't force, or over focus. Just make it luxurious and full. You'll know the difference.

Meditation can increase the healing power of your breathing even more. If you think about it, we breathe our thoughts. Thus, just as our thinking affects our feeling, so does our breathing with the kind of thoughts we have. Take it from me – I have practiced this for years – this practice can have a radical effect

on shifting the state of our bodies. (And if you don't want to take it from me, there is plenty of robust, replicated science into the mind-body-system that backs my claims.)

But do try it for yourself.

What thought would you like to breathe with right now that would make you feel better and more vitalized? A word I love is 'well being'. Another is 'vitality.' Consider how around you, in the earth's atmosphere from which you breathe, are all the abundant energies of life, growth and creation. Consider how you are actually being nourished with those same molecules and atoms of life force every time you receive and are charged with a breath from life. As you breathe in, take a big drink of these energies and think of your thought or word – the one you have chosen to infuse your being with to make it feel better. Every time you exhale, pour that breath and those qualities back through your body, infusing every organ and cell of your being.

And just a note to finish on. When I first heard people waxing on about the power of breathing, I thought yada, yada, yada. But that all changed when I experienced the massive change in state I myself could bring about in my body just by becoming conscious of my breath and making it a good breath. It's among the best anti-fatigue strategies I have and I cannot recommend it highly enough.

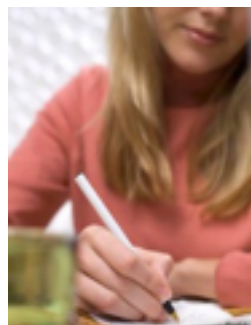
Alison Potts

Alison Potts has had MS all her adult life and was diagnosed at a time when there were no medical treatments. The journey to discovering optimum self care and thriving has been the best she could have taken. Born in England, she followed the sun for the power of vitamin D and moved to Australia where she is now a Meditation and Vitality Coach. Like her page on Facebook for more information.

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.



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.



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.



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..



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.

RECOGNISE STRESSORS AND DEAL WITH THEM

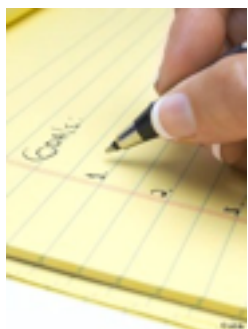
Whether you listen to music, read a book, exercise, engaging in something you find enjoyable and relaxing can help you cut down on stress, which may exacerbate MS symptoms. While there's no definitive research linking stress to the worsening of MS symptoms, experts say that too much stress can certainly 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.



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.

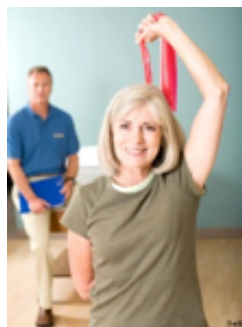
Once you're in a crisis, it can be tougher to get your life back on track. Get a support team in place and ask for help in finding treatment and solutions at the first signs of trouble, no matter what problem you face.



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.



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.



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.



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?

HOW TO PREPARE FOR AN APPOINTMENT WITH YOUR NEUROLOGIST

Does this sound familiar?

You have been seeing your neurologist for months even years and you have had moments prior to your routine appointment when you have said to yourself "I should ask about this and I should ask about that" or any number of things that have been troubling you or playing on your mind. The day of your appointment comes around and your doctor greets you in the waiting room and leads you to his room. You both take a seat and he/she is clutching your folder in his hands and he asks how you are? You are staring at the folder that holds the results from your latest MRI and you reply "I'm fine". Your Neurologist reassures you that the results of your latest MRI scan looks well and asks you about any specific concerns or symptoms that you would like to discuss. You can't remember anything that you had wanted to discuss prior to your appointment. You leave your appointment feeling relieved that your results were good but slightly frustrated that you hadn't asked the many burning questions that you wanted to ask.

A strange thing happens when we go and see our doctors. We seem to have this idea that they are going to take over and figure out everything that has been a concern for us. They are instinctively going to know the symptoms that we have been experiencing during the short time that we are in the exam room. It is time that we get more strategic about our health and help our doctors help us.

How to Prepare for Your Appointment

Treat your neurology appointment like it is an important business meeting by preparing a list of questions before you go. Ask your loved ones/caregivers if they have any questions that they would like to have answered. It is not only helpful for yourself and your doctor coming prepared to an appointment is respectful. Here are some suggestions for getting prepared:

Step 1: Take a support person.

Taking another person with you to your appointment is always acceptable and encouraged. Another person may see or hear things that you haven't recognised. They may have questions of their own that is important to your care. This person could be your note taker and can remind you of the questions you wanted to ask, provide support and clarification for you.

Step 2: Update your doctor:

Write out a few bullet points that summarize how you feel and what is happening for you. Include information relevant to your MS symptoms and how they are affecting you.

Be succinct and to the point but don't leave out anything that may be important. Ensure you include any lifestyle changes that you have made, including changes in diet, exercise and supplements.

Step 3: Decide what you want to improve.

Make a list of the things you want to improve. Some minor adjustments to your care plan can make a huge difference you just need to ask.

Step 4: List any additional questions.

There is such thing as a stupid question. There should be no question about your health that you should be afraid to ask. Remember you are the expert on you. You know yourself better than anyone else.

Step 5: Give yourself a pep talk.

Take control and get yourself "psyched up" for your appointment. Tell yourself that this is an opportunity to do something for your health. Remind yourself that your neurologist cannot read your mind or see what is happening with your symptoms outside of his/her office unless you tell him or her. It is your responsibility to be an "active patient" and let your neurologist know what is going on so that he or she can address them. Doctors prefer patient that get involved with their own health, it can make their role easier!

Here in Dunedin we are very fortunate to have available the Neurological Nurses. They are able to see you before your appointment, come in with you or see you after your consultation. You just need to ring them giving plenty of notice and make an appointment. Their contact details are:

Sharon Stevenson-Hall & Rachel McLay-Barnes

(03) 470 9286 extension 9286.

Now that you are ready for your appointment, go armed with questions and remember this is your opportunity to take responsibility for your health and wellbeing.

Try it and see for yourself!

Reference

Stachowiak, J. (2010, June 28). *How to Prepare for an Appointment with Your MS Neurologist* . Retrieved August 26 , 2013, from About.com. Multiple Sclerosis: <http://ms.about.com/od/livingwellwithms/a/Prepare-For-An-Appointment-with-Your-Ms-Neurologist>

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) says that he 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 a consultant neurologist at Dunedin School of Medicine with a special interest in Alzheimer's disease. Dr Cutfield is the Clinical Deputy Director at the Brain Health Research Centre; Clinical Senior Lecturer, Department of Medicine; Consultant Neurologist and Clinical Lead, Dunedin Hospital (Cutfield, 2013).

Professor Graeme Hammond-Tooke

Prof. Hammond-Tooke is a clinical neurologist with particular interest in neuromuscular diseases, psychogenic disorders and trans cranial 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

J Mottershead (2013). Brain Health Research Centre. Retrieved 26 August 2013 from University of Otago:

<http://www.otago.ac.nz/bhrc/staff/otago040568.html>

A Wright (2013). Dr Alan Wright. Retrieved 26 August 2013 from Mercy Hospital:

<http://www.merceyhospital.org.nz/specialists/dr-alan-wright>

N Cutfield (2013). Health Science staff profile. Retrieved 26 August 2013 from University of Otago:

<http://www.otago.ac.nz/healthsciences/expertise/profile/?id=846>

G Hammond-Tooke (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>

VOLUNTEERS NEEDED FOR THE OTAGO MS OP SHOP AND TUESDAY SOCIAL GROUP

Given some recent changes at the Society we are looking for volunteers to assist with our Tuesday Social Group.

The volunteer will need to assist with refreshments and the lunch meal (at times). There will also be time spent engaging playing games (if needed), whilst at the same time engaging with all our other regular members attending.

This volunteer will be working alongside our current staff, the time required each Tuesday is approximately 3 hours, and we will provide morning tea and lunch for you.

Alternatively you could support our Society If you have a spare couple of hours offering assistance in our OP SHOP; this could either be by sorting clothes, cleaning or assisting sales.

If this sound like you or somebody you know we would love to hear from you.

Please do not hesitate to contact the office on (03) 4555 894 to discuss further.



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 and providing services and education to people with Multiple Sclerosis and other neurological illnesses.

A gift in your Will is one way to leave a lasting legacy that continues long after you are gone.



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.

MEETING PROCEDURES.

These are the procedures to follow:

Motions:

Mover- seconder; you can only speak once on a motion. Mover or the seconder cannot amend the motion.

Amendment:

Mover – seconder; the amendment now becomes a motion.

Closure of the motion:

Anyone can call for a closure of the discussion.

Adjourning the meeting:

10 minutes to allow a break, seconder required, terminates the meeting for the required time.

Proceed to next business:

Chairman has the say, seconder required, (not required if the chair has done it). Cannot interrupt no debate.

Adjourn debate:

No need for a seconder, for as long as you need (forever) if necessary. May need to adjourn for more advice.

Motion question:

Lie on the table, must come back at another time or day.

Not debatable, not amendable, no seconder required, the chair rules.

Point of order:

Not debatable, not amendable, no seconder required, the chair rules.

Clemastine fumarate First drug shown to promote remyelination

We hear about 'breakthroughs' frequently in MS, and mostly of course, they are not! On this occasion, despite the drug that researchers were testing being an old drug commonly prescribed for hayfever, they found definite evidence of improved neurological function after taking the drug, and the improvement persisted when the drug was stopped. It seems highly likely, given what the researchers have previously tested, that the drug promoted remyelination, something which no agent has previously been able to do.

The research team at University of California, San Francisco (UCSF), led by Prof Jonah Chan tested the drug clemastine (trade name Tavist) which has been licensed by the FDA for 40 years now for use in hayfever and allergies and is now a cheap generic. Importantly they tested the drug in people with chronic longstanding MS who had quite a bit of central nervous system damage. To their surprise, they used a sensitive test of the speed of transmission of nerves in the visual pathways and showed that it speeded up substantially, meaning that transmission through the whole central nervous system was likely to be speeded up for those taking this medication. The dose of drug used was 5.36mg twice daily, for a daily dose of 10.72mg, whereas for allergy, the recommended dose is no more than 2.68mg three times daily, for a daily dose of 8.04mg. The only important side effect of large doses is sleepiness, and in this study, participants were more likely to report fatigue, which may reflect that.

While much more work needs to be done before this drug could be licensed in MS, the research is really a breakthrough, showing that repairing damaged myelin is now a realistic possibility.

Dr Ari J Green, MD Correspondence information about the author Dr Ari J Green Email the author Dr Ari J Green (agreen@ucsf.edu)

Lest We Forget

It is with great sadness that we acknowledge the passing of valued society people Bernie Walker, Paul Paardekooper and George Stewart; our thoughts are with their family and friends during this time

7 Rules Of life

1. **Make peace with your past so it won't screw up the present**
2. **What others think of you is none of your business.**
3. **Time heals almost everything, give it time.**
4. **Don't compare your life to others and don't judge them. You have no idea what their journey is all about**
5. **Stop thinking too much, it's alright not to know the answers. They will come to you when you least expect it.**
6. **No one is in charge of your happiness except you.**
7. **Smile. You don't own all the problems in the world.**



Proudly Supporting
The Otago Multiple Sclerosis Society

We Specialise In:-

- Building Construction
- Trades & Services
- Engineering
- Manufacturing
- Office & Administration
- Executive Positions

Call In And See Us At:- L2, 248 Cumberland St
(03) 474 1030 dunedin@dkw.co.nz www.dkw.co.nz