



KORU



ME/CFS & FM Support



ms.
Multiple Sclerosis
Waikato

Working Together to Provide a Service of Excellence
Mahi tatau kit e whakawkiwi he hapori rawe

November 2017 Issue 47

Kia ora and Welcome

Well the year is very quickly passing by and Christmas is just around the corner. It has been an eventful year with some great speakers at the monthly education support group meetings. I have also been busy with in-service trainings bringing awareness and educating the Community Physiotherapists at Waikato Hospital as well as the Reach team under the Ministry of Social Development. My predecessor Helen has also been helping me to ensure every medical practice throughout the Waikato has a copy of the ANZMES Clinical Primer. So far, all Hamilton practices have been visited and now we are focusing on outlying towns.

As I write this spring is trying to 'spring' teasing us with the odd lovely sunny day, but with temperatures remaining a little cool. Many of you have reported that the wet year we have experienced has caused increased pain and discomfort. NIWA predicts a 40% chance of above-normal rain fall October to December, however I'm starting to question what, exactly, is normal? Here's hoping we have a drier milder summer.

The Christmas lunch will again be held at the Hamilton Workingman's Club. This year we will be joining the other MS Waikato members providing you with an opportunity to feel part of the greater organisation, meet members with the other neurological conditions we support as well as some of the board members who govern the organisation. The lunch menu is on page 5 and please be sure to RSVP by 8th December. Please see the enclosed flyer.

Have you noticed the new additions to the Koru header? The orange ribbon is our new brand anchor which represents the objectives of MS Waikato Trust which is to **support**, **inform** and **empower** our clients and for the organisation to be **sustainable** and **effective** in what we do. MS Waikato has also started a face book page so look us up and 'like' us.



I wish you all a very merry, safe and healthy Christmas and holidays and I look forward to seeing you in 2018.

Until then... Aroha nui *Tracey Larsen*

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MS Waikato Trust
Christmas Lunch
The Hamilton
Workingmen's Club
Thursday 14th December
12.30 pm
\$10.00 for paid members
\$20.00 for non-paying members
RSVP by 11th December
Ph: Tracey 07 8344745

Download more photos at www.pixapic.com

August Support Group - Dr Vallings



It was, again, a pleasure to have Dr Vallings visit Hamilton to share key points from the latest research findings from the 2017 'Invest in ME' Conference in London as well as information regarding Orthostatic Intolerance (OI) and the importance of salt to manage this.

Only the key points regarding OT and the importance of salt will be covered here. An audio recording of the talk in its entirety is available so please contact me on 078344745 if you wish to loan this. To view the complete Invest in ME report visit ANZMES face book page or see the link <http://anzmes.org.nz/invest-in-me-2017-conference-report-by-rosamund-vallings>

Orthostatic Intolerance and Salt:

Dr Vallings explained that OI impacts the Central Nervous System which involves the mechanism that controls blood pressure and the blood vessels. Low blood volume can also be a cause for OI; some people only have 2/3 of the total volume of blood that is actually required. Less blood circulating creates less pressure on the blood vessels which results in lower blood pressure. Pulse pressure therefore becomes lower which means the heart is less powerful and has a reduced ability to 'push' the blood and circulate it around the body. Low blood pressure, lower pulse rate and sluggish circulation causes less oxygen getting to the brain as well as experiencing cold extremities and looking pale.

Postural change – moving from lying down flat to sitting, sitting to standing, changing position or bending down – can aggravate OI making you feel dizzy, nauseated and faint and cause an increase in brain fog. This is due to the lack of thrust of blood being able to reach the brain. You may also experience heart palpitations and a racing pulse, especially if you are standing for any length of time, as your heart tries to push more blood up to the brain. Dr Vallings stated that this worries many people but the heart is just doing what it needs to do, but to see your GP if you are concerned.

Those with high blood pressure can also suffer OI which is caused by a mal-functioning or "lackadaisical"

sympathetic nervous system which results in blood pressure still "falling into your boots" upon standing or other postural changes. Blood pressure medication may also be too strong and can cause it to become lower than what it needs to be.

Becoming overheated causes the blood vessels to dilate which means that even less blood reaches the brain and stomach, further aggravating dizziness, nausea, brain fog and increasing the risk of fainting or falling. Heavy menstruation will also further impact these symptoms and can cause symptoms to be experienced more frequently.

What to do:

Sitting or lying down for long periods can cause more acute symptoms therefore movement helps to keep the blood circulating, so when standing keep moving on the spot. Raise the head of the bed with extra pillows or place some books under the feet. Support hose can work well as they help to keep the blood higher up in the body. Some people have benefited from full-body pressure support stockings.

SALT: Salt deficiency is becoming more prevalent in society and symptoms include weakness, fatigue, headache, nausea, vomiting, muscle cramps or spasms, confusion, and irritability. Increased salt intake increases blood volume which can help to reduce OI symptoms. Dr Vallings suggests a good pinch of plain table salt every 2 hours during the day. Or add more salt to your food, eat salty foods such as crackers or chips or add a pinch of salt to your water if you do not like the taste of the extra salt. You can also buy electrolyte drinks or your GP can prescribe sachets. Fludrocortisone can also be prescribed which helps to the body to retain sodium better. Also remember to Increase your water.

Too much salt can cause dehydration, bloating and retaining fluid so be mindful of these symptoms. When increasing salt intake it is important to regularly check your blood pressure in case it rises to dangerous levels. Salt also can leach potassium levels so eat a banana or kiwifruit 3 times per week for adequate potassium replacement.

Have high blood pressure? Dr Vallings suggests to not take as much salt but to take a dose upon rising in the morning and going to bed at night.



September Support Group Matt Bentley – ACT & Mindfulness Meditation



Before Matt was diagnosed with ME/CFS he had been practicing mindfulness meditation for about 5 years. Later he also undertook a course in Acceptance and Commitment Therapy (ACT). ACT, Matt says,

helps you to establish and commit to goals that are based on your core values which is more likely to inspire and motivate you to create change in your life. ACT also contains some mindfulness skills to help individuals live and behave in ways consistent with their core values while also developing psychological resilience and flexibility.

Matt explained that as humans we typically have a lot going on in our minds all the time whether it be thoughts of worry, hope, planning or about the daily tasks we need to accomplish. Thinking about such things can wind us up and we become reactive to our thoughts, feelings, emotions, and the events in our lives. Our mind likes to attach labels of judgement onto our experiences of 'good' or 'bad'. It is this automatic reaction that creates negative thinking, for example "my body is sore..." "I can't do this..." "Why am I doing this...?" "I should be..." "I shouldn't be..." "I feel depressed..."

Although mindfulness practice comes from Buddhist and Hindu traditions, it has no religious or spiritual component, and has been scientifically proven to be effective in reducing anxiety and depression. It is about bringing awareness to the given moment; our thoughts, emotions, feelings and the environment around us. Awareness encourages the ability to acknowledge the thoughts, emotions and feelings without reacting to them.

Through the act of not applying labels or judgement one can become more tolerant and accepting of our experiences which results in being less bound to them. In turn, this encourages acceptance of what is

happening without having the expectation of creating change. However purely by the act of acknowledging without judgment or attaching labels change may happen, by interrupting cyclical thinking. Creating tolerance and acceptance for our circumstances can reduce our mental suffering.

The group participated in a simple grounding exercise Matt demonstrated. First, notice the pressure of the surface you are sitting or standing on; without attaching a label, focus on the experience of having vision, or seeing; then with eyes open or closed, next focus on what you hear; then, on what you smell; notice the temperature you are feeling on different parts of your body. Then, notice the thoughts in your mind; next, notice your breath without trying to change it. Lastly, bring all these experiences together into one.

Another exercise we all participated in was mindfulness meditation, observing only the breath for 5 minutes. Matt instructed to sit where you are most comfortable with a relaxed straight back. As you become aware that your mind has wandered off

MINDFULNESS IS:
the acceptance of '*what is*'
without trying to change it

to think about other things, simply bring it back without judgement. Practicing this regularly helps the mind to become more focused and aware and, in time, it will

wander off less. Another approach is walking meditation – for some, this can be easier because the body has something to do. With hands clasped together either in front or behind you, slowly walk, noticing the sensation of each part of your foot as it touches the ground during each step.

Mindfulness Meditation groups available in Hamilton:
Waikato Compassion Meditation Centre hold free meditation classes Friday nights at 7pm
wcmchamilton.org.nz;

Insight Meditation holds a group twice monthly
hamilton@insightmeditation.org.nz;

In the tradition of Thich Nhat Hhan, A Zen group meets every Wednesday night annemariet1907@gmail.com;

Erica Weerekoon, counsellor holds a mindfulness group on Wednesday nights in Chartwell. Phone 02108537516 or email ew.uniquejourneys@gmail.com for more information



October Support Group

Dr Bill Reeder



Fascinated by chronic conditions and frustrated by conventional medicine alone, Dr Bill Reeder looks outside the square in order to be a more effective practitioner. He believes in taking a common-sense approach to health, integrating

conventional medicine with alternative and natural measures by way of supplementation, as patients typically have conditions where standard treatment modalities have not been helpful or tolerated.

Dr Reeder takes a holistic approach to determine a diagnosis and treatment plan, outlining that poor sleep patterns, stress, toxins, infections, digestive disorders, genetic predispositions, hormone imbalances and autoimmune disorders all can, singularly or together, play a part in causing ME/CFS & FM.

Many of the symptoms of ME/CFS & FM can be explained by other conditions so to treat and/or rule out other conditions is essential. Checking thyroid function, for example, is important as most cells in the body requires T3 & T4. These thyroid hormones, among other functions, regulate protein, fat and carbohydrate metabolism affecting how the cells use its energetic compounds to create energy.

Dr Reeder explained that many conditions which cause fatigue can be attributed to the dysfunction of the mitochondria which is found in every cell in the body. It is considered the powerhouse of the cell, by using proteins, sugars, fats and oxygen to generate energy.

To support mitochondrial function and energy production, Dr Reeder often prescribes some key supplements: Magnesium, Vitamin B12 and Ubiquinone form of Co Enzyme Q10. He suggests that larger quantities (than the label suggests) over time are often required to make a difference in one's health, even if blood test results are normal. He suggests that often it can be a genetic predisposition which creates a barrier that disables the body in utilising the therapeutic benefits of the supplements, even hormones like thyroid.

Dr Reeder also often recommends D-Ribose. D-Ribose is a naturally occurring simple sugar found in all living cells. It is the fuel that mitochondria use to new produce adenosine tri-phosphate (ATP), which provides the body's cellular energy. It can also be effective in reducing muscle pain for those with ME/CFS & FM.

Acetyl-L-carnitine is an amino acid that the body produces naturally which Dr Reeder believes can also be helpful in supplement form. Without acetyl-L-carnitine, the mitochondria cannot absorb and metabolize fatty acids. The nervous system depends on fat metabolism and research suggests that it can be useful in cognitive functioning and reducing nerve pain.

Low Dose Naltrexone (LDN) has also been found to be helpful in regulating the immune system and the body's endorphins. In many illnesses we can become endorphin depleted so LDN can up-regulate opioid (endorphin) receptors - resulting in a very positive effect in multiple systems as these receptors are in every cell. It can also increase natural killer cells, macrophages and white cells so it has the ability to either calm a hyper-immune state or enhance a low-immune state.

Testing adrenal function and thyroid resistance is another treatment avenue Dr Reeder considers. Stress, whether it be emotional, physical, caused by chemical toxicity or infection, may cause the adrenal glands to release extra cortisol over time. He says that the brain does not like a lot of cortisol so creates blocks to make the body rest; low adrenal output may result in fatigue. However, he also states the importance of treating any underlying infection/s and changing/removing any stressors from your environment such as toxic chemicals, mould, making any required dietary changes to support digestion and dealing with any emotion stressors. Such lifestyle changes are imperative to improving one's health.

Household mould is one such environmental toxin that must be eliminated to improve health. Dr Reeder suggests reading research by Ritchie Shoemaker that identifies mould as a biotoxin and how some people do not have the immune response genes that are required to form antibodies, allowing the biotoxin free reign to cause havoc in the body. View www.survivingmold.com

To learn more about Dr Bill Reeder and his approach to health see his website <http://www.medcom.co.nz/>. He can be contacted on 07 856 8568 and is situated at 23 O'Neill St Hamilton.



Unrest, directed by Jennifer Brea herself, screened twice at the New Zealand Film Festival at the Hamilton Lido Cinema in September. Some members of MS Waikato along with a few members of the public viewed the screenings. It portrayed a confronting and realistic account of the ME/CFS condition and Jennifer's struggles with obtaining a diagnosis and managing the condition. I understand that, in time, a DVD will be available to purchase and I hope to have a copy in our library for loan. I will let you know when this happens.



Another celebrity puts the spot light on Fibromyalgia. Lady Gaga, has spoken out about her diagnosis of Fibromyalgia and had to cancel a show in Rio in September due to being hospitalised with pain. Her Netflix documentary Five Foot Two gives a brief glimpse into her off-stage life that includes her struggle with the chronic pain disorder.

Tips to reducing stress at Christmas

Prioritise: If you have limited energy you have to accept that you can't do everything. To make Christmas the best it can be don't waste energy on things you don't care about.

Delegate: But If it is important, ask for help! Especially if it is important to stick to tradition with decorations throughout the house and a real pine tree touching the roof... need I say more! Otherwise...

Be Flexible: Have a change in tradition!

Rest: It's easy to get caught up in the list of things to do, but number one on the list every day should be the rest you know you need.

Lower other's expectations: It may be helpful to have a conversation about your capabilities with those family members who know you less well so if you disappear for a rest no one will worry.

Focus on nourishing food: It is hard to avoid the sugary treats, and why should you, it's Christmas, but ensure you balance your intake well with nutritious food also.

If all else fails, try this stress reduction kit... Only kidding!!!

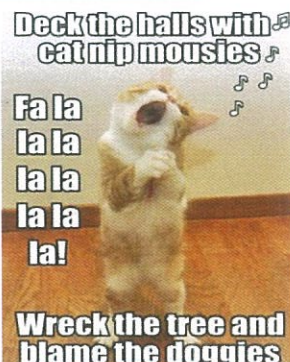
Merry Christmas
MS Waikato Trust
Christmas Lunch Menu

Mains
 Honey Glazed Ham, Coleslaw,
 Tuscan Chicken Drumsticks,
 Roast Potatoes, Pumpkin & Kumara,
 Cauliflower Mornay, Peas & Corn,
 Honey Glazed Carrots

Dessert
 Steamed Christmas Pudding,
 Fresh Fruit Salad, Custard,
 Chantilly Cream

*Gluten Free & Dairy Free
 options available
 by request*

\$10 per member
\$20 non members



Stress Reduction Kit

**Bang
Head
Here**

Directions:

1. Place kit on FIRM surface.
2. Follow directions in circle of kit.
3. Repeat step 2 as necessary, or until unconscious.
4. If unconscious, cease stress reduction activity.

AHAJOKES.COM

Page 6 Tips, Snippets & Contacts

A gold coin koha is greatly appreciated thank you

Up & Coming Events

ME/CFS & FM Education Support Group

Melville Methodist Church, Bader Street, Melville 10.30 – 11.30

November 9th 2017— Leanne Koorey will be talking to us about Flower Essence which help to reduce stress and anxiety & help to facilitate calm through life's changes and bring about acceptance of 'what is'

December 14th 2017 – Christmas Lunch at the Hamilton Workingman's Club

January 2018 – No Group

February 14th 2018 – Focused group discussion topic to be confirmed

The POCKET GUIDE to Chronic Fatigue Syndrome/ME

Key Facts and Tips for Improved Health

Dr Rosamund Vallings
MNZM, MBBS

This concise and easy-to-read book will help anyone with Chronic Fatigue Syndrome/ME manage their illness and improve their overall wellbeing. It explains how CFS/ME is diagnosed and the different ways it may affect the body, so that people with CFS/ME will be able to more actively take charge of their health and create the best chance for recovery.

- Strategies for dealing with specific symptoms
 - Easing back into exercise
 - Eating optimally for recovery
 - Dealing with work and education issues
 - Talking to others about CFS/ME, including the doctor
 - Latest research and search for a cure.
 - Plus more
- Ring 8344745 to loan

OTHER CONTACTS:

You may find it helpful to speak to others who also have ME/CFS and/or FM. Thanks to those offering such support. Please be aware that they will respond as they are able, according to how their own health is at the time:

CIANE (Sharn): 0211471933

LINDA: 8553934 or email lindaderrick@yahoo.com

BERNADETTE: 07 8686763 (Thames)

JANE: please email rjdalton158@gmail.com



ANZMES

MS Waikato have Wheelchairs available to loan short term at no cost.
Ph: 8344740 to enquire

MS Waikato would like to thank those who sponsors us.

New Zealand Post, SPAN Trust, WDFK Karamu Trust, Waipa District Council, COGS – Hamilton City, Hauraki, South Waikato and Waikato West, DV Bryant Trust, Anytime Fitness - Tristram St, Trillian Trust, Len Reynolds Trust, The Norah Howell Charitable Trust, The Lion Foundation, Glenice & John Gallagher Foundation & Gallagher Charitable Trust, Page Trust.



Sir John Logan Campbell
Residuary Estate



Harcourts

NZCT



Office Closure

MS Waikato will be closed on Friday 22nd December and will reopen 22nd January 2018.

All the MS staff wish you a Merry Christmas and safe and happy holidays



KiwiSaver
Poua he Oranga

DID YOU KNOW that you can apply for a partial withdrawal from your Kiwisaver to help cover costs for a **serious illness?** Contact your Kiwisaver provider or check out their website to download the form under withdrawals/serious illness

HEALTH PASSPORTS

contains information about your health condition/s and how you want people to communicate and support you when seeking medical treatment.

For more information view www.hdc.org.nz/about-us/disability/health-passport

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Auckland

Ph 09 269 6374 www.anzmes.org.nz

Medical Advisor

Dr Ros Vallings Auckland

Phone: 09 534 3978 for clinic bookings or enquiries

The Hamilton ME/CFS & FM Education Support Group operates under the umbrella of MS Waikato Trust. MS Waikato offers support, advice and advocacy to those with ME/CFS & FM in the Midland Health area, defined by the boundaries of Waikato DHB.

Disclaimer: Opinions expressed in Koru are those of the writer and speakers presenting to the monthly group and not necessarily those of the Hamilton ME/CFS & FM Support Group or MS Waikato Trust.