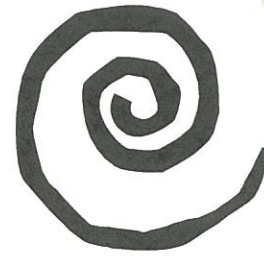


KORU

ME/CFS & FM Support

MS Waikato

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



November 2016 Issue 43

Kia ora and Welcome

It's November! How did that happen? Where has the year gone? And isn't it great to be finally seeing sunshine. It has been a busy year with an increase of 24 clients. This tells me that awareness is increasing out there. Many have found me and MS Waikato through our updated website, referrals from medical personnel, clients and as a result of the school information packs sent to all secondary schools.

Contents

Pg 2 – Dr Vallings Visit to Hamilton
Pg 2 – Christmas lunch Advertisement
Pg 3 – Mindfulness
Pg 4 – Social Group
Pg 5 – Tips on Resting
Pg 6 – Tip, Snippets & Contacts, Xmas Lunch Menu and office closure dates over January

We had a great response from the survey. This year we increased our technological savvy with a computerised survey which seemed to appeal as the response rate was a lot higher than usual. Thank you to those who participated. Results showed that overall the MS Waikato staff are doing a great job that is appreciated by many. The wish list highlighted that many of you would like more contact, either by phone or in person. However due to increased awareness and significant increase in client numbers this unfortunately means that my time is stretched further. As MS Waikato is a needs-based practice, please know that I am always available if extra support is needed. Please do not hesitate to phone, text or email at a time of need.

Please note that subscriptions for 2017 are now due, a copy of the subs form is enclosed if we have not already received your payment. MS Waikato is a not for profit organisation and we do not receive any government funding. Your support by becoming a financial member helps us to continue to provide our services to you, which includes the newsletter, phone calls and support groups.

It is hard to believe that Christmas is just around the corner. We will be holding Christmas lunch again this year at The Hamilton Workingmen's Club. They provide a great cooked lunch in a quiet atmosphere with plenty of good parking. Please see page 2 for details and the lunch menu on page 6.

Merry Christmas and Happy holidays to you and family. See you in 2017!!

Aroha nui

Tracey Larsen



August Support Group Meeting – Dr Ros Vallings Visits Hamilton



Dr Vallings visited Hamilton in August and spoke to us about the immune system and how it impacts ME/CFS, as well as sharing key points of the latest

research presented at the 2016 'Invest in ME' London Conference.

The immune system is an activity that occurs throughout the body but immune cells are located in 3 principle places - blood, gastrointestinal tract and brain. Immune system activity occurs mostly in the gastrointestinal tract, however, we have more immune cells in our brain than brain cells. We need a certain amount of bacteria and viruses to keep us healthy therefore the immune system is a protective mechanism that helps to keep the bacteria and viruses in balance. The immune system is activated when the number of bacteria and viruses become unbalance.

When the immune system is activated it switches on the immune cells, called microglia, within your brain. These cells enlarge and sparkle (detectable by MRI scan) and creates 'sickness behaviour' –the body's inner mechanism that makes you feel unwell so that you want to lie down and rest in order to heal, a recognised medical condition of any illness. In ME/CFS there is a lot of microglia cell activity particular at times of relapse. If we do not give in to the sickness behaviour warning signs and rest in order to heal, then a worsening of symptoms can occur.

Immune modulating chemicals circulate throughout the body via the blood. If these chemicals are being over produced, tiredness, fevers, headaches, sore throats and swollen glands can result.

Blood is easy to access and analyse in order to understand what is happening with the immune system. While red blood cells carry oxygen, the white blood cells fight infection, foreign bacteria, viruses and injury. They also fire up during an allergic reaction.

Natural killer (NK) cells circulate to fight viruses and cancers to keep them under control. Raised NK cells indicate that virus infections are present – determined via a blood test. B cells and T cells (also white blood

cells) make antibodies when exposed to a virus, providing lifelong protection against the virus in most cases.

Researchers are continuing to study the link between microorganisms and bacteria, the immune system and the brain, and how this could be influencing the onset of ME/CFS.

Auto-immune is when the immune response is attacking and damaging your own immune cells through producing excessive antibodies. Research is now looking at the possibility that Auto-immunity maybe implicated in ME/CFS. Research from Berlin suggests that if ME/CFS is autoimmune, damage to the central nervous system can result in sluggish brain activity and could also account for most, if not all, of the symptoms.

Norwegian research has studied the impacts of the cancer drug Rituximab on flattening autoimmune activity and has proven successful in about half to two-thirds of patients with chronic fatigue syndrome.

Professor Olli Polo from Finland spoke about the physical abnormalities which GP's should be looking at and using to identify physical illness of ME/CFS. Some of these signs are very low blood pressure, loose-jointedness, a flabbiness of the tissue, and the tendency to be light headed if you are standing for any length of time.

Some of the most exciting research is from the Gold Coast in Australia. They are very close to establishing a bio-marker, a simple blood test that can diagnose ME/CFS.



**ME/CFS & FM
CHRISTMAS LUNCH**

**Come and join us for a
Delicious Hot Christmas Lunch**
Gluten and Dairy free options available
(must pre-arrange)

Thursday 8th December 2016
Hamilton Workingman's Club
12.00 midday start
(lunch served at 12.30)

\$10.00 for paid members
\$20.00 non-paying members

RSVP and payment by
2 December 2016
Phone Tracey 8344745

September Group Meeting – Mindfulness



Erica Weerekoon visited our group again this month to speak to us about what Mindfulness is and gave us some simple ways to incorporate Mindfulness practice into our everyday lives.

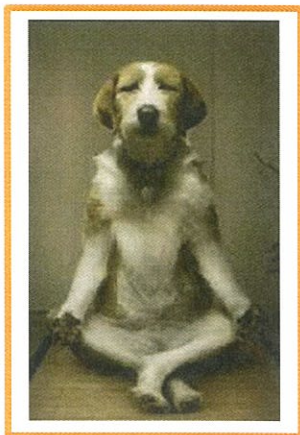
Mindfulness is a way of being that enables us to be mentally and physically present in the here and now. It encourages non-judgement, acceptance, curiosity and kindness towards ourselves and others.

Mindfulness is NOT religious, and although developed and practiced by Buddhists for more than 2500 years through the form of meditation, Mindfulness does not require worship or sitting for hours in a lotus position chanting.

Stress and frustration is a part of our lives that cannot be avoided. Many go through life reacting to stress and frustration in ways that can result in depression, anxiety, addiction and interpersonal conflicts.

Rather than ruminating on events that occurred in the past or worrying about what the future may bring, being attentive to the present moment brings awareness of the emotional state we are in, whether we are relaxed, tense, frustrated, happy, neutral, grateful or angry. Once we are conscious of our emotional state we can then acknowledge it, accept it and then choose how we respond to it.

Erica explained that our bodies respond to stress automatically; the fight or flight response increases adrenaline and cortisol. In our modern world our bodies are responding to many continuous daily stressors without us even being aware. Constantly raised adrenaline and cortisol levels is harmful to our bodies and drags on our energy supply.



Mindfulness helps us to become aware of what is happening in our body, like noticing tension, which then creates options and a choice to manage it.

Research has shown that the benefits of Mindfulness can lower stress, anxiety, emotional exhaustion and prevent depression. Other research findings showed improved executive functioning, better attention, and reduced emotional interference in cognitive tasks, better behaviour regulation and more situationally-appropriate decision-making.

Erica gave us a couple of very simple exercises that can be easily adopted into every day moments and events - Noticing and feeling your breath (shortened version):

- Sit comfortably,
- Notice the movement of your body with each in breath and out breath,
- Place your hand on the different parts of your body and feel the rise and fall of each breath,
- Notice if you are breathing shallow or deep, slow or fast, smooth or rough, regular or irregular? Do you hold your breath or sigh often,
- There is no right or wrong way, just your way! Notice your own natural style of breathing,
- You may notice that you feel more relaxed and achieve a sense of joy and energy if you continue this process of watching and feeling.

When you have experienced a stressful moment

STOP!

S - Stop, be still, sit down (if you can)

T - Take a breath, with long out-breath

O - Be open and observe; what is going on right now, physically, mentally, emotionally?

P - Proceed mindfully, be kind to self and others

Erica is interested in establishing an ME/CFS Mindfulness group for those interested in weekly practice for koha/donation or gold coin. If you are interested or want more information, please either contact Erica 02108537516 or Tracey on 8344745.

October Support Group Meeting – SOCIAL EVENT

In 2015 the monthly social group that used to meet at a café at Westfield Chartwell was cancelled due to dwindling numbers. Feedback identified that the dwindling numbers were mostly as a result of the venue not being suitable. It was very noisy, and seating not well arranged.

Due to the sensitive nature of ME/CFS & FM the requirements that need to be taken into consideration when seeking to find a new venue are:

1. A quiet environment (coffee machines can be very noisy as well as loud music)
2. Reasonably priced
3. On a bus route
4. Good parking easily accessible to the café

Garden centres can be great locations ticking the above boxes BUT chemical sensitivity poses another concern to also be considered.

Due to steady inquiry about whether a social group is offered to the ME/CFS and FM members since 2015, I decided to host a one-off social event in place of inviting a speaker to the October Education Support Group.

A good turn-out was had and feedback received was that it was nice to meet with the regulars, and also some new faces, to connect with each other and chat over everyday things, removing the focus of health/ill health from themselves for a while.

It was agreed that to have a couple of social events like this throughout the year would make a nice change so keep an eye out on page 6 of the Koru during 2017 for future events.

It was also decided that the first meeting of the year which will be held on Thursday February 9th will be a social event so you can catch up after the summer break. At this meeting I will also be asking for ideas and topics that you will like presented for 2017. Please feel free to email any ideas to tracey@mswaikato.org.nz



Monica, Ann and Sue



Miriam, Pat and Linda

CIRCLE THE CALENDAR
Next social event
Thursday 9th February
2017
\$2.00 donation

Tips on Managing Energy And Resting

Strict limits on activity and planning and pacing are key focusses to aid recovery of ME/CFS. Overexertion causes post exertion malaise and disease progression.

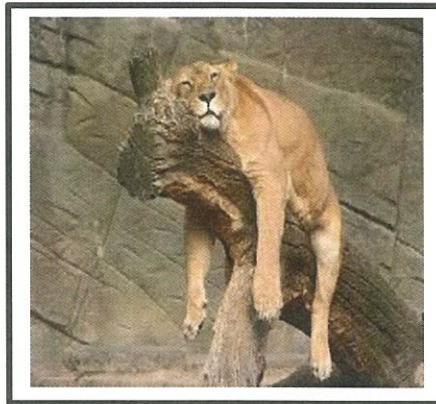
Therefore staying within your energy limits is vital, but can be difficult to maintain all the time. So here are some tips to help.

The 80% rule

Work out how much activity you can do each day and then only do 80% of that amount of activity. The goal is to do the same level of activity each day, regardless of how well you feel. This is how you manage your 'Energy Envelope'.

Preserving energy

- Sitting or lying down as much as possible.
- Use a stool in the shower, sit to dry and dress yourself
- Sit down to prepare your meals
- Lie down to watch TV, use the laptop, and to read
- Instead of reading or using the computer for an hour, rest your eyes every 15 minutes for 15 minutes before continuing. Play with these times to find what is appropriate for you.
- Mute the TV advertisements and choose documentaries, comedies or dramas instead of high suspense programs that stimulate adrenaline.
- Break up activity with regular rest periods, for example, don't vacuum the whole house at once, do room by room, resting in between. You may find that you can only vacuum a room a day or week, so take rest breaks regularly as you do the one room.



He considers watching TV, computer use, reading, even talking on the phone or talking with family as activities that need to be equated into the 80% rule.

You may find that you need to experiment with this idea to

Planned resting

Dr Bruce Campbell found that he used planned resting as a way to prevent symptoms instead of resting to only recuperate after overexertion. Planned daily rest gave him control over the swings in his symptoms and the push and crash cycle he found he was living. Dr Campbell found that a 15 minute rest reduced his symptoms and increased his stamina making his life more stable.

However he also found that HOW he rested was just as important in his recovery. He found that the most restorative rest resulted from lying down in a quiet place with his eyes closed, away from TV and noise and disruptions from others. Resting is also not necessarily sleeping as day-time sleeping disrupts night-time sleeping patterns.

find whether you need to have mini rest periods every hour, or whether a morning or afternoon rest of an hour or more is sufficient. As with finding your energy envelope, finding what works best for you regarding planned resting requires a trial and error approach until you master it.

Planning your activity around your rest and planning your activity so it is more evenly spread over the week is essential for a consistent routine that supports improved health and recovery.

- Use a calendar
- Schedule in your daily rest around 'must do' activities such as taking/picking up the children from school, preparing dinner etc.
- Schedule GP/WINZ/hair appointments etc. around your rest and 'must do' activities, being careful not to expend your 80% rule by attending too many appointments in one day.

How do I know I am resting enough?

Try intensive resting for a few days or for a week and see how you feel. Intensive resting is not much fun but is essential to gain control over the push and crash cycle that is easily established, especially if you have young children or commitments you must meet.

Page 6 Tips, Snippets & Contacts

\$2 koha

Up & Coming Events

ME/CFS & FM Education Support Group

Methodist Church, Bader Street, Melville 10.30 - 11.30

November 10th - Tai Chi instructor Doug Downs will be discussing the health benefits of Tai Chi and demonstrating some basic starting movements. Participation encouraged but not compulsory.

December 8th - ME/CFS & FM Christmas Lunch at The Hamilton Workingman's Club, Frankton, Hamilton - see pg 2

January 2017 - NO GROUP MEETING THIS MONTH

February 9th 2017 - Social Event plus - 'what would you like presented at our Education Group Meetings this year?'

ME/CFS Christmas Lunch Menu

Hamilton Workingman's Club 8th December 2016

Mains *Gluten Free & Dairy Free options available by request*

Honey Glazed Ham

Tuscan Chicken Drumsticks

Roast Potatoes

Roast Kumara

Roast Pumpkin

Cauliflower Mornay

Honey Glazed Carrots

Peas and Corn

Coleslaw

Desserts

Fresh Fruit Salad

Steamed Christmas

Pudding

Custard

Chantilly Cream



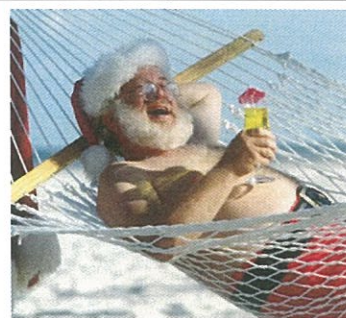
Check out ANZMES on Facebook. They post great articles that maybe of interest to you regarding research and symptom management



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

USEFUL WEBSITES FOR MORE INFO ON ME/CFS/FM

www.cortjohnson.org (Health Rising)
www.anzmes.org.nz www.co-cure.org
www.me-cfs.org.au www.iacfsme.org
www.afme.org.uk www.cfidsselfhelp.org
www.emerge.org.au



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 not necessarily those of the Hamilton ME/CFS & FM Support Group or MS Waikato Trust.

Office Closure

MS Waikato Trust
closes Friday 23rd
December and reopens
Monday
23rd January 2017

We all wish you a safe
& Merry Christmas
and Happy New Year

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)

Tracey Larsen

**Client Service Coordinator
ME/CFS & FM**

MS Waikato Trust

P.O. Box 146, Hamilton 3240

Phone: 07 8344745

Mobile: 027 3855425

Email: tracey@mswaikato.org.nz

Website: www.mswaikato.org.nz

ANZMES

PO Box 36 307

Northcote, North Shore, 0748

Auckland

Ph 09 269 6374

www.anzmes.org.nz

Medical Advisor

Dr Ros Vallings Auckland

Phone: 09 534 3978 for clinic
bookings or enquiries