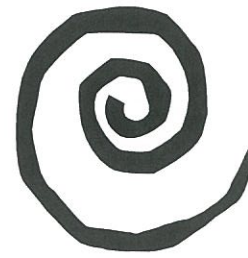


# KORU

## ME/CFS & FM Support

MS Waikato

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



August 2016 Issue 42

Kia ora and Welcome

At the time of writing this it is wet, wet, WET!!! I hear myself singing "rain, rain go away come again another day". We have experienced a mixed bag of weather this winter with unseasonably mild temperatures, hence the new catchphrase 'Sprwinter'!

As winter is a drab time of year, this is a good time to remind you of the importance of taking Vitamin D to help with energy and low/flat mood. See page 6 for details.

Our National ME/CFS guru, Dr Vallings is visiting again for our August meeting. This year she will be sharing key points of the latest research from the recent 'Invest in ME' conference but also more specifically she will be speaking about the function and role of the immune system in ME/CFS. Please register your interest in attending - Ph Tracey on 8344745.

### ME/CFS & FM AWARENESS DAY 12<sup>th</sup> MAY

A big thank you to all the volunteers- Maree, Lee, Emily, Ann, Miriam and Graeme for your time and effort helping on the stall at Chartwell. Helen also came along and gave us a hand!



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### Dr Ros Vallings

**THURSDAY  
11<sup>TH</sup> AUGUST 2016**

at

*Methodist Church, Bader Street,  
Melville, Hamilton.*

**10.30 am to 12.00 midday**

This meeting is open to the public so family and friends are all welcome.

Please register your interest in attending by phoning Tracey on 07 8344745 or email: [tracey@mswaikato.org.nz](mailto:tracey@mswaikato.org.nz)

Next Newsletter will be sent in November. Until then...

Aroha nui

*Tracey Larsen*





## May Support Group Meeting Loss and Grief



Erica Weerekoon worked at Hospice and in private practice as a grief counsellor. Although a lot of her work is regarding end of life, she also has much experience working with loss and grief with chronic illnesses.

Erica explained that many changes happen in life; where there is change there is a sense of loss and with loss there is always grief – whether it be a loss of job, health, relationships, death, moving house etc....

Grief is therefore a normal response to what we lose and a range of different emotions can be experienced such as (but not limited to) anger, denial, shock, feeling overwhelmed and sadness.

Loss brings the challenge of learning a new reality and through this process often many questions starting with WHY can be asked as we grapple with trying to understand and make sense of the change that has occurred.

Erica also spoke of how different cultures approach loss. Many eastern philosophies believe in and expect change through their lifetime which encourages an acceptance towards change when it happens. Many western cultures have an expectation that life will be orderly - we expect each other to be independent, healthy, have fulfilling careers, and to live our lives to our potential. When life dishes up pain, loss and struggle, we are not so well equipped to accept and cope with these changes.

Many of us agreed that we are expected to “get over it”, “get on with it”, “don’t cry”, and “pull your socks up”. Such attitudes force us to “soldier on” which make it hard to grieve effectively. Erica stated that it is okay to “take a break – have a kit

kat”. This is a figure of speech she uses to mean that it is important to be kind to ourselves. She used the analogy of one walking around carrying heavy bags; it is important to put them down sometimes, to take a seat and have a rest! Let yourself off occasionally, and give yourself a break – HAVE A KIT KAT!

This is a technique of the Mindfulness practice that Erica favours to support coping with loss and grief; being your own best friend, showing yourself kindness, understanding and love. Mindfulness also helps one to recognise the range of emotions one experiences and how to respond to them. This

in turn assists with acceptance and enables balance back into your life.

Walking the journey of grief alone is hard, so Erica suggests to be open with others. Open communication with others, and sharing knowledge of your situation also creates understanding and, in turn, support.

The process of grief is also very individual and sometimes just when you are feeling like you have a handle on your new normal, life can hit a pot hole and the sense of grief can come flooding back again. Mindfulness practices are very useful at these times to recognise what is happening and how to respond. Knowing that it is normal, that that *is* life, and that it is okay to take a break and ‘have a kit kat’ helps to release the burden of expecting to soldier on.



Erica holds a Mindfulness group on Wednesdays at her private practice, ‘Rose Cottage’, 83 Comries Rd, Hamilton. You can contact Erica on 021 08537516 or email [ew.uniquejourneys@gmail.com](mailto:ew.uniquejourneys@gmail.com) about this or to book for counselling services.



## June Support Group Meeting– Approaching Exercise



Kristina Jessup is a Clinical Exercise Physiologist who specialises in Chronic Disease and High Performance Rehabilitation. She spoke to the group in June regarding the importance of exercise and a healthy approach to exercise when one is suffering ME/CFS and FM.

Kristina stated that “unlike a normal response to exercise in healthy individuals, individuals with ME/CFS & FM have been found to have an altered immune response to exercise [such as] enhanced oxidative stress combined with a delayed and reduced anti-oxidant response”.

However, she explained that inactivity can lead to cardiovascular de-conditioning, muscle atrophy, weight gain and is associated with a higher risk of developing health conditions such as cancer, type 2 diabetes, high blood pressure, heart disease and stroke.

As people get older and especially for women (due to menopause), loss of bone minerals and bone density is a real risk. Balance issues and falls, which can result in fractured hips, is a further risk. Exercise therefore helps to maintain bone density, muscle condition and balance which reduces these risks.

Kristina shared some statistics from research that shows exercise therapy for those with ME/CFS & FM improved general wellbeing, reduced the number of tender points in FM as well as reduced pain levels, improved tolerance to physical activity, improved aerobic capacity, reduced fatigue, and had a positive effect on sleep.

Exercising safely is key and Kristina suggests to select an activity that you enjoy doing – walking, swimming, tai chi, stretching/yoga, Pilates, dancing, cycling etc...

Kristina says that starting slowly is KEY!

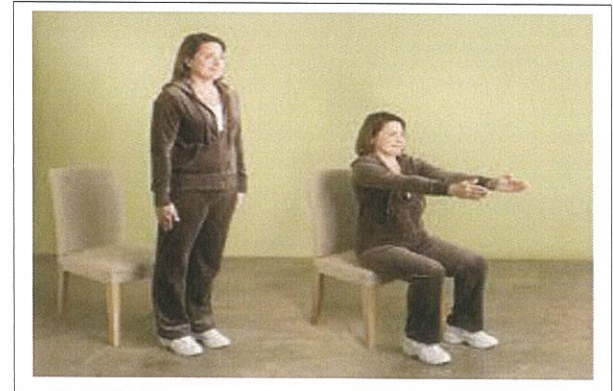
- it is important that you learn proper techniques to avoid injury
- engaging with a personal trainer will help this and they will establish a program that is individualised to you, your ability and fitness level

- make sure the personal trainer understands ME/CFS & FM
- be realistic and expect an increase of symptoms as you begin – have extra pain relief on standby and allow yourself to rest a little more during the time it takes to get used to new activity.
- do LESS than you anticipate that you can manage when you begin.
- slowly build up the time, weight, volume and repetitions as you feel able without exacerbating or irritating symptoms
- STOP if you feel an increase in pain or any unusual soreness
- pace yourself by doing 1-2 minutes of activity 2 times per day as a starting point, instead of doing 10 minutes activity in one hit.

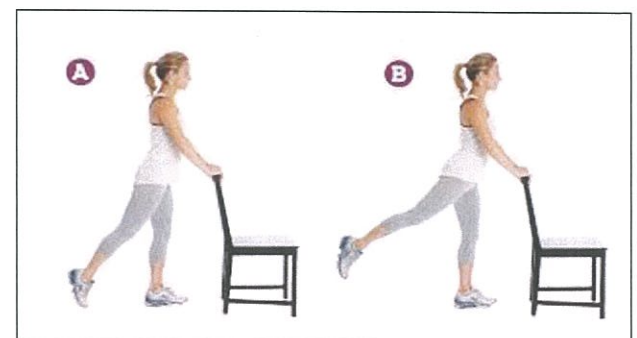
**Kristina also agrees with Dr Vallings rule of 1/3 – For example, 1 minute activity to 3 minutes rest between repetitions, or 30 seconds activity followed by 90 seconds rest between repetitions.**

### Beginning exercises to try at home:

Sit to stand and sit again



Bottom squeezes by raising your leg behind you



Also try shoulder rotations, forward and back and calf raises – move up to tippy toes and slowly lower down.

Kristina works at the UniRec at Waikato University. You can contact her on Ph: 07 8384177 or email [Kristina@uleisure.co.nz](mailto:Kristina@uleisure.co.nz)



## July Support Group Meeting - A Herbal Approach to Health



Sue Mitchell from Flagstaff Pharmacy is very passionate about a herbal approach to health which was very evident in her presentation. She explained that herbal therapies have been used specifically by the

Chinese for 1000's of years but also by mankind pre science medicine.

Even though many people suffering ME/CFS experience many of the same symptoms, everyone will have experienced a different journey to reaching their state of illness. A detailed assessment enables Sue to take a holistic approach by looking at the whole person to better understand the cause for illness and offer herbal treatments that are very individual and personalised. For this reason Sue may prescribe a different herb/s for the same ailment to different people and she often uses the whole plant - root, leaves and flowers - because each part of the plant can offer relief for varying aspects of a symptom.

Sue has noticed that many who experience ME/CFS also suffer from a condition called leaky gut. Stress, diet, alcohol and medication can cause damage to the stomach lining. This can result in holes forming in the lining allowing undigested food particles and bacteria into the blood system which can cause far-reaching negative impacts on health - mal-absorption of nutrients from food, being one major concern. Sue says that improving gut health not only improves brain health but can improve a raft of other conditions including low mood and depression. She can use a variety of herbs to help gut health and digestive issues such as ginger or milk thistle as these can aid digestion by helping nausea, bloating and flatulence. Cleaver also aids digestion and supports the lymphatic system.

Sue warns that it is important to consult a trained herbalist when considering a herbal approach as herbal remedies can interfere and react with medications. Always advise what medications you are taking when consulting a herbalist and always advise your GP if you are taking herbal remedies. How to take and when to take herbal remedies has a huge bearing on effectiveness. **It is vitally important that they are not taken together with medication**

*If you are interested in consulting with Sue ph 07 8540445 or pop in to enquire further. Consultations are \$80.00 for an hour and by appointment only.*

## LATEST RESEARCH

To support Sue Mitchell's claims regarding leaky gut, recent research findings from the National Institution of Health, Cornell NY, have shown that "the gut bacteria microbiome in ME/CFS patients isn't normal, perhaps leading to gastrointestinal and inflammatory symptoms..."

"In the study researchers collaborated with Dr. Susan Levine, an ME/CFS specialist in New York City who recruited 48 people diagnosed with ME/CFS and 39 healthy controls to provide stool and blood samples".

"Overall, the diversity of types of bacteria was greatly reduced and there were fewer bacteria species known to be anti-inflammatory in ME/CFS patients compared with healthy people".

"At the same time, the researchers discovered specific markers of inflammation in the blood, likely due to a leaky gut from intestinal problems that allow bacteria to enter the blood ... [which] will trigger an immune response, which could worsen symptoms"

"The researchers have no evidence to distinguish whether the altered gut microbiome is a cause or a consequence of disease... [but] maybe clinicians could consider changing diets, using prebiotics such as dietary fibres or probiotics to help treat the disease" said Ludovic Giloteaux.

*Information sourced from the article written by Krishna Ramamujan. I have only included key aspects of the article here. To view the article in full please view the following link*

<http://www.news.cornell.edu/stories/2016/06/indicator-chronic-fatigue-syndrome-found-gut-bacteria>



## **The Crucial Role CoQ10 Plays in Fibromyalgia and ME/CFS**

No two Fibromyalgia or ME/CFS patients are exactly alike. Each has a unique set of symptoms with varying degrees of severity. There is, however, one common denominator for the vast majority - a serious, sometimes even profound, lack of energy.

What could possibly cause that kind of fatigue?

**Multiple studies have suggested that mitochondrial dysfunction may play a significant role in both fibromyalgia and ME/CFS, which would explain much of the energy deficit.**

Mitochondria are the engines - or energy producers - that power every cell in the body. It is the job of the mitochondria to take in nutrients, break them down and use them to create energy for the cells. The more energy a cell needs, the more mitochondria it contains. Cells that require a lot of energy - like the heart, brain and other vital organs - may have thousands of mitochondria.

**95% of all cellular energy production depends on CoQ10.**

CoQ10 is the catalyst that makes it possible for the mitochondria to produce ATP (adenosine triphosphate), the molecule upon which all cellular functions in the body depend.

Given that statistic, it's not surprising to learn that, according to several different studies, people with FM and/or ME/CFS generally have very low levels of CoQ10.

There are numerous prescription and over-the-counter medications that can deplete the body of CoQ10. Unfortunately several of them are frequently prescribed for FM and ME/CFS, including many antidepressants, anticonvulsants and analgesic/anti-inflammatory medications. Statins, prescribed for lowering cholesterol, are particularly notorious for hindering the body's production of CoQ10

The form of CoQ10 found in most supplements is called ubiquinone. In order to produce cellular energy, the body must convert the ubiquinone to

ubiquinol. It is the ubiquinol that carries electrons through the mitochondria and produces energy.

Young healthy people (under 25) can easily convert CoQ10 to ubiquinol. But as we age or when we have a chronic illnesses, our ability to convert CoQ10 to ubiquinol diminishes. Therefore, it is particularly important for people with FM or ME/CFS to take the ubiquinol form of CoQ10 so they're not expending precious energy converting ubiquinone to its usable form.

The suggested dosage of Ubiquinol CoQ10 for FM and ME/CFS patients varies, but most experts start at around 150-200 mg/day.

It's important to note that Ubiquinol CoQ10 is not a quick fix that will give you an immediate energy boost. Each individual is different, but it generally takes two to three weeks to restore optimal CoQ10 levels in blood plasma and tissues.

While standard CoQ10 has to be taken with a fatty meal, Ubiquinol CoQ10 bonds with water, making it easier to absorb and eliminating the need to take it with fatty foods.

*Information sourced from Prohealth.com. To read the full article see link*

<http://www.prohealth.com/library/showarticle.cfm?libid=29063&B1=EP062716B>





## **Up & Coming Events**

**ME/CFS & FM Education Support Group**

**Methodist Church, Bader Street, Melville 10.30 - 11.30**

**August 11<sup>th</sup>**

Dr Ros Vallings will be sharing key points of the latest Invest in ME research and talking about the immune system

**September 8<sup>th</sup>**

Erica Weerekoon will be visiting again to educate us on "What is Mindfulness" and teaching us some simple mindfulness exercises.

**October 13<sup>th</sup>** - Yet to be confirmed

In previous Koru's I have asked for interest to be expressed regarding re-establishing the social group. I only received 4 replies. As our numbers are growing I am considering arranging a one-off social event in place of a monthly group meeting at the same venue as the monthly meetings. Who thinks this is a good idea? Ph me on 07 8344745 or email [tracey@mswaikato.org.nz](mailto:tracey@mswaikato.org.nz)

## **VITAMIN D3**

If you are interested in purchasing a quantity of Vitamin D3, please contact Carole Stark on 07 827 7695 or email [peterandcarole@xtra.co.nz](mailto:peterandcarole@xtra.co.nz)

*No matter how long  
the winter, spring is  
sure to follow -  
Proverb*

## **Remember**

**To register for Dr Vallings talk  
Thursday 11<sup>th</sup> August**

**10.30 - 12.00**

**Methodist Church, Bader St, Melville**

**PH: Tracey 07 8344745**

**EMAIL: [tracey@mswaikato.org.nz](mailto:tracey@mswaikato.org.nz)**

### **OTHER CONTACTS:**

You may find it helpful to speak 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

[lindaderrick@yahoo.com](mailto:lindaderrick@yahoo.com)

BERNADETTE: 07 8686763 (Thames)

Deborah: 07 8955545 (Fibromyalgia)

### **USEFUL WEBSITES FOR MORE INFO ON ME/CFS/FM**

[www.cortjohnson.org](http://www.cortjohnson.org) (Health Rising)

[www.anzmes.org.nz](http://www.anzmes.org.nz) [www.co-cure.org](http://www.co-cure.org)

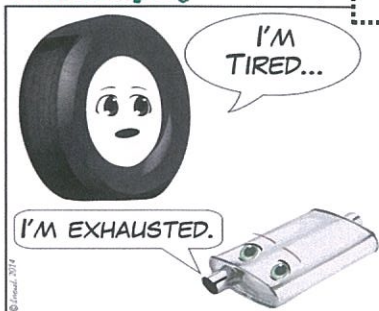
[www.me-cfs.org.au](http://www.me-cfs.org.au) [www.iacfsme.org](http://www.iacfsme.org)

[www.afme.org.uk](http://www.afme.org.uk) [www.cfidsselfhelp.org](http://www.cfidsselfhelp.org)

[www.emerge.org.au](http://www.emerge.org.au)

### **Past Expiry**

by Johnny Ar



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



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

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.

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**ME/CFS & FM**

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### **Medical Advisor**

**Dr Ros Vallings** Auckland

*Phone: 09 534 3978 for clinic  
bookings or enquiries*