

KORU

ME/CFS & FM Support

MS Waikato

Working Together to Provide a Service of Excellence

Mahi tatau kit e whakawkiwiki he hapori rawe



May 2016 Issue 41

Kia ora and Welcome

Well summer is over and autumn is well and truly here in its place. Some of you will be glad the heat is over and will be looking forward to cooler weather.

This month's Koru is jammed packed with lots of interesting bits and pieces. There is some 'BREAKING NEWS' on page 3 regarding a screening test being developed by our Australian neighbours which is sounding very promising as a diagnostic tool. Page 3 also shares information from our March meeting regarding aides to support daily living.

A focussed group discussion was held for the April meeting. Each member brought along one idea that supports their health to share with the group and also a burning question they wanted answered. See Page 4 for a brief outline of the ideas shared.

Turmeric has been grabbing my attention lately. It seems that it is a great little spice with fantastic anti-inflammatory, antibacterial and digestive benefits. Read all about it on page 5. Also here you can read about how you can attend to your spirit – an important part of wellbeing often overlooked.

ME/CFS & FM AWARENESS DAY IS FAST APPROACHING...!!!

As this date clashes with our May Group meeting we will be holding a stall at Westfield Chartwell on Friday 13th instead. I need helpers to supervise the stall for a couple of hours on this day. Please phone me on 8344745 if you can help.

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

Aroha nui,

Tracey Larsen

(what do you see in this photo?)

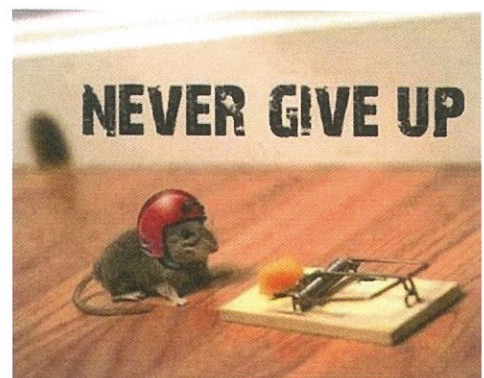


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To all the patients, carers, friends, family, advocates,
fundraisers, researchers & medical practitioners:

NEVER GIVE UP

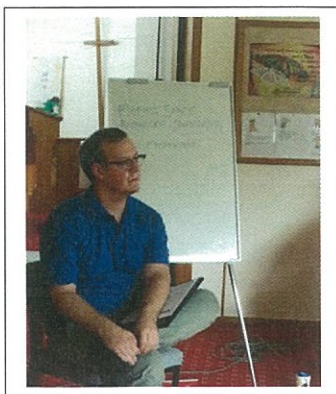


MYALGIC ENCEPHALOMYELITIS AWARENESS
DAY
MAY 12

www.mey12.org
www.constantfuckingshit.wordpress.com



February Support Group Meeting



Neil Micklewood, Psychologist, spoke to us at our February meeting about the benefits of using Mindfulness, CBT (cognitive behavioural Therapy) and ACT (Acceptance and

Commitment Therapy) principles to manage pain and wellbeing. Neil has a personal interest in this therapeutic approach due to suffering chronic back pain himself and he also has family connections with ME/CFS.

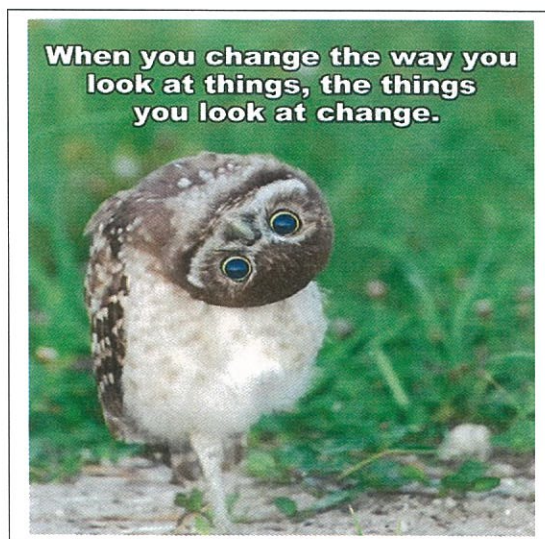
Neil first explained what psychology is, describing it as a science of the mind - thoughts, feelings, behaviour and spirituality. It has been a science since the beginning of the 19th century. People seek the support of a Psychologist not just for mental illness but for many different reasons.

It is Neil's belief that chronic illness "is not in your head" but that psychological stress sits alongside illness due to the mind/body connection. Neil's therapeutic approach works with the interplay between mind, body, spirit and family – if one area is not functioning well it will affect the other areas. He investigates thoughts, emotions, behaviours and psychological reactions and how we make sense of the world around us, what rules we apply and live by which helps him to understand the whole person. When one is suffering a chronic illness such thoughts, feelings, behaviours and reactions can feed the cycle of suffering especially when we keep applying the same rules that do not resolve the issue.

Neil's approach brings understanding of the pain cycle and how one responds to pain and other health symptoms. Such understanding can generate a mental shifting of gears which enables an accepting and an open attitude to the suffering. Suffering therefore becomes an experience rather than a complete absolute.

By this he means that pain is real and is part of human experience to which we attach meaning - interpret it as dangerous or helpful. It can alert us that something is wrong but at other times we can have pain and not be in immediate danger. If we approach symptoms less absolutely we may be less frightened by it and possibly pay less attention to it.

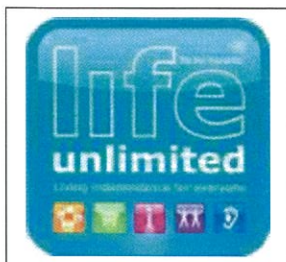
Such an attitude encourages an observer position to your symptoms which creates a distance from them and allows other aspects of your being, identity and situation to be considered. This creates a 'bigger picture'. Noticing the bigger picture and how the pieces of that picture fit together helps us notice that some pieces may not as important as they might initially appear to be. Viewing this bigger picture helps to shift our focus from the pain to the other aspects of our being.



Neil also helps us to remember our skills and talents and value what is important about one self. This can then translate into an action within one's physical constraints, helping one to live with purpose and a focus of what one can do as opposed to focusing on what one can't do. What can we do that serves our values?

To contact Neil Ph: 07 855 8413 or see his website www.neilmicklewood.com He is ACC registered and WINZ approved. He also undertakes free brief consulting (up to 4 sessions) which is funded through the PHO. Discuss with your GP to see if you qualify.

Aides for Daily Living



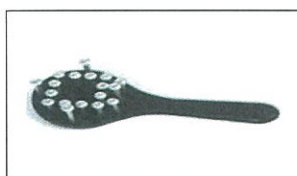
Toni from Life Unlimited presented to our March group meeting aides for

daily living. She brought along an array of items from collapsible walking sticks to lap trays, trolleys, walkers and can and tin openers. She demonstrated items that assist with putting your socks on and off, long extended grabbers to pick up items without bending and a gadget to clean and dry in between your toes without bending.

Kettle holders are ideal if you have difficulty with strength to lift one and enable you to pour boiled water without burning yourself.



Do you have difficulty pulling on your clothes?
Toni has just the thing to make it easier.



This is a tap turner. It enables you to use elbow and shoulder movement instead of wrist and

fingers strength to turn taps on and off. It fits any shaped tap and can even be useful to open some door handles.

Toni also had several items that can assist with passive exercise that enable you to tone muscle and maintain flexibility without over-extending your energy. The Aircycle is one such item that is used with your feet – by slowly stepping from one side of the air-filled pad then to the other works ankles, calf muscles, knees, thighs and hips.



There is also one available for hands; by alternating your squeeze you work fingers, wrists, lower and upper arms which helps to tone muscles and increasing circulation.

Toni also demonstrated kitchen utensils that help with chopping and cutting vegetables safely, pot grips, peelers and much MUCH more...

If you didn't make it to the meeting, no fear! All of these items and the rest can be viewed at the Life Unlimited Store situated at 20 Palmerston St, Hamilton. They also now have an online store so you can purchase products from the comfort of your own home. Have a look at their website on <http://www.lifeunlimitedstore.co.nz/shop>



SCREENING TEST FOR ME/CFS ON ITS WAY

Ground-breaking research at Griffith University into Chronic Fatigue Syndrome (CFS) is leading the way for the development of a new screening tool for the condition.

The research team from the National Centre for Neuroimmunology and Emerging Diseases (NCNED), Menzies Health Institute Queensland, has identified new markers that can be used to screen patients and is now looking to partner with diagnostic companies to bring a test to market. The screening test is expected to benefit all those with symptoms of the condition.

"This screening test may be expected to become a laboratory standard to provide more certain, and cost-efficient, diagnosis for CFS.

"This illness has traditionally been difficult to diagnose, meaning that people can go for months without getting the care and attention they require. We are confident that the new screening test currently in development will provide efficient and increasingly accurate screening for people with CFS. This test may also be used to monitor and track the progression of their illness," says Professor Staines.

Information sourced from
<http://www.prohealth.com/ME-CFS/library/showarticle.cfm?libid=27381>

April's Support Group Meeting

This month I gave the group members an opportunity to share with each other the knowledge they have gained through trialling different approaches to manage and support their health. What a fantastic discussion and sharing of ideas!

Please note that what is suitable for one person may not be suitable for others, so if you chose to try any of the following consider it as an experiment of trial and error.

One member shared that her health improved greatly when she started to use filter cartridges to purify her water. She also shared how she has very good joint health by incorporating gelatine into her daily diet. She also showed us the magnet she places by her knee which she says reduces her pain. She buys sheets of magnets (like soft bendable fridge magnets) and cuts them to size. She also swears by Vitamin B2 as helping her dizziness and tinnitus.

Another member shared that she has been having great success with Bowen Therapy treatment, providing more mobility and comfort in her joints.

First line of focus was to improve the quality of sleep, for another member, by the use of REM sleep supplement and also magnesium taken at night. Once she conquered this she then was able to focus on other interventions to assist her energy and health via supplement use and diet. CoQ10 and Omega 3, calcium and magnesium, and a good multi vitamin are now taken daily which she has found beneficial in energy production and general wellbeing.

Her new bible is the book "Stay healthy by supplying what is lacking in the diet" by David Coory, 2013. She has found this to be very helpful in guiding her to reducing and/or eliminating additives, preservatives and sugars from her daily diet and find foods that are less toxic and more supportive of health and wellbeing.

One client recently stayed at Bryant Retreat in Raglan for some much needed time out and rest.



She found it to be a wonderful caring and healing environment and highly recommends it. And it's free!

Resting in the afternoon if needing to go out at night and attending to activities such as vacuuming in small bite size time frames is an approach that another member practices often. She also ensures she has food in the pantry to make quick and easy meals when she is too tired to prepare a big meal.

A Ninja blender has become a standard feature on another member's kitchen bench for whizzing up smoothies of joji berries, linseed, kale, almond and other wonderful goodies. She has found that she feels more vibrant and it is a great option as a meal replacement when she is too tired to prepare meals.

Much discussion was generated around these ideas especially regarding magnesium usage. Another member finds taking magnesium orally disagrees with her so uses oil or lotion and Epsom salts in the bath. Magnesium can also be purchased in a powder form which enables you to play with the dosage until you find what you can tolerate.

11/8/2016

**Dr Vallings is
our guest
speaker**

Circle the Calendar!

TUMERIC

Tumeric seems to be the new 'hot word' at present. Much research has proven the remarkable properties of the ancient spice which has been used for many thousands of years in Chinese and Indian Ayurvedic medicine as a natural pain reliever and for other conditions including heartburn, diarrhoea, stomach bloating, colds, and headaches, and as a liver detoxifier.

Curcumin is the main active ingredient in turmeric and gives the spice its rich yellow colour. It has strong anti-inflammatory, antioxidant and antibacterial properties. Curcumin can help treat symptoms of arthritis and in some cases it is more effective than anti-inflammatory drugs, but without the side effects, which make it ideal for Fibromyalgia and ME/CFS. Curcumin can also improve cognitive functioning and is effective in alleviating the symptoms of depression. It also has beneficial effects on several factors known to play a role in heart disease and Alzheimer's disease.

Many users recommend taking 1 – 2 teaspoons daily. It does not have a strong flavour and can be taken in hot milk. Alternatively it can be purchased in capsule form from health food stores.

Turmeric should not be taken by people with gall stones or bile construction. Tumeric has been used as a uterine stimulant so pregnant and breast feeding women should seek medical advice before taking.



Information sourced from
<http://www.webmd.boots.com/healthyeating/features/health-benefits-turmeric>
<http://authoritynutrition.com/top-10-evidence-based-health-benefits-of-turmeric/>

TENDING TO YOUR SPIRIT

A chronic illness provides you with the opportunity for reflection and self-realisation. It is important that you find ways to nourish and replenish your soul, as it is just as important to feed your soul as much as feeding your body.

If nothing else, find a way to make peace with where you are at right now in your life. With an illness you only have control over a handful of things so know that your value is not in what you accomplish or what you own, but simply in the fact that you exist!

Participate in activities that make you feel whole, more alive and at one with the universe, such as: reading books that inspire you; watching movies that inspire you; try new things like yoga, meditation, prayer; enjoy the outdoor - see the beauty in a sunrise or sunset and experience the richness of nature; bring music and art into your environment; write about your experience - this is a good way to express your feelings.

Humour is good for the spirit, the body and the immune system. It also helps to keep things in perspective and maintain a positive attitude. Give yourself a reason to laugh every day - read a funny book; watch funny movies; socialise with funny people; laugh at yourself.

Advice taken from Cynthia Perkins M.ED Essentials for managing a chronic illness

*The Serenity Prayer
God, grant me the
serenity to accept the
things I cannot change,
The courage to change
the things that I can,
And the wisdom to
know the difference.*

Coming Events

ME/CFS & FM Education Support Group

Methodist Church, Bader Street, Melville 10.30 - 11.30

May 12th

Erica Weerekoon - Counsellor - will be sharing her wisdom on grief and loss and the benefits of acceptance when experiencing a chronic illness

June 9th

Kristina Jessup from Waikato Unirec will be speaking to us about exercise - the importance of exercise and how to approach it safely within the bounds of a chronic illness.

July 14th

Sue Mitchell is a Medical Herbalist at Flagstaff Pharmacy. She is coming to speak to us about a herbal approach to health

August 11th - Dr Vallings visiting Hamilton

Young Peoples Group

There is a Facebook page called "ANZMES under 21's group" for young people suffering from ME/CFS.

Check it out!!

*The future is fantasy
- only the present is
real*

Lisa Genova

Mindfulness Retreats

Saturdays 1pm -4pm @ Hamilton Gardens

\$20 per retreat - come to one or all

May 21st June 18th July 16th Aug 20th Sept 24th Oct 15th Nov 19th

3 hour mini retreats to learn and practice mindfulness skills

Friendly and supportive environment

(with great scenery and afternoon tea)

Open to beginners and those experienced in mindfulness

To register contact Jo Wall

Ph: 021 266 5657

Or email jowall@outlook.com

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

BERNADETTE: 07 8686763 (Thames)

Deborah: 07 8955545 (Fibromyalgia)

USEFUL WEBSITES FOR MORE INFO ON ME/CFS/FM

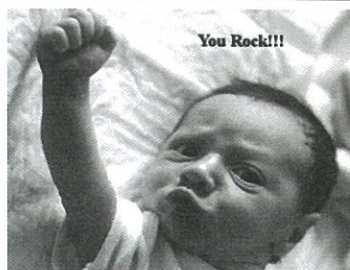
www.cortjohnson.org (Health Rising)

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



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. Phone: 8344740 to enquire

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