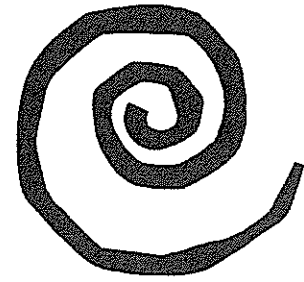


KORU



ME/CFS & FM Support

MS Waikato

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

May 2015 Issue 37

Kia ora and Welcome

IT'S MAY ALREADY!!! Where is the year going? Summer came to an end abruptly with heavy rains and evidence of autumn is now apparent with the trees changing colour and leaves starting to scatter the ground. Although winter isn't far away, I have heard that winter may be warmer and drier than normal this year (my fingers are crossed) which is great news for those who suffer the cold. As winter is fast approaching see page 3 for a discussion on 'The power of Vitamin D'.

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International ME/CFS & FM Awareness Day on the 12th May is fast approaching. An education stall will be situated at Chartwell. If you are interested in helping please contact me on 8344745. I have gained over a dozen new clients already this year so this shows that awareness is growing. This is great news and it is keeping me very busy 😊.

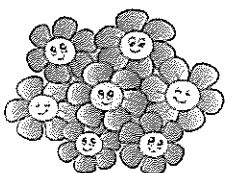
The big ME/CFS news of recent months has been the IOM (Institute of Medicine) report investigating a more appropriate definition for ME/CFS and how it can effectively represent this illness. ANZMES 2015 autumn issue of Meeting Place has an in-depth over-view of the report including reviews and opinions which makes for interesting reading. I have briefly discussed on page 2 the general opinions expressed regarding the proposed name change to Systemic Exertion Intolerance Disease (SEID). I have two copies of this ANZMES issue to lend if you are interested in reading this report.

You will also find an over view of our guest speakers and what they shared at our Education Support Groups meetings on pages 2 and 4. Please note that the next newsletter will be sent out early August.

Until then....

Aroha nui

Tracey Larsen



Dr Ros Vallings is coming to share latest information regarding ME/CFS & FM research.

Thursday 13th August

Methodist Church, Bader St, Melville at 10.30am

REMEMBER TO CIRCLE YOUR CALENDAR.
Please phone me on 8344745 to express your interest in attending

WHAT'S IN A NAME?

In a nutshell, the IOM report confirms that ME/CFS is real by clearly stating that "ME/CFS is a complex, serious, chronic, multisystem disease that frequently and dramatically limits the activities of affected patients" and it recognises that "funding towards research has been inadequate". It also confirms that it is a 'disease' and not a syndrome. However Systemic Exertion Intolerance Disease (SEID), as the recommended definition, is "simplistic and this undermines the complexity of ME/CFS. It reduces ME/CFS to a single symptom and 'exertion intolerance' [does nothing to quash ridicule and] continues to misinterpret ME/CFS is a psychosomatic manifestation of 'fear avoidance' of exercise."

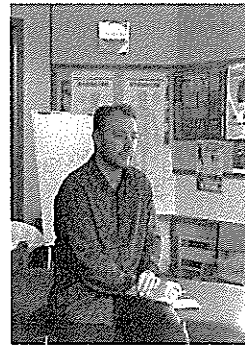
The report recommends limiting the diagnostic criteria to meet four or five non-specific symptoms (fatigue, post exertional malaise, unrefreshed sleep, cognitive impairment and/or orthostatic intolerance) which may wrongly diagnose people without ME/CFS. For example "the core symptoms of the new diagnosis fit into the clinical definition for depression (fatigue, insomnia) with anxiety (symptoms made worse by stress)". All diseases are 'systemic' and generally named by a variety of traditions – place where first identified (Lyme disease); name of person who identified disease (Alzheimer's) or a famous person with the disease (Lou Gehrig's); the organ the disease affects (kidney disease) or the primary mechanism (muscular dystrophy). Illness are never named after a single non-specific symptom.

"In naming this illness after a non-specific symptom is what has caused so much damage over the past three decades. 'SEID' repeats the error, reducing the illness that is complex with no generally accepted biomarker to a single non-specific symptom. 'Exertion intolerance' in this context is no better than 'fatigue' in CFS".

Information sourced from 'The IOM Report: The Good, the Bad and the Absolutely Hideous' written by Erica Verrillo, 16/2/2015 as published in ANZMES Meeting Place Issue 119, Autumn 2015.



Andrew Fraser – Zen Acupuncture Clinic



Andrew Fraser spoke to the Educational Support Group in March about the benefits of traditional Japanese acupuncture and Chinese herbal medicine to improve health. After 4 years of study Andrew spent several years in Japan studying under a

traditional acupuncture Master to hone techniques and understand the more subtle aspects of the practice. Accordingly, his approach towards health considers the mind, body and spirit as well as the elemental components of energy, air and blood.

Andrew stated that acupuncture is gentle, painless and an effective way to treat many different conditions and illness as it treats the root cause of the condition instead of just the symptoms. It works on the meridian energy channels in the body and by adding energy to the body through the use of needles – but not needles as we know them! Most needles are made from either silver, platinum or gold and can be used internally and externally - which is helpful for those who suffer chronic pain such as fibromyalgia.

Andrew stated that 8 of 10 ME/CFS client's present with digestive issues, further stating that 70% of good health is determined by the digestive system which in turn supports the immune system. Therefore to support the digestive system Andrew considers diet as well as environmental factors that attribute to the quality of air we breathe that support (or that is detrimental to) respiratory health. He also uses Chinese herbs in a heat treatment which is applied to the skin. This helps to cleanse the blood which assists to boost the immune system also.

Acupuncture is useful when working with phantom pain through loss of limb/s and Andrew works a lot with injuries through ACC. He states that chronic conditions can take time to heal.

The Zen Clinic is situated at 10 East St Hamilton. Please phone Andrew on (021) 072 9531 for an appointment.

The Power of Vitamin D

Vitamin D has amazing health benefits and healing power. Unfortunately most people suffer from vitamin D deficiency and although vitamin D awareness has increased more recently there is still a lot of misconceptions. For example, most people don't know that vitamin D is actually a hormone; you can't get enough vitamin D by going outdoors 15 minutes a day, by eating certain foods or drinking a cup of milk a day or taking a daily multivitamin; and many are also frightened about vitamin D toxicity, but apparently toxicity is extremely rare.

Recent research suggests that some diseases could be attributed to vitamin D deficiency. This is perhaps not surprising as symptoms of deficiency include fatigue, muscle and bone aches, arthritis pain, bone and teeth fractures, asthma, frequent colds, increased risk of heart disease, diabetes and high blood pressure, thyroid disease, forgetfulness and depression.

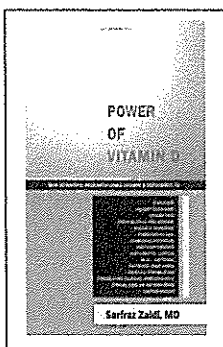
Many contributing factors can influence vitamin D levels which is why many GP's in NZ only request the blood test, 25(OH), upon evidence of other unexplained metabolic conditions and accordingly ask 'what do the results really mean?' Also, the process to test blood is not straight forward and is labour intensive - hence costing \$30. Dr Sarfraz Zaidi states that results are often interpreted in reference to the outdated and incorrect 'normal range' determined in the era when the concern was only to prevent rickets. Vitamin D is now understood to be crucial for maintaining many vital functions in the body, such as a healthy immune system and a healthy heart as adequate levels help to prevent diabetes, osteoporosis and cancer to name a few.

How much vitamin D to take? Dr Zaidi states that most people who take the usual recommended dose of 600 I.U per day continue to be low in vitamin D. He states that a general guideline is to take on a daily basis 1,000 units for each 20Lbs of body weight. For example if you weight 200Lbs you need 10,000 units per day. Dr Zaidi recommends taking vitamin D3 as it is the closest

science can get to the natural state produced in our skin upon exposure to the sun,

To learn more about vitamin D, Dr Sarfraz Zaidi (MD) has written a book "The Power of Vitamin D." We have this in our library so phone me on 8344745 if you are interested in borrowing this book.

Information sourced from www.powerofvitamind.com



THE CHIA SEED IS A NUTRITIONAL POWERHOUSE

If you're looking to boost your nutritional intake, look no further than the humble chia seed. Per gram, chia seeds contain:

- * 8x more omega-3 than salmon
- * 6x more calcium than milk
- * 3x more iron than spinach
- * 15x more magnesium than broccoli
- * 2x more fiber than bran flakes
- * 6x more protein than kidney beans
- * 4x more phosphorous than whole milk

Daily Superfood Love dailysuperfoodlove.com

Dr Vallings new book "Teens & Young People with ME" is soon to be released.

This is an easy to read book talking directly to teenagers and young people. Chapters include easy-to-follow self-help strategies, possible options for keeping up with education, and the importance of maintaining a balanced lifestyle which includes social life, good sleep and sensible eating. It addresses the changing body through adolescence and how to cope within the context of the illness. A well-illustrated book with short chapters gives a good understanding of what the illness is about and how it is diagnosed. MS Waikato will be obtaining a copy, so if you are interested in borrowing this from our library please phone me on 8344745

VITAMIN D3

If you are interested in buying a quantity of Vitamin D3 from a reputable source please contact Carole Stark on 07 827 7695 or email peterandcarole@xtra.co.nz



Dr Dam Shay –

**Adrenal Health & Ten
Point Wellness Approach
to Health**

Dr Sam Shay spoke at our April group meeting about Adrenal Health and the 10 point wellness system he has

designed. Usually Dr Sam’s presentations are given in two hour segments covering a different aspect of his work in each segment. Although he only had time for a very brief overview in the hour of our meeting it was none-the-less very interesting, offering new ideas within a holistic framework.

He started by highlighting the purpose of cortisol stating that normally we have a burst of cortisol early in the morning to switch off our sleep hormone and give us energy, and then it will slowly deplete during the day until in the evening, when our melatonin hormone releases, sending us to sleep. When we become stressed the adrenal system activates the short term survival mechanism known as fight or flight by releasing extra cortisol. When the body is functioning in this manner the immune system is suppressed. Historically, stress related to concerns of starvation and being attacked by bears and tigers and was ‘short term’. In our modern world stress is ever-present and long term – lack of time and resources to meet daily demands, meeting deadlines, financial pressures, managing careers, raising families, as well as negotiating relationships, emotional traumas, nursing injuries and high exposure to environmental and dietary toxins and chemicals.

Our ever-faithful bodies continue to respond to such stress and does not distinguish between being chased by tigers and deadlines, hence cortisol is flooding into our bodies more regularly and at increasingly longer periods of time, suppressing the immune system for extended periods as well. As the body continues to live in the continuous state of stress it stores energy to survive the (historical) threat of starvation and this is generally stored around our middles so that we can still use our arms and legs for running (from tigers).

Pain also activates the body’s stress response firing up the adrenal glands to produce cortisol, which

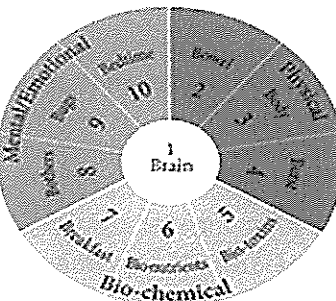
signifies the importance of spinal health – an ill-aligned spine creates pain and tension throughout the body

Dr Sam stated that symptoms of high cortisol is jittery thinking and the inability to focus attention for any length of time. Exhaustion can also result from low levels of cortisol when stores become depleted. Light headedness upon standing indicates that adrenal fatigue is present; seeing lights in your eyes is chronic adrenal fatigue and blacking out indicates acute adrenal fatigue and is the body’s response to ensure our survival (when lying down blood can get back to the brain easier). The effects of adrenal fatigue spread further by also interfering with the release of melatonin which impacts our sleep patterns and cycles, and serotonin, which impact our mood and may result in disorders of consumption (alcoholism, drugs bulimia), anxiety, concentration and memory and depression. Forty percent of our sex hormones are generated in the adrenal glands therefore low libido can also result.

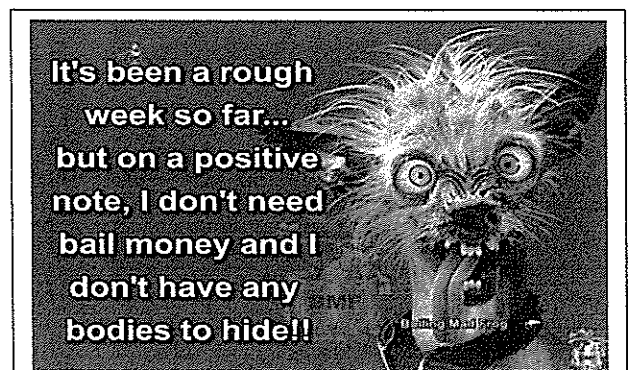
Dr Sam takes a holistic approach to adrenal health and health as a whole. First he teaches how to understand your own unique cortisol levels (ebbs and flows) through saliva testing. A nutritional focus assists to rebuild the adrenal glands and remove toxins. Bowel health, posture, untreated injuries, metabolism and the importance of breakfast and

brain balance are only some of the areas he investigates to diagnose and treat adrenal health and other health concerns.

To learn more, see Dr Sam Shay’s website



www.tenpointwellness.com. He has online learning resources and videos of his presentations. His clinic is ‘Stress Clinic’ situated at 32 O’Neill St. Hamilton. For a consultation phone 07-808-0448.



Tips, Snippets & Contacts

Coming Events

ME/CFS & FM Education Support Group

Methodist Church, Bader Street, Melville 10.30 - 11.30.

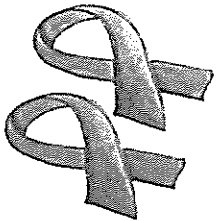
14th May - Group discussion - 'Practical Strategies for Daily Coping'. An opportunity for you all to share your ideas in a focused discussion

11th June - Our guest speaker this month is Donna from Donna's Wellness Centre. Donna is a naturopath and will be sharing her approach to treating ME/CFS via diet, environment and lifestyle considerations.

9th July - Craig Wills is a WINZ advocate based at Pukete Community House. He is coming to speak to us about what benefits are available, the process of applying for a benefit and any current changes to existing benefits.

IMPORTANT NOTICE

Due to a drop in numbers the Social Coffee Group that takes place on the last Tuesday of every month at Robert Harris, Chartwell is **CANCELLED UNTIL FURTHER NOTICE**



**ME/CFS
&
Fibromyalgia**
12 May
International
Awareness Day

USEFUL WEBSITES FOR MORE INFO ON ME/CFS/FM

www.anzmes.org.nz

www.co-cure.org

www.me-cfs.org.au

www.iacfsme.org

www.afme.org.uk

OTHER CONTACTS

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

CIANE: 8466535

LINDA: 8553934 lindaderrick@yahoo.com

BERNADETTE: 078686763 (Thames)

REMEMBER to Circle your Calendars

13th August Dr Ross Vallings's talk
Bader St Methodist Church, 10.30-11.30
Phone 07 8344745
to register your interest



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

If you have anything interesting you wish to share in the Koru please email it to me at tracey@mswaikato.org.nz



MS Waikato have wheelchairs available to loan at no cost. Phone: 8344740 for enquiries.

**SOMETIMES
I PRETEND
TO BE
NORMAL.**

but it gets
boring.
So I GO BACK
TO BEING
me.

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 area defined by the boundaries of Waikato DHB. Disclaimer: Opinion expressed in Koru are those of the writer and not necessarily those of the Hamilton ME/CFS & FM Support Group of MS Waikato Trust.

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ME/CFS & FM

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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

BOOKS & RESOURCES AVAILABLE

LIBRARY BOOKS

15 Natural Remedies for Migraines and Headaches, J.S. Cohen MD
An introduction to the Lightening Process, Phil Parker (3) 2 donated
Chronic Fatigue Syndrome M.E., Dr Rosamund Vallings (5 copies)
Chronic Fatigue/ME-Support For family & friends, E. Turp
ChronicFatigueSyndrome, Campling
Diagnosing & Treating Chronic Syndrome, Dr Sarah Myhill
Fibromyalgia and female sexuality, Marline Emmal
Fibromyalgia and Myofascial Pain Syndrome A practical guide to getting on with your life, Dr Chris Jenner
Fibromyalgia for Dummies, R. Staud
Fibromyalgia- simple relief through movement, Stacie L. Bigelow
FibroWHYalgia S.Ingebretson
FM & Chronic Myofacial PainD. Starlynyl & M. Copeland.
Food Allergy Survival Guide, Vesanto Melina Jo Stepaniak Dina Aronson
From Fatigue to Fantastic, JacobTeitlebaum
Healthie without Wheat-Anew understanding of wheat allergies, celiac disease and non-celiac gluten intolerance, Dr Stephen Wangden
Healthy Eating for IBS, Sophie Braimbridge
Hope & Help for Chronic Fatigue Syndrome & Fibromyalgia, Alison Bested
Living With Fibromyalgia, Christine Craggs-Hinton (3)
Lost Voices, families living with ME
Managing Chronic Fatigue Syndrome & Fibromyalgia, CD set by Bruce Campbell
Optimum Health the Paleo Way, Claire Yates
Parting the Fog- Sue Jones
Power of Vitamin D, Safraz Zaldi
Recovery from CFS, 50 personal storie, Alexander Barton (2)
Reviving the Broken Marionette-treatments for CFS ME and FM, Maija Havisto
Sacred Space ME/CFS Depression, Anxiety & Stres, Elizabeth Bailey
Sophie's Story-My 20 year battle with IBS, Sophie Lee
Stay Healthy by supplying what's lacking in your diet, D. Coory
Taking Charge of your Chronic Pain, Peter Abaci
Taking Control of TMJ, Robert Upgaard
The CFIDS / Fibromyalgia Toolkit-A practical self-help guide, Bruce Campbell
The CFSID & Fibromyalgia Self-Help Book A Self Management Program for CFS and FM, Bruce Campbell
The Chronic Fatigue Healing Diet, Christine Craggs-Hinton
The Great Physician's Rx for Irritable Bowel Syndrome, Jordan Rubin
The Introvert Advantage-How to thrive in an Extrovert World, Marti Olsen Lani
The Irritable Bowel Syndrome Solution, Dr Stephen Wangen
The New Zealand Gluten Free Cookbook-food everyone can enjoy, Sophie Johnson
The New Zealand Gluten-Free Cookbook, Jim Boswell
The Patient's Guide to CFS & Fibromyalgia, Bruce Campbell
The Whole-Food Guide to Overcoming Irritable Bowel Syndrome, Laura J. Knoff
Understanding Irritable Bowel Syndrome, Dr Kieran Moriarty
Verity Red's Diary-A story of Surviving ME, Maria Mann
What Your Doctor Doesn't Know about FM, L. Veilink and P. Rhodes
Wherever You Go There You Are, Jon Kabat-Zinn
Yoga for Fibromyalgia, S. L. Crotzer
Your Symptoms are Real-What to do when your doctor says nothing is real, B. Natelson

If you are interested in reading any of these books, I can post them out to you. Please phone 07 8344745

DVDS: AVAILABLE TO BORROW OR BUY FOR \$10.00

Dr Vallings talk 2014 -research	Dr Valling's Invest In ME conference 2012 / May 2013
Dr Valling's IACFS/ME Conference Nov 2011	Dr Vallings August 2010 talk
Dr Vallings - Pain Management	Dr Nancy Klimas's Hamilton talk
Relaxation for Pain Management CD (loan only)	