

KORU ME & FM Support

HAMILTON AUGUST 2014 Issue 33



Hello everyone,

Apparently last month was the warmest June on record since records began, but July has been a different story! Paying the electricity bill at this time of the year is a bit of a tough call for many. But staying warm is important as we all know that the cold can exacerbate symptoms. I learnt a good tip last winter from one of our members – she cuts off the sleeves of old woollen jumpers and uses them as leg and arm warmers for extra warmth. Cost saving and effective!

Our support group speakers for the last two months covered interesting topics and you'll find information on both on pages 2 and 4. Also on page 4 you'll find details of our August talk, which I have been reminding you about for a while. **Dr Ros Vallings** will be with us to discuss the current research from the latest Invest in ME conference she attended in London at the end of May. We are very fortunate to have such a direct link to hear about what's happening internationally, and have Dr Vallings explain it in relatively simple terms. As we know, Dr Vallings is a very busy person, and we are very appreciative that she gives up her time so generously to share her knowledge. For that reason I would like to see a really good turnout on **Thursday 14th August**. For those unable to come, Noel Morris has once again kindly agreed to make a DVD of the talk and it will be available to buy or borrow. If you want a copy contact me, and I will let you know the details, or email noel@faithnet.co.nz.

As you will see enclosed, MS Waikato has included a survey so we can determine if we are meeting our client's needs. We want to know your thoughts and any ideas for changes or improvements, so if you can manage it, we would appreciate you filling it in. Please be assured that it is completely confidential and the results are not collated by our staff.

Lastly, after much thought, I have decided that this will be my last year in this role. After nearly six fairly full-on years it is time for me to retire and hand over to someone else. That someone is Tracey Larsen, who some of you have already met, and who is very passionate about taking over the role. It's good to have new blood and new ideas, and I've no doubt Tracey will do a great job. I know I will really miss the job and all of you, but I have many plans to fill the gap, and of course, I'm still around until the end of the year!

Keep warm.

Helen

*"It's a mistake to look too far ahead.
Only one link in the chain of destiny can be
handled at a time."*
Winston Churchill

CONTENTS

Page 2: Eating for Health and Energy

Page 3: The Happiness Jar. Poem / anxiety

*Page 4: Cranio-Sacral Therapy
Upcoming meetings*

Page 5: Study - CFS stigma adds to suffering

Page 6: Resources



EATING FOR HEALTH & ENERGY



Helen Donnison studied metabolism and genetics to qualify for her science degree, intending to get in to research. However she found research work rather dull, so she then studied herbal medicine and became a qualified practitioner, later teaching it for several years. Her passionate interest in nutrition and metabolic health led her to open the Vibrant Health Centre with partner, Jag.

Helen says that eating a wholesome diet and having a healthy relationship with food are vitally important aspects to creating good health. A basic principle of health is that food is our body's first medicine; it is the source of fuel (energy), building blocks (spare parts for repair and maintenance of our body's cells and tissues), activators (vitamins) and enhancers (antioxidants and accessory nutrients). Whole foods, eaten in the right balance and prepared in a way that we can digest and absorb their nutrients, are the key to vibrant health. Sugars and processed food drain us of energy and nutrients, leading to energy fluctuations, fatigue and impaired metabolism, causing poor health and disease symptoms.

Helen initially demonstrated to us what happens to our metabolism when we eat sugary foods – insulin is produced to deal with the sugar, but the blood sugar soon drops, we become hungry again, and the pattern tends to be repeated. With an unhealthy eating pattern there are lots of insulin spikes, and if we have high levels of insulin we become leptin resistant. Leptin is a hormone which, very simply, tells the brain when we've had enough to eat. One of the problems for overweight people is that their leptin gauge is not working, and there's a subconscious drive to eat more food than needed in order to feel satisfied.

Helen says that the way to satisfy your hunger and for your metabolism to remain stable, is for every meal to contain a portion of protein. If you put two fingers of one hand into the palm of the other, this is as much protein as you need. Any more will be too much and detrimental to your body. Protein is satisfying – it slows the production of ghrelin, a hormone in the stomach that suppresses hunger. For healthy people - if we feel full

then we should be able to go 4-5 hours between meals, and therefore only need three meals a day without extras. Our appetite dictates the amount we eat, so eating healthily means that you will feel full for longer and therefore eat less. Food should give us a sense of nourishment and make us feel energised, not overloaded. Helen's own diet consists of three meals a day of a portion of protein (for her meat), and vegetables - she says two handfuls of vegetables per meal is the right amount. It's best to have carbohydrates in the form of root vegetables, e.g. potato or kumera. Helen recommends buying as good quality as affordable. Buying cheaper cuts or specials are fine if you're on a strict budget.

Helen also discussed the importance of vitamin D, saying that most of us are probably deficient, and recommends having a blood test. We should be between 125 and 200mg, but health professionals opinion on this is variable. If the doctor won't order a test you can have it done at the lab for \$30.00. Foods high in vitamin D include mushrooms, especially shitake mushrooms, cod liver oil, free range egg yolks, (chickens need to be outside to absorb the vitamin D from the sun), butter, cream, and cheese. As well, Helen recommends eating natural fats from butter, cheese and milk as opposed to margarine and processed products. She also had a brief discussion about oils, saying that the best oil is extra virgin olive oil, and that other fats contain trans fatty acids which are bad for us. Oils, such as rice bran or canola oil, are too high in omega 6 and leads to inflammation. It's also important not to eat burnt food.

Helen also discussed cholesterol, saying that it is like a wax, and has insulating properties. Briefly, HDL is good cholesterol and test results should be over 1. Triglycerides are bad fats made from sugars, and tests should be less than 2 according to Helen. LDL is variable, but it is the results of the first two that count.

Helen recommends cutting grains right back as, for many people, they can cause inflammation and allergies, and she thinks they are the cause of many of today's illnesses. Fruit should be kept to a couple of pieces a day as it contains sugar, even though it's natural sugar.

*You can contact Helen at The Vibrant Health Clinic
96 Cambridge Rd. Ph:8566991 027 6566991*

HAPPINESS JAR



One of our members told me recently that when she is feeling down or depressed she gives herself a 'pick me up' by going to her

Positivity Jar. In it she has notes that she has written to herself about things or occasions that have made her happy. This way she can reflect on some nice memories which lift her mood and keep her more positive.

Funnily enough I was reading an article on Elizabeth Gilbert's Facebook page recently (*You may remember her as the author of Eat, Pray, Love*) and she was discussing a very similar thing she did which she called her **Happiness Jar.** *This is what she says:*

"The HAPPINESS JAR is a project I started many years ago, and it has remained a practice that I've tried to keep up with regularity ever since. But in its essence, the Happiness Jar is an almost absurdly simple idea - every single day, at the end of the day, I grab a scrap of paper and I write down upon it the happiest moment of that day. And I put the date on it. And then I fold up the note and stick it in the jar. And that's the whole practice. It takes about 35 seconds to do, but what it brings me is enormous - not only the pleasure of finding a good moment in each day (for even the horrible days have one least-bad moment) but the lasting benefits of recording that moment forever. As years go by, whenever I'm having a rough time, I dig through the jar and pull out random slips of paper, and delight in them — all those momentary gems of life that I would have immediately forgotten, had I not jotted them down. They bring infinite comfort. I am continually amazed at how simple my happiest moment of the day usually is. It is hardly ever a moment of explosive achievement or delirious excess. For all my striving and all my ambitions and all my seeking of remarkable experiences, it is important to recognize that my happiest moments are generally really common and quiet and unremarkable. In fact, my happiest

moment each day is usually just a glance of something sweet and small, an unexpected flush of emotion, a bit of sun on my face, a pleasant encounter on the sidewalk, the cat-like contentment after a nap, a glimpse of a bird just out of the corner of my eye, a recognition of some tiny lovely thing."

Either of these, or a variation of the above, are great ideas and if you're feeling up to it may be worth a go!



One of our members saw this in the Listner and brought it along to our Social Support Group. We thought it would be good to share with others, as adrenaline overload causes many of you lots of anxiety!

Advice to anxious readers (Scot Stossel)

- Want less
- Relax more
- Cultivate an optimistic outlook (smile and you will be happy)
- Help others (look outward not inward)
- Simplify – declutter your life
- Train yourself to “under-react”
- Confront your fears and phobias – expose yourself to them, decondition the fear
- Resolve your inner conflicts – or at least acknowledge them, bring them in to conscious awareness
- Change what you can, but accept the things you can't
- Be inner directed, not out-directed
- Develop a sense of self efficacy. Believe that you can cope – because you probably can cope better than you think
- Sleep
- Escape the tyranny of “should”
- Meditate-cultivate mind-body awareness
- Eat healthily
- Drink less caffeine
- Accept yourself
- View life as an adventure, not as a trial
- Exercise (*within limits of course! Ed.*)
- Most important, cultivate emotional resilience

Thanks to Mary, who has very generously donated a book - 'Optimum Health the Paleo Way' by Claire Yates, which is now available in the library.



CRANIO-SACRAL THERAPY



July's guest speaker was Karen White from Hukanui Body Therapy Clinic. She is a Medical Herbalist and specializes in Cranio-sacral Therapy, which was the topic of this meeting. Karen

shared that she became interested in training in this modality after years of suffering migraine headaches. Through obtaining relief from the migraines by a Craniosacral Therapist she decided to return to the UK to train in this field.

The origin of Cranio-sacral Therapy is found in Osteopathy and is a holistic, non-manipulative, gentle approach to health. It is deeply relaxing and assists the body's natural healing process. It aids in pain relief and encourages the nervous system, organs and musculoskeletal system to balance and heal.

Karen explained how the cerebrospinal fluid flows in a tide-like ebb and flow motion creating a rhythmic pattern that involves the bones, membranes and tissues of the body. All living tissue and cells 'breathe' with the motions of life and a trained therapist can feel the subtle rhythmic impulses. Through the stress of daily living and physical and emotional traumatic events and episodes, our bodies contract and become tight, restricting the motion and flow of the cerebrospinal fluid. This is when chronic pain and fatigue, digestive disorders, depression and anxiety, sleep disorders, high blood pressure and many other ailments can be experienced.

Karen is able to 'listen to the body' by placing her hands gently on the body. She can detect the points that need releasing by feeling the sluggishness or inertia of movements and rhythms. Inflammation can be detected by heat. It is through the stillness and gentle touch of the practitioner that releases stress and tension freeing energy that encourages balance and self healing.

U.S. Osteopath Dr. William Garner Sutherland first recognized Cranio-sacral motions and rhythms and their importance to health in the early 1900's. Since then many practitioners have refined the therapy into the subtle deep healing process that is available today.

Karen can be contacted at Hukanui Body Therapies on 07 8530176, or 0273126603, email: hukanuibodytherapies.co.nz

Tracey Larsen

UPCOMING MEETINGS

THURSDAY AUGUST 14th

Dr Ros Vallings will be discussing the latest research from the recent international conferences she has attended.

10.30 – 12md at the Methodist Church (Boys Brigade Hall within the church) Crn Bader St & Normandy Ave. Melville

SOCIAL SUPPORT GROUP

Tuesday August 26th, 2pm Robert Harris Cafe, Chartwell

EDUCATION SUPPORT GROUP

SEPTEMBER 11th 10.30 – 12md
Methodist Church, Bader St. Melville
Topic: Art Therapy
(Speaker to be confirmed)

SOCIAL SUPPORT GROUP

Tuesday September 23rd, 2pm Robert Harris café, Chartwell

LAUGHTER

LAUGHTER IS MEDICINE FOR THE SOUL

"Laughter is a tranquiliser with no side effects." Arnold Glasgow



NZ STUDY SHOWS STIGMA OF CHRONIC FATIGUE ILLNESS ADDS TO SUFFERING.

Source: *Massey University NZ, 11:5:14*
This study was carried out by Dr Don Baken, an ANZMES committee member, in collaboration with ANZMES.



A new survey shows people with debilitating ME/CFS feel misunderstood and stigmatised, and more public education about the condition is needed. Dr Don Baken, a clinical psychologist at the School of Psychology at

Massey University's Manawatu campus, who has researched the issue, says the impact on sufferers of Myalgic Encephalopathy/Chronic Fatigue Syndrome can be devastating, and feeling stigmatised just adds to this. He carried out a survey of 221 people with ME at the request of the Associated NZ ME Society (ANZMES) to better understand the impact of the condition, which affects around 20,000 New Zealanders. The survey findings were released to the media to coincide with International Awareness Day on May 12th.

Survey respondents reported a very low quality of life. 'People with ME/CFS often feel that it's impact is poorly understood and trivialised,' Dr Baken says. The average respondent was in the bottom 10% of the population for measures such as the NIH PROMIS physical health scale. (A measure of physical quality of life developed by the National Institute of Health in the US. More than three quarters of respondents reported struggling with basic everyday tasks and meeting family responsibilities.' They also rated their executive functioning to be extremely low for abilities such as planning, organising, strategising, paying attention to and remembering details, and managing time and space,' says Dr Baken. Two thirds of the respondents had trouble counting the correct amount of money to make purchases, and 85% had problems reading and following directions, such as those of a new medication. Many respondents felt stigmatised by the condition. Half indicated that they often felt embarrassed by their physical limitations, and about a third felt embarrassed by the disease

itself. Only about 15% said they never felt blamed for their condition by others.

Dr Baken says those most ill would not have been well enough to complete the survey and the results would have been even worse if the most severely affected were included. 'What's particularly interesting about all these findings is that this group reported worse scores than those with other neurological conditions such as Parkinsons or Multiple Sclerosis,' he says. 'Because of the the nature of the condition and the stigma that many feel because of it, it's difficult for this group to advocate for themselves,' he says. 'More needs to be done to understand the impact of this condition and how society can support the people who suffer from it.' Maintaining friends with ME sufferers, even though they may feel too unwell to go out, was one way people can show their acceptance and give support, he says.

ANZMES president, Heather Wilson says the results confirm anecdotal evidence about the experiences of people with ME/CFS. She says 'the good news is that international biological research is making significant discoveries about abnormalities in the neurological, immune and energy producing systems of people with ME'. 'However, until these have been translated into treatments that improve the quality of life of people with ME/CFS it is important that that all those involved, including friends and family, the health system, and societal support systems understand the true impact of this serious, devastating condition and provide the support that they can'.

(Taken from the Winter issue of Meeting Place.)

NB: I suggest if any of you are having difficulties with family or friends with regards to the above you show them this article. Ed.

=====

[A USEFUL TIP?](#)

Some people like to make 'To do' lists, but Jennifer Brea, from 'A Canary in a Coal Mine', suggests making a 'Not to do' list. Write down what to consciously avoid that might make your symptoms or particular situations worse, and put it somewhere obvious for it to be a constant reminder!



RESOURCES AVAILABLE

**DVDS - available to borrow
(or buy for \$10.00)**

Dr Vallings August 2010 talk
Dr Nancy Klimas's Hamilton talk
Dr Vallings/Pain Management
2010
Dr Valling's IACFS/ME
Conference Nov 2011
Dr Valling's Invest In ME
conference
June 2012 & May 2013

LIBRARY BOOKS

**Recovery from CFS -50 personal
stories - Alexander Barton (2)**
**Lost Voices – families living with
ME**
**Living With Fibromyalgia –
Christine Craggs- Hinton (3)**
**Chronic Fatigue Syndrome -
Campling**
**Managing Chronic Fatigue
Syndrome & Fibromyalgia - CD
set by Bruce Campbell**
**From Fatigue to Fantastic-
Jacob Teitelbaum**
**Your Symptoms are Real- What
to do when your doctor says
nothing is real- B. Natelson**
**FibroWHYalgia - Susan
Ingebretson**
**The Chronic Fatigue Healing
Diet -Christine Craggs-Hinton**
**Verity Red's Diary –A story of
Surviving ME - Maria Mann**
**What Your Doctor Doesn't
Know about FM - L. Veilink and
P. Rhodes**
**Reviving the Broken Marionette
- treatments for CFS ME and FM -
Maija Havisto**
**Hope & Help for Chronic
Fatigue Syndrome &
Fibromyalgia- Alison Bested**
**Taking Control of TMJ -
Robert Upgaard**
**The Patient's Guide to CFS &
Fibromyalgia - Bruce Campbell**
**Sacred Space ME/CFS
Depression, Anxiety & Stress -
Elizabeth Bailey**
**The Introvert Advantage - How
to thrive in an Extrovert World -
Marti Olsen Lani**
**Fibromyalgia and female
sexuality - Marline Emmal**
**Chronic Fatigue/ME - Support
For family & friends E. Turp**
**Fibromyalgia for Dummies- R.
Staud**
**Yoga for Fibromyalgia S. L.
Crotzer**
**Sophie's Story - My 20 year
battle with IBS - Sophie Lee**

**Power of Vitamin D - Safraz
Zaldi**

**Wherever You Go There You
Are - Jon Kabat-Zinn**

**Diagnosing & Treating Chronic
Syndrome Dr Sarah Myhill**

**Chronic Fatigue Syndrome M.E.
Dr Rosamund Vallings (5 copies)**

**Understanding Irritable Bowel
Syndrome Dr Kieran Moriarty**
**Taking Charge of your Chronic
Pain Peter Abaci**

**The New Zealand Gluten Free
Cookbook -food everyone can
enjoy - Sophie Johnson**

**The New Zealand Gluten-Free
Cookbook - Jim Boswell**

**The Irritable Bowel Syndrome
Solution Dr Stephen Wangen**
**Fibromyalgia and Myofascial
Pain Syndrome A practical guide
to getting on with your life.**

Dr Chris Jenner
**Fibromyalgia- simple relief
through movement**

Stacie L. Bigelow
**15 Natural Remedies for
Migraines and Headaches
J.S. Cohen MD**

**The Great Physician's Rx for
Irritable Bowel Syndrome
Jordan Rubin**

**Healthier without Wheat – A new
understanding of wheat allergies,
celiac disease and non-celiac
gluten intolerance**

Dr Stephen Wangden

**The Whole-Food Guide to
Overcoming Irritable Bowel
Syndrome Laura J. Knoff**

**Food Allergy Survival Guide
Vesanto Melina Jo Stepaniak Dina
Aronson**

**Healthy Eating for IBS
Sophie Braimbridge**

**The CFSID & Fibromyalgia
Self-Help Book A self
Management Program for CFS
and FM by Bruce Campbell**
**The CFIDS / Fibromyalgia Toolkit A
practical self-help guide Bruce
Campbell**

**An introduction to the
Lightening Process**

Phil Parker (3) 2 donated

**Stay Healthy by supplying what's
lacking in your diet –D. Coory**
**Optimum Health the Paleo Way
Claire Yates**

WHEELCHAIRS AVAILABLE

MS Waikato has
wheelchairs available.
No cost. Phone:
8344740 for enquiries.



Contacts

Helen Maseyk

Client Services Co-ordinator ME/CFS
MS Waikato Trust
phone : 8344742
Mobile:027 7771344
PO Box 146, Hamilton
Email:helen@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
booking.

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

Disclaimer : Opinions
expressed in Koru are those
of the writer and not
necessarily those of the
Hamilton ME Support Group
or MS Waikato Trust.

Contact others



You may find it helpful
to communicate with
others who also have ME/CFS or
FM, especially if you're feeling a
bit down, or you may want to
know how others manage. 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.

DELWYN: 8438623

CIANE: 846653

LINDA: 8553934

lindaderrick@yahoo.com

BERNADETTE: 078686763

(Thames)

USEFUL WEBSITES

www.anzmes.org.nz

www.co-cure.org

www.me-cfs.org.au

www.iacfsme.org

www.afme.org.uk