

KORU ME & FM Support

HAMILTON OCTOBER 2014 Issue 34



*The beautiful spring came; and when Nature resumes her loveliness,
the human soul is apt to revive also.*

Harriet Ann Jacobs

Hello everyone,

It's amazing how different we can feel with a change in the weather. With the blossom trees now showing off their spectacular blooms and the spring bulbs popping up in parks and gardens everywhere, it's hard not to feel that sense of joy and wonder that nature brings. It can lift our spirits with that feeling of better things to come now that winter is over. Sometimes, in the face of pain and adversity, nature can give a brief respite from our troubles.

Mid August brought Dr Vallings to Hamilton, and the feedback from her talk about the current research findings from the overseas conferences she attended earlier this year was very positive. We all really appreciate the fact that Dr Vallings comes so far to share her knowledge and update us. (See page 5 for a brief overview.) Please contact me if you would like to borrow the DVD of her talk that Noel Morris so kindly made for us. If you wish to buy your own copy for \$10.00, contact Noel on 8538285, or email noel@faithnet.co.nz

Thanks to all those who returned the MS Waikato survey. I know it's quite an effort for some of you to fill them in and get them back to us, so we really appreciate it. The results are now being collated and we will give you feedback later.

Our speaker for October is Cherry McWha, a Hearing Therapist from Life Unlimited. Cherry's talk will include coping with tinnitus and hyperacusis, (noise sensitivity), both of which affect many of you. Our topic for November is 'Dealing with Relationship Issues'. Because of her counselling background I have asked Tracey Larsen to lead this discussion.

The last few months have rolled by fairly fast for me, and with only a couple of months to go, it's time to think about Christmas once again! I suggest that you start getting organized now for Christmas – write that 'to do' list, and gradually tick it off. Delegate as much as you can and pace yourself in-between so that you don't have a mad rush near the time and end up relapsing!

Put the 11th December in your diaries for our end of year Christmas lunch. It will be my last organized event before I hand over the reigns to Tracey! Take care,

Helen

CONTENTS

Page 2: Art Therapy New CFS app in Australia

Page 3: Turn off your TV Upcoming meetings

Page 4: Benefits of Coconut Oil

Page 5: Snippets from Dr Vallings talk

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

ART THERAPY



I invited Maree Brogden, a registered art therapist, to speak at our September meeting. Maree has worked in the health sector for a long time. First as a nurse, then studying art - later qualifying as a clinical arts therapist and working for the DHB in mental health. Currently she is doing post graduate study.

Art therapy is a form of expressive therapy that uses the creative process of making art to improve a person's physical, mental, and emotional well-being. Art therapy can achieve different things for different people. It can be used for counselling by therapists, for healing, treatment, rehabilitation, psychotherapy, and broadly speaking, it can help people to have a deeper understanding of themselves. One of the beauties of art as therapy is the ability for people to express their feelings through any form of art such as painting, drawing, dance/ movement, photography, sculpture, or a variety of other types of visual art expression.



Maree showed us several books which outlined how art therapy can be used in a variety of ways. She said art can tell a story and be another way to communicate. It can help us understand or make sense of something that has happened or something that's been experienced. Art can release tension and help 'lighten the load' for people. She told us that creativity can be about self discovery – a juggling game with a 'catcher net'. Art is an escape. It can be a diversion from unpleasant symptoms or issues. The process can give a sense of achievement when completed, and can have the therapeutic value of giving a sense of worth or growth. Art therapy can explore the senses; e.g. 'what am I feeling,' and it can help with self love – getting back to caring about ourselves again, which is required in the healing process. Art can stretch the imagination and can be a tool to help reconnect, or find new connections. In group therapy it can be valuable to 'share the pain or the experience, and may be less confrontational than singly. Art therapy can be a stepping stone for facilitating change and can have a broad range of beneficial outcomes.

Thanks to Bernadette for kindly donating - Parting the Fog by Sue Jones. As well 'Fibromyalgia and Chronic Myofascial Pain'- 2nd edition, by Ed. D. Starlynyl & M. Copeland.

Chronic fatigue syndrome clinic opens; app launched at Griffith University on Gold Coast 29/7/14



For the first time in Australia, sufferers of CFS now have access to a specialised clinic and smartphone application to help manage the debilitating condition. Griffith University on the Gold Coast has opened a specialised clinic and launched a smart phone application for patients struggling with the condition. Professor Sonya Marshall-Gradisnik said the clinic would provide individualised care for patients. 'The aim of this clinic is first and foremost to tailor individual management plans and then from that, feed that information back along with the testing we do within the research centre,' she said. Patients wanting treatment at the clinic need to be referred by their general practitioner. The smart phone application – CliniHelp, was also launched in conjunction with the opening. It allows clinicians to accurately monitor the progress of patients who record their symptoms and monitor changes in their condition. Queensland Science Minister Ian Walker was at the clinic opening and app launch. He said the technology would assist patients and help reduce health care costs. "This app is a very practical way to cap costs because it means that patients do a lot of the work themselves," he said." They do it practically, they do it immediately and then I think the important thing is that the clinicians can then interpret the data. "So I think it will take pressure off our resources, but more importantly it will help those 86,000 Queenslanders who have this disease". The clinic has the backing of the Alison Hunter Memorial Foundation which supports biomedical research into CFS/ME. Alison Hunter, 19, died from complications arising from CFS/ME in 1996 and her mother Christine Hunter said the clinic would help doctors who sometimes struggle to diagnose the condition. "Doctors spend a lot of time trying to help but with no real guidance," she said. "Patients with ME/CFS can be very reactive to treatments and it's a wonderful facility. There's nowhere like it in Australia." Griffith University researchers are also trying to discover the cause of chronic fatigue syndrome.

Coping tip – Turn off your TV

Most of us are in the habit of watching television. We grew up with it. By now it's become part of our culture. Even when you are not sitting down and watching, someone else invariably is, and it hums away in the background, adding the chatter of canned voices to our environment. Not surprisingly, many people with CFS/ME cannot tolerate the noise. Dr. John Richardson, a British physician who treated thousands of ME patients, listed the inability to tolerate chatter as one of the primary symptoms of ME. Not only do people have difficulty with the noise, they have problems with the sudden shifts of light. A number of years ago, several Japanese children suffered seizures while watching Pokemon on TV. The rapid flickering of light led to a massive firing of neurons, and the children collapsed. While people with CFS/ME do not usually run the risk of having seizures while watching TV, photophobia (sensitivity to light) is one of the most common symptoms of the illness. The nervous system over-responds to light and other stimulation, which can lead to pain, a creeping sensation, anxiety and malaise.

The ideal solution for this problem is to turn off the TV. If you live in a household, this may not always be possible. But turn it off when you can. If there is a program you would like to watch, you can minimize the effects of flickering by making sure the room is well lit. Keep as far from the screen as possible, and wear polarized sunglasses. Most important, do not watch TV at night if you suffer from insomnia. While watching a movie on a DVD can be pleasant in the evening, watching TV is too stimulating. You will have a more restful night if you read before bed.



**TODAY, I'm
doing NOTHING!
Cuz I started doing
it yesterday, but I
haven't finish it yet!**



UPCOMING MEETINGS

EDUCATION MEETING:

Thursday October 9th – 10.30 – 12md

Methodist Church Bader St Melville

Speaker: Cherry McWha - Hearing Therapist
on Tinnitus and Noise sensitivity.

SOCIAL GROUP: **Tuesday October 28th** 2pm
Robert Harris Chartwell

EDUCATION MEETING

Thursday November 13th 10.30 – 12md

Methodist Church Bader St Melville

Speaker: Tracey Larsen – Relationship Issues

SOCIAL GROUP: **Tuesday November 25th**
2pm Robert Harris Chartwell

Christmas:

December 11th is the date for our Christmas lunch. It will be catered, and as usual will be subsidised by MS Waikato. Cost will be \$12.00 if you haven't paid subs and \$6.00 if you are a paid up member. Pay on the day. *There's not much time between the December Koru and the lunch so if you want to come can you please let me know before then for catering purposes.*



I've had several requests for this gluten-free recipe that I made for morning tea at Dr Valling's August talk. It's healthy and easy to make.

Helen's Bliss Ball Recipe

2 cups dates
1/2 cup raisins
4-5 pieces dark chocolate (I use Whittakers)
A few sunflower seeds
A few pumpkin seeds
2-3 dsp tahini
1-2 tsp coconut oil
few cranberries (opt)
crystallised ginger (opt)
coconut for rolling

Method: Cut dates in half. Discard any stones. Put in processor with all ingredients except ginger. Process till reasonably fine. Add ginger last and pulse till it becomes small pieces (to keep the flavour). Roll into small balls in fine coconut. Refrigerate.

This is a very versatile recipe. You can substitute other nuts or dried fruit and add a few other seeds such as sesame or chia, or flavourings such as vanilla or cinnamon. ENJOY!

Coconut oil

Coconut oil is receiving a lot of good press lately. It is becoming recognised as a healthy saturated fat which is very easily digested and absorbed compared to other oils. Coconut oil is absorbed directly from the intestines into the portal vein and sent straight to the liver, whereas other fats require pancreatic enzymes to break them into smaller units. It is highly nutritious and provides a quick source of energy just like sugar but without the negative effect on health and insulin levels. The fat in coconut oil is used rapidly and not stored. Coconut oil also has many other medicinal benefits. Research has shown that coconut oil can:



- Improve digestion and nutrient absorption
- Increase immune defences and decrease inflammation
- Fight bacterial, fungal and viral infections and prevent degenerative disease
- Assist with weight loss
- Protect the liver and prostate
- Improve dry eyes and skin
- Treat diabetes

Lauric acid: Roughly 50% of the fatty acids in coconut oil are lauric acid – the same medium chain fatty acid found in human breast milk. Lauric acid has the additional benefit of being formed into monolaurin in the human body.

Monolaurin : Monolaurin is the compound in coconut oil responsible for fighting numerous types of infections. A large body of research has established the ability of lauric acid and monolaurin to fight bacterial, fungal and viral infections. Dr Sherry Rogers explains that, ‘Monolaurin actually disintegrates the lipid envelope or membrane of viruses, destroying their main defence.’ It stops viruses from replicating and from attaching to cells. She adds that monolaurin has been shown in studies to dissolve the protective membrane from 14 types of human viruses including measles, flu, herpes simplex, chickenpox, EBV, cytomegalovirus and SARS-type viruses.

Capric acid: Coconut oil also contains capric acid, a substance that has antimicrobial properties. Capric acid is transformed into ‘monocaprin’ in the human body.

Caprylic Acid : Coconut oil contains caprylic acid, a substance that is specifically effective for killing candida overgrowth on contact in the intestines.

Dosages and Uses: Dosage of coconut oil used medicinally varies from 1-2 tablespoons daily. Some recommend doses of higher than this. 3 – 4 tablespoons of coconut oil is the equivalent of eating half a fresh coconut. It is claimed that improvements in energy levels may be seen at a dose of 1 teaspoon 3 times daily, according to coconut oil author S. Gursche. At least 3 tablespoons daily is often recommended for weight loss – along with a reduced or moderate intake of carbohydrates in the diet, cutting out all processed carbohydrate foods and including other types of healthy fats in the diet. Caprylic acid can cause nausea and several of the antiviral and antifungal compounds in coconut oil can cause herxheimer reactions. Thus coconut oil should only be started at a dose of one teaspoon daily and raised slowly. Taking ½ a teaspoon of raw apple cider vinegar with the coconut oil taken at each meal can aid in digestion of the oil, if a digestion aid is needed. *Expect to wait 4/ 6 weeks to see an effect.*

Coconut oil is perfect for cooking as it isn’t damaged by high temperatures. Taken with meals it may aid digestion. Coconut oil can also be used as a moisturiser for skin, a lip balm or as a hair conditioner. It can also be used topically to treat rashes.

Which type to buy: The best type to buy is organic extra virgin cold pressed coconut oil. The second best type is organic virgin coconut oil. Other types are refined and bleached and not recommended. Coconut oil is stable at room temperature and doesn’t need refrigeration. It has a very subtle coconutty taste and is usually semi-solid at room temperature. In warm weather, the oil liquefies.

Dr Sarah Myhill says coconut oil is “**perfect for foggy brains**” and recommends one dessertspoonful (10 ml) twice daily. She says “the brain works well on short chain fatty acids and ketones which are in abundance in coconut oil. These must be pure cold-pressed organic virgin oils which are semisolid at room temperature”.

Overview of Dr Vallings talk 14/8/14

Dr Vallings attended a one day ME/CFS symposium at Stanford in March. The speaker was Dr Jose Montoya, a biology professor. Following that, she attended the biennial IACFS/ME conference in San Francisco, then in May she attended the London Invest in ME conference. The following is a brief overview of a composite of all three conferences.

Epidemiology *A study in Italy showed that only 40% of the clinic patients treated actually had CFS* (Symptoms of post exertional malaise must be included in the diagnosis). *There is a slightly increased risk of certain cancers* (During question time Dr Vallings was asked which types. The answer was Lymphoma. This is based on the abnormal B Cells as there is a decline in the natural killer cells i.e. the cells which control infection and cancer cells.)

Genetics – *there is real evidence of vulnerability to CFS as there is a gene connected to the illness. There is also a HUGE body of evidence that this illness is an auto immune disease.* More woman than men have auto immune disease. It may be due to viral infection, or changes in hormones.

Immunology. *Changes to the immune system have been confirmed and clarified.* Nancy Klimas from California and Sonya Marshall-Gradisnik from the Gold Coast have been doing research in this area. They've clarified that with the abnormal cells, the worse the illness is, the worse the cells abnormality is. It was also found by the Californian team that exercising causes the abnormal cells to change for the worse.

Leptin, a peptide in the immune system, has been found as being elevated in CFS patients. A potential treatment is being tested. Leptin occurs in overweight people and stressed people and affects the brain cells, causing inflammation, which leads to brainfog and concentration issues. If overweight CFS patients can lose some weight there is an improvement in the system. The more leptin you have the more prominent the illness. Weight loss and stress management are key to improving leptin levels.

Virology – *Jose Montoya from California has been conducting stomach biopsies and found high levels of gastroenteritis,* and that there is a relationship between CFS and endometriosis. Enterovirus was found in the womb and tubes of women. This is a stomach virus and is not meant to be present elsewhere. Bowels – some patients started with gastro enteritis which led to them getting CFS. Others had IBS which caused CFS. Simon Cardine said *'the bowel is like a second brain', there are more neurological and immunological cells found in the bowel than in*

the brain. The system is 9m long and contains 100 trillion bugs which weigh 1kg with a volume of 1 litre. Whole thing worsens with stress. His conclusion – it's probable that CFS patients have a mismatch of bugs in the bowel.

Brain – *There are more immune cells in the brain than brain cells.* Japanese researchers found in general people with CFS have inflammatory brain cells. They used functional MRI's to test patients. They start to use the expected part of the brain to perform a task then another unexpected part takes over to finish. The theory being that the expected part tired, so the brain compensates by using a different part. Exercise worsens the brains ability. A Mr and Mrs Zen (doctor Vallings couldn't remember their names) conducted an experiment using brain recordings and noted people with CFS have a lack of electrical connections. There were blank areas along the connection pathway.

Orthostatic intolerance – Dizziness and the feeling of going to fall. It's due to low blood pressure. *A clinical study showed 90% of patients have orthostatic intolerance.* Hot shower, baths and spas are not recommended. Low salt intake causes low B/P. Need to get B/P up; e.g. more salt. Alcohol worsens the condition. Diuretics e.g. frusemide to get rid of excess fluid also worsens the condition. Compression stockings or body suits keep blood flow strong to the brain.

Exercise – If able to. *Patients were tested and they performed at their best, but were not able to perform as well the next day.* Mathematical tasks were used to test brain function etc. afterwards.

Paediatrics – one study of 800 children/patients found that 80% recovered, though there was some speculation on whether the child had recovered or whether they were just managing their lives better. It was found that they tended to suffer from milk protein sensitivity (not allergy) and they were picky eaters.

General – For first time a woman from Mainland China gave a presentation. She spoke of a therapy called Ba Duan Jin (like a combination of Tai Chi and Yoga). Dr Vallings recommended Tai Chi and Yoga as beneficial.

CFS is not caused by fungal infections e.g. it's not caused by Candida.

Magnesium, B12, Vit D, CoQ10 - all beneficial.

Hormone level issues - can be treated symptomatically. Anxiety issues can be treated with beta blockers Antiviral medication and immunological therapy is beneficial. Don't rush off to the doctor want all of the above – it's a very individualistic treatment.

Bio banks have been storing blood of CFS patients to use later in research testing.

RESOURCES AVAILABLE

DVDS: to borrow / buy \$10.00

Dr Vallings August 2010 talk
Dr Nancy Klimas's Hamilton talk
Dr Vallings - Pain Management
Dr Vallings' IACFS/ME
Conference Nov 2011
Dr Vallings' Invest In ME
conference 2012 / May 2013
Dr Vallings talk 2014 -research

LIBRARY BOOKS

15 Natural Remedies for Migraines and Headaches, J.S. Cohen MD
An introduction to the Lightning 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
Chronic Fatigue Syndrome, 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 myofascial Pain D. Starlynyl & M. Copeland.
Food Allergy Survival Guide, Vesanto Melina Jo Stepaniak Dina Aronson
From Fatigue to Fantastic, Jacob Teitlebaum
Healthier without Wheat-A new 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 stories, 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. Crozier
Your Symptoms are Real-What to do when your doctor says nothing is real, B. Natelson

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: 8466535
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

