

**“And now we welcome the New Year,  
Full of things that have never been.”**

Rainer Maria Rilke

New Year’s greetings everyone,

2014 is well underway now with a start up of the year’s activities. For some, a new year is no more than a change of a calendar. For others, the New Year symbolizes the beginning of a better tomorrow, and a new chapter in their lives. For many people a new year will inspire



them to make resolutions, but despite good intentions, they are frequently broken! Often resolutions are centred on achieving better results or accomplishing more. Many people with ME/CFS and FM tend to be perfectionists and their self-esteem is tied in with their sense of achievement. Their typical goals for New Year are often unrealistic. Richard Eyre, in his book, ‘Don’t Just Do Something, Sit There’, argues that the traditional thinking about self improvement is out-dated or inaccurate. He feels we need new paradigms to ‘reflect our world as it really is, and our lifestyles as they really ought to be.’ This is especially true for people with chronic illness. He thinks perhaps we need to rethink these annual goals and look to the New Year with a spirit of ‘anti-resolutions’. This means ‘releasing ourselves from the obligation of things we are not able to do and consider alternatives more supportive of healing and well-being’. He calls it ‘The art of letting go’. For example the goal ‘*I will manage my time better so I can do more*’ can become ‘*I will pace myself to allow for rest and recovery*’. There is a healing value in ‘letting go’. Definitely food for thought!

We ended the year in December with our Support Group Christmas lunch. There was a very good turn out to enjoy lots of fun, food and conversation. The Metropolis caterers really excelled themselves providing a wonderful spread, including several lovely platters for those on special diets. Thanks to all those who helped clean up afterwards.

You’ll notice a few changes to the Koru layout. The upcoming meeting details are on page 5. Our first meeting this year is on **February 13<sup>th</sup>**. Kylie Phillips, from *Phillips family Chiropractic*, will be discussing ways to reduce stress - something we all need to do in our lives! Let me know if you would like the calendar for this year’s support group meetings.

Please feel free to contribute to Koru if you have something you’d like to share or something that might help others. Till next time, take care of yourselves,

*Helen*

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*What the New Year brings to you  
will depend a great deal on what  
you bring to the New Year.”*

*Vern McLellan*

## MINDFULNESS COGNITIVE BEHAVIOURAL THERAPY

*I was very disappointed to miss the talk by Jo Wall at the October meeting when I was away, as I know mindfulness can be a really useful tool, and I wanted to learn more about it. Grateful thanks to my colleague, Liz Hogan, for taking the meeting for me. Jo is an occupational therapist and counsellor, and has a special interest in Mindfulness Therapy. The following are some of the notes about it that Jo left with Liz.*

### WHAT IS MINDFULNESS?

Mindfulness is an ancient eastern practice which is very relevant for our lives today. Mindfulness is a simple concept. It means paying attention in a particular way: on purpose, in the present moment, and non-judgementally. (Jon Kabat-Zinn). Mindfulness doesn't conflict with any beliefs or traditions, whether religious, cultural or scientific. It is simply a practical way to notice thoughts, physical sensations, sights, sounds, smells, – anything we might not normally notice. The actual skills might be simple, but because it is so different to how our minds normally behave, it takes a lot of practice.

*We might go out into the garden and as we look around, we might think “That grass really needs cutting, and that vegetable patch looks very untidy”. A young child, on the other hand, may call over excitedly, “Hey – come and look at this ant!”*

Mindfulness can simply be noticing what we don't normally notice, because our heads are too busy in the future or the past – thinking about what we need to do, or going over what we have done. It might simply be described as choosing and learning to control our focus attention.



### MINDFULNESS BREATHING:

The primary focus in Mindfulness Meditation is the breathing. However the primary goal is a calm, non judging awareness, allowing thoughts and feelings to come and go without getting caught up in them. This creates calmness and acceptance.

- ❖ Sit comfortably, with your eyes closed and your spine reasonably straight.
- ❖ Direct your attention to your breathing.
- ❖ When thoughts, emotions, physical feelings or external sounds occur, simply accept them, giving them the space to come and go without judging or getting involved with them.
- ❖ When you notice that your attention has drifted off and is becoming caught up in thoughts or feelings, simply note that the attention has drifted,, and then gently bring your attention back to your breathing.

It's OK and natural for thoughts to arise and for your attention to follow them. No matter how many times this happens, just keep bringing your attention back to your breathing.

### USING MINDFULNESS TO COPE WITH NEGATIVE EXPERIENCES

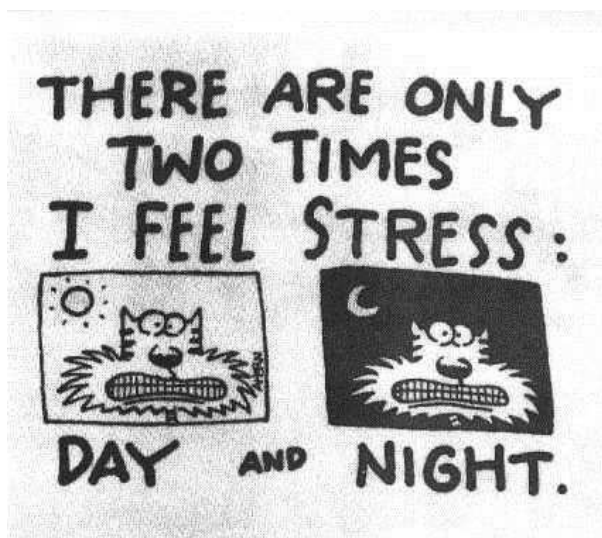
When we are more practiced in using Mindfulness, we can use it even in times of intense distress, by becoming mindful of the actual experience as an observer, using mindfulness breathing and focussing attention on the breathing, listening to the distressing thoughts mindfully, recognising them as merely thoughts, breathing with them, allowing them to happen without believing them or arguing with them. If thoughts are too strong or loud then attention can be moved to the breath, the body, or to sounds around us.

*For further information ring 021 2665657, email Jo at [jo-wall@outlook.com](mailto:jo-wall@outlook.com) or go to Jo's website: [www.actcounselling.co.nz](http://www.actcounselling.co.nz)*

**STRESSED AND ANXIOUS?!** For those interested and able, Jo is doing a 6 week night class at Fraser High School in February. It's *“full of practical tools and techniques for dealing with stress, worries and fears; including mindfulness skills.”* Cost is \$50.00. Enrol at [www.fraserace.ac.nz](http://www.fraserace.ac.nz) or phone the above number.

## LAUGHTER IS THE BEST MEDICINE!!!!

A chuckle a day keeps the doctor away!



### THE HISTORICAL BACKGROUND OF FIBROMYALGIA

#### *Did you know?*

Although fibromyalgia was not defined until the late 20<sup>th</sup> century, it was discovered much earlier. Descriptions in the literature date as far back as the early 17<sup>th</sup> century.

Until recent decades, many physicians questioned the existence of fibromyalgia. Over time, however, a growing body of evidence established FM as a syndrome comprising a specific set of signs and symptoms.

In 1987, the American Medical Association, (AMA) acknowledged fibromyalgia as a true illness and a potential cause of disability. Many well-respected organisations such as the AMA, the National Institutes of Health (NIH), and the World Health Organisation (WHO), have accepted FM as a legitimate clinical entity.

Before 1990, no guidelines for evaluating and diagnosing FM existed. To reduce misdiagnosis and confusion the American College of Rheumatology sponsored a multicenter study to develop these criteria; the results were published in 1990. In 1992, at the Second World Congress on Myofascial Pain and Fibromyalgia, the diagnostic criteria for fibromyalgia were expanded and refined.

Despite this progress, the typical patient with fibromyalgia has seen an average of 15 physicians and has had the condition for approximately 5 years before receiving a correct diagnosis. More than 50% of cases are misdiagnosed, and many patients undergo unnecessary surgery or endure costly treatments that provide little benefit.

At some point, most patients have been told that nothing is medically wrong with them and that their condition is imaginary. Therefore many patients become frustrated and sceptical. Although most patients are relieved when a correct diagnosis is made, the patient may need to be convinced that the physician actually knows what is wrong and has formulated a treatment plan.

#### NOMENCLATURE

Although the syndrome has been known by other names, the term fibromyalgia was introduced in 1976. This word is derived from the Latin root *fibro* (fibrous tissue) and the Greek roots *myo* (muscles) and *algos* (pain). Previously, fibromyalgia was most commonly described fibrositis; this was a misnomer, as "itis" indicates an inflammatory component. Chaitrow asserts that no inflammatory process has ever been found to be part of this disease.

*Author: John Buckner Winfield MD Reference: Medscape. Drugs, Diseases and Procedures*

## COGNITIVE DYSFUNCTION IN CFS/ME

*From Dr Charles Lapp's Hunter-Hopkins  
Centre newsletter - October 2013*

Cognitive problems have been cited as one of the most disruptive and functionally disabling symptoms of CFS, with up to 85% of patient's reporting impairments. Most affected are attention, concentration, memory, calculation, and processing speed. These lead to such as word searching, losing the train of thought, difficulty reading and comprehending, difficulty with mental math, brief periods of confusion or disorientation, and foolish errors, such as putting milk in the closet instead of the refrigerator, or leaving the stove running. Many PWCs can be easily distracted, and will go from one task to another, never completing any of them!

Testing for cognitive difficulties doesn't always correlate with a person's day to day complaints, however. Firstly testing is not very sensitive or specifically directed at CFS-related complaints, so the right tests must be administered in order to get results. Secondly, very intellectual patients show relatively little decline. For example, a person with a very high IQ 140 say, may drop 30 points to an IQ of 110; however this is still above average. So the PWC notes a significant decline in ability, but an examiner would testify that this individual should have no problems

Neuropsychological testing is not the only way to demonstrate cognitive deficits. Cranial MRIs show UBOs or Unidentified Bright Objects of inflammation in the brains of up to 80% of our PWCs. PWCs with UBOs report being more physically impaired than those without brain abnormalities.

SPECT scanning can reveal decreased blood flow in key areas of the brain such as temporal lobes, amygdala, hippocampus, and midbrain, while PET scanning may display areas of brainstem hypometabolism. Several researchers have shown that cerebral volume is reduced in PWCs with the most severe deficits. Surprisingly such 'brain shrinkage' can be prevented or reversed by physical activity.

Finally, Japanese studies have confirmed that body levels of carnitine or acetyl-carnitine correlate with cognitive deficits. The lower the

carnitine, the more cognitive difficulties there are. Supplementing with carnitine seems to improve thinking, concentration and memory.

### ***So what can be done to improve cognition?***

First of all, try to stimulate and exercise your mind. Consider jigsaw and crossword puzzles, word games, card or board games, and computer games. Numerous mind-stimulating websites are available also, such as [www.luminosity.com](http://www.luminosity.com) whose authors have a special interest in CFS.

Certain **supplements** have shown promise as well, most notably carnitine or acetyl-carnitine at 1000mg/day. These are available over the counter or by prescription. Ginko biloba (over the counter) has been touted to increase cerebral blood flow and improve mentation, and many practitioners recommend supplementation with phosphatidyl serine.

Defects in folate and B12 metabolism have been thought to affect brain function, so supplementation with B12 (say, methylcobalamin 1000mcg to 5000mcg daily) and methylfolate (400mcg daily) may be prudent. More potent prescriptions are available such as Deplin (15mg of methylfolate) Mentax (3mg methylfolate/2mg B12, N-acetyl cysteine 600mg).

Recently pharmaceutical companies have been developing products that claim to improve cognition in a wide variety of conditions, including Alzheimer's disease. These products include Vayacog (omega-3 fatty acids 26mg + phosphatidyl serine 100mg), Axona (an alternative energy source that the brain can use instead of glucose, 40gm twice daily), Procera AVH (acetyl-carnitine & vinpocetine + huperzine), and Prevagen (a jellyfish extract that affects calcium channels). All require prescriptions. Unfortunately we are not aware that any of these have undergone rigorous study in PWCs.

Several Alzheimer's medications have undergone brief trial in PWCs, including galantamine (Razadyne), donezepil (Aricept), and memantine (Namenda). In brief summary some PWCs will respond to these medications, but no subset of responders has been identified, and most do not respond. In general we do not recommend these medications unless dementia unrelated to CFS/ME is suspected.

## WORD FOR THE DAY

*Expressing gratefulness during personal adversity like loss or chronic illness, as hard as it might be, can help you adjust, move on and perhaps begin anew.*

*Sonja Lyubomirsky*

*Thanks to Colleen who sent this in. It arrived in her inbox on Christmas Day and she thought it was very timely and appropriate. If you would like to receive a 'Word for the Day' quote, check out:*

[www.gratefulness.org/word/index.htm](http://www.gratefulness.org/word/index.htm)

## SUPERFOODS

*Noun: A nutrient dense food, naturally high in vitamins, minerals and antioxidants; easily absorbed by the body and beneficial for health and wellbeing.*

**BLUEBERRIES:** A superstar of superfoods these deep purple berries contain high concentrations of antioxidant and anti-inflammatory compounds. Low in calories, yet high in Vitamin C and potassium, they are good for the immune system, heart, eyes and urinary tract. Also a great source of fibre, something we all need plenty of. Both fresh and frozen berries give you this power packed nutrition.

**GREENS:** Deep green **KALE** contains the highest levels of antioxidants of all vegetables and is a remarkable source of Vitamin C. It also contains calcium, iron (paired with the vitamin C needed for high absorption), selenium, magnesium, carotenes, (protects eye sight) and Vitamin E (for youthful skin and cognitive brain function.)

**SPINACH:** is an excellent source of folate (the natural form of folic acid, vital at conception and in pregnancy for DNA and cell growth), and packed with antioxidant action, carotenes, Vitamin K (great for bone strength), peptides (shown to lower blood pressure) and Vitamin E.

**ROCKET:** fuels our bodies with loads of phytochemicals, antioxidants, vitamins and minerals. It's an excellent source of Vitamin A, beta carotene, Vitamins B, K, and C, folate, iron, calcium, iron/lutein (antioxidants for the eyes).

**PARSLEY:** Known as the blood cleanser, parsley is strongly antioxidant, and anti-coagulant. It contains certain volatile oils that have been shown to inhibit the formation of

tumours, particularly in the lungs. It's these oils that can neutralize certain types of carcinogens. It is also loaded with vital nutrients, vitamins C, K, and iron, potassium, folate, iodine, and oxygenating chlorophyll.

**AVOCADO:** One of the most nutrient dense foods, they top the charts among fruits for folate, potassium, Vitamin E, and magnesium. They are high in fibre and a rich source of the monosaturated fat called oleic acid, which is heart friendly and may help lower cholesterol. They're also high in Vitamin C, iron, and antioxidants. What a powerhouse!

**PUMPKIN SEEDS:** NZ pumpkin seeds are a smooth, silky seed that deserves high marks. It's well known for its high levels of zinc which boosts the immune system and energy levels, as well as supports the prostate. This super seed contains numerous other minerals such as magnesium, manganese, iron, copper, and phosphorous; along with proteins, monosaturated fat omega fatty acids 3 and 5, Vitamin E and folate.

*If you haven't included these foods in your diet then it's time to get started!!!*

*From the 'Chantal Food Flyer' newsletter – a Napier based supplier of natural and organic food and health products.*

## UPCOMING SUPPORT MEETINGS

### **FEBRUARY 13<sup>th</sup> Education Meeting**

10.30 -12md, Methodist Church, Crn Bader St & Normandy Ave, Melville

**Speaker:** Kylie Phillips: 'Dealing with Stress'

### **FEBRUARY 25<sup>th</sup> Social Group**

2pm Hollywood Café Westfield shopping Centre, Chartwell

### **MARCH 13<sup>th</sup> Education Meeting**

10.30 -12md, Methodist Church, Crn Bader St & Normandy Ave, Melville

**Speaker:** Michelle Peat from the Health Consumer Service will discuss Patient's Rights and how to make a complaint if need be.

### **MARCH 25<sup>th</sup> Social Group**

*There is likely to be a change of venue. Please check with Helen if you are intending to attend.*



**“For every minute you are angry you loose sixty seconds of happiness”.** *Ralph Waldo Emerson*

## **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 Vallings' IACFS/ME Conference  
Nov 2011  
Dr Vallings' Invest In ME conference  
June 2012 & May 2013

## **LIBRARY BOOKS**

**Recovery from CFS** -50 personal stories - Alexander Barton (2 copies)  
**Lost Voices**—families living with ME  
**Living With Fibromyalgia** – Christine Craggs- Hinton (3 copies)  
**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**- Benjamin H. 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** - Elizabeth 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 Mindful Way through Anxiety** Susan M. Orsillo & Lizabeth Roemer  
**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 copies - 2 donated)



### **Wheelchair Availability**

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

## **Contacts**

### **Helen Maseyk**

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MS Waikato Trust  
phone : 8344742  
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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.

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