

# KORU

## ME Support Group

HAMILTON APRIL 2014 Issue 31



**“Within your heart, keep one still, secret spot where dreams may go.”** Louise Driscoll

Hello everyone,

Yes, another couple of months have passed by and it's newsletter time again! Hope those of you who dislike the heat didn't do too badly over the summer - you will no doubt be pleased that the autumn weather is with us.

I really like the quote above, and think it's very appropriate for all of us to have some dreams in life, be they big or little. Many of you will have heard me say that it's really important when you have an illness such as ME/CFS or FM to hold on to some of your dreams and hopes for the future. They are what can sustain you and can keep you going when times are tough. None of us know what is ahead of us - things can change. People can improve or get better, and who knows what the scientists may discover in the near future. So hold on to hope, because we know that a positive attitude can make a difference and prevent a slide downwards to despair and depression. And the good thing is - dreams are free!!!

We have welcomed a new member on to our staff recently. Some of you have already met her at our last Support Group meeting. Tracey Larsen has replaced Tracy Hobbs, who has left us in order to do further study. Tracey will be covering the HD role, but she will also be helping with the ME/CFS work as well, as our numbers and workload are increasing. She will be a valuable asset to our team, as Tracey's skills include a counselling qualification, which will be very useful in her new role.

Dr Vallings has informed me that she has a "choca block" schedule this year with her various commitments, clinical practise, and international travel. She will attend our August meeting to give us a report on the latest research from this year's London IACFSME conference.

Meantime, our speaker for our April 10<sup>th</sup> meeting is Linda Bell from Harmony Health. Linda is a naturopath and will be discussing and demonstrating reflexology. This is a treatment on the hands, feet and scalp using massage and acupressure techniques. Linda also takes beginner, and one on one yoga classes. Please see page 5 for meeting details, and re the changed venue for our Social Club meetings. Till next time - take care, *Helen*

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Let us be grateful to the  
People who make us happy;  
They are the charming  
gardeners who make our  
souls blossom.

Marcel Proust

## STRESS & YOUR HEALTH



Our first speaker for the year was Kylie Phillips from Phillips Family Chiropractic, who gave a very informative talk about stress and how it affects us. Kylie told us that there are six types of stress, and that

stress can be good or bad. After discussing the various types, we then did a questionnaire to see where our stress levels are at, with the majority of people attending being in the red zone i.e. highly stressed!

Kylie explained how the parasympathetic nervous system supports digestion, repair, our immune response, and our metabolism. On the other hand the sympathetic nervous system releases stress hormones when we are faced with frightening or challenging situations. This is commonly known as 'flight or fight'. Both systems need to be in balance to function smoothly. If the sympathetic nervous system is dominant through being constantly stressed then we can face symptoms of poor digestion, constipation, anxiety, increased respiration and heart rate, poor sleep quality, night sweats, waking unrested, nervousness and feeling jittery, increased muscle tension, inflammatory conditions, increased white blood count, and allergies.

On the other hand if the parasympathetic nervous system is dominant it can lead to colicky, hyperactive bowel, orthostatic failure on rising (dizziness & feeling faint) reduced respirations and perspiration, poor sleep quality - hibernation, increased mucous production, nervousness and depression, increased gag reflex, and a susceptibility to infection.

### TYPES OF STRESS

#### **Physical:**

An example of *good stress* could be movement or exercise

**Bad stress** could be over-exercising or poor, or repetitive postures

#### **Chemical:**

**Good:** Natural chemical body reactions

**Bad:** medications, agricultural chemicals

-on food/gardens, additives/preservatives,

**Bad:** medications, agricultural chemicals

-on food/gardens, additives/preservatives, colourings / flavourings in foods

#### **Electromagnetic:**

**Good** – sunlight

**Bad:** Extremely low frequency pollution emitted by electrical devices (computers, cell phones, microwaves, TV, electric blanket)

#### **Physic or Mental:**

**Good:** Thinking and using mind productively Planning and setting goals, overcoming adversity

**Bad:** Focusing on what you don't want instead of what you do - "stinking thinking", being rushed, or taking on more than you can handle

#### **Nutritional:**

**Good:** Eating in accordance with your metabolic type

**Bad:** Eating too much, too little, wrong proportions for your metabolic type

#### **Thermal:**

**Good:** maintaining body temperature at 37 degrees

**Bad:** Anything that raises or lowers your body temperature for long periods of time

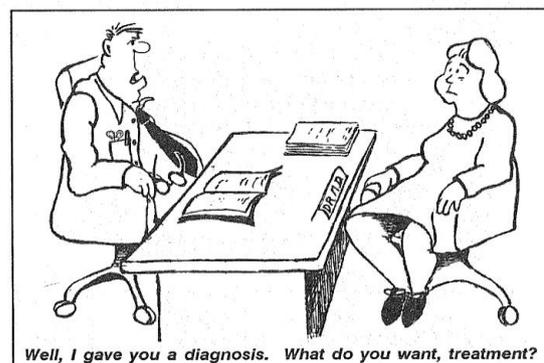
### MANAGING STRESS

1. Identify your primary stressor
2. Make a plan
3. Eat and drink right
4. Move and exercise (Zone exercises)
5. Mental exercises
6. Breathing techniques
7. Regular Wellness adjustments

### Positive Thoughts Generate Positive Feelings, and Attract Positive Life Experiences.

**'You can't live a positive life with a negative mind.'**

Kylie can be contacted at Phillips Family Chiropractic.  
07 8497252 [phillipsfamilychiropractic@gmail.com](mailto:phillipsfamilychiropractic@gmail.com)



## CARER SUPPORT

### *How to care for yourself while supporting someone with ME/CFS or FM*

Living with someone with ME/CFS or FM can be a tough job, and having a chronically ill person in your household will impact your life. It's easy to forget about your own needs when you are a caregiver, but doing that can take its toll on your health and well-being. You can, however, take steps to make things easier for yourself. Do you feel guilty for even wanting that? You're not alone – a lot of people in your situation feel like they should be worried about the sick person, and not themselves. Your first step is to accept that living with someone with ME or FM doesn't mean forfeiting the right to feelings of your own.

### *Feeling the loss of 'how things were'*

ME/CFS and FM are chronic conditions, which mean that life is not likely to ever be what it was before. That's a tough thing to accept, and you'll need to reach acceptance in your own way and your own time. Essentially you need to grieve for what you've lost before coming to accept what has happened.

*The following are some tips to help you manage, and to reduce your stress while caring for your loved one or family member.*

### **Accept your limits:**

As a carer you don't have to do it all, and you shouldn't try. Accept that there may be limits as to what you can do; admit when you are overwhelmed, and ask for help.

### **Create a carer support team:**

Before you can ask for help you need to know who you can ask. Plan ahead - make a list of people who can support or help you when the need arises.

### **Schedule time for yourself:**

Try and schedule in time for activities you enjoy. There are many more important things than doing the daily chores. Remember this is about staying healthy in mind and body, so you need to make time to have fun now and again.

### **Make your own health your first priority:**

This may sound selfish, but it's not. Being a carer can be a stressful job, and you need to stay healthy to ensure you can provide the care that's needed. Care giving can be

stressful, and trying to cope on a long term basis can lead to depression, so staying fit and healthy can help you cope, reduce stress, and make it easier to get through the tough days when they come. The following will help you stay on the right track.

- ***Eat a balanced diet*** – This is vital to good long term health.
- ***Get plenty of rest*** – Try to get plenty of sleep, because if you're tired everything can seem a lot worse.
- ***Exercise regularly*** – Regular exercise will give you more energy, reduce your stress, and elevate your mood.
- ***Relax*** – Do some relaxation exercises, such as deep breathing or meditation to reduce stress. If possible set aside a few minutes at the beginning and/or end of the day to practice these techniques.
- ***Take a break*** – At least once or twice each week, stop being a carer for a while and take some time for yourself. If you do you'll be happier and more able to cope.
- ***Make sure you have regular check-ups*** – Needed more than ever as you are dealing with emotional and stressful situations.

## **IT'S STRANGE ME BEING A CARER...**

'It's strange me being a carer.

You see, I'm not naturally the caring sort.

But here I am anyway.

I am a carer.

Sometimes I feel more like the commander of a ship, trying to steer a safe course for my wife through huge waves and treacherous rocks.

And at times I feel like the tin man

Wondering if he has a heart, and if not,

Where he might find one...

Then other days I feel huge waves of deep love for my wife

And I surf those waves for all they're worth, like a pro surfer half my age.

Those days I have the tenderness

And the words that fail me most other days.

I am her carer, yes,

But I try most of all to be her husband, lover and friend - though I was never the easiest person to live with and my many failings shame me.

But through all my grief, guilt and pain,

Frustrations, anger, and worries, I have committed myself to her no matter what.

She is the star in my sky.

*(From Rain, Hail, or Shine – Exploring change, loss and grief in a carer's world by Tricia Irving)*

## CANARY IN A COALMINE



ProHealth have announced Jennifer Brea as its 2013 “Advocate of the Year.” The Advocate of the Year award goes to an individual who has made outstanding contributions to the betterment of the ME/CFS community.

Jennifer Brea contracted ME in 2011, when she was suddenly hit with a flu-like illness. A little over a year later, she became bedridden - just a few months before her wedding - when she developed complex migraines and POTS, and began having difficulty reading, writing, and speaking (aphasia). Suspecting her symptoms were neurological, she made an appointment with a neurologist, who told her she had ‘conversion disorder,’ formerly known as ‘hysteria’.

At the time Jennifer was enrolled as a PhD candidate in Harvard University’s Department of Government. She was also pursuing a Master’s degree in statistics. Before beginning her doctoral program, Jennifer had pursued an active life as a freelance journalist covering China and East Africa for the *Guardian*, the *Scotsman*, the *Africa Report*, *China Daily*, and *Ebony Magazine*.

It was her background in journalism and politics, as well as her unwillingness to accept what she called a “Freudian” diagnosis that led Jennifer to investigate ME. (Jennifer’s opinion of “CFS” is that it is a “horrid name.”) She soon realized that the illness that had put her life on hiatus had affected more than a million individuals in the U.S. and that the medical establishment was not only ignorant of the problem, but condescending in its attitude.

Because Jennifer could not write, she began keep video diaries on her iPhone. In an effort to learn more about the illness, she read Hillary Johnson’s expose about the CDC’s cover-up of the Incline Village outbreak, *Osler’s Web*, and watched the film, *I Remember ME*. Before long, she became enmeshed in the community, and in its 30-year history of frustration. Jennifer came to the conclusion that she had to do something to convince scientists that ME was worthy of investigation.

“It’s a really tragic thing,” she says in a revealing TED interview. “There are a lot of people who are severely mistreated because of this. There are people who are getting locked up in psych wards. There are people who are encouraged to exercise and, as a consequence, are permanently harmed. There are parents whose children are taken away from them. There are people who become homeless. It’s just really hard for me to fathom the waste of life that this tragedy has created ... I thought, I’m not a Hollywood celebrity, but I have some resources, and I’m sick but I’m not nearly as ill as some people are. I can move my hands; I can go to the bathroom. That’s enough for me!”

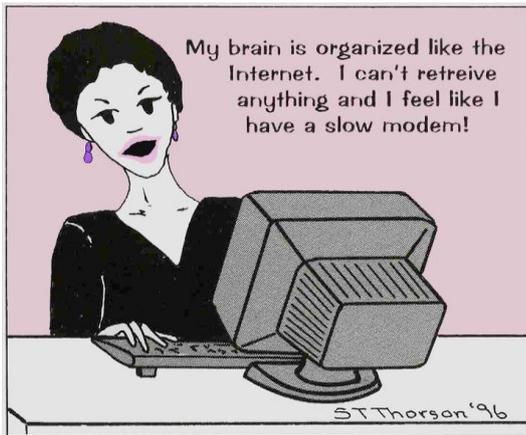
It was this courageous spirit that led Jennifer to the idea of making a full-length documentary about the illness. But, unlike other documentaries about ME, Jennifer wanted to place the people who endure it front and centre. To drive home the impact of the illness, Jennifer wanted to feature the stories of patients – those who have struggled for decades, those who have found some success, and those who haven’t – as well as the clinicians who have spent years treating those patients and attempting to unravel the puzzle of ME.

Last October, when she began fundraising for her film, *Canary in a Coal Mine*, Jennifer raised over \$50,000 in just three days. By the end of the month, the project had garnered over \$200,000 in an unprecedented outpouring of support from the ME/CFS community. This enabled Jennifer to set her sights on a larger project. In November, *Canary in a Coal Mine* won Indiewire’s Project of the Month, which won her a creative consultation with the Tribeca Film Institute, one of the industry’s most prestigious funders of innovative film projects.

This won’t be Jennifer’s last film, nor is it the end of her research into the illness. “It’s the one thing I’ve found that challenges me intellectually and creatively. I love being a researcher, I love doing academic work, but I also need to do mission-driven work. This gives me the opportunity to do all three. I believe that we will make a beautiful film and it will change things forever for our community.”

*Erica Verrillo*

## LAUGHTER IS THE BEST MEDICINE!



### Expressions of interest

One of our members is interested in setting up a small group of people who would like to meet on a regular basis to benefit from sharing their experiences about their illness. If this could be you, then please let Helen know. 07 834474 / 0277771344: [helen@mswaikato.org.nz](mailto:helen@mswaikato.org.nz)

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### UPCOMING SUPPORT MEETINGS

#### APRIL 10th Education Meeting

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

**Speaker:** Linda Bell, from Harmony Health, will discuss & demonstrate reflexology.

#### APRIL 22nd Social Group

2pm Robert Harris Café, Chartwell mall

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#### MAY 8th Education Meeting

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

**Topic** – How can homeopathy help?

*Speaker is to be confirmed.*

#### MAY 27th Social Group

2pm Robert Harris Café, Chartwell mall

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**“Not everything that is faced can be changed, but nothing can be changed until it is faced.”** James Baldwin



## AWARENESS WEEK ACTIVITIES

As most of you know May 12<sup>th</sup> is Awareness Day for ME/CFS and fibromyalgia, chosen because it is Florence Nightingale's birthday. She was ill for many years with what later was thought to be ME/CFS.



This year, with the kind offer of help from Arthritis Educator, Catherine Swift, first and foremost we are going to concentrate on educating people about fibromyalgia. As well as a stand at the Westfield shopping centre in Chartwell on May 15<sup>th</sup>, we are endeavouring to get information out to libraries and community centres throughout the Waikato. We also hope to raise general awareness via community radio and press, and even educate a doctor or two! Of course ME/CFS will get a mention as well, and I hope to have enough helpers to have an ME/CFS awareness stall at Pak & Save, also on the 15<sup>th</sup> May.

*If any of you are able to donate an hour or two of your time and precious energy to the cause on Thursday May 15<sup>th</sup>, please let me know.*

### THE COLOUR PURPLE

Purple is the colour of the fibromyalgia ribbon. So why purple? On checking this out I found out that purple is the traditional colour of royalty. It is the colour of the Crown Chakra, linked to the crown of the head, the nervous system and the brain, and is representative of pure thought. The Purple Heart represents courage in the military, and pride in Christianity, just to name a few of its associations. Purple has assumed an enlightened and vast embodiment throughout history. The study of purple in psychology has been shown to uplift, calm the nerves, offer a sense of spirituality, and encourage creativity. Purple embodies the balance of red's stimulation and blue's calm.

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**MARCH MEETING:** Michelle Peat from the Health Consumer Service spoke to the group about her role and the service provided. Because they are an independent trust contracted by the District Health Board to ensure people using a health or disability service have protection under the Code of Rights, people can therefore seek help from a free and independent health and disability advocate to help resolve concerns/complaints. Some very interesting discussions followed.

*You can contact Michelle on 07 8481268*

## **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's 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 Lightning Process Phil Parker (3 copies - 2 donated)***



## **Wheelchair Availability**

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.

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**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: 07 8686763