

KORU ME & FM Support

HAMILTON DECEMBER 2014 Issue 35



Greetings all,

Christmas is just around the corner and it's time for the last newsletter for the year, and the last one from me! As I mentioned last time Tracey Larsen is taking over from me next year, so please contact her if you need any help or advice. (*Contact details back page*)



Christmas is supposed to be a joyous and happy occasion, but it's often a stressful time for many of us - even more so when you're unwell. Do try and make Christmas as easy on yourselves as possible. Plan ahead, write lists, and make sure you delegate tasks. Keep it simple. Cut back on presents, give vouchers, money, or buy on line. Or perhaps draw one name out of a hat and buy a gift for that person only. Prioritise the things that matter and leave out those that don't. Remember to pace yourself as best you can before, during and afterwards! With summer holidays looming there are some useful ideas on page 5 on avoiding a post-holiday crash.

Speaking of Christmas – our Support Group Christmas lunch is on December 11th. It's from 11.30am through until 1.30pm. There will be entertainment, a finger food lunch and lots of fun. There's also an optional gift exchange (*no more than \$5.00*). If your name isn't already on my attendance list please let me know ASAP for catering purposes if you intend to come. (*Details pg 5*)

Tracey and I were very fortunate to meet up with Melbourne paediatrician, Dr Kathy Rowe, when she came to Hamilton recently at the invitation of Anzmes, to give a lecture to GPs and medical staff. Kathy works at the Royal Children's Hospital, specialising in young people and adolescents with ME/CFS, and has done a lot of excellent research over the years. The lecture was very informative, and quite an eye opener for many of the doctors. I have some DVD copies of the similar lecture Kathy gave at the Anzmes AGM. *If you are interested in borrowing or buying a copy please contact me.*

When I started in the role back near the beginning of 2009 I didn't realise quite what I was taking on, and what an amazing journey it would be for me. I have learnt so much and met so many wonderful people – both those of you who are struggling to live day to day with the effects of ME and FM, and those who have been associated along the way. Your stories have been heart rendering, your struggles immense, and your tenacity and courage in trying to find a way forward despite constant scepticism and disbelief from the medical profession, the public, and often your own family members as well - is truly inspirational. The good thing is that there has been a tremendous amount of research happening over the last few years and there are now numerous outstanding researchers world-wide committed to finding the final pieces to the ME/CFS puzzle. I wish each and every one of you the very best as you journey on. I hope the path gets easier and you don't have too many hills to climb along the way! Take care.

Helen

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**“Hope
Smiles from the threshold of the
year to come,
Whispering – ‘it will be happier!...’”**

Alfred Tennyson

Hearing Therapist, Cherry McWha, from Life Unlimited, gave us a very informative talk at our October Support Group meeting. She spoke about her role and followed this by showing us a range of equipment which can be used for those who are hard of hearing. She then went on to tell us about tinnitus and hyperacusis.



TINNITUS:

What is it?

It is the name given to the sensation of sound when there is no external physical sound present. Tinnitus does not sound the same for

everyone. Sounds can range from whistles to hissing, and some people hear more than one sound. Sometimes it's in the ears or head. Some can localise it to a point in space.

What causes tinnitus?

Many things can cause tinnitus e.g. exposure to loud sounds or some drugs. Tinnitus is often associated with a hearing loss, so a hearing test should be done.

Who gets tinnitus?

It's said that the majority of the population have tinnitus at some stage in their life – albeit briefly. 17% of the population are estimated to have problem tinnitus, 1% have tinnitus severe enough to cause annoyance, and about 0.5% have tinnitus that results in an inability to lead a normal life.

What is the effect of tinnitus?

For most people it's only a nuisance. However for a few it can result in loss of concentration, sleep problems and even depression.

Do we know what tinnitus is?

The actual mechanism is not known, but we know it's real, and results from a disruption of normal function somewhere in the hearing system. There is much research being undertaken to find out how tinnitus occurs.

What makes tinnitus worse?

What makes it worse for some doesn't for others. Common aggravators are: Stress, loud sounds, caffeine, nicotine, aspirin and some medications, alcohol or drugs, some foods.

Why does stress make it worse?

It tends to control the volume control of the brain. Tinnitus counselling or relaxation therapies may help to reduce this.

Is there a magic cure for tinnitus?

There is no magic pill that immediately eliminates tinnitus. All treatments take time and aim to reduce the annoyance and intrusiveness of tinnitus.

What should those with tinnitus do?

Consult a qualified audiologist. An examination by an otologist (ear doctor) may be recommended to investigate whether it is the result of a condition that can be treated medically. If no medical treatment is appropriate non medical treatments such as hearing aids, masking, habituation, or relaxation therapies can be beneficial.

Can we prevent tinnitus?

Because many things can cause tinnitus it's difficult to say how to prevent it. The most common cause is exposure to loud sounds; such as industrial noise, gunfire and excessively loud music. Hence, when exposed to loud sounds everyone should wear hearing protection.

Cherry suggests having a hearing test to get a baseline, so that any further tests will show if your hearing has deteriorated. Life Unlimited do free hearing tests and will advise you or refer you as required. They have a range of hearing devices to aid those with impaired hearing. Contact Life Unlimited: ph: 07 839 5506

“A friend is someone who knows the song in your heart, and can sing it back to you when you have forgotten the words.”

Donna Roberts



HYPERACUSIS – Hypersensitivity to sound

This condition occurs when people experience discomfort from the loudness from everyday sounds which don't bother other people, and which previously didn't bother them. It is a phenomenon experienced by many people and by almost 50% of people with tinnitus. The types and intensities of noises causing discomfort will vary. Some people will be sensitive to a particular pitch, some to one particular sound and some to all loud sounds.



The mechanism of Hyperacusis

It is caused by an alteration in the central processing of sound by the brain. The hearing mechanism itself is often normal, although some people think their ear is irreversibly damaged. Since almost all people can be helped by cognitive and “sound” therapy, the symptoms are not the result of damage to the ear. The central auditory system is first of all concerned with extracting important messages from unimportant background noise. An example of this is the ability to detect the sound of one's name across a crowded room, while other names, even if spoken loudly would go unnoticed. The original purpose of this ability to amplify small signals and to suppress others was to facilitate the detection of potential threats in the environment e.g. the detection of the quiet sound of a predator by an animal or human when living in a hostile environment. These pathways for sound perception can be re-programmed. Changes in emotional state, particularly mood fluctuations or anxiety, (often as a result of stress), can increase overall arousal and make us more sensitive to potential threats in our environment. These emotional changes can increase the apparent loudness and irritation of sounds to which we are already hypersensitive.

The avoidance of silence

Many people seek silence as a way to escape the pressure of everyday life. However, complete silence is not found in nature and should be considered unnatural. In the absence of sound stimulation of the auditory centre of the brain becomes extremely sensitive to any sound. External sounds may then increase dramatically in their relative

intensity and intrusiveness. With hyperacusis there is a great temptation to plug the ear to exclude unwelcome sounds. This actually makes things worse, as it encourages further perceived increase in the amplification of sound in the absence of plugs. Plugs should not be used to protect the ear from normal levels of environmental sounds. Overloud sounds can damage the ear and in these situations, (e.g. gunshot, discos, industrial machinery etc.), appropriate ear protection should be used.

Things that can help you live with hyperacusis

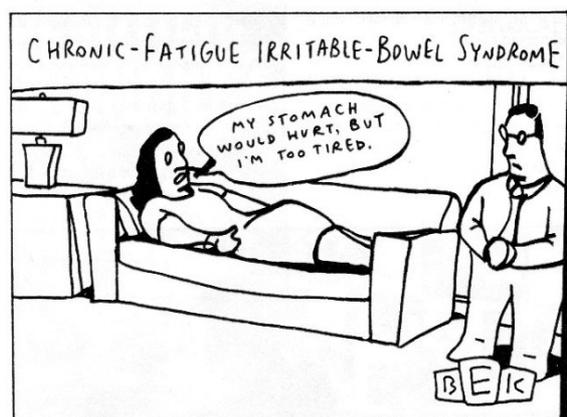
Find ways of managing stress.

Try relaxation techniques.

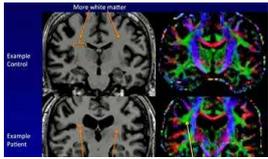
Have a sound rich environment – you need to hear very soft sound day and night. ***This must be a sound that you enjoy.*** During the day have the radio, TV or a CD on quietly. At night a bedside sound generator can be used with a sound pillow. Nature sounds are often more acceptable than music.

Learn about Cognitive Training – how you feel about the sounds that bother you is determined by what you are thinking. If you can learn to replace negative thoughts with positive thoughts about the sounds, then they will not bother you as much.

If this doesn't help, then see an audiologist to be assessed for a desensitizer. This is a white noise generator (previously termed a masker). The sound produced is the same as a radio “off station”. Initially the sound is very soft, but over a period of months it is gradually increased as desensitization occurs. Due to changes in the auditory neuronal pathways there is a permanent change in the loudness discomfort.

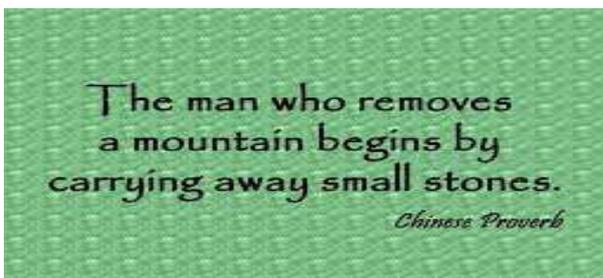


Not just lazy – CFS is real, new brains scans show. 29/10/14



Using new imaging methods, Stanford researchers found distinct differences between the brains of

patients with chronic fatigue syndrome and those of healthy people, according to a study published in *Radiology*. The findings, if duplicated in other studies could more definitively diagnose the syndrome and help researchers better understand the underlying mechanism that drives the symptoms, said Dr Michael Zeineh, an assistant professor of radiology at the Stanford University School of Medicine. The researchers found several anomalies in the brains of CFS patients, including a reduction in the amount of white matter – a part of the brain that is composed of long fibres which serve as the communication between nerve cells. They suspect the decrease in white matter is a sign that there is some sort of inflammation going on in the brains of CFS people – and perhaps throughout their bodies as well. It's possible, says Zeineh, that the inflammation was sparked by the response to a viral infection. The researchers were surprised to see find an abnormality in a bundle of nerve fibres in the right hemispheres of patients with CFS. This nerve tract, called the arcuate fasciculus, connects the frontal lobe and the temporal lobe, and appears on both the right and left sides of the brain. On the left side it appears to be crucial to language, but what it does on the right side is not known. One thing that's clear, said Zeineh, "the more abnormal this tract was the worse the fatigue was". CFS experts welcomed this study. "It suggests an actual organic basis for the symptoms of CFS," said Dr Paolo Nucifora, an assistant professor of radiology at the University Of Pennsylvania School Of Medicine. "And I think it will definitely spark other research."



RELATIONSHIPS



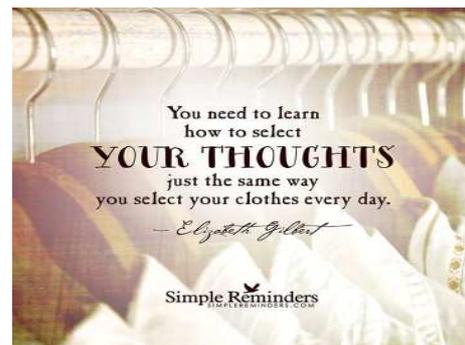
Our topic for the November Education Support Group meeting was a discussion about *relationships*, which was ably facilitated by Tracey Larsen. As you can imagine there are many aspects to this topic, and we managed to cover quite a few. These included defining what a relationship is, and talking about the many different types of relationships we have. How chronic illness can affect a relationship, and how to maintain good relationships. We also discussed the importance communication plays within a relationship.

Tracey led a very interactive discussion by those present, and afterwards they were all in agreement that it had been very helpful to discuss things together and share their thoughts and feelings. There was too much to cover here so Tracey will cover the discussion more fully in next February's Koru.

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ANZMES FACEBOOK

Those of you with a computer can find lots of excellent information about ME and FM by going to our national organisation's facebook page. You can keep up to date on the latest research and get plenty of coping tips. *You can check out their website on www.anzmes.org.nz*



LIBRARY BOOKS:

Some of our library books have been out for several months. Can you check and if you have a book that is well overdue or you have finished with it, please get it back so others can borrow them. Thanks.

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"Courage is just dreams with shoes on" Rena Riley



POST-HOLIDAY CRASH



Christmas holidays are a busy time. Families and friends get together, good food is shared, gifts exchanged. There is

shopping to be done, special meals to be planned, wrapping presents, decorating the tree....

Just reading that list is exhausting!

The fact is that whenever there is an expenditure of energy – and this goes for anyone – the inevitable consequence is the post-event letdown. For people with ME/CFS and FM, who don't have the ability to recuperate easily, the result is a crash – a period in which the exhaustion is total. All your other symptoms may flare up as well, not just because you've been expending energy, but because you may also be eating food you don't normally eat and altering your sleep patterns. People with ME and FM simply don't have the flexibility to handle changes, And Christmas is a major change from daily routine.

There are several things you can do to help mitigate the post-holiday crash.

First, if you overdo it in the holidays and crash, don't beat yourself up. Having an illness that restricts you to living your life in a box is not only restricting, it is stressful. If you do a little too much at Christmas, it is simply because you are trying to join the human race! There is nothing wrong with that. The ability to join company, to eat and drink and make merry, and to do simple, *normal* things becomes all the more precious when it's curtailed. So even if you do crash – it may have been worth it for the sake of your overall wellbeing.

Second – you can take breaks. A number of years ago when I was spending the vast majority of my days in bed, I had to attend a wedding. The reception was in a house, so I simply found a couch and lay down. Eventually someone wandered in to the room, noticed that I was lying down, and said “that's a good idea.” She lay down on the floor beside me and we had a pleasant chat. Soon, several other people had joined her. There were five now five people lying next to one another on the floor, chatting. Throughout

the evening people got up and left and others took their places. The lesson I learned was that I didn't have to (literally) rise to the occasion. And it appears that other people were more than happy to take a break as well.

Third – plan to have one or more “down days” (as many as you need). It's one thing to have a crash; it's quite another to prepare for one. I have found that whenever I need to do something that requires more energy than I have, planning to have sufficient rest time afterwards makes it easier to get through the event – and to recover from it. This may require a bit of scheduling, but it will reduce your stress levels considerably.

Managing this illness is important. The trick is to find a strategy that works for you.

(Erica Verillo cfstreatmentguide.com)

THURSDAY DECEMBER 11th

11.30am – 1.30pm

Come and join us.

Methodist Church – Crn Bader St & Normandy Ave. Cost: \$6.00 if you are a paid up member \$12.00 if not. (Catering cost is subsidised) **Optional** - Bring a small exchange gift - not more than \$5.00 ***Please let Helen know ASAP for catering purposes*** Ph: 07 8344742 or 027 7771344 helen@mswaikato.org.nz



SOCIAL GROUP:

NB: No Social Group meeting in December but the January meeting will go ahead on the 26th – Tracey is unable to attend but some members will definitely be there.

FEBRUARY MEETING:

This will be a **mix and mingle morning tea meeting**. Tracey will have a discussion about what members want from the meetings and ideas for the future.

HANDY TIP: If you are over 65 with a gold card, present it at any **Challenge petrol station** just now and you will get 8 cents a litre off. Great savings to help stretch the budget! *There are Challenge Stations in Naylor St & Lake Rd in Hamilton.*



(Thanks Stephen for this great tip.)

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.



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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 or enquiries.

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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078686763 (Thames)



USEFUL WEBSITES

www.anzmes.org.nz
www.co-cure.org
www.me-cfs.org.au
www.iacfsme.org
www.afme.org.uk