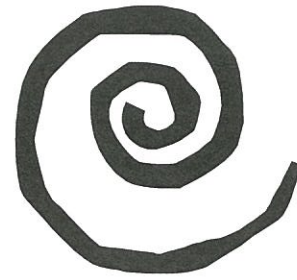


KORU



ME/CFS & FM Support

MS Waikato

Working Together to Provide a Service of Excellence
Mahi tatau kit e whakawkiwi he hapori rawe

November 2015 - Issue 39

Kia ora and Welcome



Well... winter has been and gone, spring has well and truly sprung and summer is just around the corner. And oh my goodness, so is Christmas!! I know I have said it before but I am going to say it again... where has the year gone?

It has been a very busy year. My first year at the helm has been interesting, with lots of firsts, learning the many aspects of my role. I have met some truly amazing people who have inspired me no end with the amount of bravery, strength and courage they clearly possess in order to live day in and day out with this debilitating condition.

The monthly Support Group meetings has seen some great speakers and topics covered. The focused group discussions seem to have been a highlight for many, giving you, our members the opportunity to share your own knowledge.

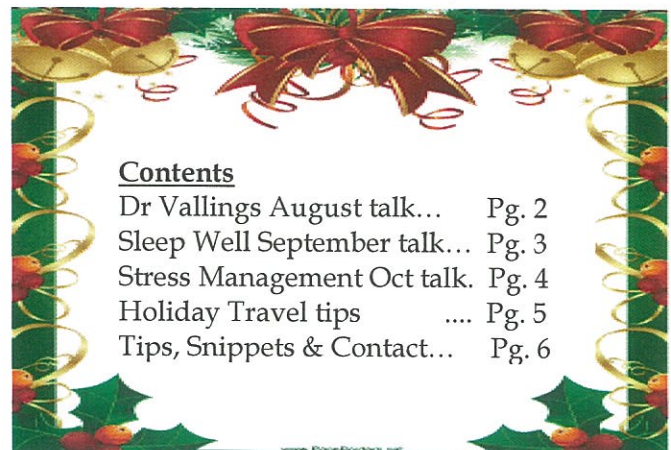
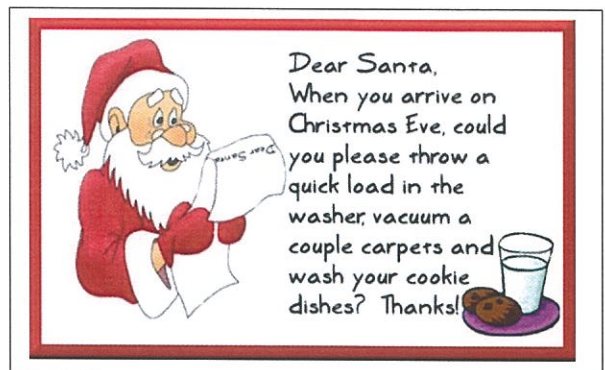
Last month I had a fantastic opportunity to attend a meeting in Wellington to meet other coordinators and support group leaders, most of who dedicate their time through voluntary means. This meeting enabled me to broaden my network of contacts and see what happens in other regions. It was great to share of ideas and resources.

Sadly this is the last newsletter for the year. I am already thinking ahead to next year and planning speakers for our Support Group meetings. I have also given much thought into re-establishing The Coffee Group. It has proven a difficult task to find a café that has good parking, is on a bus route, has reasonable prices and is quiet. It appears that Café Fresca on Alison St (by the lake) ticks most of these boxes. If you are interested in meeting others in an informal social setting please contact me on 8344745 or email me at tracey@mswaikato.org.nz to express your interest. If there is a good response I will advertise dates and times in February's newsletter, so keep an eye out!!

Until then

Aroha Nui and Merry Christmas

Tracey Larsen



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Dr Ros Vallings

In August, Dr Vallings shared the latest research efforts and findings presented at the 2015 10th Annual 'Invest in ME' conference in London.

A good turnout of clients and public came to hear her speak and feedback from those who came was very positive. Unfortunately the limited space here only allows me to comment briefly on some of the highlights, however a DVD recording of Dr Vallings' talk is available to loan. Please contact me on 8344745 if you would like to borrow this.

Dr Vallings stated that there is much ongoing research focusing on food and nutrition and bowel bacteria as an imbalance of bacteria impacts the immune system. There is constant communication between the gut and the brain, therefore the brain is also influenced by the imbalance of bowel bacteria. Dr Vallings recommended for those who experience gastro issues to try a probiotic to help to balance the gut flora.

The bowel also influences the production of Serotonin – the 'feel good' endorphin. It has been shown that for some ME/CFS sufferers there is a poor release of serotonin. Dr Vallings stated that some antidepressants can be beneficial to help with the production of serotonin.

An American gastroenterologist has been researching stomach bugs and has found an unusual virus in a large percentage of ME/CFS sufferers who experience severe gastric symptoms. He has discovered a Chinese herb that has been refined into a drug to have been helpful. Dr Vallings has had some success prescribing this to some of her patients also.

An exercise physiologist has suggested that Yoga and Ti chi is recommended as an ideal form of exercise. Building up core strength is most important as core muscles hold the body in good posture. They also suggest that a good rule to follow is a 1 in 3 plan - 3 times the amount of rest for the amount of exercise. For example 30

seconds exercise should be followed by 90 seconds rest. 30 minutes' walk = 1 ½ hours of rest.

Further studies are looking at the communication of the immune system and the brain. When the communication is turned on it can cause brain cells to become inflamed. A protective immune mechanism in the brain can make you feel very tired develop fever and headache. MRI scans shows these mechanisms are switched on but there is no understanding yet as to what causes it to switch on.

Swedish researchers are looking at proteins in the cerebral spinal fluid. So far 776 pages of different proteins have been identified and they have found some definite differences between the proteins of healthy individuals and ME/CFS patients. It is hoped that a bio marker may be established as a result of this study.

Research regarding intolerance to visual glare (light sensitivity) has resulted in interesting findings. Difficulty with eye movement and multi-tasking, explains difficulty with driving and can cause post exertional malaise of the eyes. Also what has been noted is an impairment with pupil contraction; usually the pupil will contract in bright light but researchers have noticed that the eye will contract and then dilate instead of staying contracted. By shining a light into the eye could be considered another form of diagnoses as it is a characteristic of ME/CFS and not seen in any other illness.

The cancer drug retaximab has shown positive results. ME/CFS patients who later contracted cancer and used this medication completely recovered from the ME. Trials are showing that 50% of participants are responding but some nasty side effects have been noted so this study is yet to be concluded. Improvement in activity and in clearer thinking have in particular been noted.

REMEMBER

The 3 in 1 rule for exercise!!

*30 seconds exercise = 90 seconds rest
30 minutes walking = 1 ½ hours rest*



Lisa Crow from Sleep Well Clinic Hamilton spoke to the Support Group about sleep in September.

Lisa stated that sleep is like that of an octopus - it sits over top of your life and its tentacles touch every area of your life; memory and concentration, relationships and sexual health, physical health (blood pressure, heart health, risk of stroke) energy, growth hormones (released during sleep. It is a known fact that children who do not get adequate sleep are often smaller).

About Sleep

There are four stages to sleep – non rapid movement sleep which makes up to 80% of sleep and REM (rapid eye movement sleep) often referred to as dream sleep. We cycle through these periods throughout the night.

Stage 1 – Just beginning to drop off to sleep. You have an awareness of your surroundings but you don't have the energy to respond; if someone touched you, you would wake and be back in the world.

Stage 2 – Most time is spent here through most of the night. Your body temperature drops, heart rate and breathing slows down, and it's hard to be woken during this time.

Stage 3 – You are even deeper in sleep. This is when sleep walking can happen and children are likely to wet their bed and it is difficult to wake someone at this time.

Stage 4 – REM sleep (dream sleep). Sleep is not as deep as stage 3 but your brain paralyses you during this stage; it switches you off because it has things to do; it processes data gathered during the day and decides if it is important. What is important is stored to long-term memory. It is also a time when issues and problems can be worked through which helps with decision making – hence the term 'sleep on it'!

Normal sleep will see you cycling through these stages 3 to 4 times each night. A late night or disturbed sleep



will mean that only 1 or 2 cycles occur impacting on the quality of your sleep. If the REM stage is disrupted the brain fails to process, sort and file effectively which can effect memory.

Poor sleep can result in drowsiness, lack of concentration, irritability, risk of increased accidents, less productivity, memory recall – age is often used as an excuse for a decline in recall, but lack of quality sleep is usually the cause.



Strategies to Help Sleep

Pain disrupts sleep. Dealing with pain assists with managing quality sleep and quality sleep helps to cope more effectively with pain. Therefore Lisa recommends to medicate for pain before medicating for sleep issues as medicated sleep disrupts sleep cycles. Some pain medications can disrupt sleep so check medications with your GP or pharmacist.

Lying in bed for hours trying to get to sleep is unhelpful. It can create more anxiety which will inhibit the ability to get to sleep. It is better to get up and do a quiet activity like reading a book. Avoid electronics as they stimulate your brain too much and contribute to the difficulty of getting to sleep.

To help sleep try the following:

- Avoid caffeine and alcohol from early evening onwards.
- Avoid heavy meals for about 2 hours before bed
- Avoid energetic exercise before bedtime.
- Have a restful hour before going to bed - a routine helps our brains to know that we are preparing for sleep. This is a good time to do relaxation exercises.
- Have a hot milk drink or milky milo before going to bed. However heat the milk on the stove, not in the microwave as the microwave negates the tryptophan in milk that aids sleep.
- Remove all electronic devices from the bedroom. The light confuses the brain and keeps it stimulated – keep the bedroom for sleep and sex only.
- If your mind is circling with thoughts that are stopping you from getting to sleep, get up and write them down. This helps you to put your thoughts aside and you can pick them up again on the morning.
- Have a comfortable bed and keep your room cooler; being too hot can disrupt your sleep.

Sleep is best regulated by getting up at the same time every day; after a late night, your sleep patterns will reset quicker rather than sleeping in to catch up on sleep.

Waking up unrestored? Natural light helps to stimulate wakefulness so as soon as you wake up, get up and open the curtains. If you can, also get outside into the natural light.



October's Support Group meeting was a focused group discussion on Stress Management Strategies.

We discussed what causes stress, how to recognise it

and how to manage it.

Stress is an arousal of the mind and body in response to demands made upon them. We constantly think, feel and act so it is a part of everyday life and cannot be avoided.

The stress response involves virtually every organ and tissues in the body, it raises the heart rate, blood pressure and respiration, muscles tension and the release of hormones such as adrenalin.

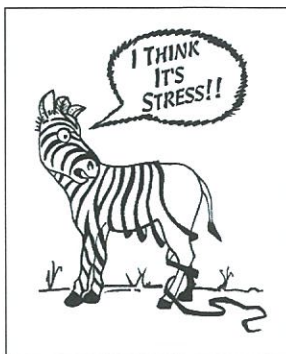
Stress can be a great motivator but it can also become harmful when we perceive the stressor as threatening to our wellbeing and if our own sense of ability to cope with it becomes overwhelmed, then stress becomes 'distress'.

Some stress related disorders

Migraines	Ulcers
Tension headaches	Chest pains
Gastritis	Back pain
Colitis	Cancer
Heart attack	High blood pressure
Dizzy spells	Panic attacks

How do you recognise that you are experiencing stress?

Poor concentration	Tight shoulders
Short-tempereddness	Depression
Sore lower back	Fuzzy thinking
Trembling hands	Edginess
Accelerated speech	Churning stomach
Anxiety	Irritability
Sleep disturbance	



A series of events happens when we are faced with a stressful event. The following diagram shows that when an event occurs it creates a perception – what we think about it. This thought then creates an emotional response – how we feel about it; and then this creates an action – how we behave.



In order to manage stress, changes can be made either to your perception of the stressful event, your emotional reaction to it or you can reduce the impacts on your body through relaxation techniques.

Stress Management Techniques

Breathing is a very useful tool and can be used anywhere. It helps to calm you and keep anxiety at bay; it stimulates energy at a cellular level and calms scattered chaotic thinking encouraging focused clarity of thought.

A simple breathing technique we practiced was inhaling deeply and slowly and then exhaling in a relaxed manner – do not force the exhale as forced exhaling can cause hyperventilation. Ensure your breath reaches the lower lungs – trying to burst the button on your pants will help you to know that you are achieving this. While focused on your breathing notice any tension in your shoulders, arms or back. Give those areas a wee stretch or shrug to help loosen away any tension. The group noticed that they felt more relaxed only after a few minutes of doing this.

When we are relaxed we are more able to practice 'mindfulness'. Mindfulness is a state of being where self-awareness can foster and grow and we gain awareness of our environment around us. It offers us the ability to become a witness in our own lives – a non-judgemental witness to our thoughts, feelings and behaviours. It also brings us the opportunity of 'choice' – how you perceive/think about what you are experiencing - you can choose to either enjoy what you are experiencing or enjoy the choice of not enjoying the experience. Changing the perception then changes the emotional reaction and in turn our behavioural reaction to the stressor.

Information sourced from Stress Management for Wellness, W.Schafer; Rebirthing made Easy by C. Sisson; and Learning Cognitive Behavioural Therapy by Wright, Basco, & Thase



Holiday Travel Tips

- Rest adequately before hand - this may be required for several days or weeks before you leave, so that you can enjoy your much anticipated holiday.
- Plan your trip well – plenty of rest stops and time between train, plane, bus or car trips to avoid rushing.
- Pack well in advance – don't leave it to the last minute. Make a list of last minute items such as toiletries and medications.
- Pack light if you have to carry your bags. Make use of trolleys at airports.
- Make use of wheelchairs at airports – pre arrange airport staff to support you with the use of a wheelchair and handling your luggage
- Remember to pack an adequate supply of medications and supplements. If travelling over seas take a note from your GP detailing your medication requirements. Using blister packs helps keep track of your medication when entering different time zones
- If you experience sensory overload use ear plugs or head phones and a sleep mask when travelling on trains, planes or buses.
- Where possible take extra food supplies – especially if you have special food requirements.

7 Wonders of the World

A group of students were asked to list what they thought were the 7 wonders of the world. The following received the most votes:

- | | |
|-----------------------------|------------------------|
| 1. Egypt's great pyramids, | 2. The Taj Mahal, |
| 3. Grand Canyon, | 4. Panama Canal, |
| 5. Empire State Building, | 6. St Peters Basilica, |
| 7. The Great Wall of China. | |

While the teacher was gathering the notes she noticed one student hadn't finished her list. When asked the student said "I can't make up my mind, there are so many". The teacher asked her to read out what she had so far. The girl replied

"1. To see, 2. To hear, 3. To touch,
4. To taste, 5. To feel, 6. To laugh,
7. And to Love".

The room was so quiet you could hear a pin drop.

The things that we overlook as simple and ordinary and that we take for granted are truly wondrous. This serves as a gentle reminder that the most precious things in life cannot be built by hand or bought

(courtesy of ANZMES Meeting Place Spring 2015)

From 2016 MS Waikato would like to email a copy of the Manuscript to you. If we do not have your email address listed please email it to me. If anyone would like to continue to receive a paper copy of the Manuscript please phone me on 07 8344745 or email tracey@mswaikato.org.nz

Tips, Snippets & Contacts

Coming Events

ME/CFS & FM Education Support Group

Methodist Church, Bader Street, Melville 10.30 - 11.30

12th November - Toni from the Life Unlimited Store will be presenting useful energy saving gadgets to make life easier.

10th December - ME/CFS/FM Christmas lunch to be held at The Hamilton Workingmen's Club. Start 12.00, lunch served 12.30

14th January 2016 - NO GROUP MEETING THIS MONTH

11TH February 2016 - Psychologist Neil Micklewood will be giving a brief overview of Mindfulness-based CBT principles to assist with managing pain, psychological distress and improved wellbeing for ME/CFS, and Fibromyalgia.

The office will close for Christmas from Thursday 23rd December and will re-open on Monday 25 January 2016. The following numbers are available should you need urgent help over this period:

Health Line - 0800 611 116

Depression Helpline - 0800 111 757

Lifeline - 0800 543 354

Alcohol and Drug Helpline - 0800 787 797

Suicide Prevention Helpline - 0508 828865

Like Minds Like Mine - 0800 102 107

Are you interested in joining a social coffee group in the Hamilton Area? Please email or phone Tracey to express your interest

USEFUL WEBSITES FOR MORE INFO ON ME/CFS/FM

www.cortjohnson.org (Health Rising)
www.anzmes.org.nz www.co-cure.org
www.me-cfs.org.au www.iacfsme.org
www.afme.org.uk www.cfidsselfhelp.org
www.emerge.org.au

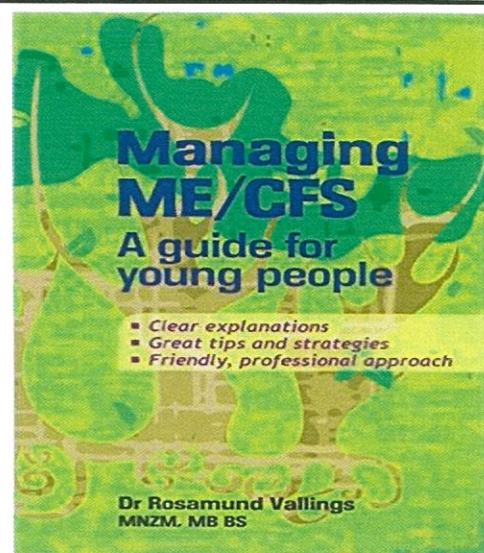


Check out ANZMES on Facebook. They post great articles that maybe of interest to you regarding research and symptom management



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

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



Dr Vallings' new book is now available to loan. Please phone me on 8344745 if you are interested. Feedback has been positive stating that it is an easy read specific for teenagers to understand what is happening to them and their health

OTHER CONTACTS:

You may find it helpful to speak others who also have ME/CFS and/or FM. Thanks to those offering such support. Please be aware that they will respond as they are able, according to how their own health is at the time:

CIANE: 8466535

LINDA: 8553934 lindaderrick@yahoo.com

BERNADETTE: 07 8686763 (Thames)

Deborah: 07 8955545 (Fibromyalgia)

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