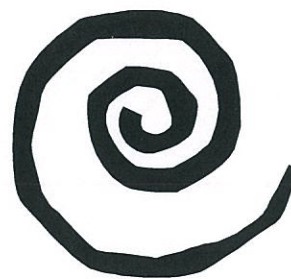


KORU



ME/CFS & FM Support

MS Waikato

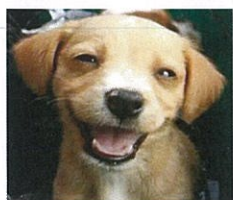
Working Together to Provide a Service of Excellence

Mahi tatau kit e whakawkiwi he hapori rawe

August 2015 - Issue 38

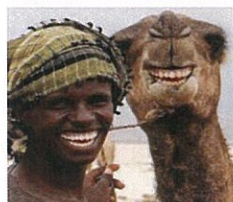
Kia ora and Welcome

Brrrrr.... winter is well and truly here! However, we have experienced some warm patches too though so I hope everyone is not suffering too much.



As winter can be so dreary and typically a time of year when

depression and flatness of mood can be more prevalent, I have decided that 'LAUGHTER and HUMOUR' is to be the focus of this newsletter. Research clearly shows that laughter IS the best medicine (page 3) so I hope the quotes and pictures I have added gives you a chuckle and helps to lift any winter blues that you may be feeling. As much as laughter can be contagious, so too can a simple smile. To receive a random genuine smile can be quite uplifting so smile at others as often as you can. 😊



It has been a busy few months since last writing. International awareness day was on the 12th May. This was very successful this year with much inquiry and \$100 received in donations. Thank you to those who volunteered to help on the stall at Chartwell. Your help is greatly valued and appreciated.



The May support group meeting was an opportunity for everyone to share their strategies for daily coping and a lively discussion was had. Please see page 2 for some of the great ideas shared.

We had Donna from Donna's Wellness Clinic come and speak to us in June. She was very informative, confirming what other speakers in the past have said; that much of our immunity starts with bowel health. See Page 4 for more details.

Benefit issues? See page 5 for details of the discussion by Craig Wills – WINZ advocate who spoke in July. Also on page 5 see how Community Law Waikato can assist you with free legal support.

Next newsletter will be out early November.
Until then....

Aroha nui

Tracey Larsen



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Dr Ros Vallings Thursday 13th August

sharing latest global research findings
regarding ME/CFS & FM
Methodist Church, Bader St, Melville
10.30am - 12.00 midday
Please phone 8344745 or email
tracey@mswaikato.org.nz to register

May's Support Group Meeting – Strategies for Daily Coping

This month a focused group discussion around ideas of daily coping strategies gave the group members a chance to share their own ideas in the hope of helping others (and themselves) and to build on existing knowledge. It was very informative with many great ideas shared...

How to manage noise – Having a low gentle constant continuous noise such as a humming or gentle music helps to reduce the effects of tinnitus and sudden unexpected noises (helps with sleep also). Another tip offered is possibly an acupressure concept; roll the ear lobes out starting from the top and working down to the lower lobe. This has helped a group member with tinnitus, noise sensitivity and also enhances clarity of mind.

To stimulate energy – To rub finger tips from the front of the head to the back through the hair and across the scalp. This apparently stimulates nerve ends in the scalp that has a flow on effect helping to stimulate energy down through the body.

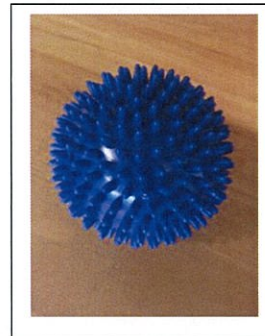
General Housework – to save bending (and energy), mop the floor using old towels; apply a little water and cleaning product and then stand on the towels and shuffle around the area.

Vinegar and baking soda are cheap and can be used in abundance and are very good products for general household cleaning. They are especially ideal for those who suffer chemical sensitivity. One group member has found good ol' 'Handy Andy' very good for stain removal; use neat with a toothbrush to spot clean the stain prior to putting in the washing machine

Bathrooms - When cleaning or spraying the bathroom for mould use a small one-litre garden pump sprayer instead of a trigger bottle as trigger bottles can hurt the wrists and hands. Steam cleaners are useful to clean mould. Consider anti-mould paint if you are repainting the bathroom. Landlords have legal obligations for managing damp and mould; if you are renting know your rights!

Condensation – creates mould which can be very harmful for your health. Don't use portable gas heaters as they create moisture. Dehumidifiers are beneficial to reduce dampness in the home and when the home is dryer it is easier to heat. Condensation on the windows can be significantly reduced if you open your curtains when you go to bed at night. Window vac's are easy to use and great for drying windows – more energy efficient than towel drying.

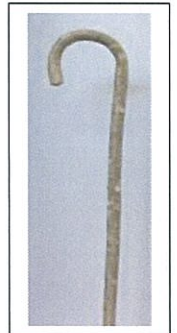
Pain – Rob gave us a demonstration of how he manages his pressure point pain. With the use of a



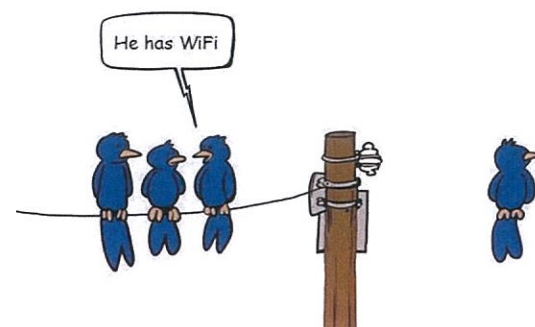
rubbery spikey ball he rolls this on his hips and back by pressing and rolling it between himself and the wall. These balls can be purchased from pet stores and physiotherapists and are about \$17. Body rollers

are also good to disperse knotty pressure points in the lower limbs.

Rob also uses the handle of a walking stick to apply pressure to painful points on his shoulders. Find a walking stick that has a good curved handle to fit over the shoulder. Its length is not important – in fact the short the better. Ice massages are also beneficial - wrap an ice cube in a handy towel and rub over sore spots.



The next focused group discussion will be held on the 8th October and the topic is 'Stress Management'

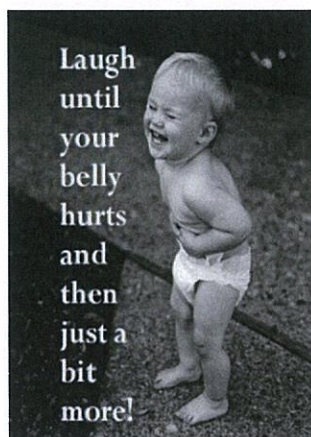


YES!

LAUGHTER 'IS' THE BEST MEDICINE

Research states that there are many health benefits that can be gained from laughing. While no research has been applied to conditions such as ME/CFS & FM, benefits are beginning to be understood regarding painful conditions like cancer and rheumatoid arthritis. Some benefits include-

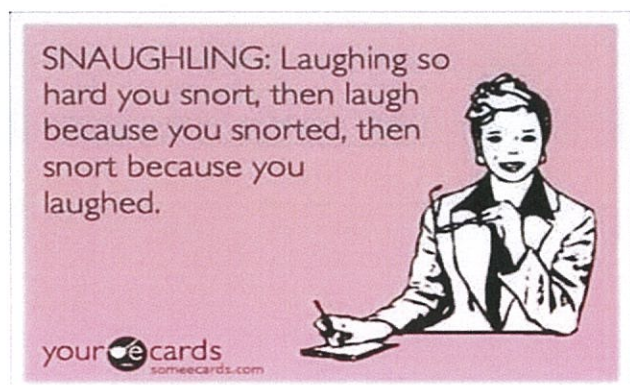
- Lower stress and the risk of heart disease
- Lower blood pressure
- stimulates blood flow
- increases immunity
- improves mood
- enhances memory
- relieves pain
- relaxes muscles
- improves concentration



Best of all it doesn't need a prescription, and its free!!

However for those experiencing ME/CFS & FM a long hard hearty belly laugh may trigger post-exertional malaise and increase pain. Therefore approach **long hard** laughter cautiously. If you find laughing beneficial for you try and include humour in your daily life - watch a funny movie or read a funny book and find ways to laugh at your self and at life. Happy laughing!!

Information sourced from 'Benefits of Laughter for Fibromyalgia & Chronic Fatigue Syndrome' by Adrienne Dellwo - About Health.com



The following article is a humorous view of FM and can also relate to ME/CFS and is written by K. L. Richards - www.prohealth.com/fibromyalgia/library

You Might Have Fibromyalgia if...

Sometimes it's good to look at the funny side of serious subjects. While fibromyalgia itself is a serious illness, there are some humorous aspects. Our brain fog experiences alone could keep an audience laughing.



You might have fibromyalgia if...

- Everything hurts – and what doesn't hurt, doesn't work.
- You feel like the morning after but you didn't have a night before.
- Your phone's contact list contains only names ending in M.D.
- You get confused playing checkers.
- Your trash goes out more often than you do.
- You finally have all the answers but you forgot what the questions were.
- You have to weigh up how hungry you are against how much effort it would take to cook and how many dishes it would create.
- You look forward to a dull evening.
- You get more excited about buying new pyjamas than a new outfit.
- You sit in a rocking chair and can't get it going.
- You have to rest halfway through applying lotion to your body.
- Your brain is like the Bermuda Triangle – information goes in and is never found again.
- After painting the town red, you have to rest for a week before applying the second coat.
- You consider a discussion of bowel problems interesting conversation.
- You know what's on TV at 3:00 a.m.
- The hardest decision of your day is whether to shower or eat.
- Dialling long distance wears you out.
- You can rise and shine but not at the same time.
- You stop to think and forget to start again
- You find yourself smiling at this list.

Donna's Wellness Clinic

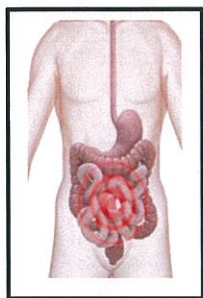


Donna has been a registered nurse for 30 years but issues with chronic health and an ME diagnosis found her seeking answers and treatment in the natural health fields. A passion for natural health soon developed and since the 80's she has worked with

relaxation massage combined with cranio-sacral therapy and reflexology. An interest in herbs and natural medicine found Donna further qualifying in Energy Medicine, Reiki, BodyTalk and Naturopathy.

To demonstrate her practice, Donna shared a case study. She diagnosed 'leaky gut syndrome' via a comprehensive assessment combining iridology techniques, considering diet and lifestyle habits, and looking at body zones. Other testing methods are also sometimes used, such as blood tests and studying genetic test results – a revealing test which Donna believes will be used in the future to identify and diagnose health issues.

Leaky gut is a damaged gut lining that can be caused through consuming wrong foods, alcohol, drugs or medication, creating holes in the lining of the gut (like holes in your garden hose). Such holes allow undigested food particles and bad bacteria to be absorbed more readily into the blood stream.



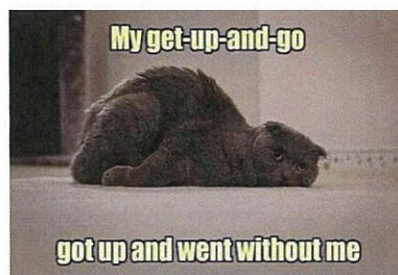
84% of our immunity starts with gut and bowel health – which involves what we eat, drink and feel...

When this happens an inflammatory response occurs

which can cause abdominal pain, fatigue, joint pain, headaches, food sensitivities plus many other symptoms all of which her client presented with.

Treatment pathways usually finds Donna looking at the PH balance of the body, as she did in this case. She explained that modern environments and diet habits often result in the body becoming too acidic that affect

the kidneys, which respond by taking minerals from the bones in an attempt to correct the PH balance. Over time osteoporosis may result. To help alkaline the body Donna recommended a morning drink of water, lemon juice and apple cider vinegar. Some fresh ginger is very beneficial also.



She also stressed the importance of hydrating the body to her client – dehydration can cause headaches, pain and fatigue. Look at your urine,

dark urine suggests dehydration - it should be clear throughout the day. Coffee is dehydrating, so she stated to be mindful of this.

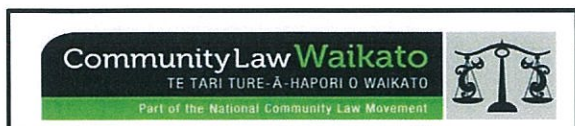
For her client Donna also prescribed (and highly recommends as a good health practice in general) the **'Low-stress food protocol'**

- Omega 3 – good fats such as coconut oil, fish oil, and hemp oil - ideal for brain fog as the brain is made up of a lot of fat
- Super foods such as chia seeds and alphalpa sprouts – high in protein plus many other beneficial vitamins and minerals
- Nettle tea – high in minerals, enhances serotonin and helps with sleep
- Magnesium is a must as it assists 3000 enzyme functions for the body. If you struggle with digestion (and therefore absorption of magnesium) try dandelion tea as this is good for digestion
- L-theanine – acts as an anti-depressant and reduces anxiety – good for boosting adrenals
- Vit D & B12 also highly beneficial to support health
- A probiotic to restore bowel bacteria.

Other therapies Donna highly recommends is Body Talk and Reiki (energy healing) and also lymphatic drainage via Reflexology as it is important to stimulate the lymph nodes and lymph system.

"It is a journey to good health – there is no magic pill or overnight cure, but a dedicated focused approach that may involve many steps..."

To make an appointment contact: Donna Barraclough at Donna's Wellness Centre, 11 Golf Grove, Hamilton
Ph: 07 8495180 or 0273120793



I recently attended a very informative presentation by Kim Morton held at Community Law Waikato regarding the findings of the research project "Access to Justice for Beneficiaries". This project provided a broad perspective of WINZ - the system, processes and services beneficiaries encounter, including individual experiences of accessing entitlements.

In-depth interviews were held with beneficiaries and representatives including MSD staff and agency advocates. Key findings of the project were:

- Main problem is poverty and inadequacy of income
- Inherent imbalance of power between beneficiary and case manager – a dehumanising experience
- Beneficiary disadvantaged by seeing a different case manager at each visit (in most cases)
- Inconsistent benefit and entitlement decisions
- Complex criteria, and lack of understanding of criteria, for benefits
- A perception that information about available benefits is withheld
- Poor communication when benefit changes, especially when entitlements are declined/stopped
- Little known about rights to review decisions and many barriers hinder access to review process – lack of disclosure given about beneficiaries right to review
- Beneficiaries supported by an advocate significantly improved chances of receiving entitlements and treated in a more respectful manner
- Low public awareness and knowledge of free services available from Community Law to assist in legal support identified.

This report has highlighted that there is an extensive need for legal support for beneficiaries when dealing with WINZ. Community Law Waikato is a registered charitable trust that offers FREE LEGAL SERVICES for a range of issues including minor criminal offences, ACC, traffic offences, employment issues, tenancy disputes, human rights and more. Ph Angela or Kirsty on 0800 529 482 for legal assistance.

**Why is money
called dough?
Because we all
knead it.**



For our July Support Group Meeting I invited Craig Wills to speak to us about WINZ benefits.

Craig provides a free, confidential service supporting clients through the process of claiming for entitlements. He can support you with regards to completing paper work required by WINZ, help you understand the criteria and your obligations, and with your permission he can converse on your behalf directly with WINZ.

He explained the different benefits - Job Seekers benefit, Solo Parent benefit and Support Living benefit. The Support Living benefit has replaced the invalids benefit and can be applicable to those who are caring for intellectual or disabled person whether a parent or child caring for a child, parent, sibling or other relative. It does not however cover a spouse caring for a spouse.

Eligibility for a Supported Living benefit is that you are unable to work due to a health condition or disability and that such a condition is likely to be unchanged for two years.

Craig stated that in his experience of supporting clients, it is important to have a supportive GP, and that often it is how the GP has completed the medical certificate that can be the difference between meeting and failing to meet criteria.

When applying for a Support Living benefit the case manager sends your details to the Regional Health Panel. Often a second opinion is required and this is sought from a WINZ appointed Medical Advisor. This often results in a negative experience for the beneficiary as little time is given by the GP to fully understand the client's situation. As already mentioned in the previous article, having an advocate support you through this process is helpful and may result in a more favourable outcome.

With supporting documentation from your GP you can apply for the Disability Allowance in order to purchase supplements, prescription expenses, transport, counselling, gym membership if needed to support your health, services from approved alternative therapies, lawn mowing, plus much more.

If you wish to learn more or seek the support of Craig you can contact him at the Pukete Community House on 8504013, 027 7106482 or pukete3@hnpl.net Craig can also support you with ACC and Housing NZ issues and he is also a JP

Tips, Snippets & Contacts

Coming Events

ME/CFS & FM Education Support Group

Methodist Church, Bader Street, Melville 10.30 - 11.30

13th August – Dr Ros Vallings will be speaking to us about latest global research findings and answering any questions. Please phone 8344745 or email tracey@mswaikato.org.nz to register your interest in attending. (10.15 to 12.00 on this occasion only)

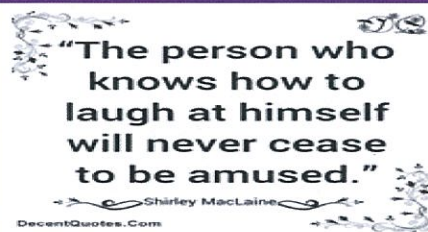
10th September – Lisa Crow from Sleep Well Clinic will be sharing ideas around sleep hygiene and strategies to help with restful sleep

8th October – ‘STRESS MANAGEMENT’ is the topic of this month’s focused group discussion. Stress can deplete energy so finding strategies to manage stress can help to save our valuable energy.



The Toilet Card

Finding a toilet when out and about can be a challenge for people with bladder or bowel problems. It could even discourage some people from going out altogether. Apply for a **toilet card**- it clearly states that the holder has a medical condition and needs to use a toilet quickly. Most places you visit will be willing to help you. See www.continence.org.nz for more details



OTHER CONTACTS

You may find it helpful to contact others who also have ME/CFS or FM, for support. 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.
CIANE: 8466535
LINDA: 8553934 lindaderrick@yahoo.com
BERNADETTE: 078686763 (Thames)
DEBORAH: 07 8955545 (Fibromyalgia)

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

If you have anything interesting you wish to share in the Koru please email it to me at tracey@mswaikato.org.nz

Tracey Larsen

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Ph 09 269 6374 www.anzmes.org.nz

Medical Advisor

Dr Ros Vallings Auckland

Phone: 09 534 3978 for clinic bookings or enquiries

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.