

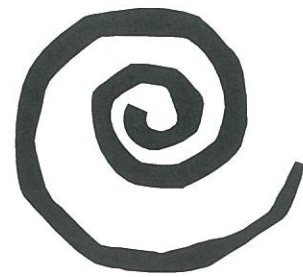
# KORU

## ME/CFS & FM Support

**ms.**

Multiple Sclerosis  
Waikato

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



May 2017 Issue 45

### Kia ora and Welcome

As I write this Cyclone Cook is bearing down on us and the ground is very soggy. I hope you all have been safe from flooding and suffered no damage or inconvenience from any of the weather systems that have passed over us this autumn. Gosh what will winter deliver? Hopefully NO MORE FLOODS!!!

It was a great honour to meet Dr Lapp last month when he visited Hamilton on his speaking tour of NZ. He shared some great information to the GP's who attended and I look forward to receiving a copy of the DVD recording. This will be available to loan so let me know if you are interested in borrowing it. Ph 07 8344745 or email me at [tracey@mswaikato.org.nz](mailto:tracey@mswaikato.org.nz)

I am aware that much information is now internet based and I often suggest to "click on the following link for more information". If you do not have a computer or find using one difficult and require articles to be printed, in the first instance please ask a family member to print it for you. Libraries also have printing available. As a last resort you may contact me and where possible I may be able to provide paper copies for you for a small fee.

Several people have commented about the request for a gold coin koha/donation when attending the monthly support group meetings. As funding has become more difficult to secure to cover costs for service provisions, a koha/donation will be greatly appreciated to help towards the cost of hall hire, a small gift for the speaker for their time and effort as well as the morning tea that is provided. If you are unable to afford a donation from time to time PLEASE do not think that you will not be welcome at the meetings. The monthly group meetings are open to all clients of MS Waikato and any donation is greatly appreciated when you can.

This month's Koru is crammed packed with great information so please enjoy! Until next time...

Aroha nui *Tracey Larsen*

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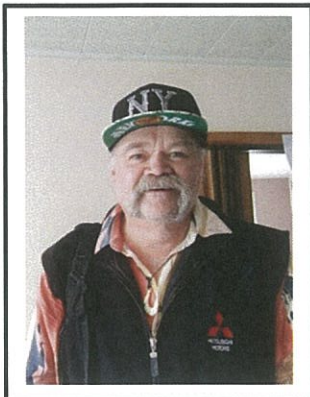


**ME/CFS  
&  
Fibromyalgia  
12 May  
International  
Awareness Day**

**To celebrate ME/CFS & FM  
International Awareness Day  
on Friday 12<sup>th</sup> May 2017  
I will again be holding an  
information stall at  
Chartwell. I am needing  
volunteers to help out  
throughout the day. Please  
contact Tracey on  
07 8344745 if you are  
interested in helping.**



## March Support Group Craig Wills - Independent WINZ Family Support Worker



Craig Wills from Pukete Community House visited the group in March to speak about WINZ benefits.

A general discussion was also had about the issues people have faced when dealing with WINZ. Not having the same Case Manager is a problem for many people as different

Case Managers can tell you different things which can often be contradictory. Craig highly advised to take copies of all paper work submitted to WINZ for your own records. Document who you are talking to and the date. This applies to both phone calls and in-person meetings.

It was also noted by many that it is a very impersonal service when you visit any WINZ office. The open planning of WINZ centres means that conversations are not private and confidential. Craig stated that some centres have interview rooms and advises that you have the right to request a more private space to discuss your details.

The general sense most people experience is that Case Managers will tell you as little as possible as to what you are entitled to. Therefore familiarise yourself with what benefits are available and claim for what you rightly believe you are entitled to. The WINZ website <https://www.workandincome.govt.nz> is fairly user friendly with links to 'who can get it' 'what you can get' and 'how to apply'. Also see the A-Z list of all benefits.

The Job Seeker benefit has three areas - Job Seekers - if you are unemployed and seeking employment; Medical Deferral - not expected to seek work until you are well but must provide 3 monthly medical certificates; 3. Solo parent benefit.

The Supported Living Payment (SLP) has two benefit types - for those who are terminally or chronically ill and cannot work more than 14 hours per week; for those who cannot work because due to caring for a disabled/chronically ill family member (excluding spouse - no benefit for this). Medical Certificates are

required only every two years so this reduces a lot of stress for those with ME/CFS & FM,

The Disability Allowance is available for health/disability related costs. The maximum payable is \$62.37 p/week and GP approval of items/services must be obtained first. As payments are made retrospectively you must provide a year's worth of receipts to determine your annual costs, so it is important to keep these. Reassessment is required when changes in GP or other circumstances occur during a 12 month period and your costs change.

An accommodation supplement can be claimed as well as urgent and unexpected costs regarding housing maintenance for items such as roofing, hot water cylinders, fences and retaining walls, sewerage such as toilets showers, sinks and drains.

Annual reviews are applicable for allowances or supplements such as the disability allowance and accommodation costs. Many group members spoke about how the annual reviews for the different supplements and allowances do not happen at the same time of year and they often feel like they are attending to an annual review or a request for 'Reviewing your Circumstances' every few months. Such reviews are highly stressful and impact negatively on the health of someone with ME/CFS & FM. To have someone support you through these processes is always helpful as they can be another set of eyes and ears to help you remember details from the meeting. Often people have reported that they have received a more respectful encounter from Case Managers when another person is in attendance.

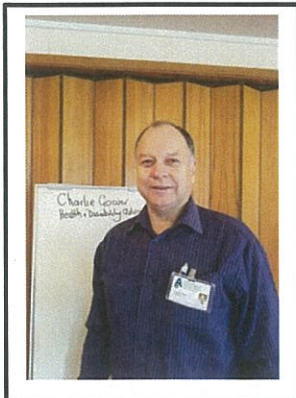
Phone Craig on 07 8504013 or email [pukete3@hnpl.net](mailto:pukete3@hnpl.net) if you want some advice or require support and/or advocacy when dealing with WINZ

**Disability Allowance can cover:** Doctors' fees and prescriptions • alternative treatments such as physiotherapist, osteopath, chiropractor, acupuncture, massage, herbalist, supplements, nicotine replacement • rental of medical equipment • surcharges that apply for ACC treatments • counselling • transport to medical treatment and consultations • gardening, lawn mowing and outside window cleaning • specialised equipment • hearing aid batteries • glasses • See website for full list

I am also available, in a limited capacity, to support clients at WINZ appointments. If you are applying for the Supported Living Payment it is important to provide supporting material outlining the impacts of ME/CFS & FM on your ability to work. I can help with this so please do not hesitate to ring me on 8344745 or email [tracey@mswaikato.org.nz](mailto:tracey@mswaikato.org.nz)



## April Support Group – Health & Disability Advocate Charlie Gower



The Health and Disability Commissioner Act was enacted in October 1994 and was passed to implement the recommendations of Judge Cartwright in her 1988 Cervical Cancer Inquiry Report. Judge Cartwright stated that there was a strong need

for the establishment of a Commissioner as an independent complaints resolution and educational body, and to promote and protect the rights of health and disability services consumers.

Charlie stated that back in the 70's and 80's people accepted whatever the medical professional said and prescribed but the inquiry found that Dr's cannot be relied upon to police their own ethical practice. A code of patients' rights was therefore established that is unique to New Zealand.

These rights apply to ANY health or disability service you receive, whether it be at your local GP, public hospital or privately sought consultation and treatment, Physio, Dentist, and also residential services.

The Commission employ approximately 40 advocates nationwide to support those who feel that their rights have been breached. Many ME/CFS & FM patients feel that they are not heard or that their situation is appropriately acknowledged and are often accused of being drug seekers, neurotic, or that their health condition is "all in their head".

Privacy and confidentiality are issues many experience when in hospital. Charlie explained that ongoing training for medical staff is still required and a typical example of this is when student Doctors are observing the Registrar at

bedside consultations without the explicit consent of the patient; details of their condition is discussed with only a thin curtain separating them from other patients. This is a breach of your rights. You have the power to ask that your privacy is respected and to point out that you have not given your consent for junior/trainee doctors to be present.

Doctors are also required to give information about a condition and offer choices of treatment/care if choices are available. Many patients who experience ME/CFS & FM often feel frustrated that their condition is not understood by their GP/Specialist and they do not receive appropriate information. You also have the right to take a support person with you to any consultations which enables another set of ears to hear and remember what is being said – this is important for those who experience brain fog.

The role of an advocate is to inform you of your rights, educate you on the process and help you negotiate the complaint process. Although you have the right to complain verbally, many policies and practices require the complaint to be

submitted in writing, however this can become a difficult task when there are multiple complaints over multiple occasions. An advocate can therefore assist with documenting the facts succinctly and efficiently.

For free advocacy support and advice please phone 0800 555 050 or email [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

### **CODE OF RIGHTS**

- 1. Respect & privacy**
- 2. Fair treatment**
- 3. Dignity and Independence**
- 4. Appropriate standards of care**
- 5. Effective communication**
- 6. Information**
- 7. Choice and to provide Consent for treatment**
- 8. Support**
- 9. Rights during teaching & Research**
- 10. Your complaint to be taken seriously**

### **CIRCLE THE CALANDER**

Dr Vallings will be visiting to share latest research findings from the 2017 'Invest in ME' London Conference

**Thursday 10<sup>th</sup> August 10.30 – 11.30**

Melville Methodist Church, Bader St, Hamilton

***Please register your interest in attending.***

Phone Tracey on 07 8344745  
or email [tracey@mswaikato.org.nz](mailto:tracey@mswaikato.org.nz)



A client shared this with me and I emailed it out last year to those on my email list. I really like how this is written and think it is a great resource for you to share with family and friends, so felt compelled to share again to benefit those who haven't received it.

Sourced from <https://themighty.com/2016/09/things-people-with-chronic-diseases-want-healthy-people-to-understand/>

## 5 Things the Healthy World Should Know About the Chronically Ill World

Sometimes, the gap between us can feel insurmountable. Maybe we've become so immersed in our world of sickness and symptoms we can't remember what it's like to be healthy. We stare at you with curiosity and wonder like you're an unknown species. Maybe you feel the same. You want to understand the chronically ill in your world, but they feel so far away. I'd like to help with that today by sharing five things the chronically ill want "healthy people" to know.

**1. We need your help.** Despite our desperate desire not to burden you and to maintain our previous level of independence, the truth is we need your help. We can't do the things we could before our illness took over and sometimes we're afraid to ask for help because we've been hurt or disappointed in the past. It can be isolating and scary to need help and yet, not know where to find it. If you're willing to help, speak up. Let us be honest about what we need. Don't assume you automatically know what help we need. And if you can find a way to lend a hand without making it feel like a big deal? Well then, extra brownie points for you.

**2. We feel like we have to pretend.** We know hearing about our illness gets old fast. Heck, it's our illness and we're tired of hearing about it. But sometimes it's overtaking us and we may feel like it's crowding out our relationship. So we might pretend. We pretend to feel better than we do. We pretend to feel more optimistic, less afraid than we do. All this pretending is done for your benefit, but can leave us feeling more alone in the long run. So when we do break down and tell you how afraid we are? When we're honest about just how bad this flare has been? Your response tells us how honest we can be in the future. The weight of our illness (es) can be a lot for one person to carry. We'd love for you to be a safe place where pretending isn't required.

**3. We didn't do this.** We didn't choose to be sick and we'd undo it in a heartbeat if we could. Many of us had a genetic predisposition to our illness, which was entirely outside of our control. While we may not be managing our illness in the ways you would, chances are we're doing our best. Fighting for health is demanding, exhausting, hard and worthwhile work and what your mom taught you about saying something nice or nothing at all applies here. If you can't cheer us on, please don't kick us while we're down.

**4. We want to thrive.** We don't enjoy lying in our beds all day or being unable to work. It may look somewhat appealing from the outside, but it's not. Resting is fantastic when it's an option, not when it's a necessity. We hate missing out on significant events in your lives. We want to be productive members of society. We're doing everything in our power to set up a profitable lemonade stand in our front yard with this pile we've been given.

**5. We envy and appreciate you.** Yes, it sometimes stings to see you out living a life I can't. This doesn't mean I'm not happy for you. In fact, it means I want this fulfilment for you all the more. I love to see people enjoying life to the fullest. But just like the woman who struggles with infertility may ache upon hearing her best friend's pregnancy announcement and still be thrilled, we may feel joy and sorrow as we watch others living out our dreams. Mostly, we're really glad we get to do life alongside you.

## VITAMIN D3

With winter approaching remember that it is ideal to take Vitamin D3 to help with regulating the absorption of calcium and phosphorous and supporting immune system function. It also plays an important role in regulating mood and warding off depression (the winter blues).

If you are interested in purchasing  
Vitamin D3 at a reasonable  
cost please contact  
Carole Stark on 07 827 7695  
or email  
[peterandcarole@xtra.co.nz](mailto:peterandcarole@xtra.co.nz)



## Fibromyalgia Healing Foods List

The following diagram of healing foods was written by Sue Ingebretson (March 2016). Sue has written several excellent books, one of which he have in our library, 'FibroWHYalgia'. She believes that **food IS medicine** and as it is becoming more and more evident that diet influences our health I thought I would share this chart. Sue's full article can be viewed at by clicking on the following link: <http://www.prohealth.com/library/showarticle.cfm?libid=27178>

### DIGESTIVE HEALING

(including inflammation, nausea, cramping, bloating, etc.):

Asparagus	Broccoli	Celery
Cabbage	Zucchini	Brussels sprouts
Spinach	Cauliflower	Cucumbers
Apples	Pears	Raspberries
Blackberries	Leafy greens	Water
Tea, green and black	Ginger	Fermented veggies (low or no sugar added)
Chia seeds	Salmon	Mackerel
Sardines	Avocado	Coconut oil
Olive oil		

### SUSTAINED ENERGY

Proteins such as –	Ancient "grains" such as –	Fibre-rich veggies and fruits (see list above)
Protein shake mixes (pea, hemp)	Quinoa	Water
Animal proteins (meats including fish)	Amaranth	
Eggs	Millet	
Chia seeds		
Flax seeds		
Almonds		
Cashews		

### BLOOD SUGAR STABILIZATION

Water	Cinnamon	Ancient "grains" such as –
Turmeric	Fibre (see list above)	Quinoa
Leafy greens	Spinach	Amaranth
Onion	Citrus (whole fruit)	Millet
Blueberries	Cherries	
Avocado	Vinegars (such as apple cider vinegar)	
Proteins (see list above)	Tea, green	

### BLOOD FLOW / CIRCULATION

Leafy greens	Cilantro	Parsley
Mint	Rosemary	Dill
Ginger	Garlic	Cinnamon
Turmeric	Cloves	





















## BRAIN / COGNITIVE HEALTH, MEMORY, and FOCUS

Avocado	Leafy greens	Salmon
Mackerel	Sardines	Walnuts
Almonds	Brazil nuts	Flax seeds
Chia seeds	Sunflower seeds	Pumpkin seeds
Hemp seeds	Coconut oil	Berries
Dark chocolate		

Sue also wrote an article '10 "Health" foods that are NOT Fibro-Friendly' in 2014. She writes about whole wheat and whole grains, dairy, nuts, fat free foods, soy & tofu to name a few. To view this article see <http://www.prohealth.com/library/showarticle.cfm?libid=19034>

## How will I use my spoons today?

*As a chronically ill person I only have \_\_\_\_\_ spoons at my disposal each day. Therefore, I must pick and choose wisely.*

 Get out of bed 1 x	 Shower 2 x	 Attend social event 5 x	 Go out for coffee 4 x
 Drive 4 x	 Make a phone call 3 x	 Garden 5 x	 Work 5 x
 Play games 3 x	 Clean the house 5 x	 Have a meal 2 x	 Walk the dog 4 x
 Study 5 x	 Watch TV 3 x	 Ironing 5 x	 Exercise 4 x
 Shopping 4 x	 Read 2 x	 Catch public transport 4 x	 Cook 4 x

*\*Note - if you exceed your daily limit, be aware that you will be taking spoons from tomorrow's allocation. So be sure to plan ahead accordingly.*

made by notalinedness.wordpress.com spoontheory by butyoudontspoon.com

Piktochart



A gold coin koha is greatly appreciated thank you

### Up & Coming Events

ME/CFS & FM Education Support Group

Melville Methodist Church, Bader Street, Melville 10.30 - 11.30

June 8th 2017 - To Be Confirmed

July 13th 2017 - Alana Scott shares her story of struggle with ME/CFS, IBS, food intolerances & finding appropriate food & recipes. She then created her website 'A little bit Yummy' so she could share recipes & what she continues to learn

August 10th 2017 - Dr Vallings sharing latest research from 2017 Invest in ME London Conference



**I've made it  
from the bed to  
the couch.  
There's no  
stopping me now.**

### HEALTH PASSPORTS

contains information about your health condition/s and how you want people to communicate and support you when seeking medical treatment. For more information view [www.hdc.org.nz/about-us/disability/health-passport](http://www.hdc.org.nz/about-us/disability/health-passport)

**KiwiSaver**  
*Poua he Oranga*

DID YOU KNOW that you can apply for a partial withdrawal from your Kiwisaver to help cover costs for a serious illness? Contact your Kiwisaver provider or check out their website to download the form under withdrawals/serious illness

**ONE DAY YOUTUBE,  
TWITTER AND  
FACEBOOK WILL JOIN  
TOGETHER AND  
BE CALLED...**



**You twitface**



MS Waikato have wheelchairs available to loan short term at no cost. Ph: 8344740 to enquire

Check out ANZMES on Facebook. They post great articles regarding latest research and symptom management approaches



### OTHER CONTACTS:

You may find it helpful to speak to 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 (Sharn): 0211471933**

**LINDA: 8553934** or email [lindaderrick@yahoo.com](mailto:lindaderrick@yahoo.com)

**BERNADETTE: 07 8686763 (Thames)**

**MS Waikato would like to thank those who sponsors us.**

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**Sir John Logan Campbell**  
Residuary Estate

**Tracey Larsen**

**Client Service Coordinator**

**ME/CFS & FM**

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Ph 09 269 6374

[www.anzmes.org.nz](http://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.