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Remember to check the Group Monthly Meetings Calendar!



Hi everyone!

Welcome to your first newsletter from **Complex Chronic Illness Support!** 

This is a new exciting chapter for our organisation! The official celebration of our re-branding will take place on **Friday May 12**<sup>th</sup> – see page 2 for more details. Keep an eye out for your invitation.

If you have expressed interest in the proposed ME/CFS exercise research to be undertaken locally mid-year, we are excited to announce that the lead researcher, Dr Lynette Hodges will be the guest speaker at our April support meeting at our Christopher Street premises (see page 3 for more).

We are pleased to report that, after a slow start, our young members' monthly gatherings (hosted by Kira) are proving popular, so will be continuing. And speaking of popularity, our waiting list of applicants for our Towards Wellness programme continues to grow!

As you can no doubt appreciate, it costs money to deliver our services, and funding can be difficult to access. Your \$20 subscription for the year ending 31st March 2018 is now due and early payment is appreciated (bank account details on back page of newsletter).

As always, we value your feedback regarding our services. If there is something you think we could be doing better, please let us know; and if you think we've got it right, likewise let us know!

We may have changed our name, but we look forward to continuing to support you as you move towards wellness.



Tina and the team at Complex Chronic Illness Support (formerly ME/CFS Support)

Want to call or write to us?....
We are at:

56 Christopher St

56 Christopher St Tauranga 3112



Ph: Field Officer: (07) 2811 480 Email: tina@mebop.org.nz Office: (07) 2811 481

**Email:** info@mebop.org.nz **Website:** www.mebop.org.nz www.facebook.com/groups/

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# Local Items of Interest



### It's Official!!

## We are now Complex Chronic Illness Support!!

As you can imagine, this has involved much planning and preparation, and ongoing work such as designing a new logo, updating stationery etc to get our new face 'out there'.

Many of you will have received a 'Save the Date' notification (invitation to follow) for our celebratory afternoon tea to mark our re-branding. This will take place on **Friday May 12**th, which is officially international ME/CFS Awareness Day, as well as Florence Nightingale's birthday, as she is believed to have suffered from ME/CFS for many years.

Our choice of date for the celebration reflects our ongoing commitment to supporting those with ME/CFS.



12.5.17

ME/CFS Support (BoP) warmly invites you to join us to celebrate our re-brand to

Complex Chronic Illness Support

Come along and hear about how our services can help...

Daniels in the Park Eleventh Ave, Tauranga 1.30-3.30pm

RSVP: (for catering purposes) by 30th April TO: info@ccisupport.org.nz or 07 281 1481





# Subscriptions now due

Member subscriptions for the financial year ending 31st March 2018 are now due.



As advised (in the February newsletter) our subscription has increased. We feel sure you'll agree that our **\$20** sub represents excellent value for money.

Early payment of the sub is appreciated – our bank account details are on the back page of this newsletter.

### Exciting news!!..

## Dr Lynette Hodges to speak at our April support meeting

You may have read in our February newsletter about the exciting opportunity local members have to take part in proposed valuable research into the effects of exercise on people with ME/CFS. An added benefit is that you will receive data on what *your* body does when it is subjected to exercise – valuable information to inform health professionals and agencies such as Work & Income etc.

You may have already expressed your interest, and even filled in the online questionnaire. You now have the opportunity to find out more about the research from the lead researcher, **Dr Lynette Hodges**, from Massey University.

She will be the guest speaker at our April meeting (Wednesday April 12th at 10.30am at our Christopher Street premises).

See you there!





## **Support Groups**

### What is their purpose?

The definition of a support group is simply: A group of people, led by a facilitator or therapist, who provide each other moral



support, information, and possible tips on handling problems related to some shared characteristic or experience.

CCI Support holds monthly support groups and coffee mornings for members in both Tauranga and Whakatane, facilitated by their respective field officers Tina and Gisela. (See page 13 for the dates of meetings/coffee mornings in your area, as well as field officer contact details if you want to find out more).

CCI Support's coffee mornings and support groups have two purposes:

- To bring together people who are suffering from ME/ CFS, fibromyalgia, and other related conditions people who could otherwise live their lives in isolation
- To educate those with these conditions on ways of improving their health and quality of life

Support groups and coffee mornings are open to members and free to attend. If you are a member and have never felt brave enough to come along, give it a go! Feel free to bring along a friend/family member/partner if you wish.



## Nicola Evans' Art Legacy

We are saddened to report that a long-time member of ME/CFS Support, Nicola Evans, died late last year, a day after her 53rd birthday.



Her dying wish was that her art be a way of generating funds for ME/CFS Support (currently rebranding as Complex Chronic Illness Support).

Nicola was an extremely talented fine artist, book designer, and illustrator. She is remembered not only for her wonderful art but also for her warm and generous personality. Her beautiful smile and face could light up a room, just like her glorious paintings.

Nicola was born in Tauranga, New Zealand on the 30th of November 1964 to Jocelyn and Ken Evans. She grew up in Tauranga alongside her much-loved brothers, Grant and Dean.

She began her career as a graphic artist and worked as a book designer and illustrator for the highly successful children's book publishing house, Shortland Publications. She then moved overseas, working

as a book jacket designer in New York and exhibiting her paintings there. Her unique design flair and creativity can be seen in her portfolio of work on this website:

www.nicolaevans.biz

Nicola battled bravely with ME throughout the later years of her life and was cruelly taken by cancer at only 53 years of age. Prints of her paintings are available for sale from the website with all proceeds going to the ME/CFS Society.

Currently the style of art that is available for purchase is mainly the 'lady' portraits as seen on the website. Nicola painted in a much greater variety of styles and our field officer Tina Richards is currently working with the family to see if some of her other works can be reproduced and made available for sale.

This is Nicola's legacy to us all. Welcome to this website in loving memory of Nicola Evans.

ME/CFS Support expresses their grateful thanks to the family for money donated so far.





### A guy is late for an important meeting . . . . .

But he can't find a place to park. In desperation, he begins to pray. "Please Lord, if you help me find a parking stall right now, I promise to go to church every Sunday and never drink vodka again!"

A moment later, he sees a beautiful empty spot right next to the entrance.

"Never mind. Found one!"

## **The Lightning Process**

by Tina Richards

From time to time I am asked about The Lightning Process. What is it? How does it work?

Does it actually work?

What works for one person with ME/CFS or Fibromyalgia may not work for another. The journey towards wellness is a highly individual one. We therefore encourage members to do their own research before embarking on a course of treatment.

The following is not an endorsement of the Lightning Process. It is an overview of my experience as an 'observer' over the years, as several members have completed the Lightning Process. Also in the article are more specific comments from three local LP graduates.

### What is The Lightning Process?

It is a 3-day (about 15 hours in total) interactive training programme based on the science of mind/body interaction. It combines elements of Neurolinguistic Programming (NLP), life coaching, physiology and osteopathy.

Participants are taught about the Physical Emergency Response (we call it the Maladaptive Stress Response in our Towards Wellness programme), and its damaging effects on our body systems and overall health and wellbeing. Using the principles of neuroplasticity, participants are taught techniques to create new neurological pathways to replace the old 'default' ones that have been helping to keep us 'stuck'.

The first time I became aware of the Lightning Process was in December 2008 when a member informed me she had enrolled in Australian practitioner Ian Cleary's LP course in Auckland. She reported back that, although she hadn't expected that her serious back pain issues (from a fall from a horse years earlier) would be resolved, she had learned some very useful techniques to help her get through a busy family Christmas and holiday schedule. She admitted to me that she had been secretly dreading the upcoming holidays, but the techniques helped her cope far better than she had expected.

Over the years I kept a record of the people who had done the course, and their outcomes. While some critics of LP claim that people have been made worse by LP (and I acknowledge that that could be a possibility), I have not seen that personally. Of 17 people that completed the course, the majority achieved a marked improvement in their

health.

Another criticism levelled at LP is that people experience some sort of placebo effect while on the course, then crash afterwards. Again, while I acknowledge that that could happen, I have not seen it. If the person achieved a good outcome from LP, they have managed to sustain that improvement.

### **KB's experience of the Lightning Process**

The Theory: Basically we were told that the beliefs of our subconscious mind was what was keeping us tired and sick, and that through using the LP technique we could change our subconscious beliefs and also rewire our neurological/nervous systems as many illnesses are a neurological loop that hasn't let go. We were told that, aside from 'true blue' conditions like a broken arm, or cancer or other illness that has a scientific reason to be there, everything else can be 'fixed'.

The Technique: The technique uses several methods including self-hypnosis, NLP, mental imagery and body language – all valuable, proven techniques. Let's say you want to use the technique to combat the effects of constant fatigue. Once you've mastered the steps of the technique and the course is over, you go home and practice the steps every time you feel tired, and you challenge this 'false' feeling of tiredness over and over until eventually you are full of energy and you no longer suffer from CFS, or whatever your condition was.

Results: Does it get results? Out of our class of 8 we did see results, although I felt we were required to be overly positive and convince ourselves we were getting results. (I do acknowledge that this is the only way you can really work the technique – a 'fake it till you make it' approach). And remember, we forked out a lot of money and really, really, really wanted to be well.

**True Results:** Let's look at the benefits down the track. My girlfriend's cousin had severe CRPS in her foot. She experienced a near 100% recovery. My girlfriend used the LP tools to help manage fibromyalgia pain so she could work. Sometimes it works wonders; sometimes not at all. She feels it's been worthwhile, although nothing like a cure.

Myself, having suffered from many allergies and reactions, tiredness and fibromyalgia, I went home and practiced the technique for several hours a day for 7 months straight. Am I dedicated or what! It did nothing for my allergies or my fibro but it is a useful tool for staying awake and energetic when I don't want to have a sleep and/or need to complete a task. So while LP has done nothing to improve my CFS, it has meant I can stick to a social

engagement, then come home later and have a rest or sleep, without post-exertional malaise.

KB's recommendation: While some experience amazing results, there may be cheaper alternatives to try initially, e.g. hypnosis.

### JM's experience of LP:

I did the LP course in late 2015 with a practitioner who came down from Auckland to train me and one other person. Each day consisted of intense training, with great emphasis on getting every detail of the programme right for it to work.

It involves learning a sequence of movements engaging both body and mind, as a form of 'reprogramming' the mind, as in NLP, and virtually the same process as Ashok Gupta (Amygdala Retraining programme), which in fact comes from the same source. I have to say the first two days were like torture! From the first hour I was exhausted by the intensity of it. This is probably normal. The practitioner wouldn't let me give up and I pushed my way through it with her constant encouragement.

While I know I am not totally cured, I have certainly lifted myself to a better level of health. I can stay out late in the evening now without losing the next day or so on the couch. Although my life remains somewhat restricted, I'm happier, and I know I can do even better. That feeling is priceless!

### JB's thoughts on LP:

The Lightning Process course teaches us how to change our subconscious brain/neural pathways so we can reset our hypersensitive stress response mechanism. In ME this damaging stress response can be triggered and maintained by the slightest physical stimulus and our thoughts. This ongoing adrenalin/stress response cycle creates havoc in our physical body, perpetuating many of the symptoms of ME.

To make the most of the LP course, a person has to be convinced of the ability of their mind to influence and heal their body, and then be able to really feel their way into 1) disrupting the mind/body patterns that are causing trouble, and 2) walk into a new way of being/thinking that calms their whole system, mind and body, towards healing.

On a personal note, I found the LP techniques cumbersome but found my own way of telling my mind/body/soul that I am OK, that I can tolerate physical symptoms and not be overwhelmed by them. Over time I have seen my symptoms improve and now feel a sense of control over them

whenever they return – and they do at times.

I don't like to strongly recommend or push the LP course on anyone because of the cost and the uncertainty around whether an individual can/will accept and really grasp it. I believe that there are lots of pieces of the ME/CFS puzzle available in other programmes, articles, websites etc (e.g. Ashok Gupta, mindfulness, diaphragmatic breathing. However I still think that having a coach take you through the steps of being able to use that mind/body connection to calm and heal your ANS is valuable.

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In ANZMES Meeting Place Issue 117 (Spring 2014) – copy available for loan in our library – there is an article on a related topic, A Mindful Approach to ME/CFS & Neurological Retraining

The following are excerpts from the article:

Neurological Retraining techniques focus on forming new 'neural networks' that take over the functioning of the damaged / dysfunctional neural networks.

**Consistency:** The aim is to rewire parts of the brain. This requires overcoming the pull of the present system and slowly shifting over to a new one. Consistent effort provides the foundation that allows one to keep building on past progress.

**Persistence:** The neural remodelling process takes time. Paradoxically rushing things – trying to get well – only impedes the process. **Dr Bruce Campbel**l notes that his journey to health took place very slowly, 1 – 2% per month he estimated, but by following his own 'mindfulness' programme he was able to recover fully over several years.

The Time Element: These practices take work and 'attention' and a significant time element, particularly at first. **Dr Fred Friedberg**, a clinical psychologist with ME/CFS, suggests that ME/CFS patients start with 10-20 minutes of relaxation exercises twice a day for the first two weeks and increase it to 30 minutes twice a day the third week. He states that one hour a day is the bare minimum necessary to put your illness on the improvement track.

In the Amygdala retraining Programme, **Ashok Gupta** also recommends 2 hour of exercises a day. (Note that you don't need to do 2 hours of mindfulness activities a day to get results, but if you can, you'll probably get better results). As the exercises move you into a more relaxed, healthful state you can get by with doing less of them.

#### A final note from the author of this article:

My experience (e.g. my lack of discipline in this area) has been that devoting a good chunk of time to these practices significantly enhances them but that practicing them in small chunks throughout the day (often for only seconds at a time) can be helpful over time. Many of these practices are, in fact,

done in 'real life' – in the midst of our daily lives – instead of in special times set aside for them.

Source: http://phoenixrising.me/treating-cfs-chronic-fatigue-syndrome-me/living-in-mindfulness/a-mindful-approach-to-chronic-fatigue-syndrome-mecfs

### On Fibromyalgia

From Maureen Clark

My concentration is all to pot

Mind over matter has been shot

The legs won't walk the walk

Nor the tongue talk the talk

Logic and words have disappeared

The feeling is most weird!

Memory is evasive

To conversation I don't have much to give

Two hours energy level makes a social life hard to live

But as I'm going to live to a hundred and one

Mind over matter has begun

And so have the days of sun and fun!





I was trying to explain puns to my kleptomaniac friend today, but she kept taking things literally......

A woman told me she recognised me from the vegetarian club, but I'd never met herbivore.......

### **A Call for Newsletter Contributions**



Here at MEBoP we'd like to hear more from you, our many members out there.

The coffee mornings have proved to be an excellent way for us all to keep in touch, to hear stories and exchange information. But the majority of members we don't get to see. Please feel free to send me anything you want to share and feel would be helpful for our readers. It can be a story of your own struggle along the ME/CFS trail, or someone else's, or a poem, or a question even, that we will endeavour to answer in print. We only ask you try and keep the content to about 1/2 page length.

Please send in your contribution to Jan at janm@orcon.net.nz Looking forward to hearing from you!

# The Benefits of Magnesium / Magnesium Oil Therapy

After oxygen, water and basic food, magnesium may be the most important element for our bodies – vitally important yet hardly known. It is more important than calcium, potassium or sodium and regulates all three of them. Millions suffer from magnesium deficiency without even knowing it.

Some of the vital roles magnesium plays in the body:	Some of	the	vital	roles	magnesiu	m plays	in	the	body:
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Necessary co-factor for more than 300 enzyme reactions in the body	
Needed for muscle relaxation; a key treatment for muscle cramps	Q Monesti V
Required for stable blood sugar and insulin sensitivity; consumption of refined sugars depletes magnesium	
Vital for cardiovascular health	
Key for balancing both men's and women's hormones because it suppobody	orts balanced minerals in the
Needed in increased quantities during periods of increased emotional burns through magnesium stores	or physical stress, as stress
Essential for mood regulation, in particular reducing anxiety and promot	ing a sense of wellbeing

# Here are a few ways magnesium oil therapy works to improve symptoms by reducing the magnesium deficiency in your body:

	Supports overall health; a suitable supplement for most individuals
	Reduces (and should eventually stop) muscle cramping, including menstrual cramps
	Improves sleep, as magnesium is a 'calming' and 'soothing' mineral
	Helpful in reducing symptoms of PMS including bloating, mood swings and breast tenderness
	Helpful for headaches, even migraines. Many have reported improvement in migraines through using magnesium oil regularly
П	A key part of any hormone-balancing protocol, as magnesium helps balance the other minerals and

# How to make magnesium oil:

hormones in the body

½ cup filtered water ½ cup magnesium chloride flakes **Spray bottle** 

Bring the water to a boil in a non-aluminium saucepan. Turn off the heat and stir in the magnesium flakes until dissolved. When cool, pour into the spray bottle. No refrigeration is necessary.



Spray it on the body and rub in lightly. You can wash it off after 30 minutes if you prefer as it may still feel a little greasy or moist on the skin. Use 10 – 30 sprays per day.

Expect a tingling sensation when you first start to use magnesium oil. If this is your first time using it, apply it to a small test patch first to gauge the intensity of the tingling.

Source: <a href="http://empoweredsustenance.com/magnesium-oil-uses/">http://empoweredsustenance.com/magnesium-oil-uses/</a> (from ME/CFS Charitable Trust, Rotorua, newsletter, December 2016)

### A Letter to Patients With Chronic Disease

by Rob Lamberts

Source: http://more-distractible.org/musings/2010/07/14/a-letter-to-patients-with-chronic-disease

From M.E. and You Newsletter, ME/CFS Group (Canterbury) Inc, February 2017

We are aware that, for various reasons, many people with ME/CFS are left feeling dissatisfied with their dealings with medical practitioners. This article makes for interesting reading as it is a plea for understanding from the other side of the consultation desk – the doctor.

**Dear Patients:** You have it very hard, much harder than most people understand. Having sat for 16 years listening to the stories, seeing the tiredness in your eyes, hearing you try to describe the indescribable, I have come to understand that I too can't understand what your lives are like.

How do you answer the question "How do you feel?" when you've forgotten what "normal" feels like? How do you deal with all of the people who think you are exaggerating your pain, your emotions, your fatigue? How do you decide when to believe them or when to trust your own body? How do you cope with living a life that won't let you forget about your frailty, your limits?

I can't imagine.

But I do bring something to the table that you may not know. I do have information that you can't really understand because of your unique perspective, your battered world. There is something that you need to understand that, while it won't undo your pain, make your fatigue go away, or lift your emotions, it will help you. It's information without which you bring yourself more pain than you need suffer; it's a truth that is the key to getting the help you need much easier than you have in the past. It may not seem important, but trust me, it is.

You scare doctors.

No, I am not talking about the fear of disease, pain, or death. I am not talking about doctors being afraid of the limits of their knowledge. I am talking about your understanding of a fact that everyone else seems to miss, a fact that many doctors hide from: we are normal, fallible people who happen to doctor for a job. We are not special. In fact, many of us are very insecure, wanting to feel the affirmation of people who get better, hearing the praise of those we help. We want to cure disease, to save lives, to

be the helping hand.

But chronic unsolvable disease stands square in our way. You don't get better, and it makes many of us frustrated, and it makes some of us mad at you. We don't want to face things we can't fix because it shows our limits. We want the miraculous, and you deny us that chance.

And since this is the perspective you have when you see doctors, your view of them is quite different. You see us getting frustrated. You see us when we feel like giving up. When we take care of you, we have to leave behind the illusion of control, of power over disease. We get angry, feel insecure, and want to move on to a patient who we can fix, save, or impress. You are the rock that proves how easily the ship can be sunk. So your view of doctors is quite different.

Then there is the fact that you also possess something that is usually our domain: knowledge. You know more about your disease than many/most of us do. Your MS, rheumatoid arthritis, chronic pain disorder etc – your defining pain – is something most of us don't regularly encounter. It's something most of us try to avoid. Even doctors who specialise in your disorder don't share the kind of knowledge you can only get through living with a disease. It's like a parent's knowledge of their child versus that of a paediatrician. They may have breadth of knowledge, but you have depth of knowledge that no doctor can possess.



So when you approach a doctor — especially one you've never met before — you come with a knowledge of your disease that they don't have, and a knowledge of the doctor's limitations that few other patients have. You see why you scare doctors? It's not your fault that you do, but ignoring this fact will only limit the help you can only get from them. I know this because, just like you know your disease better than any doctor, I know what being a doctor feels like more than any patient could ever understand. So let me be so bold as to give you advice on dealing with doctors. There are some things you can do to make things easier, and others that can sabotage any hope of a good relationship.

**Don't come on too strong** - Yes, you have to advocate for yourself, but remember that doctors are used to being in control.

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All of the other patients come into the room with immediate respect, but your understanding has torn down the doctor-god illusion. That's a good thing in the long run, but few doctors want to be greeted with that reality from the start. Your goal with any doctor is to build a partnership of trust that goes both ways, and coming on too strong at the start can hurt your chances of ever having that.

**Show respect** - I say this carefully because there are certainly some doctors who don't treat patients with respect, especially ones like you with chronic disease. These doctors should be avoided. But most of us are not like that; we really want to help people and try to treat them well. But we have worked very hard to earn our position; it was not bestowed by family tree.

Keep your eggs in only a few baskets - Find a good primary care doctor and a couple of specialists you trust. Don't expect a new doctor to figure things out quickly. It takes me years of repeated visits to really understand many of my chronic disease patients. The best care happens when a doctor understands the patient and the patient understands the doctor.

Use the ER only when absolutely needed -Emergency room doctors will always struggle with you – just expect that. Their job is to decide if you need to be hospitalized, if you need emergency treatment, or if you can go home. They might not fix your pain, and certainly won't try to fully understand you. That's not their job. They went into their specialty to fix problems quickly and move on, not manage chronic disease. They will try to be done with you as quickly as possible.

Don't avoid doctors - one of the most frustrating things for me is when a complicated patient comes in after a long absence with a huge list of problems they want me to address. I can't work that way, and I don't think many doctors can. Each visit should address only a few problems at a time, otherwise things get confused and mistakes are made. It's OK to keep a list of your problems so things don't get left out – I actually like getting those lists, as long as people don't expect me to handle all of the problems. It helps me to prioritize with them.

Don't put up with the jerks - Unless you have no choice (e.g. in the ER room), you should keep looking until you find the right doctor/s for you. Some docs are not cut out for chronic disease, while some of us like the long-term relationship. Don't feel you have to put up with docs who don't listen or who minimize your problems. At the minimum, you should be able to find a doctor who doesn't totally suck.

Forgive us - Sometimes I forget about important things in my patients' lives. Sometimes I don't know you've had surgery or that your sister comes to see me as well. Be patient with me - I usually know when I've messed up, and if you know me well I don't mind being reminded - well, maybe I mind it a little.

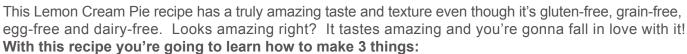
You know better than anyone that we docs are just people - with all the stupidity, inconsistency and fallibility that goes with that – who happen to doctor for a living. I hope this helps, and I really hope you get the help you need. It does suck that you have your problem; I just hope this perhaps decreases that suckishness a little bit.

Sincerely, Dr Rob

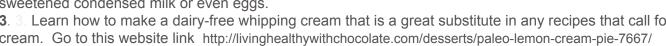


# Paleo Lemon Cream Pie (gluten/grain/egg/dairy-free)

Source: Adriana Harlan - LivingHealthyWithChocolate.com



- Learn how to make a flaky pie crust using almond flour and coconut oil as opposed to using the traditional all purpose flour and butter. This crust is versatile and you can make a ton of different pies with it.
- 2. Learn how to make a smooth lemon cream using nutritious ingredients, and without any refined sugars, sweetened condensed milk or even eggs.
- 3. 3. Learn how to make a dairy-free whipping cream that is a great substitute in any recipes that call for cream. Go to this website link http://livinghealthywithchocolate.com/desserts/paleo-lemon-cream-pie-7667/



### Ingredients

#### Crust

2 cups (228) blanched almond flour

2 teaspoons (4g) coconut flour

4 tablespoons (46g) coconut oil, melted

4 (100g) tablespoons raw honey

1/8 teaspoon salt

### **Dairy-free Whipping Cream**

1 can (403ml)full fat coconut milk chilled

1/2 teaspoon unflavoured powdered gelatin

1 tablespoon honey

### Lemon cream filling

1/2 cup fresh lemon juice ( about 5 lemons)

3 tablespoon lemon zest ( about 3 lemons

1 can(403ml) full fat coconut milk

2 cups (300g) raw cashews

8 tablespoons (190g) honey

4 1/2 teaspoons (10g) unflav powdered gelatin

1 tablespoon vanilla extract

1. Preheat your oven to 350°F. In a large bowl, mix all the ingredients listed for the crust with a spatula until the mixture resembles coarse meal. Don't over mix. Press crumbs on the bottom and sides of a 9-inch pie dish, and bake until the edges and center start to brown. Cool completely on a cooling rack.

### **LEMON CREAM FILLING**

- 1. Add the lemon juice and zest, and  $\frac{1}{2}$  the can (201.5ml) of coconut milk to a saucepan. Sprinkle the gelatin on top and set aside to allow the gelatin to soften.
- 2. In the meantime, add the cashews, remaining (201.5ml) coconut milk in the can, honey, and vanilla to a blender and process for a minute or two, or until the mixture is very creamy and smooth. Set aside.
- 3. Now heat the lemon mixture in the saucepan over medium heat until the gelatin dissolves, stirring frequently with a spoon. Allow it to cool for 5 minutes, then add it to the blender along with the cashew mixture, and blend again to combine everything. Let lemon cream filling cool in the blender for 30 minutes, then pour it over the cooled crust. Cover with plastic and refrigerate for a minimum of 6 hours or overnight to allow it to set.

### DAIRY-FREE WHIPPING CREAM

- 1. Open the can of coconut milk that has been chilling overnight being careful to not shake the can. Scoop the coconut cream that has risen to the top into a large bowl. Discard the water on the bottom of the can.
- 2. Add the honey and gelatin to the bowl and whisk with an electrical hand or stand mixer until stiff peaks form. Spread the cream over the cooled pie and serve.

**NB \*Important:** soak the cashews in hot water in a large bowl for about an hour. This will soften the cashews and make them easier to blend. Discard the water and add just the cashews to the blender in step 2 of the Lemon Cream Filling above.

Store pie in the fridge covered with plastic wrap or tinfoil.

# Library

Please feel free to come in and browse through our library collection at our Christopher St offices. (check that Tina or Joanne are in before you come). If you are on the internet you can access the titles from our website <a href="https://www.mebop.org.nz">www.mebop.org.nz</a>

### Can We Email Your Newsletter?

Costs are always a major consideration to us, and trying to make ends meet. If you are currently receiving your **MEssenge**r by normal post, and you have email available to you (ideally broadband), we ask that you consider receiving it in future by email. This will help us to keep our mailing costs as low as possible. So, if you are prepared to change, please email the office at <a href="mailto:info@mebop.org.nz">info@mebop.org.nz</a> with your details.

# Mt Maunganui, Katikati/Waihi and Te Puke meetings

If you are planning to attend the above support group meetings, remember to check with Tina before each meeting as the venues change from time to time.

### **Facebook**

Membership of our Facebook page continues to slowly but surely increase. Remember that this is a "Private" page as we want you, our members, to be able to talk freely to each other on the page. We have received requests for people who are not members to join the page, which we have declined for this very reason. This also ensures that non-members can not use the page to drive any commercial interest they may have. Should you wish to join our Facebook page, the easy link is: <a href="https://www.facebook.com/groups/203904249678311/">https://www.facebook.com/groups/203904249678311/</a>

# Acknowledgement

We gratefully acknowledge our many sources that have kindly allowed us to use their articles for information to our members. They include:

Action for ME, UK
ME Association, UK
Dr Ros Vallings

**ANZMES** 

ME/CFS Group (Canterbury)

MEISS ( Dunedin )

Nelson Bays ME/CFS & FM

Support Group

# **Appreciation to our Funders**

Complex Chronic Illness Support wishes to note our grateful appreciation to the following organisations for their financial support enabling us to provide our services:

TECT
Bay Trust
Lottery Grants
Lion Foundation
Pub Charity
WBoP Disability Support Trust
COGS WBoP & EBoP

Grassroots Trust
Infinity Foundation
Southern Trust
First Sovereign
Disability Community Trust Whakatane
NZ Community Trust
NZ Post





























**DISCLAIMER:** The views and opinions expressed in this newsletter do not necessarily represent the views of Complex Chronic Illness Support. They are not intended to replace the advice of qualified health professionals.

# **Group Meetings Calendar**

CCI Support meetings held 2<sup>nd</sup> Wed of the month 10.30am ........... contact Tina 2811 480

Mount Coffee Group meets the 1st Mon of the month 10.30 am .......... contact Tina 2811 480

Eastern Bay Group meet 1st Tues of the month 10.00 am ............ contact Gisela 07 307 1447

Young Member meetings held 3rd Thurs of the month 1pm ........ contact Kira 021 027 18127

Greerton Coffee Group meets 3rd Wed of the month at Zest, Chadwick Rd, Greerton

April 2017	May 2017	June 2017
Monday April 3rd Mount coffee morning at Bayswater Retirement Village, 60 Maranui Street, Mount Maunganui, 10.30am  Tuesday April 4th Eastern Bay group Contact Gisela 07 307	Monday May 1st Mount coffee morning at Bayswater Retirement Village, 60 Maranui Street, Mount Maunganui, 10.30am  Tuesday May 2 <sup>nd</sup> Eastern Bay group Contact Gisela 07 307	Monday June 12 <sup>th*</sup> (Deferred due to Queen's birthday) Mount coffee morning at Bayswater Retirement Village, 60 Maranui Street, Mount Maunganui, 10.30am Tuesday June 6th
1447	1447	Eastern Bay group Contact Gisela 07 307 1447
Wednesday April 12 <sup>th*</sup> Support meeting/ coffee morning at 56 Christopher Street, 10.30am – 12pm	Wednesday May 10th Support meeting/coffee morning at 56 Christopher Street, 10.30am – 12pm	Wednesday June 14th Support meeting/coffee morning at 56 Christopher Street,10.30am – 12pm
*Guest speaker Dr Lynette Hodges, Massey University re her Exercise Research Project	Friday May 12 <sup>th*</sup> CCIS launch at Daniels, 53 Eleventh Ave, Memorial Park, 1.30pm – 3.15pm *RSVP to office	For more info Contact Tina 07 2811 480

### **PLEASE NOTE**

Some of our members are sensitive to chemicals. Please refrain from the use of perfumes/strong deodorants before the meetings. Thank you for your understanding.

Formed 1981

**MEssenger** is kindly funded by WBoP Disability Support Trust & EBoP Disability Community Trust

Incorporated 1986

# **Board of Management**

President Vice-President Treasurer Board Members

Jean Scoullar Barbara Whitton Joan Willcock Andrea McFarlane

Jacqui Bassett

### **Staff**

Manager Jessie Hines
WBoP Field Officer Tina Richards
WBoP Youth Field Officer Kira Follas
EBoP Field Officer Gisela Sonntag

**Accounts & Administrator** Joanne Palmer

**Newsletter** Jan Morrison

### 10% Discount Stores

Brookfield Pharmacy – Tauranga Health Haven – Tauranga Health Shop & Clinic - Greerton Bethlehem Health Shop – Tauranga Nature Zone – Whakatane

Present **Membership Card** at these stores as proof of your Complex Chronic Illness Support membership

### Want to call in or write to us?

We are at

# 56 Christopher St, Tauranga 3112

Admin: Joanne ph (07) 2811 481
Email: admin@mebop.org.nz
Field Officer: Tina ph (07) 2811 480

027 625 4449

Email: **tina@mebop.org.nz**Website: www.mebop.org.nz

### SUBSCRIPTIONS and DONATIONS

Although our services are free to members, we charge a **\$20.00** annual membership subscription and gratefully receive donations towards our operating costs. We are registered with IRD as being for charitable purposes so donations are tax deductible. Any donation is greatly appreciated.

Subscriptions and donations can be direct credited to our bank account if that is convenient.

Our bank account is: Kiwibank A/c No: 38 9014 0140507 00

Please enter your 'name' and 'ME Sub' and/or 'donation' in the reference and email us if you would like a receipt. OR..... deposits can be made in person to Kiwibank if you go in with our account number.

#### **BEQUESTS**

Including a bequest to Complex Chronic Illness Support in your will is also an option you may consider. **ACORN** Foundation can assist you to arrange a bequest to CCI Support. Donations can be made to our endowment fund with ACORN ph 579 9839, internet banking on the Acorn website: www.acornfoundation.org.nz or cheque made out to Acorn Foundation PO Box 13604, Tauranga 3141

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Cut along here if sending by post			
Yes, I would like to make a donation / pay my su	ubscription to Complex Chronic Illness Support.		
Please find enclosed my <b>donation</b> of \$			
Please find enclosed my annual <b>subscription</b> of \$20.00			
Please send receipt to:			
Name:			
Address:	Suburb		
City:	. Post Code:		
14 Please post cheque to			