

CCI Connect June 2021

A note from the CEO:

Hello and welcome to the June CCI Connect. We can certainly feel the change in the air with the brisker mornings of Winter.

You will notice something different this month... my title change. Having started with CCI Support in August 2019, I would like to think we have made some real progress in the support CCIS can provide to people living with Chronic Illnesses. As part of this new direction however, I am no longer just running the operational aspects of the organisation. But with the support of the CCIS Board, I am also providing a new focus and strategic plan to move forward with, so along with a new position description comes a new title for the role too. I wish to thank the Board, Staff and Members for the support I have received and am really looking forward to the future with CCIS.

In April we introduced the new CCIS Waikato, and we are currently also looking at other areas in New Zealand that we may be able to provide support to. As well as working on (and have funding for) a new Towards Wellness ONLINE programme. More info will be available on this soon!!!

ME/CFS FM International Awareness day was on the 12th of May. For this each area had their own celebrations during the month.

Waikato 13th May – Dr Ros Vallings spoke at the official launch of CCIS Waikato.

Rotorua held an **online** members meeting for CCIS members on **May 14th**.

Whakatane had an Info sharing afternoon on the **12th May** at the Lyceum Club

Tauranga had Dr Trish Zingel speaking on the **26th May**

We also have the **40th celebration with Dr Ros Vallings, Dr Sarah Dalziel and Emeritus Professor Warren Tate on the 3rd July.**

We will also be trialing a 'New Members' Meeting in June. This is a chance for new members to get to know one another, see what CCIS is really about and how we can support you. So, if you are a new member that is one to keep an eye out for.

Other news in the office is we now have a new Fundraising Manager – Jo Morgan. Jo has a lot of experience in raising funds and we are grateful to have her. We are thankful for the time Catherine was able to spend with us and wish her well in her new position elsewhere.

We are looking forward to the direction CCIS is taking for the rest of 2021, we feel we are really moving towards our goal of being an organisation that is 'Empowering People Towards Wellness'. **Miranda Whitwell - CEO**

53 FRASER ST, TAURANGA

Hours: Tuesday to Friday
operations@ccisupport.org.nz

9am till 2.30pm
07 281 1481 or 022 658 0251



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From Charlottes desk in the Western Bay of Plenty



Charlotte Kelp

Health and Wellness Facilitator

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Good day to all of our members, it has been a really exciting to see our membership grow as Waikato have come aboard our ship. I have enjoyed reading posts and contributions to conversations on Facebook and getting to know new faces and names. Although I don't get to comment as often as I would like, I am always eagerly reading in the background and feel proud of the community you have built together.

For International ME & Fibromyalgia Awareness Day on May 12th we invited the cameras into Head Office and did a short film for the local Herald Focus. A special thank you to Lucy Winefield, who did a fantastic job in sharing how her life has been impacted with chronic illness. Thank you also to Miranda Whitwell CEO and to local journalist Gavin Ogden for his awesome filming and editing. We also managed to get sound bites on The Hits BOP to raise

awareness. In the WBOP we held a special event with guest speaker Dr Trish Zingel in Otumoetai.

We are so blessed to have a such a curious community of members that enlighten me with new research and interesting articles. You are often our eyes and ears on the ground, so if you come across anything you think we should know about please email the link to charlotte@ccisupport.org.nz. Knowledge as we have learned is more power to us all.

If you are struggling now, or anytime, we are here to support you. We also have the wonderful Rachel our BTI student counsellor who is also able to support WBOP members.

Charlotte Kelp WBOP FO

Lakes District—ROTORUA/TAUPO

Well winter is well on its way and I feel I am contracting in a little, spending more time inside doing puzzles and more quiet family activities. It has been a busy few months for me, I went to Taupo to meet with some of our lovely members – it's always nice to get away for a day. I was fortunate this month to meet Dr Ros Vallings and Dr Sarah Dalziel they are a goldmine of information and it was such a pleasure to speak with them and absorb some of their knowledge.

I am very sorry to advise we have had to cancel physical meetings in Rotorua for the time being. I hope to see you all at the online monthly meetings – they are perfect for cosying up at home over the winter period.

How important is Pacing? I have spent the last 6 months working on fitness, pacing, and monitoring my progress to build up slowly, frustrating at times, but worth it. I am very proud to say I completed the Tongariro Crossing in March. It took me 2 weeks to recover physically and an additional week to feel like myself again. Aftercare is so important when we have a big event, I made sure I did not have anything else planned the weeks following, which made my recovery better. I highly recommend Pacing if you have not tried it or it has been a while. I recommend dusting it off, please contact your CCIS Field Officer if you would like more information or need some help starting pacing.

Bye for now



Tabitha Ramsay

Health and Wellness Facilitator

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9am till 2.30pm

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Greetings from the East.

Greetings from the east.

The year is rushing by in the Eastern bay. We have been enjoying good attendance numbers at the monthly meetings and were excited to celebrate May Awareness with an Info Sharing Afternoon on the 12th. We had several speakers which was an informative and fun afternoon!

Really encouraging to see our membership continue to grow, its great to have new members join the group and bring in their new energy and personalities. Over the years I have noticed that people tend to need several nudges to join groups like ours, and since we do not have an advertising budget, the best way to spread the message that we are here to help is via word of mouth. So next time you hear about someone who is living with ME/CFS, FM, POTS or Orthostatic issues, please mention CCIS and the mahi that we do.

Recently Tabitha Ramsey, Lakes FO and I were very privileged to interview Dr Rosamund Vallings and Dr Sarah Dalziel as part of CCIS future projects. I was once again reminded of Ros's knowledge, empathy, and generosity to our community. Sarah is a very experienced GP, who also brings a special interest in ME/CFS to her work and understanding of the power of good self-management. It is wonderful to be part of a community which has such strong members, they are a real asset to each patient and to the wider community.

Ka kite ano au i a koutou, Elizabeth



Elizabeth McGougan
Wellness Facilitator

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From the Waikato Desk

Kia ora and Welcome from the Mighty Waikato. I hope you all remain well as the weather turns towards winter.

Word has been getting out and membership numbers in the region continue to grow. Welcome to those of you who are new and to my existing clients who transferred with me to CCIS, thank you for your patience as I have at times grappled with new ways of working. I am starting to find my feet now, thank goodness!

The Waikato Monthly Education and social groups continues to be a success with good regular attendance. We have a longstanding social group in Te Awamutu run by volunteer Fiona. If you live in the Te Awamutu area and are interested in attending this group, please contact me. Or if you who have difficulty attending any of the groups in person, we offer an online support group also.

Please note my new contact details. I am being notified by MSWT that some of you are still sending emails to my old address.

Nga mihi to you all, stay warm and take care. Tracey



Tracey Larsen

Health and Wellness Facilitator

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Office Hours
Mon—Fri
9am - 4.30pm

waikato@ccisupport.org.nz

National Members Report

We are in the process of hiring a new Field Officer that will be based in the Tauranga office, supporting the National and WBOP clients. We are hoping this position will be up and running in the next few weeks. Watch this space!



Towards Wellness HUB

We are still working towards a 'Towards Wellness Hub' on our website which we hope to have it up and running by the end of the year. Essentially, it means wherever you are and whenever you want access, the Towards Wellness programme will be available. Please feel free to email operations@ccisupport.org.nz any recommendations or feedback what you'd like to have us include.

Towards Wellness Programme

Registrations are closed for Intake 1. Taking expressions of interest for Intake 2 now.

Cost \$200.00 for TWP1 ten two hour workshops held fortnightly, TWP2 is \$100. We also take part payments too if that is needed.

To register your interest email your field officer.

Meeting with Simon Bridges

Last month Simon Bridges and Sonia (his Electorate agent) took time out of their busy schedules to come to the CCI Support offices in Tauranga, to find out what services CCI Support provides. It was great being able to explain how we support people with Chronic Illnesses and to be really heard and understood. Simon has also written a letter of support for our services, that we will be able to use for funding applications etc.

That means now that we have personally met with Simon Bridges, Todd Muller, Jan Tinetti and Angie Warren-Clarke (who is in the process of putting a CCIS document forward to parliament to be considered at a select committee, this document was written to advocate for members and our service).



Change of Field Officers Name

We also have a change of name for our Field Officers titles. For quite some time we've been thinking about the appropriate titles for the staff.

They will now be referred to as Health and Wellness Facilitators (if they have a Health qualification) and Wellness Facilitators if their qualification isn't Health based. We really feel this encompasses what they do so well. I know it's a mouthful so H&W Facilitators is fine too.



Monthly Members Meetings.

June focus is **How to get good 'Rest'**

July focus is **What "Recovery" can look like (Speaker)**

August focus is **Different types of pain**

Tea and coffee are available and we encourage self-management of time, comfort and different modes of seating. Please refrain from wearing perfume, as some clients are chemically sensitive.

Tauranga

Second Thursday of the month 10.30 - 12pm

53 Fraser St

June 10th

July 8th

August 12th

Hamilton

Second Thursday of the month 10.30 – 11.30.

Melville Methodist Church Corner Bader Street & Normandy Ave, Melville, Hamilton

June 10th

July 8th

August 12th

Whakatane

Second Wednesday of the month at 1.30 pm

Whakatane Lyceum Club Rooms - 58 Domain Road Whakatane

June 9th

July 14th

August 11th

Online Members Meeting

Is for all our members who want to attend a monthly meeting but do not have the extra energy to leave their homes. You must register with your Field Officer for this one.

Second Friday of the month on Zoom at 1.30 pm

June 11th

July 16th

August 13th

Counselling available

Rachel, our 2nd year counselling students in Tauranga and Jules our counselling student in Whakatane have some spaces available. These sessions are free. This counselling will be offered for all ages and it will be provided in a strictly confidential environment. Please contact Charlotte or Elizabeth if you'd like to have some counselling

Social Groups.

These are casual meetings with no set subject or discussion points and are essentially member run. The Kaupapa of the groups are to empower connections with each other, learning helpful information for management, sharing, laughing and appropriate friendships. Finding friends who experience what you experience is so very important. It is difficult to keep your friends when you live with a condition that means you can't go to social events when you want to. So, finding a person who understands and "gets it" can be so empowering and helpful.

Greerton Coffee Group

Venue: Greerton Mitre 10 Mega (3rd Wed of each month) 10.30am

June 16th

July 21st

August 18th

Papamoa Coffee Group

Please call Sonya if you have any more questions or would like more information about the group 027 753 2973

Venue: Double Teaspoons (outside foodcourt), Papamoa Plaza, 10.30am

June 2nd

July 7th

August 4th

Young at Hearts Social Group

Venue: CCIS Offices, 53 Fraser Street, Tauranga
(12.30pm - 2pm 4th Tuesday of each month)

June 29th

July 27th

August 31st

Waikato Social Group

Venue may change, you will be advised of location by email a week prior. 10.30 – 11.30am

June 22nd

July 27th

August 24th

EBOP Coffee Catchup

4th Tuesday of the month at 10.30am

June 22nd - Red Barn – 237 Thornton Road Thornton

July 27th - Café Coco—10 Richardson St WHK

August 24th - Robert Harris—Cnr Strand & Richardson WHK

Please note:

- Some of our members are sensitive to chemicals. Please refrain from using perfumes/strong deodorants before the member meetings. Thank you for understanding.
- Suggested cafes can be changed by membership at any time. These are casual meetings with no set subject or discussion points and are essentially member run.

<https://filmdaily.co/wp-content/uploads/2020/07/cutememe-03.jpg>



Complex Chronic Illness Support Inc.

IT'S TIME TO RENEW YOUR MEMBERSHIP



Contact us:
07 281 1481 or 022 658 0251
www.ccisupport.org.nz
info@ccisupport.org.nz

Once a year we ask our members to contribute to CCIS in a small way financially, it shows that they are committed to the cause and value us as an organisation. With a membership that is pro-active and engaged in the support services we provide, we show our funders and the community that CCIS is an integral part of support for not only the members, but their whanau/families, local health professionals and the community.

For \$40 annual subscription, you get access to:

- ☐ Health and Wellness Facilitator support and advocacy
- ☐ Newsletter - CCI Connect
- ☐ Group support meetings - educative
- ☐ Special interest speakers and workshops
- ☐ Social groups
- ☐ Library - books & other resources are available for you to borrow
- ☐ Membership to our Private Facebook community
- ☐ Access to our Towards Wellness and other Programme/s

If you have not received a renewal form please email: operations@ccisupport.org.nz

RECEIPTS

For those members who have already renewed your membership for the coming year, thank you. If you require a receipt for your membership fees payment for their disability allowance please email operations@ccisupport.org.nz to organise an emailed or posted receipt.

PAID

Fibromyalgia muscle study suggests Mitochondria link:

Fibromyalgia research for many years has noted a change in the muscle tissue and this is being linked with more recent research on mitochondria function. Could the two be linked? These are the questions that Cort Johnson from Health Rising explores in this article which outlines the most recent research.

Link:

<https://www.healthrising.org/blog/2021/05/04/fibromyalgia-muscle-mitochondria/>

Below is a copy of the article:

Major Fibromyalgia Muscle Study Points to the Mitochondria

by [Cort Johnson](#) | May 4, 2021 | [Energy Production](#), [Fibromyalgia and Pain](#), [Homepage](#), [Metabolism](#), [Muscles](#), [Research](#) | [19 comments](#)

The muscles, the mitochondria and fibromyalgia – what a potentially potent mix. Over the past six months, at least three fibromyalgia muscle studies have popped up. (Health Rising has reviewed all three). Plus, a study examining energy production problems in fibromyalgia (FM) just appeared.

[Painfully High Muscle Pressures in Fibromyalgia Put Old Paradigm to the Test – Health Rising Muscle Study Finds Key Differences in Fibromyalgia and Chronic Fatigue Syndrome \(ME/CFS\)](#)

In his 2020 Swedish study, "[Evidence of Mitochondrial Dysfunction in Fibromyalgia: Deviating Muscle Energy Metabolism Detected Using Microdialysis and Magnetic Resonance](#)", Gerdle et al. took the study of the muscles in FM to new heights.

Evidence of muscle problems in FM has been piling up.

(Image by Ryan Hoyme from Pixabay)

Gerdle had last studied energy metabolism in FM in his 2013 study, "[Decreased muscle concentrations of ATP and PCR in the quadriceps muscle of fibromyalgia patients—a 31P-MRS study – PubMed \(nih.gov\)](#)". That study found substantially reduced muscle ATP and phosphocreatinine (30%) concentrations in the quadriceps muscle. It concluded that the abnormalities probably resulted from a combination of inactivity and dysfunctional mitochondria.

The authors, though, seemed to be reaching a bit with the inactivity conclusion. The (rather simple) activity assessment they used in the study indicated that the FM patients and the healthy controls had similar activity levels.

They'd also concluded that the FM group has normal aerobic capacity, but the exercise test (1 day submaximal exercise test) they used has produced misleading results in chronic fatigue syndrome (ME/CFS).

Despite the fact that the BMIs (body mass indices) of the two groups were similar, they also suggested that the higher intramuscular fat levels found in the muscle may have reflected the higher percentage of obese individuals in the FM group.

After suggesting that fat, inactive FM patients may be contributing to their findings, the authors swung, though, to a fascinating possibility – that even though they were less active, FM patients might still be "overusing" their muscles.

They suggested that psychological factors (high persistence behavior (i.e. overly hard-driving FM patients)), plus studies showing that FM patients' muscles do not relax in between muscle contractions, plus another study showing an apparently abnormal "activation pattern (s)" (unexplained) suggested that FM patients might be overusing their muscles even as their activity levels suggested they were underusing them.

The authors, it should be noted, also suggested that mitochondrial problems could be causing the reduced muscle ATP and PCR concentrations, and the increased concentrations of lactate

Article continued on the next page...

and pyruvate that some studies have found.

To be fair, the authors simply seemed to be covering all the bases. More than anything, with these researchers swinging from one hypothesis to the other, this 2013 study simply seemed to show how in flux the muscle field of FM was.

What was causing the strange muscle findings in FM? Was it inactivity, abnormal muscle activation patterns, mitochondrial issues or all of the above? Nobody knew.

Findings Coalesce – the 2020 Study

Seven years later, the group published a study designed to make up for shortcomings in FM muscle studies. It was larger (n=64) (but not all that large), assessed metabolic status in two places (trapezius, erector spinae muscles), assessed blood flows, and used more comprehensive statistics.

The study, "[Evidence of Mitochondrial Dysfunction in Fibromyalgia: Deviating Muscle Energy Metabolism Detected Using Microdialysis and Magnetic Resonance](#)" – PubMed ([nih.gov](#)) was revealing indeed.

Sometimes it's hard to tell if a field is making progress. Eight years later, it's clear that step by step, study by study, this aspect of fibromyalgia research has made real progress.

Results

The time, the authors lead off the discussion with the rather definitive statement:

"FM was clearly associated with higher levels of pyruvate and lower levels of ATP and PCr, a finding that suggests muscle mitochondrial dysfunctions in FM."

The more sophisticated analyses the researchers used found that it was biology (lower ATP/PCr, PCr/Ptot, Pi/PCr), rather than something like obesity, which differentiated the FM patients from the healthy controls. Plus, this time, abnormalities found were clearly associated with increased pain. Noting that this was the fourth study to find so, the authors reported that FM "seems" to be associated with increases in pyruvate and lactate – two products of glycolysis.

That's a very interesting finding given the [similar findings](#) that have shown up in [chronic fatigue syndrome](#) (ME/CFS). Pyruvate is the end product of the first half of the energy production program (glycolysis/anaerobic energy production). It is converted into acetyl-CoA, which is transported into the mitochondria where it's used, in a series of five complex steps, to produce massive amounts of ATP (aerobic energy production).

The higher levels of pyruvate and lactate (a breakdown product of pyruvate) found in the FM patients' muscles suggest that pyruvate is not getting properly metabolized, thus depriving the mitochondria of the fuel they need.

The Gist

Numerous studies have found muscle abnormalities in fibromyalgia dating back for decades. This Swedish group's 2013 study found signs of mitochondrial dysfunction (low ATP, PCr) in the muscles of FM patients. The authors pointed to a variety of different factors that might have come into play (mitochondrial problems, muscle overuse, inactivity, obesity).

Seven years later the authors returned with a bigger, more effective study – and a stronger conclusion. They again found evidence of reduced ATP and PCr as well as increased pyruvate. Similar findings have shown up in chronic fatigue syndrome (ME/CFS).

With proteomic, metabolomic and other studies coming to similar conclusion the authors concluded that mitochondrial problems are present in FM.

They also proposed that mitochondrial problems are playing a role in chronic pain in general and noted that pain is common in people with primary mitochondrial disorders.

The authors also reported that reduced ATP levels have been found in a wide variety of tissues including the muscles, skin, plasma, platelets, nerve and immune cells.

While obesity was increased in FM the analyses suggested it had no impact on the muscle issues found.

An altered phosphorous/PCr imbalance and increased pyruvate levels seemed to particularly impact pain levels.

The authors suggested that a variety of factors may be in play including oxidative stress and mitochondrial induced inflammation.

There seems to be increasingly little room for argument over whether ATP levels are affected in FM. The authors noted that low ATP levels have been found in a remarkable array of FM patients' tissues, including several times in the muscles, as well as in the skin, plasma, platelets, neuronal cells, and peripheral blood mononuclear cell (PBMCs) (!)

The authors proposed that mitochondrial problems were likely the problem – not just for FM patients – but for others who experience chronic pain. (They also noted that chronic pain is common in people with mitochondrial diseases). They aren't the first to propose that and, in fact, proposed that possibility in the 2013 paper, but now have much stronger legs to stand on. At least six studies from the past couple of years have come to the same conclusion. That those studies are coming to similar conclusions from different directions (proteomic, metabolomic, urine metabolite studies) – suggest that the finding is a robust one.

When it came to explaining the findings, the authors were, again, at something at a loss. They noted that aging and obesity – neither of which could explain FM (plenty of young people have FM, and plenty of obese people do not) are associated with mitochondrial problems.

While higher rates of obesity were found in the FM patients (FM – 27.3% overweight, 42.4% obese/severe obese; controls – 22.6% overweight, 6.5% obese/severe obese; $p < 0.001$) but the multivariate statistics suggested it played no role in the FM patients. (Increased BMI in both groups, though, was associated with reduced PCr ATP and pyruvate levels.) In this larger study, the submaximal exercise test also suggested that aerobic capacity was lower in the FM patients.

Given the possible connection between altered circadian rhythms and mitochondrial activity, they suggested that poor sleep in FM might play a factor. They also brought up the possibility of overactive muscles.

The authors also noted that the low PCr levels were throwing the PCr/phosphorous balance off – affecting blood flows and pain levels. Regression analyses indicated that fifty percent of the pain intensity could be explained by problems with blood flows and the metabolic abnormalities. The phosphorous/PCr imbalance and the increased pyruvate levels were particularly important factors. They noted that another study found that proteins associated with mitochondrial production were strongly implicated in the production of pain. (Interestingly, a large cytokine study found that cytokines were not.)

In the end, the authors painted a complex picture in which increased oxidative stress, mitochondrial-induced inflammation, a mitochondrial-produced “damage-associated molecular pattern” which triggers inflammation, NLRP3 inflammasomes that tweak sensory neurons, and others could be involved.

In their conclusion, the authors noted that they'd found significant metabolic and blood flow alterations in the muscles of FM, which may result from dysfunctional mitochondria in the muscles. After the pages of dense biological discussion, it was strange to see the authors revert to their tropes from eight years ago.

“Although it is unclear why muscle mitochondrial dysfunctions are found in FM, inactivity, obesity, aging, and pain per se may be involved.”

Perhaps the editors of the journal demanded it.

All of this brings up an intriguing question: With all the evidence of ATP and muscle problems that have been found in FM, why does exercise seem to work – and how well does it work?

Cort Johnson





TAKING A BREAK FROM OUR HABITS

Breaking habits is a tough thing to do, in the first instance it can be hard to know if you need to change a habit. I started to notice that certain things I was doing consciously or unconsciously, were having a negative impact on my health and over time I recognised that I needed to break that behavioral habit.

The best way to approach breaking a habit and creating change is by starting small, pick something that is manageable and not too tough to start with. Bedtime was a good start for me, some nights I would just stay in the TV trance for hours and would stumble to bed way too late. So, I decided to set a timer on my phone to reduce the amount of TV I was watching and to help me get a good bedtime routine.

Its helpful to remind yourself about why you are wanting to create that change in your life. Motivational statements, visions for your life with the change in place, and journaling about your reasons why, can all help to remind you of the reasons you want to break a particular habit.

Making the change a part of your normal routine can also help to integrate it into your life more quickly and enable the new healthy habit to stick. And of course, we all love a reward, so giving yourself something to look forward to reinforces positive change.

This all the depends on the type of habit that you are trying to break, you may need help from professionals to work on more complex habits. But if you are wanting to create healthy change then maybe enlist a friend to help you. You can both talk about the habit and be accountable to each other about your progress towards the goal.

For many of us we need to break the habits of a lifetime, like working too hard, not having any boundaries, exercising too much, engaging in negative thought patterns, or engaging in behaviors that keep us feeling stuck. These may feel overwhelming to try to change, but by starting small, concentrating on what we can do, being kind and compassionate to ourselves, we can break habits and start living well.

Elizabeth

Reference:

Alexander, Ani. (n.d.). *10 Powerful Benefits of Change and we Should Embrace it*. <https://tinybuddha.com/blog/10-powerful-benefits-of-change-why-embrace-it/>

Raypole, Crystal. (October 29, 2019). *How to break a habit*. <https://www.healthline.com/health/how-to-break-a-habit>

Scott, Elizabeth. (April 02, 2021). *How to take a Break from Work and Why you Should*. <https://www.verywellmind.com/why-you-should-take-a-break-3144576>

NZ Covid Vaccine

Below is some general advice on the Covid-19 Vaccine which Dr Ros Vallings spoke about during her presentation at the public talk held in Hamilton last month for the launch of CCIS Waikato.



Dr Ros Vallings' Vaccine Recommendations

- Covid-19 can kill, therefore vaccination wise
- Those with ME/CFS may be "self-protected" by immune activation, but no guarantee
- Vaccine is not "live", therefore risk of serious reaction is less
- Getting Covid-19 may worsen ME/CFS (serious relapse)
- Choose time for vaccine when at one's "best"
- Allow 2-3 days before and after vaccination for rest
- Be prepared for "reaction" (paracetamol, antihistamine, prednisone)
- Stay at facility for up to an hour



Experts from around the world weigh in on Covid-19 Vaccination and ME/CFS FM

Those with ME/CFS FM may naturally be cautious when considering whether the Covid-19 vaccine is appropriate for them. Millions of people have now received the Covid-19 vaccine. In fact, there have been 1.15 billion doses given worldwide and few published reports of severe side effects. To date, 1.2% of the New Zealand population have been fully vaccinated, therefore we still have a long way to go to achieve herd immunity. New Zealand has now secured enough Covid-19 vaccines for everyone, please refer to this Ministry of Health link detailing safety and approval and the vaccine the roll out plan [MOH Covid-19 Vaccines](#).

Below you can read recommendations from ME/CFS practitioners and researchers about staying protected against the virus. Most importantly, speak with your GP who will be able to discuss and advise on what is best for your unique health situation.

Dr Charles Lapp from the Hunter Hopkins Centre, P.A.

The Pfizer and Moderna products are not made from live virus, so they are not likely to cause flares or relapses in our PWCs. They both require two doses 21 to 28 days apart. It takes about 2-3 weeks to develop a 50% level of immunity after the first dose, and that level persists for just a few weeks so the second immunization is necessary. The vaccines are about 90-95% effective, but there is no data yet on how long such immunity will last. Side effects of the vaccination include injection site soreness and fever in most cases, increased fatigue (up to 60%), headache (up to 50%), muscle aches (37%), and chills (32%), especially after the second jab. These symptoms resolve in 24 to 48 hours, and a minority of individuals has to take Tylenol or other remedies for them.

Our concern is not the short-term effects, but long term. The Pfizer and Moderna vaccines have been administered safely to thousands of individuals already, but new issues are likely to arise after millions of individuals have been immunized.

Because COVID-19 is such a severe disease we currently recommend that high risk individuals strongly consider vaccination. These include individuals with high blood pressure, diabetes, obesity, asthma or pulmonary disease, cardiovascular disease, and immune deficiency. The vaccines have not been adequately tested in pregnant or lactating women, or in children under 16 years.

Since PWCs frequently suffer immune dysregulation, many wonder if they should be considered "immune deficient." Our opinion is that many patients have an UP-regulated immune system and fend off viruses readily, so they rarely fall ill. If you are the type of individual who "catches every virus that comes along," then you are probably in the minority of DOWN-regulated patients and should highly consider the vaccination when it is available.

Despite immunization there is still a small but significant chance one could contract COVID-19; therefore, prevention is KEY. Dr. Lapp has just reviewed dozens of past epidemics and one point is clear: frequent washing, hand sanitizing, face masks, and isolation are crucial for avoiding infection.

Full article can be found using the following link <https://drlapp.com/ask-the-doctor/covid-19-vaccines/>

Dr Bateman for the Bateman Horne Center

We [the world] certainly need COVID-19 vaccines desperately and everyone who is healthy enough for the vaccine should get vaccinated, starting with those at highest risk of COVID exposure. This includes healthy family members of vulnerable people. For the ME/CFS/FM population, my advice is to stay safely quarantined and wait a couple of months while the vaccine is distributed and broadly administered. Because of the large numbers and close monitoring, we should know fairly quickly how people do with the vaccines. This advice will apply as each new branded vaccine is approved and rolled out. In general, the people who should be most cautious are those who have previously had allergic reactions to vaccines or are prone to severe allergic reactions in general. If you decide to get the vaccine, be rested and stable prior to the vaccine, and plan on resting/relaxing for at least 72 hours afterward. Supportive care will include anything you usually do for flu symptoms, PEM, allergy flares, worsened orthostatic intolerance, etc. If anything, including a vaccine, makes you sick enough that you

are unable to maintain adequate fluids and nutrition, or results in fluid and electrolyte losses (sweating, diarrhea, etc.), it is always appropriate to seek IV fluids as a primary intervention.

Full article can be found using the following link <https://batemanhornecenter.org/wp-content/uploads/filebase/COVIDVaccineGuide01072021.pdf>

Nancy Klimas, MD, Director, INIM for the Institute for Neuro-Immune Medicine

COVID kills people. It kills people with over activated and damaged immune systems preferentially – and that is what ME/CFS is all about. So while there certainly is a risk of an ME relapse with these hyper reactive vaccines (the first wave to be released), you have to weigh the possibility of an ME relapse against the risk of death from COVID-19. You can mitigate the risk in a number of ways - just the way you do when you feel a relapse coming on. Before the vaccine, make sure you are taking enough antioxidants, particularly NAC or glutathione and CoQ10. The big mediator of post vaccination relapse and immediate reactions is mast cell activation. If it happens immediately, that is anaphylaxis, but if it happens slowly and low grade over days the mediators mast cells release can drive a classic CFS relapse. So, take an antihistamine before and for several days after the vaccine – the strongest one you can tolerate. (Benadryl is one of the strongest, Zyrtec is another good choice). There are many mast cell stabilizers; watch Dr. Maitland's excellent lecture from our recent CME Workshop: Managing the Syndrome Soup: POTS, EDS, MCAS & ME/CFS, if you want to know more: <http://bit.ly/NovaDysCME>.

There are natural supplements that act to block or clear histamine and stabilize mast cells such as alpha lipoic acid, ascorbic acid, B6, diamine oxidase enzymes (DAO), luteolin, N-acetylcysteine (NAC), Omega-3's, riboflavin, S-AMe, quercetin, and natural sources of theophylline like green and black teas. If you have been diagnosed with mast cell activation syndrome, it would make sense that your risk of an immediate reaction to any vaccine should be higher, though the data on the risk to people with mast cell activation syndrome or prior vaccine allergic reactions is not yet known with the COVID-19 vaccines. I suspect we will know fairly quickly, with millions of doses already administered. So you may want to wait (taking all of the COVID-19 precautions very seriously). If you do take the vaccine, plan to stay in the medical setting for at least 30 minutes, consider several hours, to be in a safe place if you do have a reaction. In this special circumstance, premedication with a steroid, the same way we premedicate people who need a CT scan with iodine contrast dye, could be provided by your physician.

Please note: that if you take the vaccine you should take the whole recommended dose, and the current vaccines, Pfizer and Moderna, should be administered twice. It is not yet known how long the immunity will last, but there are blood tests that look at antibody levels available. Although they came to the market very quickly, we will know more about the quality of the antibody tests over the next few months. Most importantly, vaccination is not 100% (in fact the two initial vaccines trials were 95% effective in preventing or reducing the severity of infection). Vaccination does not exclude strict social distancing guidelines and mask wearing until "herd immunity" levels of vaccination have been reached (70% of the population)!

Of course, these recommendations are simply my opinion, and we will know a lot more about safety in the coming months – but 30,000 plus folks took the vaccines in the trials (that's a lot) and you must be moved by the photos of health care professionals lining up to receive their vaccine. Is there a risk? Yes. There is certainly more of a risk of ME/CFS relapse than anaphylaxis, which should be manageable. Is it worth it? Your decision, weighing all that you can find out. More than 330,000 Americans have died. The new strain of the virus is likely to make our current rate of infection go much higher. Please take this seriously

Full article can be found using the following link <https://www.nova.edu/nim/To-Vaccinate-or-Not-with-MECFS.html>

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By Charlotte Kelp (WBOP FO)

FEBRUARY MEMBERS MEETING

KNOWING YOUR RIGHTS

What are human rights?

Human rights recognise the inherent value of each person, regardless of our background, where we live, what we look like, what we think or what we believe.

Human rights include:

- The right to life and liberty
- Freedom from slavery and torture
- Freedom of opinion and expression
- The right to work and education, and many more

What is discrimination?

Unlawful discrimination is defined by the Human Rights Act 1993 and happens when a person is disadvantaged by being treated unfairly or less favourably than others in an area of public life.

- ◇ Its unlawful to discriminate in areas of:
- ◇ Employment (including unpaid work)
- ◇ Education and vocational training
- ◇ Industrial or professional associations
- ◇ Provision of goods and services
- ◇ Land, housing and accommodation
- ◇ Access to public places, vehicles and facilities
- ◇ Government services

What happens if I feel my rights have been breached?

If you feel you have not been treated well or are unhappy with a health or disability service you have received, it is best to talk to, or write directly to, the person who provided the service, or the organisation in charge of the service. Very often they will welcome your complaint, as it helps them to improve their standard of service or uncover a problem. You can also complain to The Health and Disability Commissioner.

Who can help me put in a complaint?

An advocate helps you in writing letters or can represent you over the phone in your dealings, they can also attend meetings with you to speak on your behalf. Many advocates are volunteers who give their time for free to help people navigate these systems. You can also have a family member or friend be your advocate.

Health consumer services – 'Funded to work in the Waikato, Bay of Plenty, Tairāwhiti regions. Health Consumer Services help you to take a complaint to: Medical, Surgical, Mother & Baby, Chemist, Dental, Disability Support, Home Help, Counselling, Rest homes, Mental Health, Community Health Services groups.'

<https://healthcomplaints.co.nz/> free phone; 0800 801 482

Advocacy service health and disability – ‘The Nationwide Health and Disability Advocacy Service is a free service that operates independently from all health and disability service providers and agencies. If you want to know more about your rights when using health or disability services, get questions answered, or talk through your options for making a complaint, we can help.’ <https://advocacy.org.nz/> free phone; 0800 555 050

Other places who receive complaints:

Ministry of Health – for government funded health and disability services
USE THE NZ RELAY SERVICE – FOR THOSE WHO DEAF OR HEARING IMPAIRED

HEALTHCERT AT THE MINISTRY OF HEALTH – FOR REST HOMES AND RESIDENTIAL DISABILITY SUPPORTS WITH OVER FIVE BEDS.

ORANGA TAMARIKI – ABOUT THE SAFETY AND WELLBEING OF CHILDREN

THE NEW ZEALAND POLICE - A CRIMINAL ACT.

HDC HEALTH & DISABILITY COMMISSIONER
TE TOIHAU HAUORA, HAUĀTANGA

Your Rights when receiving a Health or Disability Service

- **Respect**
You should be treated with respect. This includes respect for your culture, values and beliefs, as well as your right to personal privacy.
- **Fair Treatment**
No one should discriminate against you, pressure you into something you do not want or take advantage of you in any way.
- **Dignity and Independence**
Services should support you to live a dignified, independent life.
- **Proper Standards**
You have the right to be treated with care and skill, and to receive services that reflect your needs. All those involved in your care should work together for you.
- **Communication**
You have the right to be listened to, understood and receive information in whatever way you need. When it is necessary and practicable, an interpreter should be available.
- **Information**
You have the right to have your condition explained and to be told what your choices are. This includes how long you may have to wait, an estimate of any costs, and likely benefits and side effects. You can ask any questions to help you to be fully informed.
- **It's Your Decision**
It is up to you to decide. You can say no or change your mind at any time.
- **Support**
You have the right to have someone with you to give you support in most circumstances.
- **Teaching and Research**
All these rights also apply when taking part in teaching and research.
- **Complaints**
It is OK to complain – your complaints help improve service. It must be easy for you to make a complaint, and it should not have an adverse effect on the way you are treated.

**If you need help, ask the person or organisation providing the service.
You can contact the local advocacy service on 0800 555 050 or the
Health and Disability Commissioner on 0800 11 22 33 (TTY).**

MARCH MEMBERS MEETING

SKIN AND TEMPERATURE SUPPORTS

Skin and temperature related issues are commonplace for those with ME/CFS/FM, and can not only be used to diagnose these conditions but can also indicate fluctuations occurring. Some of the most common related skin and temperature issues and how to manage them are discussed below.

Functions of the skin include:

- Protection** against infection, dehydration, UV light, and injury
- Sensation** to pain, temperature, touch, and deep pressure
- Mobility** allowing flex and smooth movement of the body
- Vitamin D production** for calcium absorption and healthy bones
- Excretion** via sebum and sweat
- Immunity** via production of cytokines
- Temperature regulation** via sweat glands and blood vessels

The skin and onset of ME/CFS

Some people with ME/CFS link the onset of their condition to a skin problem. This may have been a rash due to a viral infection such as chicken pox or glandular fever. There are two types of herpes virus HSV-1 – cold sores and shingles and HSV-2 genital herpes. These can lie dormant and reappear when a person is rundown. Relapses can accompany a recurrence in the skin condition. Treating the symptoms can give relief and help overcome a relapse.

Managing your rash at home

- Drink plenty of water – Dry skin can cause itching which can lead to a rash. Increase fluid intake to hydrate your body and skin
- Apply sunscreen – Apply SPF 30+ sunscreen and wear protective clothing (even on over-cast days) to avoid sunburn and a skin rash
- Take a lukewarm shower or bath – this can ease itchiness associated with a rash
- Apply a topical over the counter anti-itch cream following the instructions of your pharmacist
- Don't scratch a rash – This exacerbates itchiness, can damage the skin and worsen the rash
- Apply a cold compress – Wrap an ice pack in a towel or use a cool flannel for. This can help to stop itchiness, inflammation and pain
- Avoid scented soaps and lotions as these can irritate and worsen the rash

Temperature dysregulation

Temperature dysregulation, heat intolerance and cold intolerance are common symptoms of many chronic illnesses including Dysautonomia, Fibromyalgia and ME/CFS.

The International Consensus Criteria for ME indicators of temperature instability are listed as; - subnormal body temperature - marked fluctuations of temperature throughout the day - sweating episodes - recurrent feelings of feverishness with or without low grade fever - cold extremities, e.g. fingers and toes. It has been reported that 75-80% of those diagnosed with ME/CFS have one or more of the above symptoms.

If you find that you are sensitive to temperature and your symptoms flare you may need to monitor the temperature around you and take steps to keep yourself comfortable.

Ways to manage heat intolerance:

Avoiding direct sunlight or going out during the hottest times of the day (11am-3pm)

Using air conditioning or a fan if you are inside

Plan ahead- a portable handheld fan can be useful for when you are out and about

Wearing light coloured, loose fitting, breathable fabrics

Wear layers you can easily peel back

Use a broad brimmed hat or sunshade such as a parasol

Sip on a cold drink, and/or suck on ice cubes or frozen fruit

Invest in an insulated bottle to keep fluids ice cold

Spray face and wrists with a mister or a cooling spray available at the pharmacy or shop

Choose light meals such as salads, cold fruit smoothies or a cooling desert

Take a cool bath, shower or swimming in a pool

A cool damp fabric or towel around the back of the neck can help to cool the body

Avoiding more strenuous activities during warmer weather or in warm rooms

Cooling garments are available such as cooling pillows, cooling neck wraps and cooling vests

Ways to manage cold intolerance:

Layer up with turtlenecks, long-sleeved shirts and leggings

Invest in clothing made of polypropylene (a chemical that keeps you warm and draws water away from the skin).

Wear a hat with ear protection

Have hand covering options – light gloves, woollen gloves, fancy gloves

Scarves - you may use a scarf all year round so look for one that's washable and compact

Hot food gives your body the fuel it needs to generate heat

Sip on hot beverages

Thermal socks and thermal underwear can be a good option

Carry a sweater even in the summer months for cool airconditioned buildings

Move regularly to improve circulation and minimise muscle stiffness brought on by the cold

If you are sitting for long periods use a blanket that you can wrap around you - some even have sleeves

Keep your home warm by closing windows, shutting internal doors, and drawing curtains as soon as it begins to get dark

Turn up the heating if you need to - if increased fuel costs are a worry, check out this [government website](#) out for energy saving tips

Ensure that your home is well insulated and there are no gaps around the doors

Pull up a comfy chair in the sunny spots of your home

Electric blankets, hot water bottles and heat pads are useful at home for keeping warm

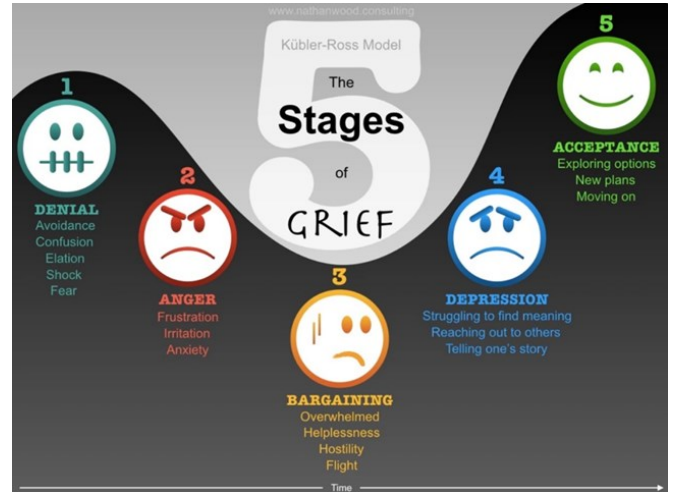
Portable hand warmers or heat activated strips can help you to manage the cold when you need to be outside

APRIL MEMBERS MEETING

HOW TO MANAGE THE FEAR OF CHANGE

The essence of change is an alteration or difference in a situation or in life. For most of us the development of our complex chronic illness is a major life change which in turn causes stress.

Chronic Illness is one of leading causes of stress in our society, along with divorce/relationship breakdown, death of a loved one, loss of a job, increased financial obligations, getting married, moving to a new home and traumatic events.



To help understand some of these life events Elizabeth Kubler-Ross in 1969 developed the Grief Cycle and this has been successfully used to help enable people to understand the process that grieving/loss/change may follow. Grief, shock, sadness, and relief are often felt when we first receive the diagnosis. After that we can move through the stages of denial, confusion, and avoidance. Then we often find anger, anxiety and frustration. After that we may experience bargaining, depression and finally acceptance. This is not usually linear journey, but a cycle.

How we can manage fear

There are many ways that we can help to reduce the fear of change that we are experiencing and to shift from this fight, flight and freeze response and 'stuck' state towards being in a healing state.

Explore the information

Information is power and the more we can learn about the conditions which we find ourselves living with, the more we will understand what is happening.

Breath

The most direct way to calm our fight, flight & freeze response is through deep breathing. Practice relaxation, mindfulness, meditation, or grounding techniques each day to help to calm your body.

Lean into accepting what is

Our fears often hinder us from trying new things as we can fear that we may fail at this as well. By recognising that failure is a universal part of life and that change is a constant, we can begin to lean into accepting our new situation and the changes that it creates.

Gain control of your symptoms

Tools such as pacing, sleep hygiene and restorative movement help you to manage your

energy levels.

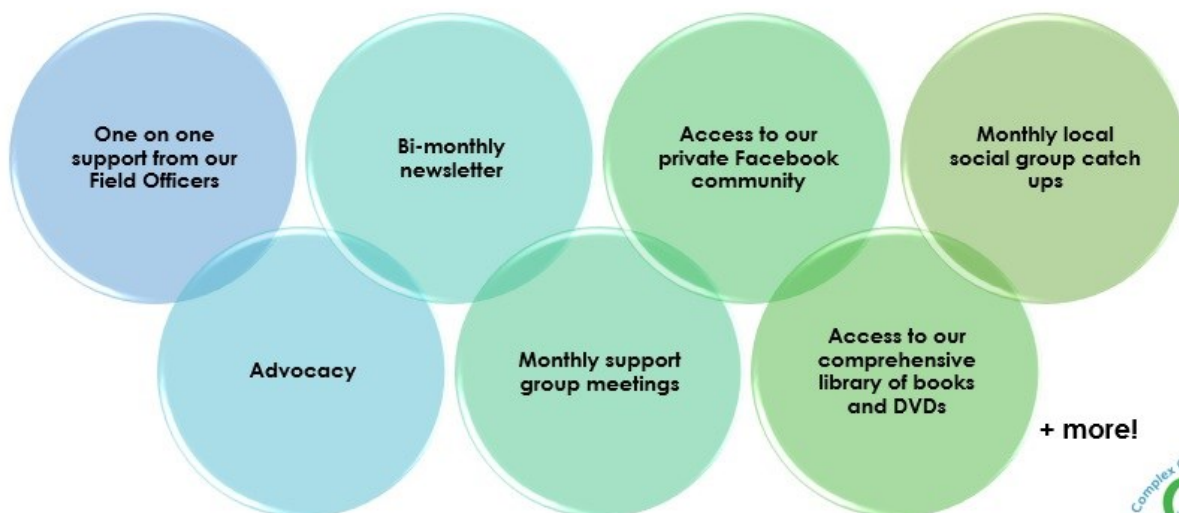
Let it go

Often, we hold on to ideas of ourselves and what we thought our lives would be like, which can create blame. The more we can let go of these strongly held ideas the better. We can start our lives again in any moment and at any time as a new chapter.

Try a little self-compassion

Image source: <https://nathanwood.consulting/portfolio/the-five-stages-of-grief/ku%CC%88bler-ross-model-of-the-five-stages-of-grief-nathan-wood-consulting/>

SERVICES WE OFFER



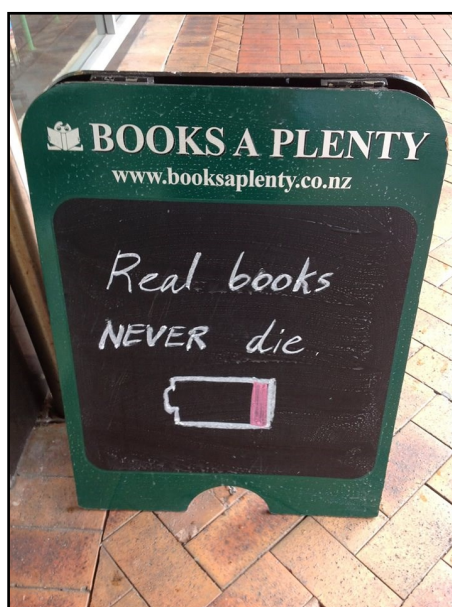
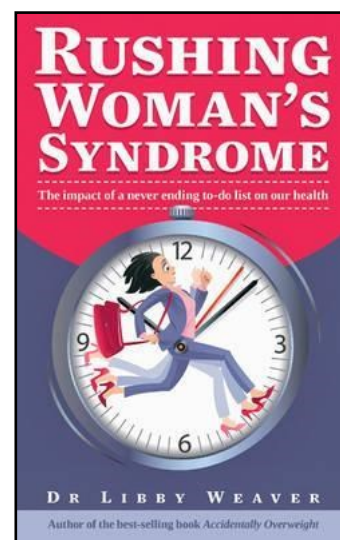


Rushing Woman's Syndrome

by Dr Libby Weaver

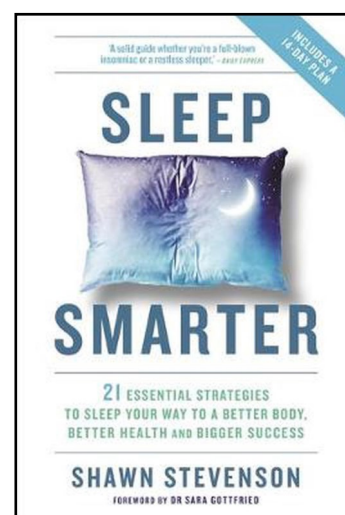
I found this book to be an easy and enjoyable read due to Dr Libby's conversational writing style. This book is written primarily for women as indicated in the title. Dr Libby offers scientific explanations of how stress affects the nervous system and our hormones. She offers practical strategies and suggestions to calm the mind and body, bringing together the spiritual, emotional, mental and physical aspects of health.

Charlotte



A big **THANK YOU** to **Books a Plenty** bookshop in Grey Street, Tauranga who have donated a new book to our library:

Sleep Smarter by Shawn Stevenson



Seed Crackers

I don't know about you, but crackers are my downfall when it comes to sticking to food that is nutritionally sound for my body. I found this recipe a few years ago and it works for me. I also substitute in and out seeds depending on my mood, if my quantity adds up, its good to go. I just add in more almond flour if I remove something altogether. I've also found adding in some pureed dates makes for a tasty, sweet cracker, making a great cracker for all round eating and a quick fix when I need it.



Tabitha Lakes FO

Ingredients

1/3 cup Almond Flour
1/3 cup Sunflower Seeds
1/3 cup Pumpkin Seeds
1/3 cup Flaxseed or Chia
1/3 cup Sesame Seeds
1 tbs Psyllium Husks (powder)
1 tsp Salt
1/4 cup Melted Coconut Oil
1 cup Boiling Water

Method

Preheat oven to 160 c

Mix all dry ingredients together in a bowl. Add water and oil and mix it all together(I would add in 1/3 c date puree here and reduce water). Let it rest for 10 minutes – this is important as seeds soak up the water and forms a dough.

Place dough between to sheets of baking paper and flatten with a rolling pin.

Either cut into squares or just bake it whole and break once cooked.

Cook for 20-40mins – keep a close eye on them, depending on your oven and cracker thickness.

Top with your favourite toppings or crumble over salad, ENJOY.



The Community Noticeboard

This is a space we have created in our newsletter to give locals and members the opportunity to share notices. Please email or call a Field Officer to add your notice for our next bimonthly newsletter.

U3A Tauranga



The purpose of U3A, (An international organisation), is to encourage further learning by listening, understanding, contributing and participating in discussion and relevant excursions about new topics.

There are just under 1000 members in Tauranga, with around 100 groups the members can join, from interests including Jazz and Blues, Current Affairs, History, Geology, to Hiking or even Ethnic Dining! Meetings are held in the members' homes or in local halls.

Once a month the members can meet at the Tauranga Yacht Club for a social morning where invited keynote speakers present illustrated talks of major interest

<http://www.u3atauranga.kiwi.nz/index.php>

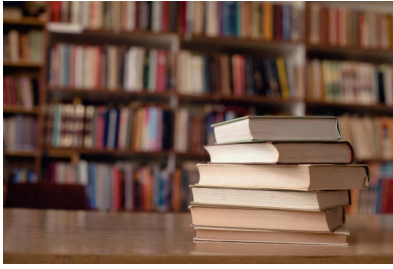
Yoga for Fatigue with Kasha Latimer in Hamilton.

I have been advised her next session will be held in July. Keep an eye out for more information coming soon.



It's important for planning, it's important for funding and it's important we get the service right for you. Please fill in the annual members survey attached and return to CCIS.

Thanks so much!! The team at CCI Support.



LIBRARY UPDATE

The Library Catalogue is now online or just drop in after the members meeting and have a look at the treasures on offer.

The CCIS Library is online, which means you will be able to browse through our library book titles from the comfort of your home. If you spot a title you would like to read, we can reserve it for you until you stop by and collect it. If you are interested in reading one of our many treasures, please stop by and check out a book, we have lots to choose from! We also aim to provide short book reviews to give you a quick synopsis of the books content for your online perusal. If you would like to support this mammoth bookworm task, we would love your short book review for our library. If you have any book recommendations to add to our library, relevant to the conditions we support, please contact your Field Officer to make a request. If you have borrowed a book that has passed its **4 week** return date, please could it be returned to the office ASAP. Please do not pass on books to other members of CCIS, they need to be returned and checked out by that person, you are responsible for any books checked out under your name. Thank you



FACEBOOK: Just a reminder, for paid members, we have an online members Facebook page. Keep up with the latest research, make friends and support each other.

Contact your Field Officer for more details.

REMEMBER: It's winter now!!! It is important to get a sensible amount of unfiltered light directly on the skin each day (for vitamin D absorption and melatonin release).



DONATIONS: We want to thank all those people who donate time and/or money to CCIS, on top of their annual subs. As a charitable organisation, we rely solely on donations, grants and subscriptions in order to provide the support for our clients. So every \$ counts. We are registered with IRD as being for charitable purposes, so donations are tax deductible over \$5.00. Donation receipts are sent by email unless asked to be posted. IRD now accepts receipts at any time of the year. Please check the IRD website for details on how to submit. Thank you for supporting us.

COMPLEX CHRONIC ILLNESS SUPPORT

Complex Chronic Illness Support Inc. is a charitable organisation that was set up in 1981 in the Bay of Plenty region to support, connect, advocate and educate people diagnosed with Complex Chronic Illnesses to improve the quality of their lives. We provide this service across the Bay of Plenty and Waikato including Tauranga, Whakatane and Rotorua.

THANK YOU TO OUR AMAZING SPONSORS AND DONORS



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