

# CCI Connect

September 2021



## ANNUAL GENERAL MEETING 2021 NOTICE

We warmly invite you to join us for our Annual General Meeting.

Our Special General Meeting  
will be held 30 minutes prior to the main AGM  
We will be covering some changes to the Constitution

For more information, please contact us on  
[info@ccisupport.org.nz](mailto:info@ccisupport.org.nz) or **07 281 1481 / 022 658 0251**

We look forward to seeing you!

**Saturday 25<sup>th</sup> September 2021**  
**Special General Meeting 10:30am**  
**Followed by the AGM straight after**  
**Venue: ONLINE**

53 FRASER ST, TAURANGA

Hours: Tuesday to Friday 9am till 2.30pm  
[info@ccisupport.org.nz](mailto:info@ccisupport.org.nz) 07 281 1481 or 022 658 0251



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## From Charlotte's desk in the Western Bay of Plenty



### Charlotte Kelp

Health and Wellness Facilitator

Phone or Txt:  
027 625 4449

Office Hours  
Wednesday and Thursday  
8am till 2.00pm

[WBOP@ccisupport.org.nz](mailto:WBOP@ccisupport.org.nz)

Greetings to our Western Bay of Plenty Members, I hope that everyone is surviving this chilly weather. We have some exciting changes happening in the Tau-ranga office with Karen Maxwell joining the team. Karen will be sharing my role in this area as well as supporting her national members.

I am currently managing a project getting our amazing Towards Wellness Programme online. This also means my office hours will

be changing to Wednesday and Thursday 8 am – 2 pm. A reminder to make use of our online booking system Cliniko, this is a great way to book a face-to-face appointment, an online appointment or a longer phone call at a time that suits you. You can also phone or email. Please reach out if you are needing support.

Stay warm, stay dry and stay safe  
Charlotte Kelp WBOP FO



## Lakes District—ROTORUA/TAUPO and EBOP

Well, It's been a few months of hibernation for me in the Lakes District. The winter has been a bit cold and wet, with pollen from all the pines spreading in the winds. I hope you are managing to keep warm, and your allergies are fairing better than mine are.

It has also been an interesting few months as I venture into the Eastern Bay of Plenty. It has been wonderful to meet our members in person. What a beautiful part of our country Whakatane is, the sun always seems to be shining when I visit.

My winter garden is however doing well. I managed to grow broccoli, cauli, cabbage, spinach, carrots and Brussel sprouts. Though I am ready for some warmer weather. It's been a great reminder to eat healthily and eat what's in season.

Keeping my diet healthy helps to manage my pain levels, though a few pieces of cake have sneaked in.

If you would like to get out a little more and socialise, as well as monthly meetings we have a monthly coffee group catch, and we would love to see you there. Unfortunately the Rotorua coffee group had to be postponed. Remember we do have online members meeting which you are all welcome to join.

Keep well and if you have any questions or concerns, please do not hesitate to reach out and make contact.

Bye for now  
Tabitha



### Tabitha Ramsay

Health and Wellness Facilitator  
Office Hours

Thursday and Friday  
9.30am - 2..30pm

Lakes

Phone: 020 4017 9091

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EBOP

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Email: [ebop@ccisupport.org.nz](mailto:ebop@ccisupport.org.nz)

## Greetings from the Wellington and National Desk.

Hi, my name is Karen Maxwell and it is a real privilege to be working alongside the dedicated team at CCIS as the new National Wellness Facilitator.

I am a mum of two teenage boys and currently studying towards a degree in a Bachelor of Applied Science (Psychology). I have worked in Community Pharmacy for the last 6 years and gained a certificate in Pharmacy (Community Pharmacy Assistant) Level 4.

Having experienced Chronic Fatigued Syndrome myself, I know how debilitating this illness can be and how it affects every aspect of one's life. Understanding the condition through education and having the support and guidance supports the recovery process and gain back the quality of life. I look forward to working with you to provide support and guidance with managing your illness and support you in your journey towards improved wellness.

Karen Maxwell



**Karen Maxwell**  
Wellness Facilitator

Office Hours

Thursday and Friday  
9am - 2.00pm

Wellington

Phone: 027 245 5961

Email: wellington@ccisupport.org.nz

National

Phone: 022 658 0251

Email: nz@ccisupport.org.nz

## From the Waikato Desk

Kia ora and welcome from the Mighty Waikato

My goodness, the year surely is zooming by. It is nice to see the daffodils out and the trees starting to bud with the promise of new growth readying themselves to bloom.

As a write today, we have entered Level 2. In the past we noticed many of you were anxious about reintegration back into the community as the lockdown levels decreased. To provide a sense of security in gathering together again at our support groups, the CCIS team have agreed that there will be no support groups until we are back in level 1. However,... great news!! Online meetings are continuing so keep an eye out in your inbox for the link to our next meeting.

Please remember that I continue to work during lockdown and can be reached by text, phone, or email. I have been having many conversations about the covid vaccine as there is a high level of worry among many of you. Please don't hesitate to be in touch to discuss your concerns.

Until next time, please take care.

Nga mihi  
Tracey Larsen.



**Tracey Larsen**

Health and Wellness Facilitator

Phone or Txt:  
022 154 7076

Office Hours  
Mon—Fri  
9am - 4.30pm

[waikato@ccisupport.org.nz](mailto:waikato@ccisupport.org.nz)

Here we are again, out of COVID-19 level 3 and back to level 2. What does this mean for CCI Support? The offices at Fraser St Tauranga are open, by appointment only.

NO group meetings will be happening in person until Level 1, but we do encourage you to join us online on for the Member's meetings, please contact us if you need help joining in. This months meeting is on BOUNDARIES!! Such an important one, no matter where you are on your journey.

We are completely aware that whilst many of our clients/members are most comfortable in 'lockdown' (doesn't it take that pressure off a bit to not 'go out'), we are also aware that reintegration AFTER the lockdown is particularly difficult for some. If you need extra support, please make contact with your Facilitator.

**Miranda Whitwell** - CEO



## 40th Celebration

On 3rd July 2021, CCI Support came together in Tauranga to celebrate the 40th anniversary of the organisation supporting people in the Bay of Plenty. We had Dr Ros Vallings, Dr Sarah Dalziel and Emeritus Professor Warren Tate speak, and had a lovely lunch and cake. It was an awesome day with 110 people sharing the occasion and we want to thank the Board, Staff and Volunteers past and present for their dedication and hard work over the years.

The Videos for the event are now available on our [YouTube Channel](#) and the PowerPoint Handouts will be available in the member resources on the website or available on request as soon as possible.



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## 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 [info@ccisupport.org.nz](mailto:info@ccisupport.org.nz) for more information

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## Top 10 Tips to Deal with Covid



### **1.Sick...**

Stay home, get tested

### **2.Keep up with MOH guidelines**

But don't dwell

### **3.Use contactless options**

Telehealth, phone appointments, delivery services

### **4.Vaccination**

Recommended

### **5.Stay savvy**

Listen to official sources

### **6.Long Covid research**

This may benefit us long term

### **7.Protect your emotional health**

Seek professional support if needed

### **8.Ask for support**

Reach out

### **9.Remember health foundations**

Sleep hygiene, nourishing foods, gentle movement

### **10.Good self-care**

It's vital

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### **Mental Health Foundation**

Looking after mental health and wellbeing during COVID-19 <https://www.mentalhealth.org.nz/get-help/covid-19/>

### **Anxiety around COVID-19**

Care for your Coronavirus Anxiety by Shine Tool kit – Resources for anxiety and your mental health in a global climate of uncertainty.

[https://www.virusanxiety.com/?](https://www.virusanxiety.com/?fbclid=IwAR2BZPuM9wJunh528RErEZHyry92PBdzk5aMNLjHfzc7luPl1Mi5v0ZYK1k)

[fbclid=IwAR2BZPuM9wJunh528RErEZHyry92PBdzk5aMNLjHfzc7luPl1Mi5v0ZYK1k](https://www.virusanxiety.com/?fbclid=IwAR2BZPuM9wJunh528RErEZHyry92PBdzk5aMNLjHfzc7luPl1Mi5v0ZYK1k)

## 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 in May 2021 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



## Useful Links

### Reliable information on COVID-19

For all your questions around COVID-19 from alert levels to financial support  
<https://covid19.govt.nz/>

### Booking a Covid-19 Vaccination

<https://bookmyvaccine.covid19.health.nz/>

BOOK OVER THE PHONE

You can call the COVID Vaccination Healthline 8am–8pm, 7 days a week.  
**0800 28 29 26**

### Time In The Line

Check on available Covid 19 vaccination appointments.  
<https://timeintheline.co.nz/>

## **Monthly Members Meetings.**

October focus is **POTS/OI/NMH Awareness month**

November focus is **Nutrition and why it's important**

December focus is **Managing the festive season**

*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.*

*Please note all meetings will be held online under Covid 19 Alert Level 2 or above.*

### **Tauranga**

Second Thursday of the month 10.30 - 12pm

53 Fraser St

**October 14th**

**November 11th**

**December 9th**

### **Hamilton**

Second Thursday of the month 10.30 – 11.30.

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

**October 14th**

**November 11th**

**December 9th**

### **Whakatane**

Second Wednesday of the month at 1.30 pm

Whakatane Lyceum Club Rooms - 58 Domain Road Whakatane

**October 13th**

**November 10th**

**December 15th**

### **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

**October 15th**

**November 12th**

**December 10th**

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### **Counselling available**

Rachel, our 2nd year counselling student in Tauranga has 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 for enquires. [wbop@ccisupport.org.nz](mailto:wbop@ccisupport.org.nz)

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.

## 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.

Please note we will advise members of any cancellations due to Covid-19 alert levels. **These only run in LEVEL ONE!**

### Greerton Coffee Group

Venue: Greerton Mitre 10 Mega (3rd Wed of each month) 10.30am  
**October 20th**  
**November 17th**

### 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**  
**October 6th**  
**November 3rd**

### Young at Hearts Social Group

Venue: CCIS Offices, 53 Fraser Street, Tauranga  
(12.30pm - 2pm 4th Tuesday of each month)  
**October 26th**  
**November 23rd**

### EBOP Coffee Catchup

4th Tuesday of the month at 10.30am  
**October 26th** - Whitehouse Café—8B Thornton Road  
**November 23rd** - Quay café—22 Pohutakawa Ave, Ohope

### Waikato Social Group

Jukebox Diner at 2pm  
**October 26th**  
**November 23rd**

### Young Ladies Hamilton Social Group

Please contact Tracey for more information

### Cambridge Social Group

Please contact Tracey for more information



<https://imgflip.com/i/1pco3u>

Tracey can be contacted on [waikato@ccisupport.org.nz](mailto:waikato@ccisupport.org.nz) or phone/Text 022 154 7076

### Te Awamutu Social Group

**Thursday 7th October, 1pm, Gillz Cafe**  
**Thursday 18th November, 10.30am Gillz Cafe**  
**Thursday 16th December, 10.30am Columbus Cafe, Mega Mitre 10**



# Empowering People Towards Wellness – A Management Perspective

## These are the personal ponderings from the CEO of CCI Support

As CEO of Complex Chronic Illness Support, I am often asked about our tagline “Empowering People Towards Wellness”. Depending on who you are and how you’ve got to where you are, as well as your understanding of the conditions that CCIS support, you may have your own understanding of what that tagline may mean.

I want to break down what it means to me, as the person in the management role of the organisation.

**Empowering** – When people come to CCI Support, they could be accessing it from a referral from their Health Professional. Someone who recognises the symptomology and realises that with their limited resources, the support they can provide that person is limited. Or they could be accessing our services directly, after years of tests that provide no diagnosis, just being used to rule things out. They could be in a situation that they recognise their body isn’t functioning ‘well’ and at the end of their rope of how to ‘fix’ themselves, because they want their ‘life’ back. They could have been medically gaslit, and told ‘it’s all in your head, a psychological condition’. But for almost all of the people who come to us... they have been disempowered. They no longer have control over their bodies, they didn’t ask to be unwell, their health is not only affecting them but their homes, relationships, financial situation and so much more. For the most part, it’s been after a virus or infection has attacked them, and they never fully recovered – or they did from the initial symptoms, but new symptoms have taken over.

Empowering someone is to “make (someone) stronger and more confident, especially in controlling their life”. Has CCI Support got all the answers? No, we are first to admit that we don’t. There is no ‘magic pill’ and no ‘fix’, but we do give people tools to take control of their symptoms – or at least teach them to manage them better, within their limitations. That may even mean that they are able to be stronger mentally to deal with what has and is happening ‘to them’. Sometimes empowering someone is as simple as acknowledging what they are going through. Giving them validity. Other times it’s teaching them more skills like pacing, boundaries, nutrition, or an understanding of their condition/s. Knowledge is power – I learnt that as part of my high school tagline. We aim to support them by authentically caring for them holistically. Seeing the ‘bigger picture’.

**People** – It’s an absolute given that we work with people who present with symptomology of ME/CFS or Fibromyalgia and related conditions and symptoms, but we are not limited by that. A person very rarely is completely isolated. They have someone who has or is walking through life with them, and these illnesses affect them too. They often are dealing with grief and loss, an unintentional lack of understanding of what the person is going through. With a little education, support and if necessary, some counselling, they are able to offer more support and understanding to the person afflicted with these conditions.

**Towards** refers to the journey. Many people with complex chronic illnesses, such as ME/CFS and Fibromyalgia struggle. They may look well but feel ‘unwell’ or are in constant pain or misunderstood. There is no ‘cure’ and despite some claiming graded exercise therapy (GET) [\[1\]](#) [\[3\]](#) and Cognitive Behavioural Therapy (CBT) being good treatments, research is very clear that ‘treatments’ such as these are actually more harmful than beneficial.

We work with people to identify what parts of their lives are affected and provide tools and support for them to work on or improve these areas. We are ‘the guide by the side’ in the journey. I believe that on your own an illness can be overwhelming but have a tribe of people who authentically have your best interests at heart, and we can turn the I into We and from the Illness onto a step on the journey towards ‘wellness’. A person doesn’t need to walk the journey alone. There are people that understand, CCI Support understands, people also walking this journey can understand, and with support your loved ones can understand. With a tribe, we can help these conditions become less isolating.

Does this mean the journey will always be a straight line upwards with a state of wellbeing at the end? No such luck, life isn’t like that, and life can be particularly unfair at times. A journey is not the destination. There will be many crashes and ups and downs, but with the right tools, a person can learn to understand and/or take control over how these crashes affect them and how severe or debilitating they can be. That’s the goal anyway.

## Wellness

Does wellness mean recovered? Not at all. For people with chronic conditions, such as ME/CFS, there is a wide spectrum of where a person may sit as far as functionality goes. We know there is no 'cure', no 'quick fix' or 'magic pill'. We are completely aware that 25% of people with myalgic encephalo-myelitis (ME), will be classed as severe or very severe. Meaning being housebound or bedbound at some point in their illness,<sup>[2]</sup> typically needing to use a wheelchair, unable to do any kind of work or study, and often unable to do basic self-care activities unaided. For these people on their journey 'towards wellness' it may mean their goal is to walk to the gate or even to the front step. It might be that they can even just shower themselves. CCI Support will provide encouragement for them to reach for a realistic goal that they choose to make for their journey. Empowering them to recognise their limitations and safely make changes that will help them reach their goal.

For others, wellness is an understanding of their bodies, their warning signs, their ability to 'function' within the life they have created or want to create for themselves.

CCI Support does not see wellness as a destination... it's increasingly improving and reaching the realistic goals we choose to make on the journey. With many ups and lots of downs too.

Recently, it was said that CCIS works 'alternatively', because how can people with ME/CFS ever be 'well'? CCIS Support provide a holistic service, and that means that we look at a person as more than 'a condition' or their illness/es. We completely understand that as humans, there are many facets to us. Our health affects not only our physical health, but our mental health, our relationships with loved ones and friends, our livelihoods, our finances, our homes, our spirituality (whatever that means for you) and in fact every area of this doesn't work in isolation. This isn't alternative thinking... within the health industry and my own training as a registered nurse, this was the only thinking.

So, the fact we provide alternative therapies to achieve that couldn't be further from the truth. We align our services on evidence-based research. But we are also open to the fact that sometimes what works for someone, will not work for another and sometimes anecdotal evidence can sometimes provide some answers and be acceptable too. Who are we to disempower someone, by telling them they 'have to/cannot do' certain actions in order to reach their 'state of wellness'? I don't know about you, but as our bodies age, our idealistic view of 'wellness' changes. For one, it might be being perfectly 'healthy' (do you know anyone who is PERFECTLY healthy?) or it might be a deeper understanding that "I am happy with where I am and where my health is". We understand that as part of a person's 'journey' is a privilege and with that comes a responsibility to provide the best support we can for people going through something so incredibly difficult. We aim to support people in 'their' individual journey.

Everyone's journey is unique, I haven't even met two people going through the same exact symptoms with the same co-morbidities. Our clients and members certainly have similar stories, but each journey is different. We provide appropriate resources, support and tools to be the 'guide by the side' and part of their 'tribe', as we want people to live the 'best life they can', irrespective of circumstances.

Miranda is a Registered Comprehensive Nurse by training and now the CEO of CCI Support, since 2019.

## Reference:

[1] Vink, M., & Vink-Niese, A. (2018). Graded exercise therapy for myalgic encephalomyelitis/chronic fatigue syndrome is not effective and unsafe. Re-analysis of a Cochrane review. *Health psychology open*, 5(2), 2055102918805187. <https://doi.org/10.1177/2055102918805187> Institute of Medicine (U.S.)

[2] Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Beyond myalgic encephalomyelitis/chronic fatigue syndrome: redefining an illness*. Washington, D.C. p. 32. ISBN 9780309316903. OCLC 906233426.

[3] [https://m.e.awareness.nz/statements-from-academics?](https://m.e.awareness.nz/statements-from-academics?fbclid=IwAR2tG1esL6oIP_7XcwuYB2NxpSn0SXYbHbAznya9dhYrn-8ldgKrWSlqQp8)

fbclid=IwAR2tG1esL6oIP\_7XcwuYB2NxpSn0SXYbHbAznya9dhYrn-8ldgKrWSlqQp8

# JUNE MEMBERS MEETING

## HOW TO GET GOOD REST

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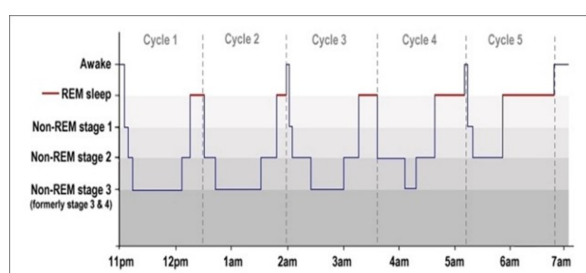
Rest is a natural requirement for the human body. It allows the immune system the essential resources it needs to heal and restore. Sleep naturally provides restoration, but for many with ME/CFS sleep is disrupted, disordered, non-refreshing.

Today we will be discussing sleep cycles, the impacts of disordered sleep, and sleep hygiene ideas. The importance of rest and four types of rest will be discussed through the lens of the Maori Health model of Te Whare Tapa Wha and we will also share some great words to encourage a change in your mindset around resting.

## Sleep

### Sleep Cycles

The pineal gland releases melatonin to control our body clock, with peak levels occurring at night to make us feel drowsy. Regular exposure to daylight maintains our body clock rhythms and regulation of melatonin. We cycle through 4 stages of sleep several times during the night, each cycle lasting approximately 90 minutes.



<https://www.mattressadvisor.com/sleep-stages/>

### Chemical reactions during sleep

Growth hormone is released during the deep sleep stage 4 and REM sleep, which is responsible for the many repair and restorative processes that occur. During these stages, the brain also ceases active processing, which adds to high quality sleep.

With ME/CFS & FM, it is suggested that the deep sleep state and REM sleep is inadequate, so regardless of whether you sleep 16 hours or day or only a few, restorative processes are not fully functioning. A vicious cycle starts – healing is insufficient which impacts Growth Hormone function, which is required for healing and restoration.

### Impacts of Disordered Sleep and Sleep Deprivation

With hypothalamic dysfunction causing disordered sleep, a vicious cycle therefore begins with poor sleep further suppressing the hypothalamus and growth hormone production. Pain and fatigue also impact sleep, making it difficult to get to sleep.

Getting to sleep can be difficult for many living with ME/CFS & FM. This is due to the continually aroused stress response in the body making quieting the brain waves into the delta zone, which is needed for sleep, difficult or impossible. You may know this state as being “wired but tired”.

Sleep becomes fitful and is devoid of calm when you do not obtain enough deep sleep and REM sleep. The mind remains alert, and you may find your legs restlessly move in response to pent-up muscle

tension. It can have profound effects on thinking, emotions, and physical health. Sleep deprivation results in immune dysfunction, and blood pressure, hormonal systems, temperature control systems maybe impacted. An increased risk of cardiovascular complications may also occur.

### Strategies/Sleep Hygiene

So, what can be done to help you get to sleep, stay asleep and have quality sleep? Routine is very important before sleep, if you don't have one, create one! Sleep hygiene is a name given to a night-time routine you undertake before going to bed that tells your brain and body you are preparing for sleep. What are your routines? What strategies do you use?

#### Ideas to consider:

1. Get at least 10-15 minutes of sunlight directly on your face/skin without sunglasses each day where possible. Sunlight regulates melatonin production
2. Ensure your bedroom is cooler than the rest of the house. Have a window slightly ajar to allow cool air in
3. Dr Sarah Myhill states the importance of having a dark bedroom. Any glimmer of light on your skin will reduce melatonin production. So, ensure you have heavy curtains and no light peeking through. If your bedroom is lit by a streetlight contact the council and have them change the light to a yellow/red light or ask to have it put on a timer, so it turns off
4. Check the light bulbs in your house, if they are white or bright, change them to warmer tones
5. Reduce the amount of screen time in the hours leading up to bedtime. Screens contain blue light which stops the production of melatonin. Or try screen filters/glasses of yellow or amber shades
6. Studies have shown. Access to a screen-media device in the bedroom at night is associated with shorter sleep duration, later bedtime, and poorer sleep quality. The studies suggest turning off screens and devices one hour before bed to reduce impact on poor sleep quality
7. Undertake a sleep study if you can to determine whether sleep apnoea is an issue for you. Very important to treat sleep apnoea
8. In the hour before bed – create a routine
9. No stimulation. No adrenaline producing movies, no arguments, no family matters discussions, park them for the evening to be picked up the next day. Avoid coffee after mid-afternoon. Avoid Alcohol
10. Limit fluid intake after 6pm if our sleep is disturbed with the need to pee
11. Apply some relaxation practices in the evening. Gentle stretching to ease tension, breathing, meditation to help calm the mind
12. A warm bath or shower before bed can be helpful for some
13. A small carbohydrate snack before bedtime can help reduce nocturnal hypoglycaemia, which manifests as night sweats and vivid dreams, which disrupts sleep
14. Symptom relief is vital to ensure an undisturbed night. Take appropriate pain relief and medications for sinus, reflux, nausea etc..
15. Consider sleeping in separate beds if your partner snores
16. Dr Sarah Myhill speaks of creating a sleep dream. This is using visualisation to image yourself in a relaxed warm comfortable space where sleep comes easily to you
17. She also speaks of the sleep wave. Sleep doesn't quietly creep up on us in the evening, it comes in waves every 90 minutes or so. You may find yourself nodding off in from of TV at 7.30, then after

a time you are more awake again. So, by 9.00pm another sleep wave will start to hit, so be in bed by this time so you can" ride the wave" to sleep

## **Resting**

It has been suggested by Dr Dalton-Smith in her book Sacred Rest that

**"Good sleep results from good rest"**. Approaching sleep in a restful state may assist the ability to fall asleep sooner and help provide a more restful, restorative sleep. Although the author does not focus specifically on ME/CFS/FM, some of her ideas are very fitting.

I can relate Dalton-Smith's book to that of Te Whare Tapa Whā, a Māori Framework for Health. It speaks of the balance between 4 keystones of wellbeing – physical health, mental health, relationships/family and spiritual health. All 4 foundations need to be strong to hold up the roof of the house (the human being). With ME/CFS/FM, at least one keystone is impacted. Naturally physical health is one, and with chronic health conditions so too can emotional and mental health be impacted. When our health impacts our goals and dream for the future, this can then impact our spiritual health.

So let's look at resting through the lens of this framework. Today we will briefly look at **4 Types of Rest – Physical, Mental, Emotional and Spiritual**.

## **Physical**

HOW MANY OF YOU ATTEND TO PHYSICAL RESTING? WHAT STRATEGIES DO YOU APPLY?

Are you suffering from physical rest deficit? (Are you living outside of your energy envelope?) Signs include:

- Lack of energy
- Tired but wired
- Frequent episodes of cold and illness
- Frequent muscle pain and soreness
- Depend on substance for energy – caffeine, sugar
- Depend on substances to wind down – alcohol, drugs, medication, comfort food

## **Ideas on how to Physically Rest**

Active physical rest – stretching, breathing exercises, soaking in the bath. This form of rest releases tension in your muscles and restores calm to the body

Listen to your body and note where the tension is held

Passive physical rest - lying down either flat on the ground or with legs raised on the couch or up the wall, whatever you find most comfortable. Focus on your breathing

Be in a quiet environment to allow your senses to rest also

## **Mental**

HOW MANY OF YOU ATTEND TO MENTAL REST? WHAT ARE YOUR STRATEGIES?

Mental Rest Deficit signs include:

- Brain Fog!
- Can't mentally keep up with conversations or your to-do list
- Experience irritation and frustration when thinking about your day
- Avoid activities in the fear of error or failure
- Snappy at others over irrelevant things
- Feel overwhelmed by daily tasks



## Ideas on how to Mentally Rest

Observe what thoughts occupy your mind. Don't analyse, judge or try to understand them, just notice and acknowledge your thoughts

Create a mental sanctuary to allow the mind to rest. Choose to reframe from any negative thoughts and think caring and nurturing thoughts of love, joy, kindness, gratitude, peace, gentleness

Make a conscious effort to fill your mental space with restorative thoughts daily. Positive affirmation statements can be very helpful.

*"I accept the things I cannot change..."*

## Emotional

HOW DO YOU ATTEND TO YOUR EMOTIONAL REST? WHAT STRATEGIES DO YOU USE?

Many things can lead us to emotional fatigue

- Regular negative emotional exposure from others. Trying to live up to demands, and societal expectations

- Feeling undervalued in your relationships and associations

- Feeling pressure to regularly "perform"

- Not living your own authenticity and truth (not accepting your health limitations)

Are you suffering from emotional rest deficit? Signs include:

- A tendency to focus on failures and flaws

- Self-doubt and insecurity, which prevent you from trying new things

- Constantly compensate for who you are with apologies or clarifications

- Beat yourself up when you make the smallest mistake

- Feel depressed and angry when you think about your life

- Excessively worry or display feelings of anxiety about your situation

## Ideas on how to Emotionally Rest

- Practice mindfulness to notice your emotions. Acknowledging our emotional feelings can help to release them from being bottled up

- Practice S.T.O.P

**S** = **S**top, be still, sit down

**T** = **T**ake a slow deep breath, with long exhale

**O** = be **O**pen and observe, what is going on right now physically, emotionally mentally. Notice sounds, smells, etc..

**P** = **P**roceed mindfully, be kind to yourself and others

Cease comparisons between yourself and others – comparisons limit individuality and destroy the ability to be authentic. Trying to fit in is emotionally exhausting. Stop hustling for your worthiness. Instead rest in the self-awareness of your uniqueness

- Risk Vulnerability – When we conceal our truth or deny our reality, we only hurt ourselves. Accept your health and diagnosis, knowledge is power

- Be emotionally aware – notice how toxic personalities impact you negatively. Evaluate your relationships, make appropriate changes by putting in place personal boundaries

## Spiritual

HOW DO YOU ATTEND TO YOUR SPIRITUAL REST? WHAT STRATEGIES DO YOU USE?

ME/CFS may result after traumatic experiences. Trauma can leave us feeling broken. The dictionary defines "broken" as shattered into separate parts, disconnected, disunity, not complete. Trauma, including chronic illness, penetrate into our very soul, the core of our being, breaking our faith and

wounding the spirit causing a disconnect with ourselves. It changes how we view ourselves. (Note: faith can be religion, or some other spiritual system that can bring enlightenment and security to your life).

#### Signs of Spiritual deficit rest

- Decreased satisfaction and sense of accomplishment
- Feeling helpless, hopeless, trapped or defeated
- Lack of motivation
- Feeling numb and apathetic or depressed

#### Ideas on how to Spiritually Rest/Tend to your Spirit

- Find ways to nourish and replenish your soul that encourages the creation of a loving relationship with yourself
- Participate in activities that make you feel whole, more alive and at one with the universe
- Read books or watch movies that inspire you
- Try new things like yoga, meditation, prayer
- use encouraging affirming affirmations
- Notice the beauty in nature – a sunset, a moonrise, colour of flowers and leaves changing in the seasons
- Be creative with art or writing a journal about your experiences
- Use mindfulness and give yourself permission to feel the range of emotions associated with your brokenness
- Listen to music that speaks to and soothes your soul
- Humour is good for the spirit, body and immune system. Also helps with maintaining a positive attitude and a healthy perspective. Give yourself a reason to laugh everyday – learn to laugh at yourself too
- If nothing else, make peace with where are right now in your life
- Know that your value is not in what you accomplish or what you own, but simply in the fact that you exist
- Give yourself permission to nurture and love your whole being and who you are

#### Do you feel guilty resting? Do you think you are being lazy?

Here are some snippets from Sacred Rest by Sandra Dalton-Smith that may encourage a change in your mind-set.

*"There has to be a bridge between good and bad sleep, and that bridge is rest. Sleep is solely a physical activity, Rest, however, penetrates into the spiritual. Rest speaks peace into the daily storms your mind body and spirit encounters. Rest makes sleep sweet".*

*"I am resting because my body is weak, I need to remember that I am not wasting the day doing nothing. I am doing exactly what I need to do. I am recovering.*

*"Rest is about replenishing, restoring, renewing, recovering, rebuilding, remoulding, and repairing".*

*"Rest is a vital activity required to attend to the garden of our lives. Rest is the water that replenishes dryness, the fertilizer awakening us to growth and greatness".*

*"The body requires an opportunity to heal, and rest from movement, the mind a reprieve from thinking, emotions need a release and the senses desire to be quietened".*

*"Exchange guilt for the freedom to choose best".*

*"It means saying NO, having limits with ourselves and others. It takes courage to rest in the midst of an outcome driven society".*

*"Watching TV as a means to rest – escapism is not rest".*

# AUGUST MEMBERS MEETING

## WHAT RECOVERY CAN LOOK LIKE

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For many people living with ME/CFS/FM, they dream of 100% recovery, but with Chronic Illness this is sometimes not possible and can be an unrealistic target.

Seeing "recovery" as being an improvement in your health to a point where you can live a productive, fulfilling life is a great goal to aim for. Some may be able to return to work, part time or full time, or find other meaningful ways to contribute to their family and society on a consistent, committed basis.

Many report that their life is more meaningful now, than prior to their illness and they live more authentically.

Many report that their functioning levels are not at 100%, but more realistically at 75-80%.

Where are you on your journey?

Where have you been?

Where are you now?

### The ME/CFS & Fibromyalgia Rating scale

100	Fully recovered. Normal activity level with no symptoms
90	Normal activity level with mild symptoms at times
80	Near normal activity level with some symptoms
70	Able to work full time but with difficulty. Mostly mild symptoms
60	Able to do about 6-7 hours of work a day. Mostly mild to moderate symptoms
50	Able to do about 4 – 5 hours of work a day, or similar activity at home. Daily rest required. Symptoms mostly moderate.
40	Able to leave the house up to 5 days per week. Moderate symptoms. Physically active 3 – 4 hours a day
30	Leave the house several times a week. Moderate to severe symptoms. Active 2 – 3 hours a day
20	Leave house once or twice a week. Moderate to severe symptoms
10	Leave house occasionally. Severe symptoms
0	Bedridden. Unable to care for self

How does today's rating compare to when you were first ill? The 2<sup>nd</sup> year? Last year? Have you seen your illness rollercoaster up and down? Steadily improve? steadily decline?

### Raelan Agle – 20 personal stories of recovery

<https://www.youtube.com/watch?v=kX6zyGDGKrl>

Raelan has recovered from her own experience of ME/CFS. She has created a lot of video clips on you tube, sharing her own journey to recovery. She has also interviewed many others who share their stories too.

In the link above she brings together the key themes of everyone's stories that was instrumental in their recovery.

Mindset

Everyone speaks of a belief that they can recover. They held determination and a refusal to not give up.

However, they spoke of how the journey was not linear and they allowed depression to walk beside them in their journey. They still experienced peaks and troughs but never gave up.

**Pacing** It was important to get out of the boom-and-bust cycle. Acceptance of their limitations was key!

### **Stress Management**

Getting stress under control. Relaxation practices and meditation were some of the strategies used to bring a state of calm to their lives.

Recovery-focused

Made themselves number one priority in their lives. Deprioritised outmoded ideas/habits/relationships

Listen to their own intuition/gut instinct

They followed ideas that resonated with them. There are many ideas, diets, supplementation, programs on offer that can be followed. Raelan speaks of the small fortune she spent seeking "the magic bullet". All her interviewees spoke of listening to the different ideas, but ultimately followed only the ones they resonated with.

Raelan speaks of the many paths her interviewees took, which highlights the need for a holistic approach.

What they did NOT do was rest their way out of ME/CFS. Yes, rest is an important component, but total rest made them feel worse. Sometimes short-term total rest is required, for a few days, but not for weeks or months on end.

Hope alone also did not work. Action is required!

The holistic approach that was a common theme among the interviewees were:

- Diet – some followed vegan, plant based, keto, paleo, anti-inflammatory diets, carnivore diets

- Gut health – supplementation, fasting

- Energy medicine

- Ayurveda/Indian medicine

- Movement - increase slowly as able

- Healing trauma's/counselling/psychologist involvement

- Healing mould toxicity/detoxing

- Relaxation strategies

- Living more authentically

## **Shannon Emelia - 2020 Chronic Fatigue Syndrome Year Review** **(My recovery story) 10% to 60%**

[https://www.youtube.com/watch?v=ef7x\\_uVOPVM](https://www.youtube.com/watch?v=ef7x_uVOPVM)

In this video Shannon describes her year, month by month of her progress from 10 % functioning in January 2020 to 60% in December 2020 . What she highlights is that throughout the year her energy and activity levels yoyo a little bit but ultimately, she sees a steady improvement throughout the year.

At the 18 minute mark of this video she lists three things that she credits to her increase in the rating scale from 10% in January 2020 to 50% by October 2020.

**Diet** – paleo/keto diet

**Vitamins and mineral regime** – Daily doses of B12, Vit C, Di ribose, Magnesium, C0Q10, Hemp seed oil, B3, Vit D, Multi mineral supplement, (8.39mins into video)

**Pacing**

Supplement regime as prescribed by Dr Sarah Myhill.

# SEPTEMBER MEMBERS MEETING

## HEALTHY BOUNDARIES

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**"Daring to set boundaries is about having the courage to love ourselves,  
even when we risk disappointing others" Brené Brown**

Creating healthy boundaries is important for our physical and emotional health. This is especially true for those living with chronic illnesses. We have more constraints around our energy and our ability to give to others. On a positive, chronic illness can allow us to go inwards, to clarify our values, what is important and how we want to be treated by others. These insights form the foundation for boundary setting. This handout will discuss what boundaries are, why healthy boundaries are important and how to create them. Creating healthy boundaries is empowering!

### **So, What is a Boundary?**

*"A boundary is a limit or space between you and the other person; a clear place where you begin and the other person ends . . . The purpose of setting a healthy boundary is, of course, to protect and take good care of you"* (IPFW/Parkview Student Assistance Program. n.d.).

An easy way to think about a boundary is to think about a fence around your home. The fence prevents people from wandering into your garden and clearly defines your space. Personal boundaries, just like the fence around the house, define where you end, and others begin. They are determined by the amount of physical and emotional space you allow between yourself and others.

### **Why Should I Set Boundaries?**

Each person's boundaries are a reflection of their individuality and uniqueness. Importantly, for those of us with a chronic illness, setting healthy boundaries can allow us to preserve our precious energy, live within our energy envelope and support pacing. Not setting clear boundaries can lead to resentment and anger as we try to meet other people's needs before meeting our own.

Healthy boundaries can help us to feel at ease, in control and respected. They also give us time and space to recharge, recentre and reflect.

### **Setting Healthy Boundaries Allows you to...**

- Practice self-care, self-esteem, and self-respect
- Communicate your needs in a relationship
- Make time and space for positive interactions
- Set limits in a relationship in a way that is healthy
- Protect your emotional and physical space from intrusion
- Have equal partnerships where the power is shared

### **Self-compassion and Boundaries**

Self-compassion provides the foundation for setting boundaries. This means developing a healthy, solid relationship with yourself and connecting with your inherent self-worth. With this baseline of self-esteem, you naturally become clearer about your own needs and will be better able to set appropriate and healthy boundaries.

### **How to Create Healthy Boundaries**

BE ASSERTIVE. ASSERTIVENESS MEANS COMMUNICATING YOUR BOUNDARY IN A FIRM BUT KIND WAY.

Use your no as a complete sentence. This can be daunting at first and can take practice.

You can also set boundaries for your time and energy without announcing it e.g. not answering texts or phone calls after a certain time

Reach out for support if you are struggling to implement or maintain a boundary



## Selfishness vs Self Responsibility

Feelings of selfishness or guilt can surface when we begin to assert our boundaries. We can feel guilty when we prioritise our own needs over others and begin to ruminate whether this will affect the relationship. This is not surprising given the nature of our society, reflected in sayings like "pull yourself up by your bootstraps" and "toughen up".

Remind yourself you have a right to self-care and looking after you is your priority. Furthermore, when we do have the capacity and choose to give to others, we do it from a place of authenticity - without feeling depleted or resentful. Setting boundaries is a skill, which gets easier the more you practice. The more you practice, the less guilt you will feel. People will also become more accustomed to your boundaries.

## When Setting Boundaries

- Be respectful, calm and clear
- Use as few words as possible and be firm
- Do not apologise or justify
- Start with smaller boundaries and work up to harder ones
- Practice, this is a process, start with people who will be on your team
- Learning to set boundaries takes time

## Encountering Resistance

You are not responsible for the way another person reacts to your boundaries. If a person is not used to you setting boundaries they may be surprised, shocked or upset. Waking up to a boundary can be a problem for some and you may start to feel some resentment from them. This is a good sign! Be prepared for this and plan your response rather than reacting.

## Hurt vs Harm

If people react negatively when you set a boundary, this does not make you 'bad' or 'wrong'. The question is when you set the boundary did you hurt or harm them?

Hurt means temporarily hurting a person's ego/feelings/putting their nose out of joint

Harm means damaging their spirit at a fundamental core level

## 9 Boundaries I Have Set to Live my Best Life

by ME/CFS recovery blogger Liz Calson

- [1. I set my own pace.](#)
- [2. I say "no" without an apology or detailed explanation.](#)
- [3. I say "goodbye" when I'm ready to go.](#)
- [4. I ask for what I need.](#)
- [5. I remind myself that other people's energy \(and what they say or do\) cannot affect me.](#)
- [6. I wait to respond.](#)
- [7. I carve out time for what's important to me.](#)
- [8. I don't hold myself responsible for taking away someone else's pain.](#)
- [9. I do all the above with a recovery mindset.](#)



## And Finally...

Be respectful of other people's boundaries. Often people will give you verbal and physical cues about their limits. Notice their body language. Ask questions if you are not sure, e.g. Would you mind if I called you at 7 pm? May I ask you a personal question?

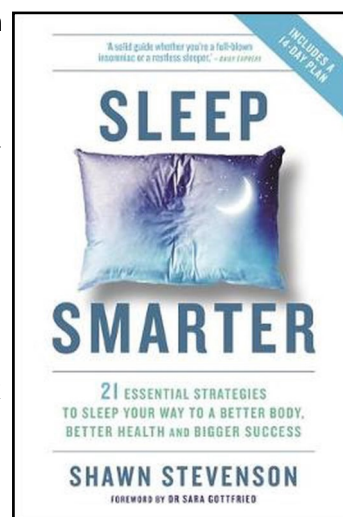
We have just scratched the surface of boundaries. If you are interested in learning more the course below is fantastic, you can take it in bitesize chunks, pause and rewind, all from the comfort of your own home. The concepts and information are accessible and easy to understand. Thank you to Dr. Henry Cloud and Dr. John Townsend for making this available online. They have also published a book if you prefer this format.



## Sleep Smarter

by Shawn Stevenson

Sleep is an essential part for the function of your mind and body, however many of us struggle to get the right amount and quality of sleep our body requires. In the book *Sleep Smarter*, Shawn Stevenson provides an explanation of why sleep is important for our health and the consequences of poor-quality sleep. Stevenson provides twenty-one strategies on how to improve your sleep and sleep patterns. I found this book to be written in clear language with easy-to-understand examples, however some of the scientific research quoted may require further reading. The end of each chapter has tips one can implement every day from all aspects of life from nutrition, exercise and your sleeping environment. The book also includes a fourteen-day sleep-makeover plan and a lot of further references. If you are struggling with sleep and are after an easy read with practical advice, this book is for you!



Karen Moulton

Book is available to borrow from the library

## Do you love reading and reviewing books?

CCI SUPPORT WOULD LOVE TO HEAR FROM YOU IF READING AND WRITING BOOK REVIEWS ARE YOUR THING. PLEASE CONTACT US IF YOU ARE INTERESTED IN REVIEWING SOME OF THE BOOKS IN OUR LIBRARY  
INFO@CCISUPPORT.ORG.NZ



<https://www.pinterest.nz/pin/462322717977193618/>

## **Blueberry and Cashew Cheesecake – Revive Cafe**

Lockdown destroyed all my 40<sup>th</sup> birthday plans so we decided to do a potluck dinner instead 3 weeks late, but still nice to celebrate. So out came my Revive Café Cookbook – which contains some wonderful DF, GF, SF recipes. I chose a Blueberry and Cashew Cheesecake (though hubby insists its not a cheesecake because there is no cheese) and OMG I was not disappointed this is a beautiful dessert for those who are DF, GF, SF. Desserts are my weakness so having a beautiful dessert that won't hurt my tummy is a win, it taste amazing and didn't actually take that long to make. With Christmas fast approaching I thought I would share. Doesn't it look licking lips good. (Photo of my finished cheesecake)



### Base Ingredients

1 cup cashew nuts  
1 cup almond  
1 cup dates  
½ boiling water

### Filling ingredients

2 cups cashew nuts  
10 pitted dates  
¼ tsp vanilla essence  
Pinch of salt  
1 cup boiling water

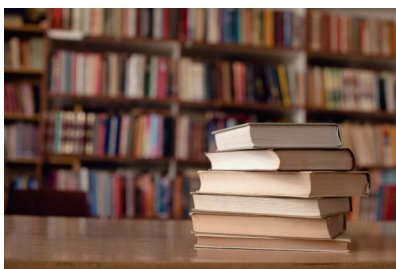
### Topping Ingredients

2 cups froze blueberry  
2 tsp of arrowroot or cornflour  
½ cup cold water  
Juice of ½ a lemon

1. Put dates and boiling water in a cup for two minutes to soften
2. Combine all other ingredients into a food processor and process clumpy, if its to dry at a touch more water.
3. Press base mix into a 25cm tart dish, ensure you get a thick crust on the sides
4. Soak filling dates in boiling water for 2 minutes, then combine with all other filling ingredients in a food processor and process until you have a smooth cashew cream.
5. Pour over base and make it level
6. Topping: mix arrowroot, lemon juice and water, in a cold pot. Add blueberries and start heat, stirring until a gel forms.
7. Pour blueberry mix over the top to complete cheesecake.
8. Refrigerate for a few hours to help firm up then serve chilled

ENJOY

Tabitha – CCIS Health & Wellness Facilitator



## 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 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.





## 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.

### **Money Smarts Made Easy Course**



In a small and safe environment, we talk about money which is one of important things in your life. It is a free course for people who has a learning disability.

At 74 14th Ave Tauranga, CCS Disability Action Kowhai Room  
October 2021 10am - 12.30pm

Friday 1 st October Session 1 "What do you know about your Money?"  
Friday 8 th October Session 2 "Where does your money come from and where does it go?"  
Friday 15 th October Session 3 "Saving for a Money Smart Goal" Friday 22nd October Session 4. "Keeping your money safe" There are no more than 12 people in this course. Morning tea provided.

Contact: Course Facilitators- Rachel Johns / Yi Small Phone:  
0275547507 / 027 5263387  
Email: racheljohns@peoplefirst.org.nz / yi@peoplefirst.org.nz

### **Crafting for Confidence**

Cardmaking and drawing classes with Myra in Tauranga.

Contact  
fos@ccisupport.org.nz for more information.



**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.**



## BOARD OF MANAGEMENT:

Keith Appleton: President and Treasurer

Matt Appleton: Vice President

Sarah Davey: Board Member

David Harris: Board Member

Karen Moulton: Board Member

Fiona Charlton: Board Member

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 and Greater Wellington Region.

## THANK YOU TO OUR AMAZING SPONSORS AND DONORS



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