MEssenger

July 2020

Complex Chronic Illness Support

Empowering People Towards Wellness

Greetings from the East.

Level 1; I for one am feeling pretty pleased about this, and I could see that the East had come back to life again, Whakatane was booming! I was surprised some people went back to "normal" so soon. It felt a bit over-whelming for me to go out and see so many cars and people and did take me a while to get back to hugging people again.

I am still being cautious, as I was before Covid and after it, I am always cautious of communicable diseases and try to keep away from very fluie people as much as I can. I am lucky that I work within the ME/CFS/FM community and that we all are cautious of not only our needs but others. Members are very aware of keeping others healthy and really do try not spread any bugs they may have; we really have a great community.

I am really delighted to be able to run the next **Towards Wellness 1 Online.** This means that members from places like Whakatane, Opotiki and Rotorua can receive the benefit of the programme without having to burn hours of energy travelling each week. I am also running **Towards Wellness 2 – Everything is Connected**, online this July which is going to be lots of fun. It's a great programme which really dives deep into understanding and creating the conditions for recovery.

And on a personal note, I have a cat. Its been a year since my dear old nurse Greta died and finally I said Yes when my sister sent me yet another picture of a homeless cat. So, Kaya/Freya/Coco/Schrodinger now lives with me on the farm. She was due to be put down but the vet choose too re-home. her. She's 5 years old and likes lots of pats and to hide when she feels like it. One leather couch torn and a hiding place blocked up and we are getting on fine.

For me cats help to create more balance in my life as I work to not work too hard which is my Archilles' heel. What helps you create more balance in your life?

EASTERN BOP (WHAKATANE REGION)

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INSIDE THIS ISSUE

SPECIAL POINTS OF INTEREST

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From Charlottes desk in the Western Bay of Plenty

Greetings to all our wonderful members and a big welcome to those that have recently joined our organisation.
We have had people from all around New Zealand reaching out to our service and have been supporting those near and further afield. We are passionate about actively supporting those with complex chronic illness and so grateful for the resources we have to do this.

I have been on my journey with ME/CFS for 8 years now, only receiving a diagnosis in October 2018. If only I had known there was support out there sooner with information and resources, I could have started to improve my health a lot quicker. Once we know more about our illness, we can start to make positive changes to support an improved quality of life. I would love to have had the information that told me to rest when my body told me to rather than believing I needed to just push harder. I could have avoided all the long and hard crashes and instead known the signs to look for, honouring my body when it spoke to me.

Holistic management is an approach that I studied and speaks to every cell in my body. This is our philosophy and one that we encourage for all our members. I have learnt so much over the past year and continue to learn all the wonderfully simple and positive things I can be doing to support my ME/CFS. Just recently I watched a documentary on grounding otherwise known as earthing. Although I had heard of it, I didn't really understand how it worked. Earthing can be used as a therapeutic technique using the electromagnetic field or the earth to restore the body. There have been some small studies so far showing positive outcomes by those that practice earthing, it is thought to improve sleep, reduce inflammation and pain, and more. I have added this as another tool to my toolkit. I encourage you to check out the documentary on Netflix and see what you think. Its free and its safe so I think I will give a go! I am always trying to stay open and curious.

"Being worried about not sleeping is not going to help you sleep, try not to be worried about being worried about not sleeping, take a breath, breathe and just follow that."

LAKES DISTRICT (ROTORUA REGION)

Elizabeth is currently taking care of the Lakes District. Elizabeth has the expertise to be able to take this on and as a valued member of CCI Support we thank her for stepping up into this role.

We are recruiting for a new Field Officer in Rotorua at the moment.

A NOTE FROM THE OPERATIONS COORDINATOR

Welcome to the July issue of MEssenger. Hasn't it been a surreal few months? We are back in the Fraser St offices now and getting back into the swing of things. We still have the 'government issued' QR scanning at the door for your self tracing of movements. Also we do still request that you sanitise on entry.

We have been listening to the feedback from our members, and one area of feedback was the MEssenger. We asked if you would prefer a shorter monthly edition or a longer 3 monthly edition. It's come back 50:50, so we are going back to the bi monthly edition and taking it online for the most part. Hopefully this means we can link you through to the latest research easier.

Recently it was Volunteer Week in NZ, and I want to say a massive THANK YOU to all the volunteers we have had this last year. They make an amazing difference to the organisation, especially in these times.

Covid-19 has without a doubt impacted the world, society and also CCI Support too. It was a very difficult situation to go through for our members, staff and the agency as a whole. I am so proud of the staff, without hesitation and in a moments notice they took all of our services online and virtually. I hope that as clients you still felt the "We are here and we care" vibe.

We have however been hit in the pocket. As a charity in NZ we are completely reliant of many of our funding partners and their generosity and focus of donations and grants. With the lockdown and the economy in disarray, many of the funders were hit with uncertain financial stability and the gambling sites were closed down. Both of which affect the level of grants received and also the amounts granted. We have been grateful to receive the wages subsidy that the government offered. This was able to sustain us through the lockdown and with the instant loss of income we experienced. Unfortunately, though this wasn't enough to stop the full impact. The Board of CCI Support did the wise thing and relooked at the structure of the agency. We in turn had to restructure the Tauranga office.

I can say that we now have a sustainable, efficient and future focussed view within the agency. Charlotte is now working Tues to Fri and 30 hours a week. Unfortunately, Waltraut was made redundant with the restructure and she has now finished with CCIS. We will miss her unique skill-set and warm personality, she was a valued member of staff. We wish her well for the future.

We are now looking at future possibilities of where to take CCIS and working towards best practice in our support and hoping to make a real difference in our community/country.

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Operations
Coordinator.

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We have been contacted by livewire who are an Australian based charity called Starlight. They are offering an online portal for younger persons to make connections with others who are experiencing similar ill health. See below for more information on their service and how they support and keep their young members connected and safe.

About Livewire
'As I'm sure you'll remember, being a teen is tough. It's tricky finding your niche, figuring out where you 'fit' and finding others who might be going through the same things as you. Add living with illness or disability on top of that and life becomes a real challenge. This is why Starlight developed Livewire, an online community exclusively for these teens to have fun, share their experiences and support each other. Inside the Livewire community they have can meet other members and special guests in the chat room, express themselves through posts on the newsfeed, participate in groups and access fun content be it an article, podcast, video, or livestream'.

Our Q&A to find out more about their service
Q) Can you tell me about the experience or background of the moderators? – I see they have training in moderation – is this in-house or from an outside institute?
A) All of our moderators are trained in-house. They have different experiences and backgrounds but a lot of the moderators have worked as in-hospital facilitators in our paediatric hospital programs (Livewire in-hospital for young people 12 - 20 or Starlight Captains for children up to the age of 12).

Q) Do they have other skills in counselling etc?
A) We function as a moderated peer support service and are not trained counsellors. For any situations requiring a counselling level of assistance - we refer to services including Kidsline and 0800 What's Up.

Q) Are they skilled in recognising patterns of abuse or trauma?
A) The transcripts of any activity on the site are reviewed by a moderator and the program manager. A debrief for site activity is written each day and moderators are required to read all previous debriefs since their last chat hosting shift - so that any patterns or issues can be identified.

Q) What processes are in place for issues that crop up?
A) If anything occurs on the site that is against our Livewire Community Standards and Values (pdf attached) or is deemed an issue - we delete the content from public display on the platform immediately and open up private messaging windows with the young person responsible to check-in and see how we can best assist - as well as to any other members who may have witnessed or been affected by the content or situation.
Part of the verification process of joining Livewire Online is that we need to have a confirmed parent or guardian contact - as well as a home address - so that in the event of an emergency we are able to make contact with a parent / guardian or relevant authorities.

Q) Are your moderators police checked and vetted?
A) They are. All moderators are police checked and have relevant working with children qualifications. Further details of our Safeguarding of Children and Young People policy and certification is available here: https://starlight.org.au/safeguarding-children-and-young-people

Q) What is the tone which the moderators take with the members?
A) One of support and understanding. Moderators listen and facilitate conversations to ensure the platform serves the purpose of offering genuine peer support as well as positive distraction based on a wide variety of daily events and community activities (competitions, monthly themes, live streaming etc)

Q) Are your guests – TV personalities, sports players and writers, also police checked?
A) I have attached the form that guests must sign before making an appearance on the platform. As there is always a chat host present - we are able to see and control all site activity. Guest logins are given limited site functionality and are not available before or after the designated chatroom appearance time.

Q) Is all the members information held in a private location and not shared with any 3rd party?
A) That is correct. All member information is kept only on our database.

Q) Are you confident about the online security which you use to keep the members information safe?
A) Yes. Our primary focus is the safeguarding of children and young people. The site doesn't allow members to display their last names within the platform and there are no external links on the platform.

Q) Our members have a "hidden" disability, they tend to look well, will they still be welcome even if they look well and are not in hospital? (most are taken care of at home as hospital care and GP support for people with ME/CFS is very poor in NZ and Oz)
A) 100%. The community is very understanding of living with a hidden disability. In terms of ME/CFS we are also in the process of partnering with Emerge Australia to help as a resource for youth peer support. It's not a requirement to be in hospital - only that the young person identifies as living with an illness, health condition or disability.

Q) I see that you are an Australian based charity for Children, why have you decided to include New Zealand in Livewire?
A) A combination of a lot of youth culture similarities and understanding, a compatible time zone and that we find there are a lot of organisations in the Not For Profit sector working successfully across both countries. It would be wonderful to eventually have an in-hospital presence with our programs in New Zealand as well - but for now this is a way for us to be able to help young people with our current level of resources.

Q) Would your moderators have awareness of NZ based social supports if a member was at risk?
A) We are currently in the process of expanding our NZ based supports and would love any suggestions you have on this front. Our current main referrals are Kidsline and 0800 What's Up.

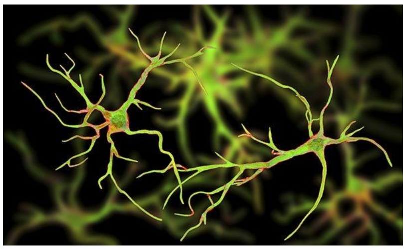
Q) Do you have any NZ Moderators? And if not how would your moderators deal with NZ's cultural diversity?
A) We don't currently have any NZ based moderators though this could change as the platform expands. The focus of the platform is on the similarities of a youth experience and providing a safe and supportive space to share and build genuine friendships.

DR ROS VALLINGS ME/CFS AUCKLAND SEMINAR—PART TWO
22ND FEBRUARY 2020

Here is the second part of Dr Vallings' Auckland seminar, which is transcribed for accessibility. Although the recording of the seminar is no longer available, you can read part 1 in our May MEssenger

Microbiome – the microbiome is the huge cluster of trillions of cells and viruses that inhabit our gut. We inherit [these bacteria and viruses] initially from our mother when we are born. As you come through the birth passage to the outside world, bacteria and viruses get on the tissues around the mouth and begin to inhabit the gut, then they grow and multiply and that is it for life. It depends where you live as to what balance you have to a large extent, there may be changes with your diet too, as you get older, and certain diseases cause abnormalities. They are now saying that the gut is a very large part of your immune system and it's very closely linked with the brain. The brain gut connection is very much acknowledged as being part of the abnormalities in this illness.

There are some top researchers in these areas looking at these abnormalities. Will re-organising the gut bacteria make a difference to one's illness? There has been some work looking at faecal transplants which could be an option, which involves putting healthy bacteria and viruses into a non-healthy gut, may make a difference and there's hope on the horizon. A big research base in England; Norfolk are working along these lines for ME patients and in Australia. Probiotics have not been found to be particularly useful as a form of treatment. The only time probiotics have been found to be useful is in the early stages if your illness started with Gastroenteritis. It may be worthwhile then to rebalance the microbiome into a so-called normal state. Or if you are going to take a large dose of antibiotics it may be appropriate to take a probiotic in the few days before and during or 7 to 10 days afterwards. Diet, again we are what we eat; up to a point, but there has not been shown to be any particular diet that's been extremely useful. Just eating sensibly and a good range of foods.



The Brain - "Research into not just the brain; but the spinal-cord, the central nervous system, and the peripheral nervous system. So many of the symptoms are related to the nervous system. The ones that stand out are the so-called **glial** cells in the brain. Basically, glial cells are sparkling away when people are particularly ill. If you are a healthy person and you get a cold or flu you might want to go to bed and lie down. Even though you want to go to work, your glial cells come alive; that is the way your brain is telling you to lie down and rest up.

It is the kind of thing that people with ME/CFS experience all the time, usually. So, there is slow processing, there are parts of the brain that are not functioning as well as they should. There are abnormalities in the little ventricles, which are sort of holes in the brain whfind all sorts of abnormalities in some of the brain scanning. And of course, we have got much more knowledge about it all because the brain scanning techniques are so sophisticated. ich are normal, but abnormal in this illness. We find all sorts of abnormalities in some of the brain scanning. And of course, we have got much more knowledge about it all because the brain scanning techniques are so sophisticated.

Exercise - "Exercise studies are going on in various centres and have shown to be very abnormal. They are hoping to explain why exercise as such is not the way to go with this illness, actually exercise in more than a very minimal amount can make you a lot worse and can lead to relapses.

Sleep - Sleep studies are going on all around the world. Sleep is key to our well-being. If we sleep well; we produce hormones and chemicals that have a positive healing effect on our body. If we have a very shallow type of sleeping or sleep that is not what it should be, then our bodies do not self-heal. This is evidenced by not waking up feeling really refreshed and restored in the morning, so if you do not wake up feeling really refreshed you have had a messy sleep. A lot of research is focusing on how to improve sleep quality.

All the clinical researchers say, until you get sleep right, nothing will come right. I think that is very true, so many people will need medication. Non habit-forming benzodiazepines and the low dose antidepressants e.g. amitriptyline can have a very positive effect on sleep. A man called Partinen in Finland has shown that it's terribly important ***to have a snack at bedtime.*** e has uncovered a system in the brain that is abnormal in people for Chronic Fatigue Syndrome and a snack at that bed time can keep all these systems activated and in a regular routine. Also, shutting off tablets and devices for a good hour before you go to sleep."

Possible Biomarkers - "Then we looked at research showing definite biomarkers or tests that proves whether you have got this illness. I am sure you realise by all we have talked about so far there are lots of potential possibilities. There are definite very clear abnormalities which do not seem to be occurring in other conditions, but one of the problems researchers say is that we must prove that it's not happening in other illnesses.
Of course, there are thousands of other illnesses and how many of them can you do the research on? Research is so expensive, but they are getting there, and it may well be that there are two or three of these abnormalities, which at the end of the day seem to come together. So, it may not just be one thing that is abnormal on the test, but it may be some sort of test that links these things together in some way. TRPM3 it is probably one of the nearest to being the likeliest outcome test".

Drug trials - There are drug trials going on at the moment. People get terribly frustrated, understandably, "Why can't I just take this drug? Why are they not releasing it? Why have they not proved it?". **Nancy Klimas** who is the top researcher in this field gave a very good presentation in London last May. She said that when you get an idea that a drug could help it probably takes about three years to produce or prepare the research that might show that it's going to be useful - and you have to apply for funding and that can take another year at least. If you get the funding you've got to do a free trial of a new drug to prove its long-term benefits.

We are talking sometimes up to 10 years from the beginning of trialling the drug to actually being able to prove whether it is worthwhile or not. Some of the research going on in Norway is still very good, their trial on Rituximab is very disappointing. Disappointingly negative, but they are now looking at the drug called cyclophosphamide, which is another which has nasty side-effects, getting very fatigued with cancer drug type side-effects. We do not know it may take a little while before these trials give us any real answers.

Continued on next page...

CONTINUED... DR ROS VALLINGS ME/CFS AUCKLAND SEMINAR—PART TWO 22ND FEBRUARY 2020

Health pathways - The other I was asked to just mention, and I'll do it very briefly is; what are we meaning by these so-called health pathways? Health pathways are a series of ways that doctors can identify, investigate, make a diagnosis, and treat a particular illness.

I've worked with a couple of other doctors in Auckland on the health pathway for Chronic Fatigue Syndrome and that's now available online for any doctor, be they hospital or GP to access these health pathways wherever they happen to live in New Zealand. Different health areas are working on different health pathways and there's a huge benefit, because it means you can look up something just like that. The New Zealand theme is not like an American website with a lot of drugs that you've never heard of, it's a fairly simple plan a GP or hospital doctor can use to understand the illness more clearly - now widely available for doctors in New Zealand to access whenever they need too.

There is also an organisation called the **Goodfellow Unit** that's part of the GP unit of Auckland University. They have become very proactive in educating doctors in Auckland about this illness and have produced a very good module for GPs who can learn as much as they want about the illness. They will also put online case studies for doctors to work on with this illness. They have a big conference in March, and they are going to have a whole special on Chronic Fatigue Syndrome, so things are looking up".

Recognising our Guest Speakers

Thank you to those professionals that provide their knowledge and expertise to our members via our Towards Wellness Programme, Monthly Members Meetings and Workshop facilitation.

Doctor Heath Sumpton
General Practitioner and guest speaker on ME/CFS management for our Towards Wellness Programme

Justine Laidlaw
Nutritionist and guest speaker on nutrition for our Towards Wellness Programme

Kathryn Vickers
Physiotherapist and guest speaker on restorative movement for our Towards Wellness Programme

Kate Fyfe
Meditation coach and guest speaker for Monthly Members Meetings

Phil Jones
Mindfulness coach workshop facilitator

RECOGNISING BOUNDARIES - WITH OURSELVES, OUR FAMILIES AND FRIENDS

ELIZABETH MCGOUGAN FO

Its easy to let got of our boundaries when we are enjoying spending time with others or doing something that we love. But as time passes and we keep on ignoring that our boundaries are being crossed, we can fall back into patterns and feelings that do not serve us.

For me I have an issue with work. Yes I admit it, I am a workaholic, sadly its an addiction that this world rewards, so it's a pretty hard one to break and it took ME/CFS/FM for me to realise the extent of my lack of boundaries around work. Covid made it really tough for me recently as I could not use the tools, I usually use to create boundaries for me with work.

I recognized that I needed a break, took it, and took that time to see that I had fallen back into negative patterns of behaviour which did not help my wellness journey. The action of "recognising" where a boundary has been crossed, is so very important, it's the part that shows us how far we have come on changing damaging patterns of behaviour.

I have recently been speaking with several members who have begun to "recognise" that their loved ones are not supporting them in a way that helps them with their wellness. They are noticing that their families are crossing their boundaries and are causing them to feel sadness, shame and guilt about living with a complex chronic illness. Its really hard to hear this because our members really need unconditional love, kindness and support from their friends and family. But the fact that our members are noticing this, talking about it and choosing to take action is so incredibly important.

This recognition is the first step to detachment – this helps us to create space around the behaviour and then assess how the behaviour impacted on us. This space helps to reduce the amount of emotion and stress around the pattern of behaviour. This can then lead to changing of these patterns, if that's helpful.

An example is that you may notice that you are starting to say yes to doing something with your family member even though you know it will make your symptoms worse. The reason only you are doing this is because of the comments they make when you say no – negative personal comments which imply that you are not trying hard enough or are always grumpy.

Recognising that you are crossing your own boundary because someone you care about has caused you to feel upset is good, pausing and taking a breath will help you to not get too angry about this incursion. Then you need to make a plan of how you will communicate your needs to this person. It can help to talk to a friend, Field Officer, counsellor or journal about some ways to tackle these issues.

Learning to communicate our boundaries is tough, its hard enough to communicate them with yourself! These links have some information on behaviour patterns and a few boundaries courses.

https://psychcentral.com/blog/how-to-recognize-and-change-toxic-behavioral-patterns/
https://www.stpetershouse.co.nz/boundaries
https://positivepsychology.com/great-self-care-setting-healthy-boundaries/

LIBRARY UPDATE

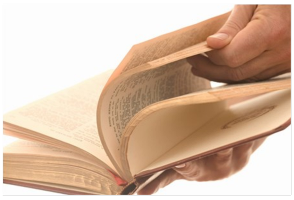
Soon we will be taking our library catalogue online, which means you will able to browse through our library book titles from the comfort of your home. If you spot one you would like to read, we can reserve it for you until you stop by and collect it.

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.

Also, if you have any **book recommendations** to add to our library, relevant to the our members, please contact your Field Officer to make a request. *Please see some of the newest titles added below.*

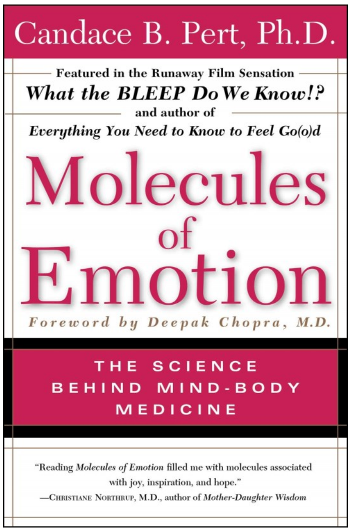
If you are interested in reading one of our many treasures, please stop by and check out a book, we have lots to choose from!

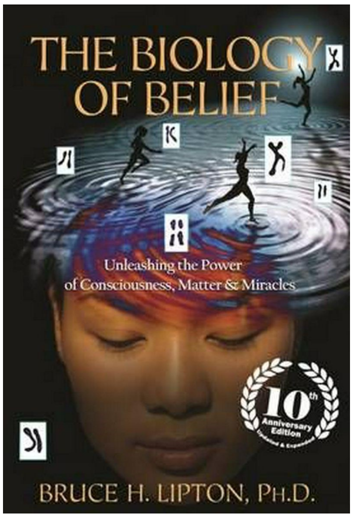
We do have a few library books that are being requested by members to borrow, can you please check your shelves for the following books?

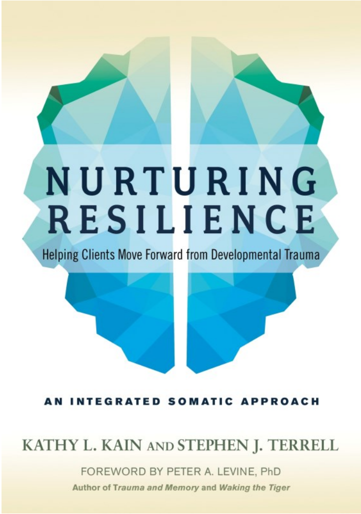


- An introduction to the Lightening Process
- Chronic Fatigue - the silent epidemic
- M.E. How to live with one
- The Pocket Guide to CFS/ME
- Mindfulness for Health
- Rewire your Brain
- When the Body Says No
- The Amygdala Retraining Program for ME/CFS/FM and Associated Illnesses

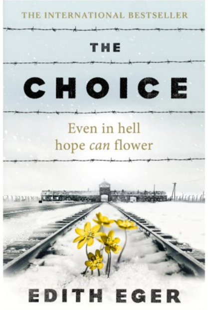
NEW BOOKS IN THE LIBRARY







BOOK REVIEW BY CHARLOTTE **"THE CHOICE"** EDITH EGER



This book had been recommended, so when it came into the library I was super excited to take it home for a read. We have a choice when faced with our illness… to be closed or to be curious. What can we do today to support ourselves and improve our experience?

The Choice is an international bestselling memoire that's tells a survivor's story of remarkable strength and courage. Edith and her family were rounded up by Nazi Germany and sent to Auschwitz. In line waiting for there fate, it was one word uttered by Edith that sent her mum in one direction and Edith and her sister in the other. Her mother left her with these few words *"We don't know what's going to happen. Just remember, no one can take away from you what you've put in your mind"*.

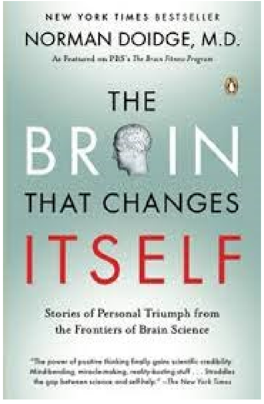
Edith takes us on a journey of the inhumane cruelty and suffering on her journey through the camp and how she made a choice to survive. After walking the death march Edith is hauled from a pile of lifeless bodies by an American soldier and liberated hours from death. Physical freedom could not set free the mind, Edith was plagued by survivors' guilt, horrifying memories and flashbacks.

Edith goes on to raise a family, earn a PhD in Psychology and become a successful psychologist. We get journey with some of her clients during their therapy sessions reading how her experience informs her work today. Today Edith helps others learn that "the biggest prison is in their mind".

Farewell from Waltraut

"It is with a very heavy heart that I write these lines to say goodbye to you. Unfortunately, my position as Field Officer ended this week due to Covid-19 and reduced funding, which I deeply regret. It was my great desire to improve your quality of life and to support you in every possible way. It has been a pleasure to meet many of you and I thank you for the trust you have placed in me. I wish you all a particularly blessed future! Kind regards Waltraut Speidel"

Book Review by Elizabeth : "The brain that changes itself *Stories of personal triumph from the frontiers of brain science".*



Over the years I have been interested in the science of brain plasticity and the ability of the human brain, at any age, to learn and grow new neural.

We meet many people in this book who have found brain plasticity the break through for learning to help with physical and psychological disabilities.
The books goes on to cover children with learning physical and learning disabilities, people with phantom limb syndrome and those with psychological issues, it shows that with time and effort they can learn to rewire neural networks and overcome or manage their disabilities. I find this really helpful as a person living with ME/CFS/FM who has a damaged stress response. Pre-ME/CFS/FM I thrived on stress and really enjoyed living and working in stressful environments and after I found even small amounts of stress would trigger a full-blown fight, flight, or freeze response. Over the years I have learnt that I can overcome this by retraining my brain when it comes to stress. I have made a conscious effort to stop or slow down when I feel stress coming into my body and over time have increased my resilience to stress.

Also, like many with an overactive stress response, I developed anxiety. My brain would rush to patterns of thinking that made me jump to the worst outcome and to low self-esteem. None of this helped me on my recovery as I would often think that it was all my fault, you cannot find "home" and flexibility when you brain is in that pattern of thinking. Using the practice of **meditation**, I have re-trained my brain to stop running down those well-worn pathways and have instead created a higher level of self-awareness and self-esteem.

None of this has been easy or fast but it has happened because of books like this and others in the area of brain plasticity, mindfulness, and meditation. I find it fascinating that we can help to grow and improve our brains over time, no matter what. “Neurons that fire together, wire together” this means that the more often we try new physical patterns, the higher chance we have of creating new pathways in our brain.

With the research outlined in this book it has been proven that if we lose a physical or mental process we can, with the right training, rewire a new pathway and use another part of the brain or body to perform a task. This opens the door for so much possibility for our ongoing development as humans and lets us know that we have not even scraped the surface to the capacity of the human brain and body.

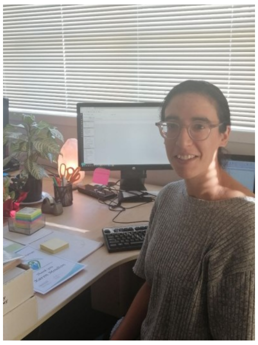
National Volunteer week

'Te Hua o te Mahi Tahi - The benefit of working together'.

Last week was National Volunteers week honouring the collective energies and mana of volunteers in Aotearoa. They grow our people, open minds, open hearts and create joy. National Volunteer Week 2020 was run from June 21-27.

We are so privileged that we have volunteers that have chosen to give their time to support our organisation. Each has a unique skillset to offer and are a fantastic fit for our charity. They have big hearts and always willing to lend a hand along with their ideas to accomplish the many tasks we pass on to them!

Without volunteers' charitable organisations like ourselves at CCI Support wouldn't exist. It is this generosity of time and hard work that have relieved some of the enormous workload on staff, giving them more time to spend working directly with members, improving the quality of service we are able to provide.

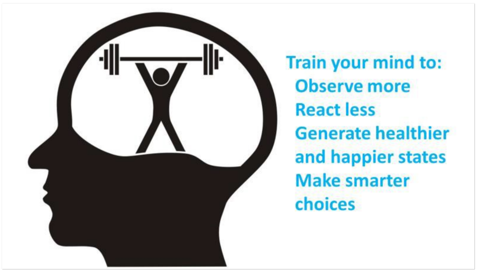


And for that we at CCIS are truly thankful for these wonderful people who choose to give up their time for us. You keep us strong and tenacious and are the glue that holds all our different parts together.

To those members that have given their precious time and energy to support our organisation a huge and heartfelt THANK YOU!!

Kelsi England – Towards Wellness & Monthly Members Meeting Power-Points
Angela Larson – Facebook curator
Kaye Dickson – Facebook curator
Jeremy Nixon - Technical support
David Harris - Technical support
Jacqui Bassett – Member outreach
Jeannie Scott - Library support
Sue Goodlet - Library support
Ebony Whitaker – Young guys online group and photography
Tricia Jones - Administrator extraordinaire
Karen Moulton – Administration & Field Officer Support

Programmes and Meetings



MINDFULNESS WORKSHOP BY PHIL JONES

Phil is an experienced leader and coach in mindfulness and has led successful workshops for CCIS members which were valued highly by our membership. Phil offers a series of 3 individualised session for $150 (payment plans can be arranged) Sessions include: Mindfulness, Mindful self-compassion, Mindful self- emotion Contact: calmclearmind@gmail.com

Towards Wellness Programme - Registrations now open for Feb 2021 Intake.

The 2020 TWP programmes are now full. But you can always register now for the 2021 February intake. Cost $200.00 for TWP1 ten two hour workshops held fortnightly, that's $20.00 for each class, It is now $100 for TWP2. We also take part payments too if that is needed.

Important Calendar Dates

Month	Date	Topic
Sept	5/9/20	AGM / Special AGM
Oct	1 - 31	Dysautonomia Month
Dec	5	Volunteers Day
Dec	12	Christmas Picnic

Carers Workshop

Month	Date	Time	Topic
August	Sat 8th	10-12pm	TWP Carers
September	Sat 5th	10-12pm	General

CCIS Young Persons ONLINE group

Tuesday at 1.00 pm we have a younger person's group online. It is on Zoom and run by a volunteer member who will cover CCIS monthly meeting content but will do it in a youth focused way.
The group is open to **all members aged between 12 - 25 years,** (25 - 30 years members being those who developed the condition when they were younger.)
The Kaupapa of the group is to empower connections with each other, learning helpful information for management, sharing, laughing and appropriate friendships.
Finding a friend who experiences 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 attend school, go on to university or leave home when you want to. So, finding a person who understands and "gets it" can be so empowering and helpful.
If you are interested in joining please email elizabeth@ccisupport.org.nz to be added to the list.

Second Tuesday of each month at 1:00 pm – 2:30 pm.

August 11th	Restorative movement
September 08th	Pain Strategies

Tauranga Monthly Members Meetings

Month	Date	Time am	Time pm	Topic
August	Thurs 13th	10.30am -12pm	1pm-2.30pm	Restorative movement – Kathryn Vickers
September	Thurs 10th	10.30am -12pm	1pm-2.30pm	Pain Strategies
October	Thurs 15th	10.30am -12pm	1pm-2.30pm	Dysautonomia

Coffee Groups

GREERTON:
Venue: Greerton Mitre 10 Mega

August	Weds 19th	10.30am
September	Wed 16nd	10.30am

NEW—PAPAMOA:
Venue: Double Teaspoons, Papamoa Plaza

August	Weds 5th	10.30am
September	Wed 2nd	10.30am

Young at Hearts Social Group

"An easy going social, monthly focus topic resources also provided"
Venue: CCIS Offices, 53 Fraser Street, Tauranga (4th Tuesday of each month)

July	Tues 28th	1pm - 2.30pm
August	Tues 25th	1pm - 2.30pm
September	Tues 22nd	1pm - 2.30pm

Whakatane Meetings

Held on the fourth Tuesday of each Month at 10.30am at a local café with the aim of finding a suitable set café. 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.

July 28th	L'Epicerie Larder -128 Commerce St WHK
August 25th	Little Goose Eatery – 1a Luxton Rd WHK
September 22nd	Robert Harris – Cnr Strand & Richardson WHK

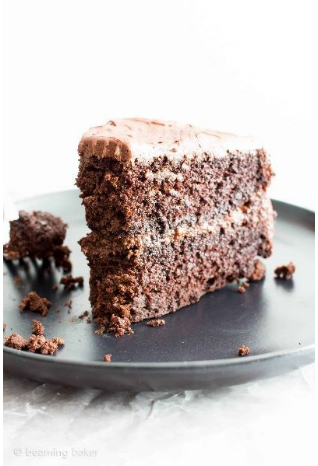
Online Monthly Meetings

Is for all our members who live outside the Bay of Plenty or those who want to attend a monthly meeting but do not have the extra energy to leave their homes. Please email elizabeth@ccisupport.or.nz if you are interested in joining the meetings.

August 14th	Restorative movement
September 11th	Pain Strategies

DO YOU HAVE A SIMPLE RECIPE YOU WOULD LIKE TO SHARE? CONTACT YOUR FIELD OFFICER OR EMAIL INFO@CCISUPPORT.ORG.NZ

VEGAN CHOCOLATE CAKE RECIPE



3 cups Flour
6 teaspoons Baking Soda
6 Tablespoons Cocoa
sift together

2 cups Sugar
2 Tablespoons White Vinegar
2 teaspoons Vanilla Essence
2 cups Water
10 Tablespoons Oil

1. Mix everything together until smooth
2. Bake Cake approx 45 min at 180*c or in muffins tins approx 20 min at 180*c
3. Sit down and relax whjile cake is cooking - do the dishes later ;)

It's really tasty, everybody loves it. Rich and Moist and stays fresh for several days.

Kind regards,
Myra

"Is your pain waking you in the night? Have a plan in place before you go to bed of what you do when you wake in pain and follow it. Know that resting and breathing is enough."

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.

FEEDBACK: We love it!! We want to know how we are going 'through your eyes'. If you would like to give us some feedback about our services, programmes, staff or management. For the members feedback formplease contact us at info@ccisupport.org.nz

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. In April, you will receive a tax receipt for all donations made during the financial year. Thank you for supporting us.

ACCESS AWARE APP

The Access Aware app was developed in partnership with SaferMe and is a world first initiative set to revolutionise the reporting and enforcement of mobility parking abuse.

Access Aware is now being widely used in Wellington, Christchurch, Hutt City and **Tauranga**, with the help of those city councils. It is designed to allow the reporting of mobility parking abuse in real time to enforcement officers so they can monitor the use and respond to abuse of their parks. You can also use the app to see the locations of known mobility park locations on a map in real time to help you find a park when you need it.

For more information : https://ccsdisabilityaction.org.nz/mobility-parking/access-aware

LOL LAUGHTER CLUB

Laughter wellness for everyone! A group gathering engaging in exercises so that laughter becomes easily accessible for everyone. Did you know that laughter is a natural antidote to stress? Laughter can have profound effects on your mental and physical state. These are just some of the reasons Trish suggests laughter yoga:

- Releases endorphins and serotonin
- Improves cardiovascular health and reduces blood pressure
- Reduces stress levels
- Boosts the body oxygen and energy levels
- Helps to beat depression and anxiety
- Boosts the immune system and stimulates the lymphatic system
- Increases circulation
- Is an aerobic workout that exercises the heart diaphragm, abdominal, intercostal, respiratory and facial muscles
- Improves communication, creativity and self-confidence

When: Saturdays 11-11.45am
Where: Penguin Room, Arataki Community Centre, Zambuk Way, Mt Maunganui
Cost: Gold coin donation. No booking required
For further information contact Trish on 022 036 6768 or email lollaughterwellness@gmail.com

BOARDER WANTED

Full board is offered to careful, quiet person to share with Christian house owner. Greerton area of Tauranga. Warm sunny house, easy driving access to all parts of Tauranga. Bus route a 2 minute walk. Greerton shops,library and takeaways a flat easy 5 minute walk. Room is fully furnished with double bed, chest of drawers, TV with remote, wardrobe, desk an optional extra (included in price) if wanted. All linen supplied. $250 per week, includes meals, rent, power, lawns etc. No Sky TV. Will need to be willing to be fragrance free and nut and kiwifruit free as owner severely allergic even to the smells. Contact Jean (022) 348 9594 for more info

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 including Tauranga, Whakatane and Rotorua.

THANK YOU TO OUR AMAZING SPONSORS AND DONORS

As a charity, we were hit hard by Covid19 with the funding aspect. But I want to say a big thank you to the following organisations for helping us out with the Covid19 resilience and recovery funds. This is on top of our normal funding from the Disability sector, Lotteries etc.

Western Bay of Plenty Resilence Fund by the WBOP District Council
Covid 19 WBOP Recovery fund: BayTrust, TECT, Acorn and TCC.

“The Recovery funding will truly help us recover – it will help us top up the wage subsidy so we can provide full pay for our three full time staff members, including after the wage subsidy extension runs out, so we can keep supporting over 218 clients, their whanau and support networks.”
And the Resilience fund will help us support those clients in the WBOP with Field Officer contact, Publications for the Towards Wellness Programme and GPs and the equipment to be able to take our services online. Watch this space!!! It's getting exciting!

Lottery Grants Board
Te Puna Tahua
LOTTO FUNDS FOR YOUR COMMUNITY

TECT

Pub Charity Limited

BayTrust

ANZ Staff Foundation

COGS
Community Organisation Grants Scheme

DCT
DISABILITY COMMUNITY TRUST
Serving with Head and Heart

MINISTRY OF SOCIAL DEVELOPMENT

WBOP DST
Western Bay of Plenty Disability Support Trust

Rotorua energy charitable Trust

Infinity Foundation

iDS

metro MARKETING

Four Winds FOUNDATION

Community Post

Western Bay of Plenty District Council

Tauranga City

THE LION FOUNDATION
Here for good

ACORN FOUNDATION

BRAVE WORLD

Complex Chronic Illness Support
53 Fraser St
Tauranga South
TAURANGA 3112
NEW ZEALAND

Phone: 07 281 1481
Cell: 022 658 0251
E-mail: info@ccisupport.org.nz
Charity Number: CC20874

Complex Chronic Illness Support
Empowering People Towards Wellness

BOARD OF MANAGEMENT:

Keith Appleton: President and Treasurer

Matt Appleton: Vice President

Sarah Davey: Board Member

David Harris: Board Member