

MEssenger April 2019

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Hi everyone!

I am sure that some of you will be pleased that the hot summer days are now behind us as we enjoy the more moderate temperatures of autumn days.

Our current **Towards Wellness** programme is in full swing, and we have recently been fortunate to be able to offer a 4-part **Mindfulness** course to CCI Support members, presented by Mindfulness trainer, **Phil Jones**.

Member Donna Frederick recently enjoyed a holiday getaway and shares her experience of travelling with ME/CFS/FM on page 6.

On a less light-hearted note, funding for CCI Support's operations has been more difficult to access in recent times. As a result, the Board has found it necessary to propose a restructure of the organisation. Consequently, there will be changes to some services (see page 2 for more on the changes).

A major change is the loss of our administrator, **Joanne**. (Staff and members alike will miss your cheery, efficient presence in the office Joanne!)

We welcome new operations coordinator **Julie Cross** to the CCI Support team. (see page 3).

Despite the changes, rest assured that we remain committed to assisting you in your journey towards improved health.

Tina and the team at CCI Support



Remember to check the Group Monthly Meetings Calendar!



CCI Support:
56 Christopher St
Tauranga 3112
Office: (07) 2811 481

Email: info@ccisupport.org.nz Website: www.ccisupport.org.nz





Should you wish to join our Facebook page, the easy link is: https://www.facebook.com/groups/203904249678311/

Local Items of Interest

Update from the CCI Support Acting Board President Jacqui Bassett

As many of you will be aware, CCI Support has experienced several changes over the last 5 months since Michelle Fraser, CCI Support Manager and Jean Scoullar, Board Vice President and Treasurer resigned their positions last October.

The Board at that time became aware that we needed to adjust our budgeted expenses to our actual revenue to continue to remain financially viable. While we had grown and expanded our service, increasing staff hours in both administration and service delivery, we had not achieved an increase in funding revenue to meet those costs.

The CCI Support Board delayed appointing a replacement manager (to save several months' salary costs and avert a serious budget shortfall by the year end 31 March 2019) and undertook a review of CCI Support Operations/Services and our projected budget. The Board provided the management function in the interim and restructured the organisation in order to maximise our limited resources to enable a break-even budget in the coming financial year.

The following changes will be taking effect immediately:

- We are cutting back on some of the extended services our Field Officers have been offering as we have had to reduce the number of hours field officers are employed. They will be concentrating more on our core services such as facilitating educational/ support meetings, providing consultations and support to new and existing members via office consultations, by phone, email and social media, e.g. facebook groups and delivery of our Towards Wellness workshops.
- We will need to scale back the effort that goes into the production of our newsletter with less content able to be produced at

this stage and have less focus on facilitated coffee groups, perhaps encouraging more member-led social groups to meet this need. I do thank Tina, Kira and Elizabeth for their continued commitment, professionalism and support during this difficult time of change.

We will endeavour to keep you all informed of any future changes as we roll them out and we ask that you support us through this transitional time over the next few months. We will continue to seek to assist our members by providing empathetic, therapeutic support and information, encouragement, tools and strategies to help you manage this complex chronic illness and hopefully experience an improved level of wellness and sense of connection as you engage with CCI Support.

We will also be looking to appoint a new Field Officer based in the Rotorua area as soon as possible.

It is with much sadness that we announce the departure of **Joanne Palmer** from her position as administrator, a position we have unfortunately had to make redundant. Joanne has been an amazing member of our team at CCIS and her warm nature and lovely smile along with her great work efforts will be sorely missed. We very much appreciate her dedication and continued assistance during this transition and wish her every success in any future endeavours she undertakes.

The Board are very pleased to now announce the appointment of **Julie Cross** as Operations Coordinator for CCI Support (see introduction on P.3). Please welcome Julie to our community and support her in her role coordinating CCI Support services and providing office/financial/funding administration to benefit all our members.

Thank you in advance for paying your annual membership fee (due 1 April 2019) and for your generous donations too. With your financial support, we have been able to assist 60 new members who have joined over the last year as well as provide support to all our existing members.



Hello to everyone

It's great to be able to introduce myself to you all. My name is Julie Cross and I will be the new Operations Coordinator for CCIS.

I am married with 2 teenage children and have lived in NZ for 7 years, after emigrating from the UK in 2012. For the past 6 years I have been working as Executive Officer for the NZ Kiwiberry Industry and also providing fundraising and support to Maketu Volunteer Coastguard. Previous to this I worked in the NHS for 13 years in Wales (UK).



I have a successful history of fundraising having raised in excess of over \$1 million dollars for coastguard over the last 5 years with new boat builds, operational funding, equipment, sponsorship, commercial ventures etc. I hope to bring my skills and experience to this role to support the organisation, members, employees and volunteers in the best way possible and to take the organisation into the years ahead, allowing it to develop and grow.

I look forward to getting to know many of you, hear your stories, your successes and how CCIS has helped you achieve them.

Kindest regards

Julie Cross

Young Persons' Group Meeting

The formal educational monthly meeting of the "Young Persons' Group" was held in the Christopher Street offices in February.

The group discussed topics of interest that they would like to learn more about in the coming months.



Members of the CCI Support Young Persons' Group



Kira at the white board

Members relax in the park

Picnic in the Park

In February CCI Support held its inaugural "Picnic in the Park" a chance to meet other members in a relaxed and social environment.

The next picnic will be held Wednesday 27 April, 12:30 to 2:30, Memorial Park Tauranga, under the trees, past the miniature railway station. You are more than welcome to come and stay the whole time or just pop in to say "Hello".

by Youth Field Officer Kira Follas.

A Warm Hello from the Eastern Bay!



It is still summer here but we are starting to feel a drop in the overnight temperature which is helping with sleeping and we even had some rain.

February was a busy month with excellent turn outs for the monthly meeting in Whakatane on the 11th and the coffee catch-up in Ohope on the 26th - such a vibrant group!

I am often asked "How will I know when I am getting better?". It's a very pertinent question. Once I had worked out that I was not going to wake up one morning "all better", I often wondered how would I know if I was seeing real recovery or just little short periods of better health.

The answer has come for me in small ways, because it's the small things that I have noticed about my body and self which are telling me that I am moving towards recovery.

Firstly, I noticed that I could sit upright without leaning on the back of a chair for 20 minutes. I was aware of this because when I began meditating in 2016 I was unable to sit without support, sometimes lying down. But over time my muscles have become stronger and they can hold my torso upright without causing pain.

I also began to breathe better. As my flexibility increased, I could breathe deeper thanks to the return of more normal muscle function. My "fitness" developed very gradually as I very very slowly added more time to my restorative movement programme. I had found my baseline with the help of the many tools like fitbit, pacing and daily healthy maintenance practices (DHMP).

Next, I noticed that I began to feel more even energy levels, and a calmness came with this. I noticed that I wanted to do more, but in a paced way. And my brain, when applied to new tasks, worked better than before.

But it was very different. Learning was different and applying pacing was tough. Over time I have been able to increase the number of hours I spend working and still be able to maintain my DHMP, my home and keep up family and friends.

Very subtly most of my symptoms have quietened down. The IBS is less, the light and sound sensitivity is much less, the joint pain is less, the cognitive issues are less, the headaches are much less, and sleep has improved etc.

When I push too much or something else knocks me (changes in the environment -physical and emotional, the weather, the seasons, normal illnesses etc) these symptoms do come back to my attention again, but they serve me now. I notice when they are becoming more present and I change tack and lessen my activity to suit how I am right now.

I have learnt that I have more EVEN energy, less pain and fatigue. I can be very active (3-4 hours of work, play with family etc.) and NOT experience PEM in the days that follow. My normal level of activity has doubled over the past 2 years.

So, to answer the question "How will I know when I am getting better?", you will by paying attention to your body, to how it is right now, and to the little things.

These small changes over time show you that you are on the right course. For me personally, they have provided me with the encouragement to keep working towards wellness. It's well worth all the effort.

Elizabeth McGougan EBOP Field Officer

US Study of Onset Patterns and Course of Illness in ME/CFS - 29 January 2019

by Charlotte Stephens, Research Correspondent, ME Association (Abridged from article in newsletter of ME Information and Support (Otago and Southland) Inc)

Epidemiology = The study of the incidence (how many), distribution (who, when and where), and risk factors relating to a particular health condition.

Epidemiology studies are few and far between in the field of ME/CFS. They are important as they can tell us how many people in a given population are likely to have the disease or are likely to develop it.

They can help identify patterns which may give useful clues for studying the cause of ME/CFS and could help with diagnosis and treatment. Their findings can also be used to help shape policy decisions in evidence-based practice, and demonstrate the impact of a disease to other official bodies and organisations.

This new epidemiology study from Dr Lily Chu (with help from Professor Jose Montoya) of Stanford University School of Medicine, describes the results from 150 respondents to a survey who met the Fukuda criteria for ME/CFS. The study was investigating the factors that led to the onset of ME/CFS and asked about the illness experience.

Main findings

The most common 'illness triggers' that led to ME/CFS were:

- ☐ Infection (64%)
- Stressful incidents (39%) e.g. major life events, especially work and family related
- ☐ Exposure to environmental toxins (20%)

For 38% of those surveyed, it took over 6 months from the onset of initial symptoms to the development of the full set of symptoms associated with ME/CFS. Could it be that this delayed development is a result of continual 'pushing' through initial warning signs and bad advice? Would they still have gone on to develop ME/CFS had they, for example, stopped and rested? This would be worth investigating to possibly help prevent more people developing ME/CFS.

97% of those surveyed suffered from at least one other illness, with the most commonly diagnosed co-existing conditions being anxiety (48%); depression (43%); fibromyalgia (39%); irritable bowel syndrome (38%); migraines (37%).

13% came from families where at least one other first degree relative was affected, rising to 27% when chronic fatigue of unclear aetiology was included. This could indicate a genetic component to ME/CFS.



47% of those surveyed were unable to work. This shows the impact of ME/CFS on function, and could also be a useful statistic when calculating the economic burden of the illness.

While 4% felt their condition was improving steadily, 59% described a fluctuating course of illness. This emphasises the need for education and treatment, and shows that most people do not recover on their own. It would also be worth investigating the 4% who felt they were improving to see what was different between them and the rest of the survey respondents.

For the full report see https://www.frontiersin.org/articles/10.3389/fped.2019.00012/full

Travelling with ME/CFS – It Can Be Done!

By Donna Frederick

Travelling has always appealed and I have done a little here and there until Fibro curbed my adventurous spirit somewhat.



I want to share with you the holiday we had a few weeks ago and encourage you to do that trip you have been considering. For me, planning was the key, although not factored in was the Northern Hemisphere winter and back we came, yes indeed with a nasty flu! But I digress.

At Auckland airport, as Tony dropped me and the luggage off before taking the car to the pre-arranged parking area, he produced a stowaway - TED E Bear! My stuffed companion of many years. How glad I was and it quite made my day! Ted sat with us on the plane and captured the attention of the flight attendants.

I organised everything myself on line - flights, hotels, cruise, transfers etc., hoping that I had times and connections just so. The direct flight to Houston (13 hours) was a squish in those cattle class seats but anticipation and excitement buoyed me up!

Despite organising a wheelchair from check-in to the plane, I ended up not using it as I did not wish to make a great deal of it. At the Houston end they were marvellous, rounding up all the wheelchair customers and although I did walk, they took us down in a lift so the walk was very short and we were loaded first. On reflection, and seeing the advantages of using the wheelchair service by other passengers at both Auckland and Houston airports, I certainly recommend using the service.

We arrived at Houston mid-afternoon, picked up our rental car (left hand drive and first challenge for Tony) and travelled to our hotel in Humble, and there began enthrallment in everything-accents, people, simply everything! It was advised to be in the time zone, i.e. stay up until the local bed time. We therefore suffered very little jet lag.

Next day we intrepid travellers hit the road! Ten to twelve lanes in some places and going what at first seemed the wrong way on the wrong side! We stopped at a service station and I didn't recognise a thing in the shop! The cost for a gallon of petrol was less than a litre costs here. I LOVE Texas! I love the way they all say "Yes Ma'am!" and "y'all" Ha-ha. We stopped at a delightful cafe where I had to try Key Lime Pie. I asked where to get the water for tea, and she said, "Y'all just use that spigot there".

On to Webster where the Holiday Inn proved to be fantastic, so clean, and comfortable. We visited NASA Space Centre the next day. Again planning is the key. We took a taxi to NASA as it was only a few miles. Of course with these things, there is a lot of walking, so we chose to take the tram trip tour around the centre first and then go inside to the where the space craft and history of space travel were displayed. The space centre is located in a Wildlife Park which covers 16 hectares. Mind boggling! There were Texas long horn cattle, deer, rabbits, and all manner of other critters.



at NASA

We took regular snack breaks so walking was balanced with sitting. We even, with the aid of the help desk, downloaded the Uber app and a lovely, very talkative black lady driver (Mamie) was there in an instant and took us back to our hotel. I have her on video tape to record her talking - she was previously a teacher until the numerous school shootings and subsequent advice that teachers carry firearms, led her to her new job. She was delightful, as was everyone we met.

On to the very colourful Galveston, absolutely delightful! although the first hotel we had booked turned out all wrong. There was a strong chemical smell, and even before I saw the man with a back-pack sprayer, I started having a full-on reaction.

I asked him what he was spraying and he held up his hands and said "no danger, no danger!" Apparently for cockroaches and spiders. We left that place and the hotel we went to instead turned out to be great, and cheaper as well!

Word of warning about prices in USA - they have a sales tax (like our GST) but it is not included in the price shown or quoted. It is added on when you go to pay.

Everything in Galveston was a delight! My mate indulged my every whim in sightseeing, from the Bubba Gump Shrimp Company to the Bishop's mansion. The best was the Bryan museum in the old childrens' orphanage which had survived the devastating 1900 hurricane, which wiped out about 3600 buildings and killed an estimated 6000-12000 people. This museum was all about the settlement of Texas and battles for occupation with the Spanish and Mexicans by USA troops. Lots of Wild West cowboys, saddles, guns etc. Had to drag hubby out when it was time to leave.



Bubba Gump Shrimp Co. (as in the movie Forrest Gump)

Even doing the laundry, once we figured out how to use the machines in the Washerteria, was intriguing. Talking to the folk there and listening to them was so fascinating.

We thought we had time travelled when we entered an amazing old fashioned shop, full of chocolates, taffy, and the best malted milkshakes ever. I have always wanted to taste Southern food and drink in the atmosphere. Here in Galveston it was in abundance, Gumbo (eye wateringly spicy) po'boys, hushpuppies, grits, fried shrimp, grilled shrimp, and barbequed shrimp! And I tasted the lot!

Yes, I admit to battling pain, headaches, and tiredness. My debility was there but masked with heaps of medication along with adrenalin and excitement and delight in my circumstance. I made a deal with it. Shut the heck up, okay! and let me enjoy this time. Most of the time it complied, albeit grudgingly.

Then, in the twinkling of an eye, the week had passed and it was time to embark on the next phase. We returned our rental car and were transported to the port to board our cruise on Liberty of the Seas. More planning required here because checking in and customs were tedious. Tony stayed in the queue while I was able to sit to the side.

On the cruise the most arduous thing one has to do is decide what to eat, where, and which show to watch and when to swim and all those things. There was lots of walking on the big ship, and we noted an amazing number of wheelchair bound people and mobility scooters. However, everything is done for you and our room attendant changed linen and cleaned twice a day. We usually chose the complimentary room service breakfast which we enjoyed on our balcony watching the sea. And remember my loyal friend TED E Bear, the room attendant put him to bed each night and made a towel friend for him, borrowing Tony's sunglasses.



Two days of cruising, first stop Cozumel, Mexico, next day George Town, Cayman Island where my sister and her husband met us and we enjoyed the day with them. Finally, Falmouth, Jamaica, where we purchased our only shore excursion and it was delightful - a trip on a bus to Montego Bay and out on a catamaran to snorkel and learn about Jamaica. I can't even begin to tell you how absolutely enthralled I was by the whole thing. I even got a foot massage on that boat. Of course, gratuities play a big

part... nothing for free!

We chose the first dining option for obvious reasons; I retire early. A couple we sat with were interesting. They were quite religious and both carried firearms, and defended strenuously their right to do so. She had an antique pistol in her hand bag and he carried a Glock. Their son, a defence attorney advised them thus. Most people on the cruise were from Houston and surrounds, so easy and inexpensive for them. They were captivated by our accents and asked where we were from. Most people thought we were from Wales, UK, Canada, Ireland, or Australia.

There was always lots happening on the ship, and one could do as much or as little as you liked.

All too soon the seven night cruise had ended and we met a grey old Galveston with the only rain we saw the whole time. We had come into port early the night before because of fog threatening to close the port.

As it was, it was eerie and amazing and sleep eluded me as I stood out on the balcony as we were coming in to port at midnight, the fog horn sounding every couple of minutes. I was feeling so ill from jamming down all the amazing and delicious food possible, and suffering the consequences.



There was a great deal of waiting this last day, including hours waiting until the airport checkin opened and more hours in the departure area, which I explored to the full, buying last minute tee shirts for family and just fully taking in the atmosphere, knowing I was taking leave soon of the States after an incredibly wondrous time.

Although the 15½ hour flight home was long and seemed to take forever, and I think by the time we arrived home from Auckland we had been up in the vicinity of 30 hours, this was an experience that I wouldn't have missed for the world!

Life is like a road trip. Enjoy each day, and don't carry too much baggage. HEARTFELTOUOTES. BLOGSPOT.COM

Caught in the Act!

The leader of the vegetarian society just couldn't control himself anymore. He just needed to try some pork,



just to see what it tasted like. So one summer day he told his members he was going on a short holiday. He left town, and headed to the nearest restaurant.

After sitting down, he ordered a roasted pig, and impatiently waited for his delicacy. After just a few minutes, he heard someone call his name, and to his great chagrin he saw one of his fellow members walking towards him.

Just at that same moment, the waiter walked over, with a huge platter, holding a full roasted pig with an apple in its mouth.

"Isn't that something," says the leader after only a moment's pause, "all I do is order an apple, and look what comes with it!"



Fermented Vegetables

These are perfect for the beginner as you really can't go wrong. They are super tasty; even children love them. They keep for many months in the fridge and become more flavoursome as time goes by. We have used a popular carrot and cauliflower combination.

Salt brine:

2 tablespoons sea salt

1 litre filtered or spring water

Carrots & Cauliflower:

3 garlic cloves, slightly crushed but still intact

Approx 2/3 of a cauliflower, cut into florets, rinsed in cold water

3-4 large carrots, cut into bite-sized pieces

2 tsp za'atar (from specialist stores), or 2-3 tsp whole coriander seeds

3 fresh bay leaves

2 tsp whole black peppercorns

To make the salt brine, dissolve the salt in the cold water and set aside.

- Pack vegetables into a clean 1-litre glass jar. Tip in the spices and leaves and pour over the brine.
- Cover the jar with a tight-fitting lid and place on the bench or pantry shelf to ferment. Culture at room temperature (15-20 degrees C is preferred) until the desired flavour and texture are achieved. This can take anywhere from 3-7 days, depending on how warm your kitchen is.
- You will need to 'burp' the pickles daily to release excess pressure. To do this, slowly open the lid and allow the gases to escape before replacing the lid.

Transfer the jar to the fridge. The flavours will continue to develop with time. The pickles are

ready to eat once chilled.

Don't throw away the pickle juice; it's amazing added to bowls of broth for a little flavour and probiotic boost, or added to salad dressings. It can also be used as a starter to speed up the process for the next jar of pickles.



Moving house? If so please advise your new contact details



....so we can keep in touch

Library

Please feel free to come in and browse through our library collection at our Christopher St offices.

Check that Tina or Joanne are in before you come. If you are on the internet you can access the titles from our website <u>www.ccisupport.org.nz</u>

Can We Email Your Newsletter?

Costs are always a major consideration to us. If you are currently receiving your MEssenger by normal post, and you have email available to you (ideally broadband), we ask that you consider receiving it in future by email. This will help us to keep our mailing costs as low as possible. So, if you are prepared to change, please email the office at info@ccisupport.org.nz with your details.

Acknowledgement

We gratefully acknowledge our many sources that have kindly allowed us to use their articles.

They include:

Action for ME, UK ME/CFS Group (Canterbury) MEISS (Dunedin) **ANZMES**

ME Association, UK DR Ros Vallings

Nelson Bays ME/CFS & FM Support Group

Appreciation to our Funders

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

































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

Group Meetings Calendar

April 2019	May 2019	June 2019
Wednesday April 10th Support meeting at 56 Christopher Street, 10.30am – 12.00pm Speaker: Barry Maurer from Health Consumer Service	Wednesday May 8th Support meeting at 56 Christopher Street 10.30am – 12.00pm Topic to be advised Ph Tina: 027 625 4449	Wednesday June12th Support meeting at 56 Christopher Street 10.30am – 12.00pm Topic to be advised Ph Tina 027 625 4449
Wednesday April 10 th Eastern Bay group - 1.30pm Topic: Stress Management Little Orchard Activity Room, Whakatane Library Ph Elizabeth: 021 838 217	Wednesday May 8th Eastern Bay group - 1.30pm Topic: Acceptance Little Orchard Activity Room Whakatane Library Ph Elizabeth: 021 838 217	Wednesday June 12 th Eastern Bay group -1.30pm Topic: Nutrition Little Orchard Activity Room Whakatane Library Ph Elizabeth: 021 838 217
Wednesday April 17th Coffee morning 10:30am at Mitre 10 Mega Café, 1066 Cameron Rd, Gate Pa	Wednesday May 15th Coffee morning 10.30am at Mitre 10 Mega Café, 1066 Cameron Rd, Gate Pa	Wednesday June 19th Coffee morning 10.30am at Mitre 10 Mega Café, 1066 Cameron Rd, Gate Pa
Thursday April 18th Young members' meeting 56 Christopher Street at Midday 12pm Ph Kira: 021 027 18127	Thursday May 16th Young members' meeting 56 Christopher Street at Midday 12pm Ph Kira: 021 027 18127	Thursday June 20th Young members' meeting 56 Christopher Street at Midday 12pm Ph Kira: 021 027 18127
Rotorua coffee mornings & Support meetings. To be advised Ph Tina: 027 625 4449	To be advised	To be advised

PLEASE NOTE

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

Formed 1981

MEssenger is kindly funded by WBoP Disability Support Trust & EBoP Disability Community Trust Incorporated 1986

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10% Discount Stores

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

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

Want to call in or write to us?

We are at 56 Christopher St, Tauranga 3112

Admin: Joanne ph (07) 2811 481

Email: info@ccisupport.org.nz

Website: www.ccisupport.org.nz

SUBSCRIPTIONS and DONATIONS

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

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

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

Please enter your 'name' and 'ME Sub' and/or 'donation' in the reference and email us if you would like a receipt.

OR...... deposits can be made in person to Kiwibank if you go in with our account number.

BEQUESTS

Including a bequest to Complex Chronic Illness Support in your will is also an option you may consider. ACORN Foundation can assist you to arrange a bequest to CCI Support. Donations can be made to our endowment fund with ACORN ph 07 579 9839, internet banking on the Acorn website:

www.acornfoundation.org.nz or cheque made out to Acorn Foundation, PO Box 13604, Tauranga 314
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