

# Messenger Spring 2019

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Hi everyone!

It's hard to believe we are now entering into the Spring season, especially when the skies are grey and accompanied with a lot of rain! If it's any consolation daffodils are appearing in my garden, so I figure this is a signal for kinder weather ahead.

CCI Support has seen a few more changes since the last newsletter. We would like to farewell Julie Cross – operations manager – who has been incredibly supportive and productive during her time with CCIS. We wish Julie all the best in her next endeavours.

In Julie's place, we welcome Miranda Whitwell, who comes to the organisation with an enviable skill set and look forward to her fresh approach and expertise in helping the organisation reach new heights.

As you most likely know, a new board was elected at the last AGM. Thank you to Jacqui Bassett for her dedication to and compassion toward the ME/CFS cause. CCIS will miss Jacqui's leadership and we hope Jacqui will remain active in the CCIS community in some other way.

Welcome to our new Board members - Keith Appleton, Matt Appleton, Sarah Davey and David Harris. I am sure their unique talents, expertise and perspectives will strengthen CCIS' vision moving forward and continue to provide the much-needed support for our members.

In the meantime, enjoy your Spring newsletter and remember to keep warm and well.

Remember to check the Group Monthly Meetings Calendar!



Dorotka and the team at CCI Support. 🙂



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/

Send a friend request...!

# Local Items of Interest

# A Warm Hello from Our New Operations Coordinator

It is with pleasure that I introduce myself; I am Miranda Whitwell.

I come to the organisation with a background in nursing, social agency coordination and contract management. I am also a mum of 3 children and live in Tauranga. I will be working in the CCIS offices from **Tuesdays to Thursdays**, overseeing the operations of the Tauranga, Whakatane and Rotorua branches.



Having started Complex Chronic Illness Support only a couple weeks ago, I am starting to find my feet and create new systems going forward. There have been many changes within the organisation within the last few months and we know this has been unsettling. I understand that, and hope to build a strong team going forward.

I want to say a big thank you to those that have gone before and created and maintained the best parts of CCIS. Having said goodbye to Julie last week as well as Jacqui standing down from being Board President, I have big shoes to fill. But I am looking forward to the challenge.

Over the next few months we will see some changes in staff again, with the Rotorua Field Officer position coming up for renewal and some changes to the roles within the Tauranga branch as well. We are grateful for **Dorotka**'s energy and enthusiasm for being the Tauranga Field Officer with the support of **Joanna** with the Towards Wellness program. It is with great anticipation that we look forward to the changes and challenges and embrace the new start.

At the latest AGM, **Keith Appleton** was appointed as Board President and is keeping his role as Treasurer. Many will already know **Matt Appleto**n, who is Vice President and still running the Young Members Support group. We also have **Sarah Davey** and **David Harris** on the board. So the fresh start and focus will be invigorating for the organisation.

I look forward to working with you and am thankful for you, as members of CCIS. Your support and active promotion of our organisation with friends, family, colleagues and medical people, helps us to be able to support those within our community. Thank you for your kind donations, for paying your membership fees and donating your time as a volunteer. We are humbly grateful.

Miranda

Kind regards,

Miranda Whitwell Operations Coordinator

### Our Farewell to Tina and Kira

We were all thrilled with the large turnout for Tina and Kira's farewell luncheon at St Enoch's church in June, with a lot of members even making the trip from out of town to honour the two field officers.

That alone is testament to the high esteem members have for these two and there was a really strong sense of gratitude in the room as people gathered. Tina has served many years as our field officer and Kira introduced a new focus on youth, establishing the support group and social events that give young people a place a safe place to meet together.



Senior FO Tina (L.) and Youth FO Kira

The Towards Wellness course grew swiftly from small beginnings and evolved to a programme that has been a life-line to sufferers near and far who have found themselves in the cruel and lonely grip of chronic fatigue syndrome.

Tina told us she was delighted to have been part of a movement to make a difference, to make a change.

She thanked the Board for putting their trust in them to create the Towards Wellness course, dubbed by Tina as "the beautiful monster".









Finally a course was being provided that offered them support, honest information and a raft of skills and techniques for them to use to help them manage the illness.

While Tina is off to new beginnings in Rotorua, Kira plans to focus on her own business and we wish them both well in their new ventures.

## Newsletter To Arrive with the Seasons

You will have already noted that the CCI Support newsletter will now be coming to you 4 times a year instead of 6, either emailed, or a hard copy delivered to your letterbox. How you receive it is your choice, and if you need that to change, just contact the office and that will be done for you.

It makes sense to align ourselves with the seasons of the planet. So you can in the future look forward to hearing from us via our **Spring**, **Summer**, **Autumn and Winter** editions. Consequently you can expect your newsletter to arrive at the beginning of September, December, March and June.

We will of course continue to work hard to get to you the most relevant and up-to-date information about activities at CCI Support BoP, and results of the latest important global research. Enjoy. Ed.

# **Eastern Bay Report**

It's the small things that I am once again grateful for as I find myself in a blip. I count my blessings each day so make sure that I don't miss the big picture; Even though I am less well than I have been, I know that I can get back to where I was, because I have the tools and I have done it before.



This knowledge helps to makes it easier for me to accept that I have to do a lot less than I want to and that I need to make changes in my life, quickly, to make this easier to achieve. It's lucky for me that I have made a life which is easy to adapt to these changes, but it is still not easy to accept less "life".

"Can I have some more please..." made famous by Dickens because it links into our very human need to ask or take more. It's part of our nature to want to make our lives bigger and brighter, if not for ourselves then for our children. So, wanting to have more in our lives than eating and sleeping is pretty natural.

One of the ways I quell the desire to keep pushing for more is to practice gratefulness for the small things that I find in the world.

Like this slug in a clover flower after rain. Who notices slugs? Probably only gardeners who want to kill them, but I notice them. I notice them because I am lucky enough to walk slowly, I can't walk fast, I need to stop, so I notice the fat slug in its petal bed in the lush winter grass.



It's a moment that I get to see the small things in nature, in the world around me. I watch my nephew's face as he views the world, I see the clouds pass by, listen to the wind rush through the trees, feel the sun on my face or the frost on my fingers. I get time, to pause and breathe. I get to be in the moment, and this is a privilege.

It is also a privilege to welcome new members to our Eastern Bay group, **Lou**, **Jo and Aidan**, as they share their knowledge, ask questions and get to know the membership. We have had really interesting monthly meetings and very funny coffee catch ups, I am so grateful that people gather their energy, plan and pace to arrive at the meetings ready to enjoy the social contact. Even if the cafes are noisy and the coffee is bitter, the company is warm, caring and wickedly funny.

Our monthly meetings are on the **second Wednesday** of every month at **1:30pm** at the **Whakatane Library** and our Coffee Catch ups are at various cafes around town on the **fourth Tuesday** of each month at **10:30am**.

So I will continue to count the small things and keep my life wee for a while. All the while being grateful for the skills I have that enable me to be able, day by day to improve and put these symptoms back under my control again.

Best wishes to you from your Eastern Bay Field Officer, Elizabeth McGougan

# A Deserved Placing for Dr Vallings

Our own **Dr Rosamund Vallings** (Auckland) was one of 3 finalists for the 'Senior New Zealander of the Year Awards' earlier this year, in case anyone missed that fact. The overall winner was Dr Bill Glass a well deserved winner who was described as "The father of occupational medicine".

Dr Vallings is highly respected throughout the ME/CFS community, in fact many of us have been diagnosed by her. It is only fitting she be honoured for the extraordinary work she does representing us in this country and internationally.



Dr Vallings (L) pictured with her certificate

# Friends, Family, Life & ME/CFS/FM

People with ME/CFS and FM experience many frustrations in their relationships, including:

- Loss of Relationships: The unpredictability of symptoms, together with our limitations, often leads to misunderstandings. Some relationships may be lost, while others are redefined.
- **Feeling Not Understood:** Other people may not believe we are ill or may not understand the seriousness of our condition.
- Guilt: You may blame yourself for getting sick or for not contributing to family or society.
- **Feeling Undependable:** The unpredictability of symptom often leads to cancelling out of commitments, creating misunderstanding and threatening some relationships.
- **Isolation:** You may feel a sense of isolation, either because of spending more time alone or because of feeling different from other people.
- Fears of Dependency and Abandonment: You may worry about losing your ability to care for yourself or fear that others upon whom you depend will leave you.

Try some of the following, they may help to improve your relationships:

**Assess & Triage** If you have ME/CFS or FM, it is likely many relationships will be redefined and some will end. We suggest you make this transition a conscious and deliberate process by using relationship triage.

The general idea is to concentrate on the more valuable or necessary relationships. In the words of Dr. David Spiegel of Stanford: "Save your energy

and use the illness as an excuse to disengage from unwanted social obligations. Simplify the relationships that are necessary but unrewarding, and eliminate the ones that are unnecessary and unrewarding."

Adapt How You Socialise You may be able to preserve a good number of relationships by adapting how you socialise. For example, if you have severe limits and cannot often get out of the house, you may be able to stay in touch with people using phone calls and emails, plus having them make occasional visits.

Be aware of how much time you devote to being with others and if it is using too much energy adapt i.e. set a timer on phone calls, set a limit on time at gatherings, only invite 2 people around at the time etc.

**Do Your Part** One step toward easing strains in your relationships is to acknowledge that the illness creates problems for others. Your symptoms and moods, for example, may make you unpredictable, and your limits may force others to take on additional responsibilities. Express your appreciation for their efforts.

Take responsibility for the problems the illness creates for others. For example, if the illness makes you moody, make a list of things you can do to help yourself feel better so that you avoid inflicting your moods on others.

Acknowledging that your role in the family will change, try being open and honest about how you are feeling, coping and what your fears are.

Try letting them know how you are feeling each day, and therefore what you will be able to do by using Spoons, or Percentages or one of the many illness rating tools. Open honest communication is key to any relationship, regardless of ME/CFS/FM.

# Change Expectations, Use Assertiveness, Create Boundaries

Because of guilt or pressure from others, you may do more than your body can tolerate. A solution is the combination of changing your expectations and being more assertive. Changing expectations is a gradual process by which we come to accept that we have limits and need to adapt to a "new normal".

Learning assertiveness or setting boundaries, can also be a gradual process, as you educate others about your limits.

### Here are four ideas to consider:

- 1 Be very specific in the requests you make or limits you set.
- 2 Show that you understand the other person's situation. You might say something like, "I know my illness makes your life more difficult and that some things I say and do may be frustrating.
- 3 Preface your request with a statement of appreciation, such as "I appreciate all you do for me."
- If you find it difficult to be assertive, practice saying your request to yourself or someone you trust before making it to the person whose help you want. Remember, "no" is a complete sentence.

### **Accept Help and Help Others**

Other people often feel helpless about our illness. By giving them something specific to do, you can do them a service while helping yourself. As one person in our program said, "People are often thrilled when I ask for help in

clear, practical ways." A caution: asking too much of others in total or of one person in particular can risk caregiver burnout.

Helping others aids self-esteem and also gives others an incentive to stay in the relationship. As someone in our groups said, "I ask myself what I am doing to make a relationship valuable to the other person."

### Issues that family members face include:

- □ Extra household tasks
- Extra parenting responsibilities
- □ Financial strains
- Caregiving responsibilities (for person with CFS or FM)
- Strained relationships
- Worry and uncertainty about the future
- Uncertainty about how to help the person who is ill
- □ Resentment and frustration
- ☐ Sadness and depression
- □ Increased stress
- Loss of companionship
- □ Sexual difficulties
- □ Strained communication
- Less socializing

For more information on this topic and others visit: <a href="http://www.cfsselfhelp.org/library/eight-ways-improve-relationships-0">http://www.cfsselfhelp.org/library/eight-ways-improve-relationships-0</a>

This document is for CCIS Clients personal use only, it has been developed by CCIS BOP Field Officers for the Towards Wellness Programme and for CCIS clients only, please do not share this content without consent. Thank you.

Moving house? If so please advise your new contact details



....so we can keep in touch

# ME/CFS: New Test in Sight

Scientists at Stanford University School of Medicine in California have developed and tested a new diagnostic tool for ME/CFS, a test that detects the reaction of the immune cells and blood plasma to stress. The findings may also help screen effective drugs for the condition.

AS we all know now, Myalgic encephalomyelitis, or chronic fatigue syndrome (ME/CFS), is a serious condition with symptoms that include extreme tiredness, difficulty sleeping, trouble with thinking and remembering things, muscle pain and aches, a recurring sore throat, and tender lymph nodes.

Currently, physicians can only diagnose ME/CFS by examining a person's symptoms and medical history, and by excluding other possible illnesses. However, the results of a new study may soon change this. Scientists at Stanford University School of Medicine in California have discovered a **biomarker** for ME/CFS and developed a test that could soon diagnose the condition accurately.

Ron Davis, Ph.D.—a professor of biochemistry and of genetics at Stanford University School of Medicine—devised the test together with his team, which includes first study author Rahim Esfandyarpour.



Prof. Davis and colleagues published their findings in the journal Proceedings of the National Academy of Sciences.

### How does the test work?

Prof. Davis shares the motivation for his research, saying: "Too often, [ME/CFS] is categorized as imaginary." He goes on to explain that physicians often misguidedly test liver, kidney, and heart function, as well as take blood samples and immune cell counts from people who seek help for ME/CFS.

"All these different tests would normally guide the doctor toward one illness or another," says Prof. Davis, "but for [people with ME/CFS], the results all come back normal." The issue, he adds, is that none of these tests look deep enough. Instead, their new diagnostic test looks at how a person's immune cells react to stress. Specifically, the scientists used a nanoelectronic assay, which measures small changes in energy to assess the health of immune cells and blood plasma, to see how the immune cells and blood plasma process stress.

To develop the test, the team took advantage of "advancements in micro/nanofabrication, direct electrical detection of cellular and molecular properties, microfluidics, and artificial intelligence techniques."



Scientists have developed and tested a new diagnostic tool for ME/CFS

The test detects "biomolecular interactions in real time" by using thousands of electrodes to create an electrical current, and by using small chambers that contain blood samples with only immune cells and blood plasma.

Inside the small chambers, the immune cells and plasma interact with the electrical current, altering its flow.

The scientists used salt to stress the blood samples of some people with ME/CFS and some people without the condition. They then assessed the changes in electrical current.

The bigger the changes, the less healthy the blood sample, explain the scientists; the changes in electrical current reflect the changes on a cellular level. A significant change indicates that the immune cells and blood plasma do not react well to stress and cannot process it effectively.

In the experiments that Prof. Davis and team carried out, all of the blood samples that came from people with ME/CFS showed a clear spike indicating large changes in electrical current, whereas blood samples from people who did not have the condition showed an even course.

"We don't know exactly why the cells and plasma are acting this way, or even what they're doing," says Prof. Davis. However, the findings offer "scientific evidence that this disease is not a fabrication of a patient's mind."

"We clearly see a difference in the way healthy and chronic fatigue syndrome immune cells process stress."

The researchers applied the test to the blood samples of 40 people, 20 of whom had ME/CFS and 20 whom did not. Their test accurately identified all of the people with ME/CFS without misidentifying any of the people who did not have the condition.

Also, they wish to apply the test to identify effective drugs for ME/CFS. "Using the nanoe-

lectronics assay," explains Esfandyarpour, "we can add controlled doses of many different potentially therapeutic drugs to the patient's blood samples and run the diagnostic test again."

This way, if the test still finds spikes in electrical current after the treatment, it means that the drug didn't work and the immune cells still respond poorly to stress. However, if the drug smoothes out the spikes, it could mean that they are helping the immune cells and blood plasma process stress more effectively.

medicalnewstoday.com This article was published in April 2019. An abridged version.





### Guy Talking to a Friend:

My wife sent me a text that said "Your great."
So, naturally, I wrote back: "No, you're great."

"She's been walking around all happy and smiling as if she's just won Lotto. Should I tell her I was just correcting her grammer or leave it?"

### A Call For Newsletter Contributions

Here at CCI Support we'd like to hear more from you, our members out there. This is, after all, YOUR newsletter. The coffee mornings and support meetings have proved to be a good way for us all to keep in touch in a safe environment, to hear others' stories about their M.E. journey and to exchange information. But a majority of members we don't get to see or hear. And we'd like to.



Please feel free to send me anything for the newsletter you want to share and feel may be helpful for our readers. It may be a story, a poem or a question even, that we will endeavour to answer in print. We only ask that you try and keep the content of inside 1/2 page in length.

Please send in your contributions to the newsletter editor Jan Morrison at: janm@orcon.net.nz. Looking forward to hearing from you .....!



# Minestrone - a Soup to Warm the Cockles....!!

This here is a true dinkum hearty budget meal..... not just for those of us who are seriously having to watch our pennies, but with the members in mind who may be by themselves a lot, and are tired, and just need to throw a few ingredients together in a pot without too much hassle.

Inexpensive and simple. A lovely soup to enjoy on a cool Spring evening. This hearty minestrone is full of vegetables and can be prepared in less than 30 minutes.

### Ingredients:

1 bay leaf

a sprig or 2 of rosemary or thyme

1 onion, diced

2 stalks celery, sliced (if you have it)

2 x 420g cans of condensed tomato soup

1/4 cup of pasta/spaghetti of your choice

425g can of red kidney beans, drained & rinsed

300g frozen vegetables

### Method:

- Heat a dash of oil in a large saucepan. Add onion and celery and cook over medium heat until the vegetables have softened. Pour over the 2 cans Wattie's Extra Rich and Thick Condensed Tomato Soup and add 3 cans of water. Add bay leaf and rosemary. Stir while bringing to the boil.
- 2. Add orzo pasta and simmer for 5 minutes. Add Craig's Red Kidney Beans and Wattie's frozen Super Mix Vegetables. Stir and bring back to the boil. Reduce heat and simmer for 5 minutes until vegetables are tender and orzo is cooked. Season to taste.
- 3. Remove the herbs, garnish with grated Parmesan and chopped parsley, and serve with crusty bread.

**To serve:** On top - grated parmesan - or any cheese of choice - and a sprinkling of chopped parsley

https://www.foodinaminute.co.nz



# Library

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

Check that Dorotka or Miranda are in before you come. If you are on the internet you can access the titles from our website <a href="https://www.ccisupport.org.nz">www.ccisupport.org.nz</a>

### 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.

# Te Puke and Rotorua meetings

If you are planning to attend the above support group meetings, it might pay to check with Dorotka before each meeting as the venues change from time to time. Also please note: The Mt Maunganui and Katikati/Waihi meetings are currently on hold.

# **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)

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:





























**ANZMES** 





**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.

	eetings Calen September	October	November
Tauranga Support Group Meeting 10.30am-12pm	Wednesday 11th	Wednesday 9th	Wednesday 13th
<b>2</b> <sup>nd</sup> <b>Wednesday of the month</b> 56 Christopher Street Contact Dorotka 027 6254449			
Topic for the month	TBA	TBA	TBA
Tauranga Young Members Support Group Meeting 12pm onwards	Thursday 19th	Thursday 17th	Thursday 21st
<b>3<sup>rd</sup> Thursday of the month</b> 56 Christopher Street Contact Dorotka 027 6254449			
Tauranga Coffee Morning 10.30am-12pm	Wednesday 18th	Wednesday 16th	Wednesday 20th
<b>3<sup>rd</sup> Wednesday of the month</b> Mitre 10 1066 Cameron Road, Gate Pa			
Whakatane Support Group Meeting 1.30pm-3.00pm	Wednesday 11th	Wednesday 9th	Wednesday 13th
<b>2<sup>nd</sup> Wednesday of the month</b> Whakatane Library Contact Elizabeth 021 838217			
Topic for the month	Pain	Health Practitioners and You	Research
Whakatane Coffee Catch-Ups 10.30am onwards 4 <sup>th</sup> Tuesday of the Month	Tuesday 24th White Island Café 12 The Strand Whakatane	Tuesday 22nd Baxter's Café 208 The Strand Whakatane	Tuesday 26th Café 4U 93 The Strand Whakatane
Rotorua Support Group Meeting/Coffee Group To be advised	whakatane	WHARATAILE	wnakatane

# **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

### **Board of Management**

Ops. Coordinator Vice-President Treasurer Board Members Miranda Whitwell Matt Appleton Keith Appleton Barbara Whitton Sarah Davey David Harris

### Staff

President WBoP Field Officer EBoP Field Officer TW Facilitator Newsletter Keith Appleton Dorotka Wisniewski Elizabeth McGougan Joanna Delaware Jan Morrison

### 10% Discount Stores

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

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

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

We are at: 56 Christopher St, Tauranga 3112 ph (07) 2811 481

Hours: Tuesday to Thursday 9 - 2

Friday 9 - 12

**Email:** info@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 3141

Cut here if sending by post		
Yes, I would like to make a donation / pay r	my subscription to Complex Chro	onic Illness Support.
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