

CCI Connect

November 2021



We are nearing the end of another year. We have a few changes happening with staff coming and going, Welcoming Waikato and Wellington to the fold, as well as adding Karen and Annabelle to the staff. It is sad to say goodbye to Charlotte, as she heads back to England to be closer to family. But with change brings new areas being supported, new connections and new friends. I want to wish you an early Merry Christmas as this is the last Newsletter for the 2021 year. We are still open till mid December, and we will reopen all member meetings etc in February... along with our new 'Towards Wellness Hub'.

Unfortunately due to COVID, we won't be holding our annual regional break ups this year, but instead planning (COVID dependant) February welcome back parties instead.

Tauranga Office Hours over the Christmas Break.

We will be closing the offices on **Thursday 16th December at midday and re opening 9am on the 4th January.** Please be aware, if you need support during this time, your GP and other health services will be available.

Miranda Whitwell - CEO.

53 FRASER ST, TAURANGA

Hours: Tuesday to Friday

9am till 2.30pm

info@ccisupport.org.nz

07 281 1481, 022 658 0251 or 0800 224787



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Western Bay of Plenty

Hi to all our WBOP members. I hope everyone is doing well and enjoying some of our warmer weather. I am also so pleased to welcome our newest member of the team Annabelle. Annabelle will be working from head office and will be working to support the WBOP and National clients alongside Karen. It is with sadness that I will be saying goodbye to CCIS as I will be moving back to England to be with family. I have

really enjoyed my time at CCI Support and it has been a real privilege getting to know each and every member. Thank you for sharing your journey with me and I wish all our members, the team and the agency the very best for the future. Take good care, **Charlotte**.



Annabelle

Health and Wellness Facilitator

Phone or Txt:

027 625 4449

Office Hours

Tuesday to Friday

9am till 3pm

Hello, my name is Annabelle. I have a teenage daughter and Irish husband and originally from England. However, have lived in Tauranga Moana for 15 years after travelling for 8 years. I am in love with nature and my interest in holistic health started after completing my Clinical Aromatherapy qualification in 2002. Over the years I have managed a massage therapy business, taught/teach yoga/mindfulness, and worked/supported people of all ages with various disabilities. After completing my Bachelor of Community Health (Majoring in Public Health) in 2020, I am passionate about integrating previous holistic approaches into my work ethos. I believe there is a place for both medical and complementary approaches and that everyone is entitled to a good quality of life best suited for them. I thrive in helping people achieve this and look forward to walking this path with you. I look forward to meeting you soon.

- Bachelor of Community Health
- Diploma of Rehabilitation
- Clinical Aromatherapist
- Qualified Yoga teacher & Massage therapist

Wellington and National areas

A warm welcome from the Tauranga Office to all of our National and Wellington members. The year is flying by and we are already in November. I am certainly enjoying some warmer weather and the brighter evenings.

We are so pleased to be able to offer our services and support to our members across New Zealand. I will be sharing the National and the Western Bay of Plenty role with our new staff member, the lovely Annabelle O Cinnseala.

It has been a busy three months, coming onboard as a Wellness Facilitator with CCIS and settling into my role well. It is fantastic getting to know you all and to walk along side and support you in your journey toward wellness. Our Wellington membership is growing and we are pleased to announce that we are hiring a Health and Wellness Facilitator for the Wellington Region. Please let us know if you have someone who would be interested in this role. We have started the process of filming our innovative and award-winning "Towards Wellness Programme" which will be available online from the end of January 2022. Watch this space.

Our thoughts are with our communities still in lockdown and hoping you are taking good care of you during these uncertain times. We are here to support you and can be reached by text, phone, email or by booking an appointment using the link below.

For National clients we have a new 0800 number 0800 224 787 Karen Maxwell



Karen

Wellness Facilitator

Office Hours

Thursday and Friday
9am - 2.00pm

Wellington

Phone: 027 245 5961

Email: wellington@ccisupport.org.nz

National

Phone: 022 658 0251

Email: nz@ccisupport.org.nz

Lakes District—ROTORUA/TAUPO and EBOP

Greetings from Lakes/EBOP

Hello Everyone,

Wow this year is flying by. I'm really enjoying the spring sunshine, especially as it's warming and welcoming without being overwhelming.

I am desperately missing all the in-person meetings and coffee catch ups in Rotorua and Whakatane. Unfortunately, we are unable to meet again until we return to level one. We had a fabulous turn out for October's Online meeting and I highly encourage everyone to come along and try out online meetings. We are here to help if you need some guidance navigating technology.

With December just around the corner I find myself thinking about Christmas events, I'm already starting to plan how I am going to manage my dietary requirements and socialising. If you are like me this is quite a draining (but enjoyable) time for our systems, having a plan in place to manage all the energy required is a must.

I hope you have a wonderful time over the festive season, and I look forward to catching up with you soon.

Bye for now Tabitha



Tabitha

Health and Wellness Facilitator

Office Hours

Tues to Thurs
9.30am - 2pm

Lakes

Phone: 020 4017 9091

Email: lakes@ccisupport.org.nz

EBOP

Phone: 020 401 7909 2

Email: ebop@ccisupport.org.nz

From the Waikato Desk

Kia ora and welcome from the Mighty Waikato

We are in the middle of spring and the season is turning on its finest display of weather. "Spring adds new life and new beauty to all that is" – Jessica Harrelson, seems very apt today. I do hope you are all able to enjoy at least some moments of these amazing days sitting in the garden or on the deck in the sunshine to soak up nature's beauty.

Covid -19 is still playing havoc with our freedoms for many of my Waikato community. Until we are back in Level 1, no education support groups, or social groups will resume. I am SO missing you all!! It has been great to see some of you who have joined our online monthly members meetings. For those who would like to join in but are yet to get your head around the technology, please let me know. I am happy to do a zoom test run just with you, so you get the feel of it.

With the end of year quickly approaching I will be arranging a zoom social meeting for our Waikato community, if we haven't reached level one by then. Please keep an eye out on your inbox for the link. This will be scheduled for early December and there will be a Christmas theme, so dress up by putting on a Santa hat, or drape some tinsel around your shoulders, or just wear red if that is all you have. Bring a cuppa along and let's mingle and jingle online!! I look really look forward to reconnecting with you then.

Until then, take care

Nga mihi Tracey Larsen



Tracey

Health and Wellness Facilitator

Phone or Txt:
022 154 7076

Office Hours
Mon—Fri
9am - 4.30pm

waikato@ccisupport.org.nz

Update on Dr Ros Vallings



Dr. Vallings will be retiring January 2022 and is no longer accepting any new patient referrals.

This will no doubt be a shock to a lot of people, but I am going to gradually wind down and retire after 60 years in practice!!! I feel the time is right, as I have over the years educated a lot of doctors about the illness and there are many doctors around now who are totally capable of dealing with CFS etc.

I will still carry on giving talks, keeping involved in the research and writing stuff. I would miss it all to stop entirely.

Congratulations for retiring, you will be missed terrible, but we wish you all the best. Thank you for all the years of service you have given to our ME/CFS/FM community. What a trooper!! 60 years in practice! You well and truly deserve to give yourself some time now.

Kindest regards from the CCIS team.

Towards Wellness HUB

We are getting there. Filming is happening right now and we are hoping that by January it will be all up and running.

The Hub means wherever you are and whenever you want access, the Towards Wellness programme will be available.

Please feel free to email info@ccisupport.org.nz for more information





Useful Links

Reliable information on COVID-19

For all your questions around COVID-19 from alert levels to financial support

<https://covid19.govt.nz/>

Booking a Covid-19 Vaccination

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

BOOK OVER THE PHONE

You can call the COVID Vaccination Healthline 8am–8pm, 7 days a week.

0800 28 29 26

Time In The Line

Check on available Covid 19 vaccination appointments.

<https://timeintheline.co.nz/>

Dr Ros Vallings' Vaccine Recommendations

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



Mental Health Foundation

Looking after mental health and wellbeing during COVID-19

<https://www.mentalhealth.org.nz/get-help/covid-19/>

Anxiety around COVID-19

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

[https://www.virusanxiety.com/?](https://www.virusanxiety.com/?fbclid=IwAR2BZPuM9wJunh528RErEZHyry92PBdzk5aMNLjHfzc7luPI1Mi5vOZYK1k)

[fbclid=IwAR2BZPuM9wJunh528RErEZHyry92PBdzk5aMNLjHfzc7luPI1Mi5vOZYK1k](https://www.virusanxiety.com/?fbclid=IwAR2BZPuM9wJunh528RErEZHyry92PBdzk5aMNLjHfzc7luPI1Mi5vOZYK1k)

COVID-19 Vaccination Survey

Recently we sent out an email, asking those that have had the COVID-19 vaccination how they fared, what the reactions were like for people with Complex Chronic Illnesses, like the ones we support.

EVERYONE REACTS DIFFERENTLY, and whilst we recommend vaccination, as per the medical advice, we cannot say for certainty how each individual will react. A reminder this was a survey, not research and is self reported reactions only.

However the results were encouraging—184 surveys received, 166 have been vaccinated

- ◇ No clear difference between reactions and how long between vaccinations
- ◇ 51% had no improvement to original ME/CFS or FM condition, 45% had improvements for up to 3 weeks and then a return to normal symptomatology and 4% medium and long term improvements since vaccination.
- ◇ 23% had no discernible reactions. 69% had medically expected reactions (of which 58% showed between 1-4 'medically expected' reactions with majority being fatigue, muscle/joint pain and headache and sore arm). 8% had 'other reactions', including increase in original symptomatology, mainly anxiety, dysautonomia issues, heart and digestion issues and Influenza symptoms, and even one 4 weeks post 2nd vaccine who suffered a stroke, this cannot be confirmed as a vaccine reaction, due to the length of time after 2nd vaccine, however it was noted. This is obviously concerning, and we really feel for those that have and are dealing with these reactions. Please contact us if you require further support.
- ◇ 45% reactions lasted only 1-2 days and 24% up to 6 days, 10% had reactions last up to 2 weeks. 15% of reactions lasted longer than 2 weeks.

If you have any concerns about getting the vaccine, please talk to your GP or health professional for best advice for your personal circumstances.

Monthly Members Meetings.

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

December focus is **Managing the festive season**

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

All Monthly Member Meetings will be online for the rest of 2021 due to COVID restrictions.

We are working through the issues and will find a way to meet in person soon.

Online Members Meeting

Is for all our members who want to attend a monthly meeting but do not have the extra energy to leave their homes.

Just contact your Facilitator to get a link to join.

You just click the link on computer or smart phone and you can easily join with us.

Thursday November 11th

Thursday December 9th



The flyer features a green and blue water background with bubbles. At the top, a white rounded rectangle contains the text "Online Members' Meeting" in a blue cursive font. Below this, a white rounded rectangle contains the following text: "Join the CCIS Facilitators for our Online Members' Meeting!", "Date: Thursday 11th November", "Time: 10:30am", "Topic: Nutrition, Stress & Digestion", and "Location: Zoom*". To the right of this text are four circular headshots of women, each with a name tag below: Charlotte Kelp, Tabitha Ramsay, Tracey Larsen, and Karen Maxwell. At the bottom left is the CCIS logo, which consists of a stylized heart shape with two figures inside, and the text "Complex Chronic Illness Support" and "Empowering People Towards Wellness". At the bottom right, the text reads "From our bubbles to yours!" and "*Link and password found in email".

Counselling available

Rachel, our 2nd year counselling student in Tauranga is continuing with us. These sessions are free. This counselling will be offered for all ages and it will be provided in a strictly confidential environment. Please contact Karen or Annabelle for enquires. wbop@ccisupport.org.nz

Social Groups.

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

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

Greerton Coffee Group

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

Papamoa Coffee Group

Please call Sonya if you have any more questions or would like more information about the group 027 753 2973
Venue: Double Teaspoons (outside foodcourt), Papamoa Plaza, 10.30am
November 3rd

Young at Hearts Social Group

ON HOLD— due to no meetings being held at Fraser St

EBOP Coffee Catchup

4th Tuesday of the month at 10.30am
November 23rd - Café Coco—10 Richardson Street, Whakatane

Waikato Social Groups

ON HOLD—due to COVID
Tracey can be contacted on waikato@ccisupport.org.nz or phone/Text 022 154 7076



Chris Armstrong and the Hunt for the Metabolic Underpinnings of ME/CFS

[HTTPS://WWW.HEALTHRISING.ORG/BLOG/2021/10/17/CHRIS-ARMSTRONG-CHRONIC-FATIGUE-SYNDROME-METABOLISM/](https://www.healthrising.org/blog/2021/10/17/chris-armstrong-chronic-fatigue-syndrome-metabolism/)

Chris Armstrong PhD (biochemistry and molecular biology) was there at the beginning of the metabolomics field in chronic fatigue syndrome (ME/CFS). In fact, Armstrong was the lead author of the [first ME/CFS metabolomics study](#) published in 2012.

I asked him how he got started in ME/CFS. He said ME/CFS was a good fit for him in a number of ways. For one, he was interested in the role of energy metabolism in chronic disease – a field that has only grown in importance in ME/CFS over the past ten years – and which occupies his thinking more and more.

Metabolomics, with its focus on what's happening in the metabolism right now, potentially provides an excellent way to get at the functional underpinnings of disease. Our metabolism, for instance, shifts all the time, in response to exertion or infection or digestion – making metabolomics a good fit for studying the energy metabolism problems in ME/CFS and symptoms like PEM.

OPENING THE [5TH OPEN MEDICINE FOUNDATION-FUNDED RESEARCH CENTER IN AUSTRALIA](#)

After a couple of years working with Ron Davis and the Open Medicine Foundation in the US, Armstrong said he welcomed his return to Australia to open, in collaboration with EMERGE Australia, the [5th Open Medicine Foundation-funded research center](#). He's got access to all the equipment he needs, he's been successful in government and philanthropic grant applications, the cost of doing research is relatively less expensive, and the formation of the Australian ME/CFS Biobank was another plus.

The idea is to do more with less, and right now Armstrong actually has more. In fact, Armstrong has been on something of a roll regarding getting his ME/CFS grant applications funded. Scouring the ground for possible funding, Armstrong somehow landed grants from more than 5 different funding sources (federal/state sources, philanthropy) and is now, get this, collaborating on 15-20 separate studies. The new Australian ME/CFS research center may be new, but it is already very busy.

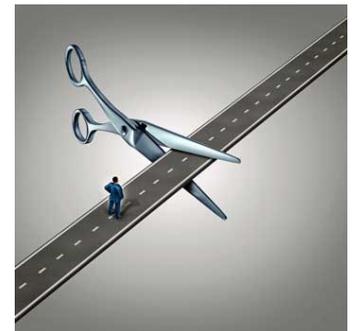
THE "CRASH COURSE" STUDIES

A [longitudinal study](#) that tracks how metabolites change over time in response to good/bad days in ME/CFS has been on Armstrong's wish list for years. Armstrong predicts that the study will help uncover some of the biological underpinnings that are driving key symptoms such as post-exertional malaise.

Finger-prick blood and urine samples in combination with wearables (to assess sleep, activity, blood pressure and heart rhythm) and surveys will enable researchers to find out which parts of ME/CFS patients' metabolism go screwy when they crash. Those, in turn, will provide a roadmap they can use to dig deeper, hopefully, into the core problems in ME/CFS. They expect to have preliminary data available by next year. Armstrong is currently collaborating with the multiple teams to initiate a [longitudinal study on pediatric ME/CFS](#) patients in Melbourne and a 3-month adult study called the "[Crash Course](#)" that follows ME/CFS, Long COVID, and Chronic Lyme disease at Stanford.

Hungry Cells?

Another study will attempt to determine fundamental elements ME/CFS patients' cells may be missing/ hungry for. ME/CFS patients' and healthy controls' cells will be put in different media and



then tracked. Armstrong and his team will then add in their compounds of choice – such as big players in energy metabolism like hydroxybutyrate, glutamine, glucose – tag them – and then, in an effort to see where the breakdown in energy metabolism occurs – follow them.

An ME/CFS cell that starts sucking up one kind of media could inform us about a compound that is, in a very fundamental way, missing in our cells.

An ME/CFS cell that feeds voraciously on all sorts of substrates, on the other hand, might be working overtime simply to stay alive. It's possible, in other words, that our cells are starving in a field of plenty. In an effort to compensate for a broken energy production system, they may be taking in more resources than usual. That would jive with findings from the early metabolomic studies which uncovered a similar profile to that seen in starvation. Armstrong reported that the "starvation" finding seems to be holding up and corroborates well with Fisher's recent finding of inefficient ATP production in ME/CFS.

Looking For Waldo

Thanks to a nice donation, Armstrong is also following up on a unique hypothesis in ME/CFS that could explain those energy production problems. In fact, Armstrong's "Looking for Waldo" study appears to be the first of its kind *done in any disease*.

It probably comes as no surprise that excess ammonia can be a problem. When a dysfunctional liver fails to break down nitrogen, excess ammonia can produce neuroinflammation and encephalopathy. Nobody, until now, has applied the excess ammonia issue to cells.

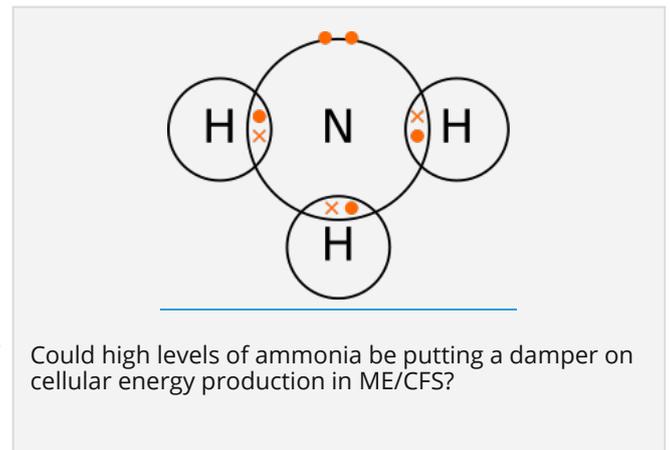
Armstrong glommed onto his cellular ammonia accumulation hypothesis when metabolomic studies suggested that people with ME/CFS were using amino acids for fuel at a faster rate than healthy controls.

Amino acids are usually used for fuel at an elevated rate during a stress response or starvation. When you're starving, for instance, your body will save your

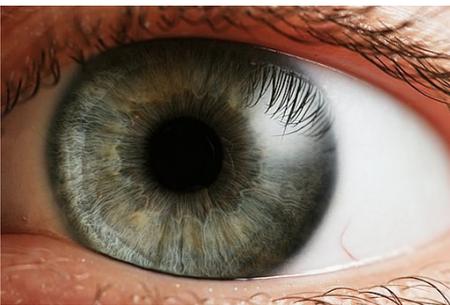
carbohydrates to make sure your brain and immune system are getting them. The rest of your body will use fats and amino acids in greater proportions. The long-term use of amino acids for energy will reduce digestive enzyme production and break down muscles and connective tissues.

For some reason, people with ME/CFS also appear to be preferentially turning to amino acids to power their cells. That presents a potential problem because amino acids have this pesky nitrogen atom attached to them that needs to be taken care of. The body usually eliminates the nitrogen from amino acids in a variety of "safe" forms, but the ME/CFS metabolomic studies are not finding as much of these "safe" forms as expected.

That suggests that all that nitrogen is being eliminated all right – but in "unsafe" forms such as ammonia or peroxynitrite – two highly reactive compounds that can wreak havoc in our cellular energy production system. In this novel study, Armstrong is tracking the molecules in cells to see what happens to nitrogen as it passes through the energy production systems found in ME/CFS. These cells will be grown and monitored in more stressful and less stressful conditions. The way these cells use amino acids, sugars, and fats for energy production will be compared between the ME/CFS and healthy participants.



DO THE EYES HAVE IT? THE OCULAR MOTOR PROJECT



The Ocular Motor Project falls into the "Isn't technology great?" or "What will they think of next?" categories. Whether or not the eyes are windows to the soul may be debated, but they can certainly function as windows to our health.

It turns out that humans devote an unusually large part of our brains (50-80%) to visual processing. Simply the act of following a dot across a screen requires that multiple systems work together properly. It takes, for instance, sensory processing to direct the eyes to move, muscles to move them, pupil

dilation/contraction to adjust to the light present, etc.

Tracking anything that complicated can reveal a lot about neurological and other diseases. This is the first time, though, it's being applied in ME/CFS. The project is already producing some very interesting findings indicating that some sort of pathology is present. Armstrong and collaborators hope to develop their findings

into a diagnostic or objective marker for ME/CFS and its symptoms.

The tool may even be able to pick up the early fatigability and exertion intolerance that occurs as the eyes (and brains) of people with ME/CFS tire over time. Thus far, Armstrong is finding, in contrast to healthy controls, that the eyes of people with ME/CFS get worse over time at following that dot – leading to the possibility that the Ocular Motor Project could lead to the first easy test for exertion intolerance.

CONCLUSION

Chris Armstrong and the [5th Open Medicine Foundation-funded research center](#) in Australia are on something of a roll. Armstrong is continuing his focus on energy metabolism as he and his team try to understand the metabolic underpinnings of ME/CFS. If all goes well, we should learn more about why people with ME/CFS are so susceptible to crashes, why their cells may be starving (and what they are starving for), and if excess ammonia is wreaking havoc on cellular energy production. Plus, the eye study could potentially provide a cheap and accessible diagnostic test.



Christmas Parties

Unfortunately with the unpredictability of COVID-19 this year, we have made the hard decision to not have any regional break ups this year. We will endeavour to make up for this with planning a New Year welcome in February.

We are sorry and completely heartbroken about making this decision, because we know how much fun they can be.



OCTOBER MEMBERS MEETING

DYSAUTONOMIA

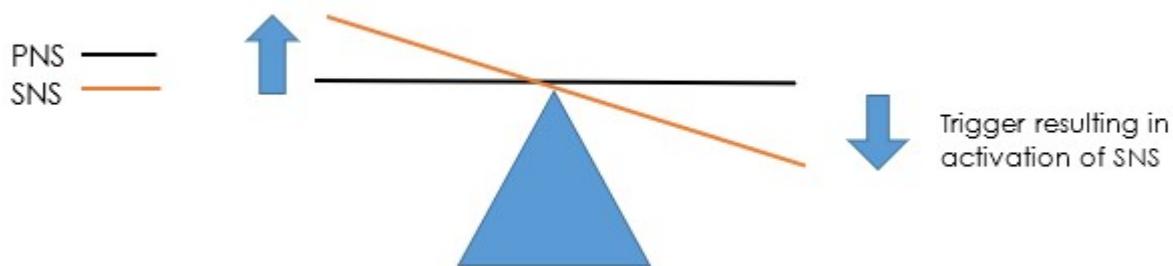
Prepared by Tracey Larsen

References available on request

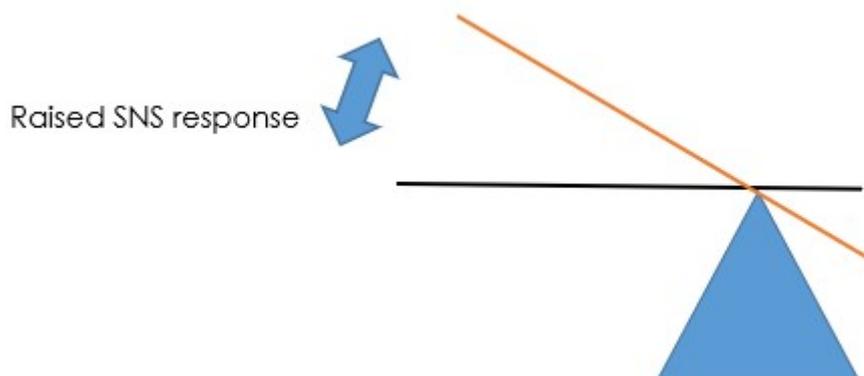
Dysautonomia (Dis-Auto-No-Mia) is an umbrella term for multiple conditions which causes a disturbance in the Autonomic Nervous system (ANS).

The ANS is responsible for regulating and maintaining a constant internal temperature, regulating breathing patterns, and heart rate and keeping blood pressure steady. It is also involved in pupil dilation, sexual arousal, and excretion.

The ANS is made up of the Sympathetic Nervous System (SNS) and the Parasympathetic Nervous System (PNS). The SNS is aroused by stress or a trigger that results in the fight/flight stress response and produces adrenaline, raising the heart rate, breathing rate, blood pressure, dilating the pupils etc.. (like an accelerator of a car). The PNS calms the body back to a balance state after the stressor or trigger has gone or as we get used to the new situation (often known as the rest and digest system and acts much like the brake of a car).



With Dysautonomia, the pivot point for the SNS and PNS is much more sensitive, meaning that a much smaller trigger results in a much higher and prolonged SNS response. Therefore, for example, a change in posture or the simple act of standing can result in much more pronounced and prolonged stress response.



DYSAUTONOMIA CAN IMPACT THE WHOLE BODY

<p>BRAIN fatigue brain fog migraines vertigo fainting lightheadedness</p> 	<p>HEART tachycardia bradycardia palpitations chest pain</p> 	<p>STOMACH bloating nausea vomiting pain</p> 
<p>MOUTH dry mouth tooth decay difficulty swallowing</p> 	<p>BLOOD VESSELS hypotension hypertension poor perfusion</p> 	<p>INTESTINES impaired motility constipation diarrhea pain</p> 
<p>EYES dryness sluggish pupils sensitivity to light greyed out vision</p> 	<p>IMMUNE CELLS increased allergies inflammation</p> 	<p>GALLBLADDER reduced motility inflammation pain</p> 
<p>SKIN dryness reduced sweating increased sweating</p> 	<p>BLADDER frequent urination retention nocturia pain</p> 	

...and MUCH more!

WWW.DYSAUTONOMIAINTERNATIONAL.ORG

DYSAUTONOMIA INTERNATIONAL

		
AWARENESS	ADVOCACY	ADVANCEMENT

Common Symptoms Include:

- An inability to stay upright
- Dizziness, vertigo, and fainting
- Fast, slow, or irregular heartbeat
- Chest pain
- Low blood pressure
- Problems with the gastrointestinal system
- Nausea
- Disturbances in the visual field
- Weakness
- Breathing difficulties
- Mood swings
- Anxiety
- Fatigue and intolerance to exercise
- Migraines
- Tremors
- Disrupted sleep pattern
- Frequent urination
- Temperature regulation problems
- Concentration and memory problems (brain fog)
- Poor appetite
- Overactive senses, especially when exposed to noise and light

These symptoms occur in a range of combinations, making dysautonomia a difficult condition to diagnose.

Is Dysautonomia Rare?

No. Dysautonomia is a common condition, with up to 15 different types that can occur on its own through inheritance, or with other conditions and/or injury:

Ehlers–Danlos syndromes	Pre-Diabetes
Sjögren's Syndrome	Lupus
Anti-Phospholipid Syndrome	Multiple Sclerosis
Parkinson's	Lyme Disease
HIV	Guillain-Barre
Mitochondrial diseases	Genetic diseases

Paraneoplastic Syndrome associated with some forms of cancer, certain chemotherapy and other drugs that can cause autonomic nerve damage, as can vitamin deficiencies, heavy metal poisoning and alcoholism,

ME/CFS/FM are two such conditions whereby dysautonomia can often be associated.

The most common dysautonomia conditions for those living with ME/CFS/FM are:

- Orthostatic Intolerance (OI)
- Neurally Mediated Hypotension (NMH)
- Postural Orthostatic Tachycardia Syndrome (PoTS)

Orthostatic Intolerance (OI)

Dr Vallings explains that, for many people living with ME/CFS/FM, they can have low blood pressure, or be on the low end of normal. Many also have decreased blood volume. Both issues can result in sluggish blood circulation. Upon standing one can experience:

- Dizziness and/or fainting
- Light-headedness
- Nausea
- Looking pale
- Heart palpitations

When standing for too long, blood may pool in the lower limbs. The dysfunction of the SNS does not compensate properly for gravity in order to maintain effective blood circulation back up to the brain. Heart palpitations can then result, as the heart is doing just what it needs to do to, to ensure blood gets back to the brain.

Neurally Mediated Hypotension (NMH)

NMH is very similar to OI, however NMH results from confused communication between the blood vessels, the brain, the heart, the nerves and the endocrine organs. A drop in blood pressure due to standing for long periods therefore occurs. Symptoms are:

Dizziness

Nausea

Fainting

Fatigue

Dr Vallings refers to this as "3rd Isle of the Supermarket" – after getting from the car to supermarket and around the first few aisles, you suddenly feel like the plug has been pulled. You may have a sudden desire to sit down as a heightened risk of fainting and falling can occur.

Postural Orthostatic Tachycardia Syndrome (PoTS)

An abnormal response by the ANS when up right and/or standing is signalled by an abnormally large increase in heart rate (of at least 30 - 40 beats / min) within 10 minutes of standing up. POTS patients usually have a drop in blood pressure on standing too, but some experience no change, or an increase in blood pressure.

Symptoms include:

Tachycardia (with or without chest pain)

Fatigue

Headaches/migraines

Nausea

Brain fog

Visual problems/changes

Shaking or tremors

Sweating

Purplish discolouration of hands and feet (blood pooling)

Some of the physical symptoms overlap with anxiety, but POTS is **not** caused by anxiety

POTS is normally a secondary dysautonomia. Researchers have found high levels of auto-immune markers in people with the condition, and patients with POTS are also more likely than the general population to have an autoimmune disorder.

There are differing levels of severity for all these conditions. In some cases, they are mild to moderate, a few are unable to sit or stand and some are bedbound.

Triggers

Holding an upright posture for long periods of time

Heat and a warm environment can dilate the blood vessels – hot weather, hot, over-crowded rooms, shower/bath too hot, spa pools, over dressing.

Exercise and physical exertion

Emotionally stressful events

Inadequate fluid/salt intake

REM sleep – can trigger SNS, resulting in disrupted sleep and exacerbating fatigue, pain and other ME/FM symptoms

Diagnosis

Is by a prolonged standing test or a tilt table test whilst taking blood pressure readings

As tilt tables are not typically available at your local GP practice, the NASA 10-minute lean test can be used by your GP

Involves lying down for 5 – 10 minutes, blood pressure and pulse rate are then taken before standing and leaning against the wall. BP and PR are monitored every minute, for 10 minutes, as well as other physical signals and symptoms experienced

The NASA test recommends limiting fluid and sodium intake, some medications and wearing compression clothing for 24-48 hours prior to test

Increased fatigue and malaise often occur for a few days after the test. This can be minimized with intravenous saline solution treatment immediately after the test

Some Simple Self-help Measures

For sudden onset of symptoms, take 2 glasses of water quickly, with a pinch of salt, lie down on the floor and raise legs up the wall, or on the couch, for 10 minutes or until symptoms (or heart palpitations) subside. This helps the blood to get back to the heart and brain



If unable to lie down, cross your legs whilst standing, or rock up and down on your toes, clench buttocks and abdominal muscles, clench your fists – tightening muscles helps to circulate blood

Symptoms can be worse in the morning, so have a drink before getting out of bed

Drink extra fluids (at least 2-3 liters per day); have electrolytes; take extra salt (unless

you have high blood pressure)

Extra salt in the diet can leech potassium so take potassium supplementation, or eat bananas and kiwifruit

Change posture; move, recline, lie down

Stand up slowly and avoid prolong sitting and standing

Pressure garments, support stockings, compression clothing – supports blood circulation

Raising the head of your bed

Keeping your feet up when seated

Good diet – Smaller meals more often – low sugar

Limit or avoid alcohol and caffeine – these are both dehydrating and can also activate SNS by producing a stress response

Heat can aggravate by dilating blood vessels – have cooler, shorter showers and baths; dress in layers

Being cold, on the other hand, can constrict blood vessels, reducing blood flow, so keep yourself at a comfortable temperature

Massage can help improve blood circulation and help manage stress and activate PNS

Pacing and task switching regularly to keep heart rate lower

Physical exertion/exercise can worsen symptoms, but fitness is important. Increasing leg strength and core muscles can be beneficial in pumping blood back to the heart

For those with more frequent or more severe symptoms, self-help measures may need to be supplemented with medication e.g. fludrocortisone (Florinef) – helps to increase blood volume

Ensure your sleep hygiene is excellent

Manage pain well – pain in itself can activate SNS

BREATHE! – Breathing is the only way we can consciously affect our ANS. Diaphragmatic breathing is excellence in helping circulate blood and bring more oxygen into the blood. An excellent way to help calm an accelerated heart rate and also manage any anxiety that may exist during sudden episodes

NOVEMBER MEMBERS MEETING

NUTRITION, WHY IT'S IMPORTANT: STRESS & DIGESTION

Prepared by Tabitha Ramsay

References available on request

In scientific terms, nutrition is the process of providing or obtaining food necessary for health and growth. Basically, we need to feed our bodies to keep them alive and healthy. Without nutrition we would become sick and weak, and our body would not have the ability to function and cope with daily life. As we age and move through life our nutritional needs change and it's important to listen to your body and make changes that will benefit your life. Having good nutrition can help with energy, mood, physical and mental health.

Of course, reading and thinking are important but, my God, food is important too. How fortunate we are to be food-consuming animals. Each meal should be a treat and one ought to bless every day which brings with it a good digestion and the precious gift of hunger - *Iris Murdoch*

Around 90% of people with ME/CFS/FM report experiencing IBS, food intolerance and gastric issues as part of their condition. We will explore what response stress has on our digestive system and what nutrition plan can best support our wellness journey.

The Digestive System

The digestive system is a group of organs working together to convert food into energy and basic nutrients to feed the entire body.

Possible ME/CFS/FM Symptoms

- Malabsorption
- Intolerance/allergies
- Indigestion
- Irritable bowel syndrome
- Diarrhoea and Constipation
- Nausea and vomiting
- Increased risk of gastritis and other gut issues such as ulcers and colitis.
- Bloating
- Hypoglycaemia
- Leaky gut, candida, parasites – alternative perspectives

The Response Stress has on our Digestive System

Stress has a negative impact on your digestive system. It's not just the big stressful events, like moving or losing your job, that can wreak havoc on your digestion, but the everyday stressors of life.

Life sustaining functions of our body are regulated through our autonomic system, this has

two main divisions: The sympathetic nervous system, which triggers the fight or flight response and the parasympathetic nervous system, which calms the body after the danger (stressor) has passed. When the body is in a stressed state, energy is diverted away from the digestive system (seen as non-urgent), and towards the heart, muscles, legs and arms (for 'fight or flight'). There is a less effective breakdown and absorption of food, leading to bloating, flatulence, pain, irritable bowel syndrome etc.

The sympathetic and the parasympathetic nervous systems work with another component of the autonomic nervous system called the Enteric Nervous System; it is this system which helps to regulate digestion. The enteric nervous system is sometimes referred to as the second brain, because it relies on the same neurons and transmitters found in the central nervous system (brain and spinal cord). When we eat our stomach registers the food intake, the digestive tract neurons signal muscle cells of the intestines to propel food along further, breaking it down into nutrients and waste. At the same time the enteric nervous system sends neurotransmitters (serotonin) to communicate and interact with the central nervous system.

The "GUT- BRAIN AXIS" helps us to understand how the psychological stress and social stress might cause digestive problems.

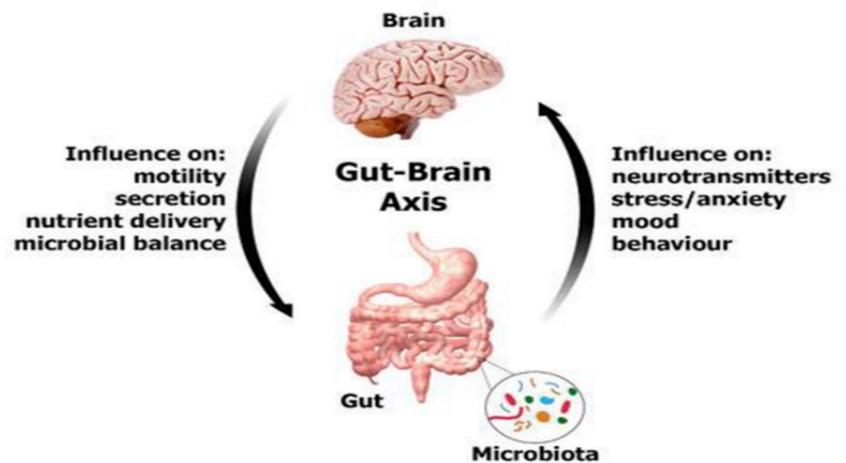


Image Source: <https://beyondaddiction.ca/2016/09/04/gut-brain-addiction/>

Let's Break this down Further

Gastrointestinal system - The gut has hundreds of millions of neurons, which can function independently and are in constant communication with the brain. Stress can affect this brain-gut communication, and may trigger pain, bloating, and other gut discomfort to be felt more easily. Stress can affect the bacteria in the gut which influences its health as well as the brain's health, which then impacts the ability to think clearly and starts to affect our emotions. Thus, the gut's nerves and bacteria strongly influence the brain and vice versa.

Oesophagus - When stressed, individuals may eat more or less than usual, increase the use of alcohol or tobacco, resulting in heartburn or acid reflux. Stress or exhaustion can also in-

crease the severity of regularly occurring heartburn pain. Stress can make swallowing foods difficult or increase the amount of air that is swallowed, which increases burping, gassiness, and bloating.

Stomach - Stress can make pain, bloating, nausea, and other stomach discomforts felt more readily. Vomiting may occur if the stress is severe enough, the digestive system shuts down and food is ejected.

Bowel - Stress can make pain, bloating, or discomfort felt more easily in the bowels. It can affect how quickly food moves through the body, causing either diarrhoea or constipation. Stress can affect what nutrients the intestines absorb. The intestines have a barrier to protect the body from (most) food related bacteria. Stress can make this barrier weaker and allow gut bacteria to enter the body causing inflammatory responses.

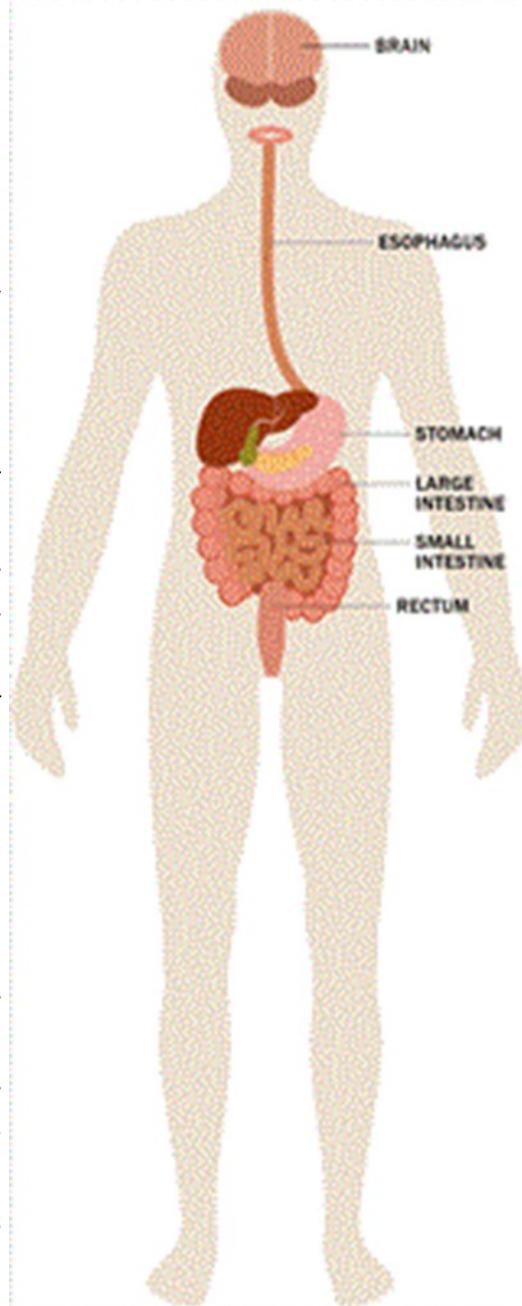
Stress Eating (Emotional Eating)

Stress can have the opposite effect on some people and cause them to eat more, this is often called emotional eating. When you are stressed the body sends out cortisol and insulin, this signals the need to fuel up, so the body has energy for fight or flight. This can result in cravings and over-eating of salty and sugary foods for quick energy. Because the body is under stress blood flow to the stomach has slowed and digestion has reduced or even stopped, even though you are still eating. This can lead to stomach/bowel discomfort or your body storing the food as fat as it can't turn it to energy with digestion disrupted, and so the cycle continues. The best way off this cycle is to reduce your stress when you're eating to start or keep your digestion working properly.

How do we reduce our stress to allow our bodies to digest better?

To allow our bodies to digest more easily, we need to calm our sympathetic nervous system down and spend more time in parasympathetic dominance (rest and digest). Here are a few ways we can achieve this:

Diaphragmatic breathing: Diaphragmatic breathing is a type of a breathing exercise that helps strengthen your diaphragm, an important muscle that helps you breathe. It can help lower your stress levels. Try this step by Step guide <https://www.smallsteps.org.nz/app/deep-breathing?>



[gclid=CjwKCAjwzOqKBhAWEiwArQGwaJSZXgQzmKqakuA4hP1pJU8VxMLtrfxsxDv9qkDOOERDflu-ukcfbRoCXp8QAvD_BwE](https://www.healthline.com/nutrition/mindful-eating-guide)

Mindfulness/meditation: Various techniques can help to reduce your stress, find the one that works best for you

Mindful Eating: Mindful Eating 101 <https://www.healthline.com/nutrition/mindful-eating-guide>

CPDR –Bringing awareness to our eating experience (awareness = being present). This is an amazing force for metabolism. CPDR- (the brain phase of digestion) – involves anticipation, aroma, visual stimulation, taste, pleasure, of the meal, and is responsible for 30 – 40% of the total digestive response to any meal

Chewing food thoroughly will increase blood flow, oxygen, and digestive enzymes in the gut

Being in a relaxed stress-free state when eating allows our digestive system to do its job. Easier said than done I know. Hopefully by implementing some of these strategies we might be able to help ourselves reduce our stress so we can better digest our food.

Nutrition Plan to Best Support our Wellness

The best defence is a proactive one. Ensuring you are meeting your nutritional needs and keeping a healthy diet can go a long way to helping your digestive system. People with CFS/ME/FM may experience IBS or food intolerances creating stress on the digestive system, and as discussed above being stressed creates even more problems.

It is important to manage your own nutrition, as we know what works for one person may not work for another. Keeping a food diary can be an important start to discovering what food intolerance you suffer and give indication for what foods are causing you additional stress, as well as practicing some of the ‘rest and digest’ strategies we touched on.

Here are a few guidelines around nutrition from Dr Rosamund Vallings book on CFS/ME that may help improve your nutrition.

12 Steps Towards Better Nutrition with CFS/ME – Dr Rosamund Vallings

Eat as varied a diet as you can, rotating foods to avoid excesses

Choose food that are as fresh and natural as possible

Do not over cook, as this may destroy important nutrients

Eat little, and often to avoid stomach overload (graze like a sheep)

Drink minimally with meals, and drink mainly between meals

Get medical checks for gastrointestinal symptoms, particularly if they started recently

Minimise your caffeine and alcohol intake

Take a good pinch of salt every 2-3 hours if you blood pressure is low, also increasing you fruit intake for potassium

Use vegetable or fish oils in cooking, but increase cholesterol intake if your blood level is very low

Supplements can be added your diet to help boost your good nutrition

Avoid diets that are very restrictive, as nutritional deficiencies can easily occur

Reject diets and supplements that are expensive and promise a cure

Supplements

Supplements are extras we take in addition to our diets and are generally used when we are deficient in something or can't get it from our diets. Vitamins and minerals are better absorbed from our diets. Not everyone needs to take supplements and its best to discuss with your health professional what would work best for you and get a blood test to find a deficiency. If you have IBS or food sensitivities, you should take it slow adding in supplements to ensure you don't encounter any problems, using alternative

Here are a few supplements that may help with CFS/ME/FM.

Pro and Pre-Biotics – great for irritable bowel, also found in yoghurts

Magnesium – important mineral for the body my help alleviate muscle pain and cramps

Omega 3 & 6 – May help for brain function

Vit D – can be affected by lack of sunlight

Vit B12 – may help relieve some fatigue

CoQ10 - a mitochondrial nutrient which acts as an essential cofactor to produce ATP in mitochondria, a good antioxidant for energy support

Youtube Videos on Stress and Digestion

How does stress effect digestion. <https://www.youtube.com/watch?v=RyVcZ77IPQY>

Stress and Digestion <https://www.youtube.com/watch?v=foptV7iTPC4>

The metabolic Power of Awareness with Emily Rosen (Head phase of Digestion) CPDR. <https://www.youtube.com/watch?v=xLLNjjLOJW4&t=4s>

DECEMBER MEMBERS MEETING

MANAGING THE FESTIVE SEASON



In New Zealand, Christmas, summer holidays and road trips to visit family all go hand in hand and gets all wrapped up together under the umbrella of "The Festive Season" Today we will be sharing tips to help navigate this busy time of year, discussing how to reduce stress at Christmas, how to keep cool in the summer heat and some tips when travelling.

Reduce Stress at Christmas and Avoid Over Exertion

Make a list – It works for Santa! Checking items off a list gives a sense of accomplishment and is satisfying in itself. Lists also ensure you remember what you need to accomplish.

Prioritise – Attend to what is most important and set your own realistic boundaries. Avoid being caught up in the frenzy of Christmas. It is important to attend to the evergreen basics – sleep, rest and eating well.

Decorate like a minimalist – If you are able to decorate, there is no need to decorate the whole house, just the social areas where others can enjoy them. Simple decorations on the table or mantel can be just as effective.

Ask for help – Don't feel the pressure of providing the entire meal for everyone. Go potluck!

Lower others' expectations – Be realistic by creating your own idea of the perfect Christmas that suits you and your family.

Buy online – No need to cope with busy shopping centres or supermarkets, but order early so they arrive on time.

Delegate - A problem shared is a problem halved. Plan to have Christmas at someone else's house, so all you need to do is turn up.

Learn to say NO – Learning to say no to other's demands can be a struggle at this time of year, so start thinking of your needs when family and social activities are being planned.

Rest – rest up when ever possible. Use pre-emptive resting strategies so your batteries are charged regularly throughout the festive season.

Planning – Ensure you plan adequate rest periods throughout the weeks leading up to, and after, Christmas.

Meal Energy-Saving Tips

Invest in a slow cooker, blender and food processor; these tools are great to use when energy is low or pain in your hands makes chopping food difficult.

Prepare food at your highest energy points of the day – when you feel organised you feel emotionally better.

When feeling well, cook large meals and freeze, or use leftovers for lunch and/or dinner the next day.

When preparing a meal, bulk prepare vegs and store in snap lock bags for meals later in the week.



Make enough salad and coleslaw to last several days.

Eating out? Ring the restaurant before hand to see which meals can be tailored to your digestive needs – take own dressing or sauce if need be.

Invited to a dinner party? Communicate with the host to see if certain dishes can be tailored to your digestive needs.

Travel tips

Rest adequately before you travel – this may be required for several days or weeks before you leave, so you can enjoy your much anticipated holiday.

Plan your trip well – plenty of rest stops and rest time between train, plane, bus or car trips to avoid rushing.

Pack well in advance – don't leave it to the last minute. Make a list of last-minute items such as toiletries and medications.

Pack light if you have to carry your bags. Use luggage with wheels. Make use of a trolley at airports.

Make use of wheelchairs at airports – prearrange airport staff to support you through the terminal with your luggage and wheelchair.

Remember to pack an adequate supply of medications and supplements. Take a note from your GP detailing your medication requirements. Using blister packs helps you to keep track of your medication, especially if travelling through different time zones

If you experience sensory overload, use ear plugs/earmuffs and a sleep mask when travelling.

For those with POTS or OI, recline your seat in the car (if you are the passenger!). Some have found putting their feet up on the dashboard helpful. Other helpful tips from clients, is to use a magnetic bracelet designed for travel sickness and take ginger supplements for nausea when travelling.

Where possible take extra food supplies – especially if you have special food requirements.

Keep cool this summer and sleep better

Keep well hydrated.

Place ice cubes, ice packs, or cold presses on your pulse points – inner wrists, base of neck, chest, inner elbows, under breasts, groin, ankles and behind the knees.

Wear loose cotton breathable clothing.

Use cotton sheets on your bed instead of polyester.

Dampen a sarong or cotton sheet and place on top of you when going to bed

Fill up your rubber bed hotty with cold water and freeze. Place in your bed before going to bed.

If energy allows, have a cool shower before going to bed.

Place a fan facing out of the window to pull the hot air from inside to send outside.

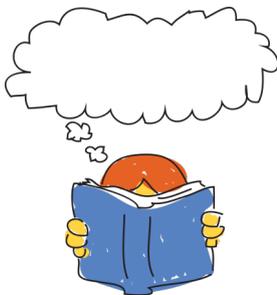
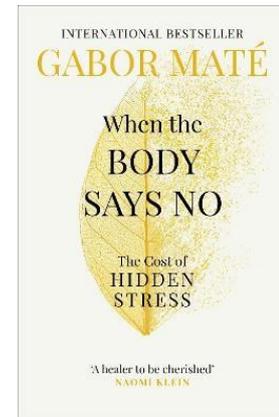
Invest in a hydro vest, or pet cooling pad for yourself to lie on.



When the Body Says No: The cost of hidden Stress

by Dr Gabor Maté

Dr Gabor Maté is a physician, speaker and author and is one of my favourite holistic practitioners. In this book he speaks to the link between trauma and how it can manifest in the body as a chronic illness. This book is based on the understanding that the body and mind are not separable and holds a mirror to our stress driven society and its effects on the body. Easy to read with a good mix of scientific theory and personal stories.



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

We now have an 0800 number

0800ccisup

0800 224 878

If you'd like to text you can still just txt each facilitator and we can call you back or if you still use landlines, you can contact us on 07 281 1481

Chocolate Fudge Cake – Bridget Davis

Woohoo Christmas is racing towards us; I've started hunting down some recipes for the festive season. We tend to have a few visitors so quick and easy recipes are a must, as well as ensuring I can eat them myself. Here is a very tasty recipe for all occasions. Dress it up with some fresh fruit and yogurt for a lovely dessert.

Reference: <https://bridgets.shop/products/bridgets-healthy-christmas-50-festive-recipes-for-the-christmas-and-party-season>



Ingredients

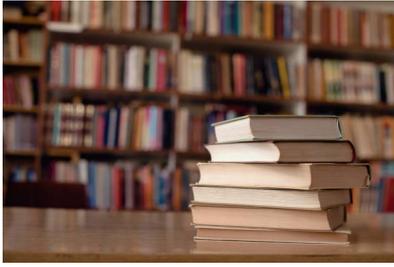
400gms Chocolate (use what works for you, DF, SF)
240ml full fat Coconut milk
90gm Fibre syrup or maple syrup
4 large eggs

Method

1. Pre heat oven 150degC and line a 20cm loaf tin with baking paper
2. Add chocolate, coconut milk and syrup into a saucepan over low heat, stir the ingredients together and allow them to melt until chocolate is smooth and flowing.
3. Remove from heat and allow it to cool for 5 minutes
4. Whisk eggs into chocolate mixture then pour into loaf tin. Place loaf tin into a roasting dish and fill with water until it reaches 2/3 of the way up the loaf tin.
5. Bake for 60 minutes
6. Allow cake to cool completely (overnight) before removing from the loaf tin.
7. Carefully slice the fudgy chocolate cake to serve.
8. Store in the fridge for up to 5 days.

ENJOY

Tabitha – CCIS Health & Wellness Facilitator



LIBRARY UPDATE

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

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



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

Contact your Field Officer for more details.

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



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



Update on WELLINGTON

Due to the Generosity of NZ Lotteries, Wellington Community Trust, WellME, TradeME and the local members, we are in the process of hiring a local Health & Wellness Facilitator for the Greater Wellington region. This is going to change the support and care for those in this area.

It is fabulous news. Thank you for your support.



It's important for planning, it's important for funding and it's important we get the service right for you. Please contact Miranda on info@ccisupport.org.nz with any service feedback.

Thanks so much!! The team at CCI Support.

BOARD OF MANAGEMENT:

Keith Appleton: President and Treasurer

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Sarah Davey: Board Member

David Harris: Board Member

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

THANK YOU TO OUR AMAZING SPONSORS AND DONORS



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Empowering People Towards Wellness