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www.ccisupport.org.nz

ISSUE 03



CCI CONNECT

CEO Report

Winter is certainly upon us, and wild weather through the country to boot, I hope everyone is managing to stay dry and warm.

It's been another busy few months, trying to finish off the Towards Wellness Programme online Hub and that all important end of year audit etc. Soon we will be having the AGM, so keep an eye out for information on that.

We've had some new staff join the team, the invaluable Christie is now supporting the staff and Roisin is the new National Facilitator. Roisin comes to us from a Social Work background, so it's great adding another dynamic expertise into the mix. I love how professionally diverse the team is, it's a great tool to be able to bounce ideas off each other and learn new ways of approaching situations.

Stay safe, keep warm and I wish you a wonderful month.

Miranda



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The Annual General Meeting is coming up!

Due to COVID-19 we expect that the meeting will once again held online.

Keep an eye out for the time and date, or contact your Facilitator for more information.



Bay of Plenty

Hello lovely WBOP members. I hope you're keeping warm and cosy during these cold winter nights. I don't know about you, but I just love having my wood fire going. It just makes everything seem warm and is so good just to watch in the evenings. A time to zone out!

As we celebrate the Māori new year (Matariki), we can reflect on the year that has been and look forward to new beginnings and the warmer months to come. With that in mind we say a farewell to Karen our National Wellness facilitator and wish her well on her journey. Then welcome our new National Health and Wellness Facilitator, Roisin (Rosh). I am looking forward to working with and getting to know Rosh over the coming months.

The past month has been a time to get to know my members more in the area, as I attend our social gatherings and engage in some interesting discussions. I cannot wait until we can confidently begin our monthly member meetings and other meetings in person.

I am playing around with the idea of holding monthly yoga nidra sessions. So watch this space. If you haven't heard of yoga nidra, it is basically a deep relaxation, where you are guided into relaxation, exploring your body and other visualisations that plant the seeds of hope and wellness. So, watch this space.

We are so very near the end of our Towards Wellness Hub. It has been a mission, but we can see the light at the end of the tunnel as we make the finishing touches to the videos.

Lastly, don't forget to make the most of our meal deal with Meal Box and supplements discounts. To find out more visit our website or ask your Health and Wellness Facilitator. Till next time, keep taking care of yourself.



Annabelle

Health and Wellness
Facilitator

Phone or Text:

027 625 4449

Email:

wbop@ccisupport.org.nz

Office Hours:

Tuesday - Friday

9am - 2pm



Phil

Health and Wellness
Facilitator

Phone or Text:

020 4017 9092

Email:

ebop@ccisupport.org.nz
lakes@ccisupport.org.nz

Office Hours:

Tuesday - Friday

9am - 2pm

Eastern Bay of Plenty & Rotorua

Hi everyone. Winter is doing its thing. For me that means many layers, being careful where there are a lot of people are and keeping a plentiful store of Liposomal Vitamin C and Viralex Epicor, for if I feel a bit vulnerable to a flu or cold. But even with all that, my grandchildren generously gifted me with the flu. So, the last few weeks have been a return to some old familiar symptoms and a reminder to stay on top of my self-management strategies - Strategies I find it so easy to let go of when I am feeling good. Hopefully you have escaped the bugs and if not, you have recovered quickly.

For the next workshop in Whakatane, I will see how the library works out for everyone - It is central, it's easy to get parks and there are other facilities around it you can access.

In Rotorua, the Arts Village seems to work fine for people ... Let me know if you have a recommendation for a better venue.

Staying safe through these next weeks of winter and early spring is really important and at the same time, isolation is a risk factor so use the Messenger groups to chat or organise a get together at a cafe anytime.

For anyone that would like to book a telehealth appointment, Monday to Wednesday 11am - 4pm is available. If you would like to discuss ideas on where to from here on your towards wellness path or how CCI Support can help you ... I have sent you a link to book this. It is a video appointment and its easy to set up and use.

The days are getting longer, and the sun can still soak us with its warmth during the afternoons so enjoy that. A friend sent me a photo of daffodils blooming in her garden yesterday, so things are looking good for an early spring.

Waikato

Kia ora and welcome from the mighty Waikato.

I do hope you are all well and coping with the winter weather fluctuations – Rain, wind and in some places, snow. I hope you have not had to endure any flooding where you live.

I can't believe the weather today though ... What a cracker day!! This is what greeted me upon waking today... Amazing!!



Well, Covid is again hitting our news headlines. Despite rising numbers, I am continuing to go ahead with the Waikato Social group meetings. I have just got them up and running again so I am reluctant to stop. It appears that our community have a very strong need to connect as attendance has been great. No pressure for you to attend, please only attend if you feel comfortable doing so. If wearing your mask at the café helps you to feel more comfortable, that is all good!!

Nga mihi,
Tracey Larsen



Tracey

Health and Wellness
Facilitator

Phone or Text:
022 154 7076

Email:
waikato@ccisupport.org.nz

Office Hours:

Monday - Friday
9am - 4.30pm

Wellington

Kia ora Wellington members!

We are deep into winter and it is important to remember to look after ourselves, not just physically but emotionally during these cold months, where we are more susceptible to illnesses and viruses. Winter is always tough for many, with the shorter days, rain and grey skies, but I always appreciate those beautiful sunny winter days that we get to experience here in Wellington, they are always so great for the soul.

I tested positive for COVID this week, and I am trying to rest as much as possible and be mindful of keeping hydrated and lowering my stress levels (Which for any of those who are parents can understand that sometimes that can be hard when you are isolating with children). Isolation is pretty hard for a lot of us, so staying connected virtually or over the phone with friends and family is not just great for distraction, but also for our health.

I am really looking forward to warmer months that should hopefully bring less sickness in our community. This will also mean that we can hopefully go back to meeting one another in person for our members meetings, which is something that I'm really looking forward to.

I hope all of you are keeping well, and please reach out if there is any support you need or even just for a chat. I always love hearing from our members!!

Luisa

Health and Wellness
Facilitator

Phone or Text:
027 245 5961

Email:
wellington@ccisupport.org.nz

Office Hours:

Tuesday, Thursday
& Friday
9am - 2pm

National

Hi everyone,

I hope you are all doing well. As a new member of the CCIS team it has been lovely to meet with the new members who have signed up over the last few weeks and current members who I have met since starting. I have learned so much from speaking to you and have gained so much respect for and understanding of the challenges you face on a day-to-day basis.

Please know it is normal for most people, even those in good health, to find winter a long and difficult time. For many it can mean feeling depressed, sleeping difficulties, including oversleeping, changes in appetite or weight and difficulty concentrating.

Frequently, we allow the weather or situations to impact on our mood so that we can forget to appreciate the good things in our lives or that we have another day to be alive. Like with anything, sometimes we need to change our way of thinking. Whether it is spring, summer, autumn, or winter, it helps if we can focus on the positive in each day that is given to us.

I read somewhere that there is a season for everything, and winter is the season for rest, relaxation, and reflection. Nature takes time off to prepare itself for the busy spring, summer, and autumn seasons so why shouldn't we? Why don't we use these darker, shorter days to rest our bodies and restore our minds?

Try cooking some warm comfort food or even just have a cup of hot cocoa or tea during the evening, wrapped in a cosy blanket. Read a book, listen to your favourite music or binge some Netflix. Listen to your body and don't feel guilty about taking a well-needed rest. Allow your body to heal before we get into the heat and bustle of summer.

All About Mindset. When we cannot change the situation, sometimes we can change how we react to it. It sounds easier than it is, but self-care and an attitude of gratitude can help us feel more positive when everything around us feels grey and difficult.

Kind regards,

Roisin



Roisin

Health and Wellness
Facilitator

Phone or Text:
027 245 5961

Email:
nz@ccisupport.org.nz

Office Hours:
Tuesday - Friday
9am - 2pm



Pre-emptive Rest

Prepared by Phil Jones

Rest is not a waste of time. It is a biological need - A process for restoration and rebuilding. Rest is not useless it is a major pathway to our renewal.

Pre-emptive rest is rest taken before you feel symptoms, that way you rest on your terms and you can be proactive in how you rest rather than reactive.



During rest, the body rebuilds, renews, re-wires and recreates itself.

Rest is a process that allows us to heal.

With pre-emptive rest we are **choosing to rest** rather than reacting to our symptoms.
We choose to rest for a set period of time.

So we can eventually do more over time with fewer symptoms.

Rest is essential - Skillfully balancing rest and activity is critical. If you want to slowly build up your energy levels so you can become more active and expand quality of life, skillfully balancing rest and activity is critical.

PRE-EMPTIVE =

Resting early

NOT WAITING

- Till you feel symptoms
- Till you feel tired
- Till you feel like resting

You may not feel like resting

BUT REST ANYWAY

Pre-emptive resting is resting before you need to rest. It is preventative maintenance. If you wait to rest once, you feel like crap, it is too late. Pre-emptive resting is about proactively doing nothing. Yes folks, doing nothing! Perhaps for you, resting purposely twice a day for 20 minutes (A period of total rest) will make a difference, perhaps your planned rest breaks will be longer or more frequent ... We highly recommend you plan them and follow the plan. Even if you have ants in your pants and you're just itching to do something - Stop and rest. This is pre-emptive resting. You may hate the idea of it but do it anyway and you will grow to love it (Not a promise).

Rest Early When $\frac{1}{4}$ full - Half full



**Become utterly at ease
for a while**

We have patterns of behaviour which counter our need for rest. We need to let go of these habits as they do not work for us anymore.



"Addiction is "Any behaviour in which the individual finds temporary relief or pleasure in and craves for that reason, despite negative consequences"" - Gabor Mate.

When we declare ourselves in need of rest, what we are essentially saying is that we need to stop. We recognise a need to remove distraction and activity from our experience so that we may find some kind of quiet. However, we often find distraction and frustration along the way, and indeed, we very often fail to feel rested regardless of our trying to create the conditions in which we believe rest will come. We make an effort to schedule-in activities that we believe are restful, rather than face the fact that what we really need to do is nothing.

During activity the body consumes more energy. Rest periods allow the body to rebuild - That requires energy as well and if we are active, that is where the energy goes. For a while, we need a lot more rest than activity just to heal.

Find the joy of rest to help balance the joy of doing.

Experiment a bit find what works for you

Frequency

Timing

Length

Over time, do you feel better with a few longer rests or frequent shorter ones?

Where

What you do in that rest period
What is most restful for you?

Pre-emptive rest definitely helps me. I rest three times a day, 30 – 40 minutes.

Late morning (about 10.30 am)

Early afternoon (after lunch about 1.30/2pm)

Late afternoon (about 5/5.30pm)

I'd say of all the things I've done this makes the most difference. I have found set rest times helpful, no matter how I'm feeling. There were times when I mostly rested, and only got up for scheduled meals.

Later I would be up a bit more for 15 minutes here and there.

I fared well with resting every hour for at least half an hour and one bigger rest after lunch for a while.

1. Schedule rest.
2. Follow the plan - Rest even if you feel full of energy.
3. Test and measure (Experiment) with the length and frequency of those rest periods.
4. Improve the quality of rest that you have in that scheduled time. Aim for conscious skilled rest rather than just passive blobbing. Focus on ways to rapidly get into a healing state.
5. That rest transfers into the "doing part" of daily life. As you become more familiar with the resting state and more practiced in different approaches to getting there, you can start to rest while you are doing things and achieve a state of relaxed performance.

Some suggestions to practice in that time:

- Long slow deep breathing. Your out breath should be slower than your in breath - Whatever breath practice works for you.
- Body scan and release tension.
- Feel your body being held by the ground, supported.
- Fall asleep.
- Repeat to yourself gently ... A few favoured affirmations.
- Visualise a favourite place.
- Bring to mind people, pets or places that help you feel good.
- Gentle meditation using the sounds of breath or body (E.g. Soothing music).
- Look for the good - What has gone well or okay today? What is good right now?
- Self-soothing skills.

Suggested further reading:

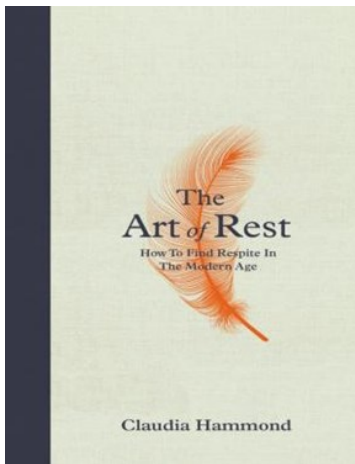
- ◇ Rest Presentation 2021 (CCSI Resources):

<https://ccisupport.org.nz/wp-content/uploads/2021/08/How-to-get-good-rest.pdf>

- ◇ Ideas on self-soothing:

<https://eddinscounseling.com/grounding-techniques-self-soothing-emotional-regulation/>

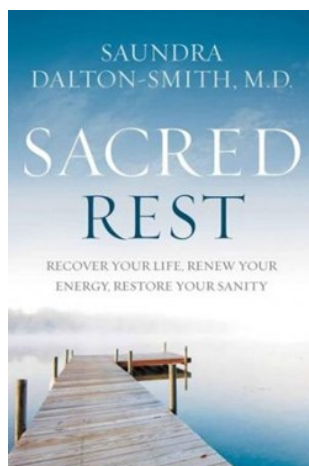
* Hard copy in library and digital copy also available.



The Art of Rest

“How to find respite in the modern age”

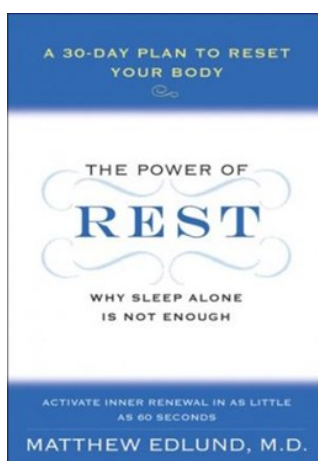
- Claudia Hammond



Sacred Rest

“Recover your life, renew your energy, restore your sanity”

- Sandra Dalton-Smith, M.D.



The Power of Rest

“Why sleep alone is not enough”

- Matthew Edlund, M.D.



What WINZ category does ME / CFS come under?

ME / CFS comes under the Supported Living payment as a medical benefit, but it does depend on how good your doctor is. It does come down

to each particular doctor - We have situations where we talk to people about this, and I always advise them to keep a copy of the medical certificate that the doctor sends to Work and income. It is really important to keep a paper trail. Check the forms, make sure that if there are any changes in what the doctor is saying, it's consistent within three months of the medical review.

The doctors must indicate that the client hasn't had work capacity for the last two years (for example). If the doctor is not working with you, you may need to possibly look at changing your doctor or you can ask a case manager for an independent opinion.

Is a partner's income still taken into consideration with WINZ support?

Yes, it does, for both the Supported Living payment and for Job Seeker Support. It does not stop you from applying for a Disability Allowance (As the threshold is set relatively high) and possibly an Accommodation Supplement.

What is the income threshold to be eligible for support?

The threshold is set at \$1092.55 (Gross income) per week. Any more than that and you would not be eligible for a Disability Allowance. This is the income limit if you are in a union, if you earn under that then you are eligible.

I've heard it's hard to get home help unless you need personal care as well.

People with ACC can get home help, but as with anyone, it usually applies to people over the age of 65, where a doctor has made a referral to Disability

Support Link to complete a Home Help Assessment. Home help for anyone under the age of 65 is a little different, and it mostly depends on people being assessed by an Occupational Therapist for ACC. It is very difficult to get home help for anyone under the age 65.

I don't receive help from Work and Income or ACC. I live off monthly payments I receive from Income Protection insurance. I'm not entitled to a Community Services card either. Is there any other support out there?

It really depends on how much the income protection payments are, and if it is enough to cover your cost of living and your living situation (Such as cash assets, relationship status, etc). Depending on those factors, you may be eligible to claim a Disability Allowance.

What do you mean by non-beneficiary assistance? What does this entitle people to?

Non-beneficiary assistance applies to a person who is not eligible for a main benefit, that means they are not eligible for Job Seeker Support with a medical referral, or the Supported Living payments. A "non-beneficiary" is a person that doesn't receive a main benefit. Being a non-beneficiary, you are not excluded from receiving supplementary assistance such as an Accommodation Supplement, the Winter Energy payment or any extra help that there may be out there (Housekeepers Allowance and Community costs, Unsupported Child benefit, Foster Child benefit, are among a few other types of benefits that you do not normally hear about or aren't very common).

You can test your entitlement depending on your circumstances.

If you have a family member that lives close - How can they continue to work full time and be a full-time carer as well?

You don't necessarily need to live in the same

place as someone for them to become your carer, as long as you are fulfilling the obligations. Most people carry out their caregiver duties during the day and go back to their own home once finished - They can be income earners. It does not need to be a 24/7 job. Some people do have full time, live-in carers but it does depend on the type of care needed.

If you have some assets, but no income due to being too ill to work at all, can you still be eligible for Supported Living and / or a Disability Allowance? What do Work and Income see as an asset and what are the limits?

You could be eligible for the Supported Living payment as that is classed as a medical benefit. Work and Income would not look at assets for the Supported Living payment. Assets can however have an impact on payments like the Accommodation Supplement. If a person has been granted the benefits due to their current health, then the assets have not been a problem.

When looking at the Disability Allowance, if someone has assets that are earning interest, it will count towards earnings. If that interest is over \$1092.55 (Gross income), you will be over the threshold.

Having cash assets means that you are not able to apply for Hardship Assistance. Work and Income would expect you to use your cash asset before applying for assistance.



A beneficiary is allowed one or two boarders, as long as food is provided. I have one part time boarder that I provide food for however she chooses not to eat what I have and buys her own food. Is this ok for me? The pantry and freezer are full of things I have paid for.

Work and Income do not mind a beneficiary sharing the costs and having up to two boarders in their home. If anyone has more than two boarders, Work and Income would take this into consideration.

In this case, you are providing full board and meeting the obligations. It is up to the boarder whether they eat the food you have provided or if they purchase other food.

I find it very difficult to fill out all the forms with brain fog. The last form was 21 pages long and was a Review of something (Maybe a Disability Allowance) of \$5 a week.

You can get an Advocate to help you complete the form. There are organisations out there such as Age Concern who can help you. It does depend on the availability of volunteers to do that.



When my roof needed replacing, Work and Income could not help with a replacement, but they would have helped with repairs to a similar value. What should have happened?

Essential home repairs are things that are an emergency (Problems with a leaking pipe, septic tank water, electrical etc). They can access a payment that would help with the immediate situation. An Advance Benefit Payment (ABP) can be paid for various things such as essential home repairs (This is one of the categories). There are different situations for which you can use the ABP.

The work that needs to be done has to be essential, and no more than \$1,000 (This is a guideline and is not set in stone, as they can pay more than this if needed!). It is probably best to take an Advocate along with you that has the right information to get the best outcome for you.

Extra comments from the meeting:

The whole process with Work and Income can be very complex and everyone's situations are so different. One way to see what you may be eligible for is to call Work and Income directly and chat through your situation. They will ask questions regarding your income, partners income, investments, family situation, rent / mortgage etc, so it will be best to have this information on hand. Also, be prepared to wait on hold for a long time. I found this method a clearer and faster way to find out what I was or wasn't eligible for, rather than trying to work it out myself. If you are then eligible for support, they can then tell you exactly what information you need from your GP (Medical certificate etc).

Work and Income Advocacy:

Nationwide Health & Disability Advocacy Service
Ph: 0800 555-050
www.advocacy.org.nz

Beneficiaries Advocacy & Information Service
Ph: 09 444-9543
www.bais.org.nz

To find a local advocate, visit the Community Directory at www.cab.org.nz.



Counselling Available

Counselling is available in some areas and also available online.

These sessions are with third year Counselling Students from Bethlehem Tertiary Institute.

If you think you could benefit from some counselling, please contact your Facilitator.



Facebook

Don't forget, for our CCI Connect members, we have a Facebook page where you keep up with the latest research, connect with each other, share stories and advice, ask questions and be a part of the CCI Community.

Contact your Facilitator for more details.



COMPLEX CHRONIC ILLNESS SUPPORT

Monthly Member Meeting August 2022

Join the CCIS Facilitators for our
Online Members' Meeting
Mindfulness

Tuesday 9th of August
10.30am
Via Zoom



SPEAKER: PHIL JONES



The Monthly Members Meeting for August will be held online from 10.30am on Tuesday the 9th of August.

Information and a recording of the meeting will be available by visiting the CCI Connect page of our website from the 16th of August 2022.

The remaining Monthly Member Meetings for this year, will be covering the following:

September - Pain Management

October - Dysautonomia

November - Sleep

December - Pacing

Pumpkin & Cherry Tomato Risotto

You will need:

- 300g pumpkin, peeled and chopped (Try butternut for a change)
- 150 grams of cherry tomatoes
- 1 litre of vegetable stock (Organic if possible)
- 1 cup Arborio rice

Preheat the oven to 220°C.

Lay the pumpkin in an even layer on a large, paper lined baking tray. Season with sea salt and cracked pepper and roast for 10 - 15 minutes or until tender. Remove the tray from the oven, add the tomatoes and roast for a further 6 minutes.

Meanwhile, place the stock in a saucepan and bring it to a gentle boil, add the rice and stir well. Cook for 12 minutes or until the rice is cooked but still firm to the bite. Add the pumpkin and tomatoes. Cook for a further 6 minutes or until most of the stock has been absorbed and the rice is tender.

Food is first eaten with the eye - Garnish with bright and vibrant herbs or the zest of a lemon.



"The Invitation" by Oriah Mountain Dreamer

*It doesn't interest me what you do for a living.
I want to know what you ache for,
and if you dare to dream of meeting your heart's
longing.*

*It doesn't interest me how old you are.
I want to know if you will risk looking like a fool for
love,
for your dreams, for the adventure of being alive!*

*It doesn't interest me what "planets are squaring
your moon".*

*I want to know if you have touched the centre of
your own sorrow,
if you have been opened by life's betrayals -- Or,
have become shrivelled and closed from fear of
further pain.*

*I want to know if you can sit with pain, mine or your
own, without moving to "hide it" or "fade it" or "fix
it".*

*I want to know if you can be with joy, mine or your
own; if you can dance with wildness and let the
ecstasy fill you to the tips of your fingers and toes! --
Without cautioning us to "be careful", "be
realistic", or to "remember the limitations of being
human".*

*It doesn't interest me if the story you're telling me is
true.*

*I want to know if you can disappoint another -- To
be true to yourself.
If you can bear the accusation of betrayal and not
betray your own soul.*

*I want to know if you can be faithful, and therefore
be trustworthy.*

*I want to know if you can see beauty even when it
is not pretty every day, and if you can source your
life from God's presence.*

*I want to know if you can live with failure, yours
and mine, and still stand on the edge of a lake
and shout to the silver of the full moon, "Yes!"*

*It doesn't interest me to know where you live or
how much money you have.*

*I want to know if you can get up after a night of
grief and despair, weary and bruised to the bone --
And do what needs to be done -- For the children.*

*It doesn't interest me who you are or how you
came to be here.*

*I want to know if you will stand in the centre of the
fire with me -- And not shrink back.*

*It doesn't interest me where or what or "with whom
you have studied".*

*I want to know what sustains you -- From the inside
when all else falls away.*

*I want to know if you can be alone with yourself
and if you truly like the company you keep -- In
the empty moments.*



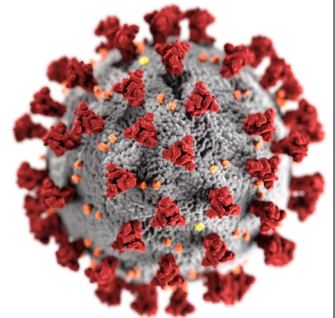
Does inflammation link stress to a poor COVID-19 outcome?



We are not strangers to the idea that stress is not conducive to good health, but a new review that integrates preclinical and clinical literature suggests that preexisting psychological stress and inflammation interact with the immune response to the COVID-19 infection. This type of stress can be related to the fear of contracting COVID itself, or the stress that social isolation can bring.

The review suggests that prolonged chronic stress should be considered a significant risk factor for COVID-19 related morbidity and fatality, which is yet to be fully discussed in medical and scientific communities.

When cortisol is elevated during high periods of acute stress, it evokes the suppression of cells that activate the production of anti-inflammatory cytokines necessary for immunity. Elevated cortisol causes immediate immunosuppressive consequences that can cause susceptibility to negative health outcomes, including infectious diseases. This reduces our immune system's ability to respond to anti-inflammatory actions, and proinflammatory processes then become dominant.



The review suggests that adults with adverse life experiences, particularly those with post-traumatic stress disorder, often show hypercortisolism which is due to a compensating sense of self preservation. Individuals with a history of both chronic stress and trauma are at increased risk of poor diseases prognoses, due to the activation of conserved transcriptional response to adversity (CTRA). CTRA is most noticeable in the context of social environmental conditions, for example interpersonal conflict or social isolation, which can upregulate genes that are critical for the initiation of inflammatory responses and downregulate those that promote antiviral responses.



All is not lost!! Knowing what we know of the role of cortisol in influencing inflammatory responses, stress reduction practices are important to promote better immunity and faster recovery from COVID-19. Practices such as meditation, which is highly recommended for stress management, is one of the things we can do to support our stress response during isolation periods. Mindfulness meditation in particular has the ability to influence cortisol and reduce inflammation responses. Physical exercise (or movement) has also been associated with the reduction of stress and anxiety.

It is also important to remain connected with one another, as social relationships could protect against COVID-19 related complications. In times of isolation, virtual communication is an effective alternative to stay connected, and just as effective as in person support for regulating negative emotions.

www.mighty.com is a great website where others who are living with chronic illness can share their stories, offer hope and support through the written word.

Below is a story I read recently which stood out to me as a story that is worth sharing at this time. Many conversations that I have had with clients, highlights how chronic illness impacts one's sense of self-worth and plays with the minds of intelligent people, making them doubt their sanity and confidence. If this resonates with you, I hope you find some solace and comfort from this article.

- Tracey Larsen
Waikato Health & Wellness Facilitator

Finding Self-Worth in Life With a Chronic Illness

- Written by Tessa Hearth, 1 January 2021

"But how will she earn her bread?" The voice on the other end of the phone asks my soon-to-be husband expectantly. The question surprised him, and he didn't really know what to say. To him, it didn't matter. But that question, casually thrown out by my soon-to-be in-law, echoed things buried deep down in my subconscious — although I would not realise it for many years.



At this point in my life, I had quit my job in order to move in with my boyfriend. Distance and commute limitations dictated that I would have to find work somewhere closer to where I was now living, but I had not yet started working again. I expected to go back to work shortly, though we had already discussed that when we started having kids we both wanted me to be able to stay home with them, especially when they were small.

Although I already had frequent pain and fatigue, at this point in my life I had no idea it wasn't the norm. So I continued life as it was, with no consideration or thought to what the future would bring for me in regards to my health. We had children not too long after we got married. By the time our children were school age and I had an inclination to re-join the workforce, my health had taken significant downturns and I had daily debilitating pain and fatigue with no answers.

Like many of us here, I started to recognise that what I could do versus what others my age

could do, were drastically different, and in a world that is not very understanding of differences or disabilities, I felt considerable and constant pressure to be doing *more*. In America, at least, there is very much the cultural mindset that **your value is in your job**. How much money do you bring in for the family? How many *things* do you do for others? I couldn't say how true that is in other countries, but certainly, I have run into this mindset frequently in the United States.

I grew up in a very demanding and abusive environment, where there was no room for failure, differences, disobedience, illness or self-worth. It was a grave sin to "raise yourself above others" and suffering was expected. The **trauma** experienced from my childhood had given me a very solid foundation of personal persecution and the inability to trust my own instincts, which had been systematically suppressed while growing up.

This was added to when I started seeking medical care and was met with "You're faking it" and the like. It was so easy to believe them. I'm just being dramatic. Nobody has pain every day. My instincts were telling me something was wrong, but I was woefully unprepared in skills, knowledge and self-confidence to listen to that instinct and act on it.

Because on top of fighting doctors, I was fighting myself. That voice in my head that told me I had to keep going was enforced when I was told "push through" and would come out loudly. And often. When I couldn't push through, or I had pushed through so long that the inevitable



crash was debilitating for weeks, I laid there feeling useless. Worthless. Work was a distant memory. I feared that my husband would get sick of me always being sick and leave. I thought I was lazy, weak.

I struggled with this for almost two more decades. I still struggle with it in many ways. It took two years of weekly therapy to even begin to realise that my sense of self-worth was so low because I put on such a good front I could fool even myself sometimes. I was taught that acknowledging your own skills and intelligence was vanity. It was a weird shift when I started seeing the things that my family and friends would tell me about myself.

That I *am* intelligent, and what's more, I've learned to wield that intelligence expertly. This in itself has given me confidence in a lot of areas that were lacking before.

That I am kind, at least to others. I'm working on being kinder to myself.

That I am absolutely *not* lazy, but instead have limitations that many people don't have to think about or understand. And that not all strength is obvious.

That the things I am able to do for my family are enough, even though there is always more that needs to get done. That's just life. There will always be more things to do. I don't have to break myself for others in order to be loved or valued.

That I'm a good writer. Writing articles for The Mighty has helped build my confidence, and I am about to start a project that has been a long time coming, which will hopefully lead to me having a book published. Hopefully more than one, eventually! This has been a dream of mine for a very long time.



That I'm a great patient advocate, and I've learned to use those skills for myself. I learned them for my daughter, and a few years ago

had that light bulb moment where I realised I didn't apply those skills to myself and started going, "And why *don't* I?" Once I realised that, it changed my entire approach to how I manage my health care.



Part of the process of recognising my value outside of the things I do for others was building trust in my instincts. Instincts that had been trampled through childhood, then trampled by the health care system I was in for 15 years as an adult. Turns out, my instincts are often spot on.

It hasn't changed the fact that I hurt every day. It hasn't changed that I am always tired. I still have **lupus**, Sjogren's, **fibromyalgia**, chronic headaches, spine issues and more, or that I now work too much for the state of my health. But it's allowed me to stop when I have to with less guilt, and hopefully, eventually, that will be with no guilt. That in itself has made my pain better because I am much better about not just **pushing through** until I crash for weeks (though it still happens). I take time off now just for the sake of having time off, since we all know that time off due to crashes is not restful or pleasant. It also takes a lot of mental energy to beat oneself up. I had to find an equilibrium within myself that allowed me to see these things and really start to *feel* them.

It's not a process I would have been able to do by myself. But I can say that finding a sense of self-worth and confidence in myself, even though it is still a work in progress, has been one of the most positive changes in my life. That question of "But how will she earn her bread?" no longer represents the way I think about myself.

Remember this — Your illness does not define you. While it dictates many things in our lives, remember that you have value because of who you are.

Article sourced from:

https://themighty.com/2021/01/finding-self-worth-chronic-illness/?utm_source=cordial&utm_medium=email&utm_campaign=segment_hot_daily_article_recommendation

Book Review

Quiet your mind & get to sleep

Solutions to insomnia for those with depression, anxiety, or chronic pain.

Written by Colleen E. Carney PHD & Rachel Manber, PHD

Good sleep is vital for healing and well-being and plays a central role in every aspect of human life including regulating emotion, reducing stress, worry and irritability and strengthening the immune system. In addition, there is resounding evidence that treating sleep will improve other problems such as depression and pain.

If you are finding it hard to sleep then you need to read this book, available now from our CCIS library. Written by two of the world's leading experts on insomnia, it provides a straight-forward guide to solving sleep issues, especially insomnia related to depression pain and anxiety. It is sensitive to the types of

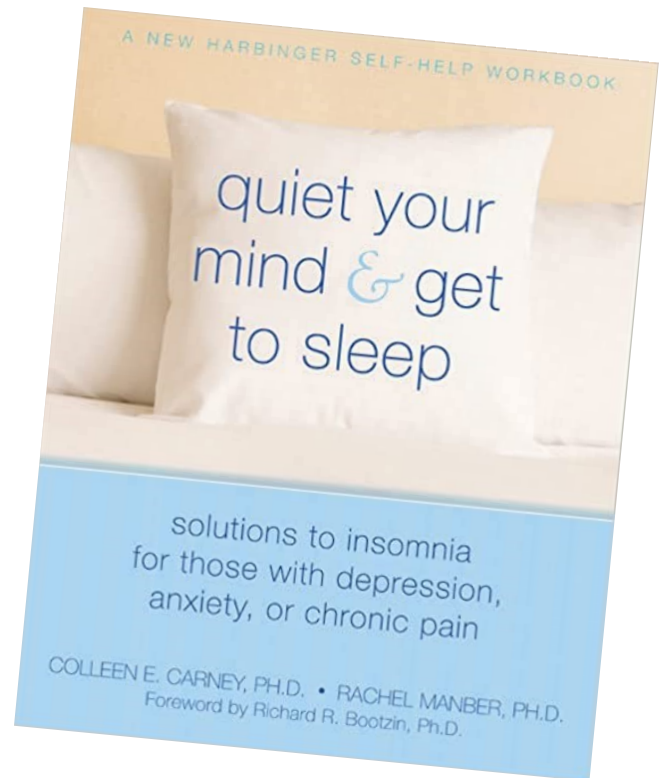
challenges faced by people with complicated health issues and takes a direct approach to eliminating the factors known to contribute to insomnia.

Often people with sleep disturbance have unrealistic expectations about sleep and anxiety about the impact of not sleeping well. Sleep is important but sleep cannot be forced. This workbook is unique in that it provides a series of interactive exercises to build the knowledge and skills to treat insomnia.

Each chapter provides strategies to overcome insomnia and covers sleep-related information, self-tests and simple worksheets.

Topics include, learning about your sleep, how some medications interact with sleep, keeping a sleep log, sleep hygiene and changing poor habits for a better night's sleep.

This book is available for loan from the CCIS library along with a range of recent books covering chosen to support our members manage their health and wellbeing needs.



Social Groups

Social groups are casual catch up's and are essentially run by our members. They have no set topic or subject, it is just a chance to create connections with each other, learn helpful information, share, laugh and build friendships.

Having friends who share similar experiences as you are very important, it can become difficult when you are maneuvering health conditions and existing friendships at times, so it is lovely to connect with people who "get it".

Please contact your Facilitator if you have any queries or if you would like to join a group.

Waikato Coffee Group

Jukebox Diner, 11 Railside Place, Hamilton
Third Tuesday of every month at 1pm

Waikato Young Ladies Coffee Group

Jukebox Diner, 11 Railside Place, Hamilton
First Thursday of every month at 11am

Te Awamutu Coffee Group

Venue - To be advised
Third Thursday of each month at 10.30am

Cambridge Coffee Group

Being organised now!

Please contact Tracey if you are interested

Greerton Coffee Group

Greerton Mitre 10 Mega
Third Wednesday of each month at 10.30am

Papamoa Coffee Group

Double Teaspoons, Papamoa Plaza
First Tuesday of every month at 10.30am

EBOP Coffee Catchup

Café Coco, 10 Richardson Street, Whakatane
Fourth Tuesday of the month at 10.30am

Lakes Coffee Group

Arts Village Café, 1240 Hinemaru Street, Rotorua
First Tuesday of every month at 11am

Wellington Coffee Group

Venue & date - To be advised
Please contact Luisa for each months location and day.

Men's Group

Online
Time & date to be advised
- Please contact Phil



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Thank you for supporting us.

Group Touchstones

Keep discussion flowing within the group.

Withhold off-topic questions for individual participants until after the session.

Speak your truth in ways that respects other peoples truth.

Speaking one's truth does not mean interpreting, correcting, or debating what others say.

Refrain from fixing, saving, advising, or correcting each other. Respond to others with open questions.

Help 'hear each other into deeper speech' when doing activities.

Be curious and turn to wonder.

If you feel judgmental or defensive, ask yourself 'I wonder what brought this person to his or her belief?'

Moderate patterns.

Some of us are more confident to speak than others.

If you contribute often, allow space for others to contribute. If you are reserved, take opportunities to share

Watch and Observe....

Although we learn from others ideas and thoughts, we also learn from our own reactions and responses.

Honor confidentiality.

Safety is built when we can trust that our words will remain with those with whom we choose to share, and will never be passed on to others without our explicit permission.

Know it is possible to leave this room with whatever you needed.

Most 'aha moments' occur between sessions.

Refrain from sharing information about products and events until after the session.

Refrain from using cellphones, unless for emergency.

* Adapted from the Centre of Courage and Renewal Touchstones, as used in the Towards Wellness Programme





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53 Fraser Street, Tauranga South, Tauranga 3112

• P: 07 281 1481 / 0800 227 787 or text 022 658 0251 • E: info@ccisupport.org.nz • W: www.ccisupport.org.nz