



Messenger

June 2019

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Remember to check the Group Monthly Meetings Calendar!



Hi everyone!

As you read this, we will be officially getting into the winter season – not everyone's favourite time of year, but a great time to hunker down and take especially good care of yourself!

There have been several changes at CCI Support over the past few weeks (see page 2 for more). As many of you will already know, Kira is now focusing on her private counselling practice, and I will retire from CCI Support as of 14th June. (We will co-facilitate our final Towards Wellness workshop for CCI Support that day).

While I am sure we will feel some sadness on this occasion, and as we say farewell to many of you later that day, I am equally sure that we are leaving you in very capable hands! We introduce you to **Dorotka Wisniewski** and **Joanna Delamere** on page 3.

Good news also for Rotorua members! We are pleased to introduce your new field officer, **Philippa Webb (Pip)**, also on page 3.

Dorotka, Joanna and Pip will join Elizabeth (who does a wonderful job working with our Eastern Bay members) to make up the CCI Support field officer team.

I have enjoyed the 15 years spent in my role. While it has presented the occasional challenge, it has always been interesting and extremely rewarding.

I wish you all the very best on your journey towards better health.

Tina 😊

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Tauranga 3112
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Website: www.ccisupport.org.nz



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

Send a friend request...!

Local Items of Interest

Introducing our new staff members: Operations Co-ordinator Julie Cross; Western Bay Field Officers Dorotka Wisniewski and Joanna Delamere, and Rotorua Field Officer Pip Webb.

Greetings from our New Operations Coordinator

Hello Members

Since my start in late March, it has been a whirlwind few months. The resignations of both Tina and Kira within a short space of time of my starting did make me contemplate if my English humour had been taken the wrong way!

Their decisions to move on are for their own personal reasons, which as an organisation we support. As Operations Coordinator for the organisation I personally thank them both for the wonderful work and commitment they have given to the organisation and its members over many years, and wish them every success and happiness in their new ventures. It takes a brave person to step out of a comfort zone and take on a new venture.

This leads me onto Joanne, she has been a rock within the organisation. I know for many of you she has been the go to person for many years, always willing to help you all. For me, Joanne has also been my rock for the past 2 months, showing me the intricacies of the organisation. Desperately trying to teach me the systems that hold the running together. The next few months will show whether or not I was listening! Thank you, Joanne from myself, the board and all the members for all you have undertaken over the past few years.

Not forgetting Elizabeth in Whakatane who has been a great help in the last few months and has worked extremely hard, alongside myself and Jacqui from the board to ensure that we now have the right people in the roles to take us through our next journey.

We welcome **Dorotka Wisniewski, Joanna Delamere** and **Pip Webb** to the organisation.

The next Chapter

Onwards and upwards is my philosophy, and this we will do as an organisation, building a new team based on some excellent ground work put in place by Tina, Kira, Elizabeth and Joanne. We will continue to thrive and develop.

You as members of CCI Support can also play your part, by continuing to support the organisation and the great work it undertakes on your behalf, by ensuring that your membership fees are paid, and promoting our service within your friends, family and colleagues.

Without such funds, support and donations we would not be able to exist.



Thanks to you all

Julie Cross



Dorotka Wisniewski

I have been interested in health and wellness for as long as I can remember. My passion for figuring out what helps people heal began when our youngest child was diagnosed with chronic respiratory issues that the doctor advised would be a lifelong condition. Daily massages using immune boosting essential oils led to a full recovery within a short space of time, surprising the paediatrician.



This life-changing experience sparked my appetite for studying various disciplines which have contributed to my reputation as a successful and holistic chronic pain therapist. As well as being certified in a Therapeutic Massage, Neuromuscular Therapy, Craniosacral Therapy, Neurolinguistic Programming, Quantum Touch and Wellness and Personal Development Coaching, I hold a Bachelor degree in Health Science.

Having had 20 years experience working with people from all walks of life, I believe that given the right conditions, and by drawing on strengths and resources, people can find ways to heal and become well again.

I am excited to be part of the CCIS team, and look forward to supporting members in their health and wellness journey.

Joanna Delamere

Hi, I have a private practice as a Somatic Experiencing Practitioner and Therapeutic Coach and have been working with clients with chronic and complex illness for several years. This has also been my own journey, having successfully navigated and learnt to manage, chronic adrenal fatigue, C-PTSD and burnout.



I am currently enjoying living back on a farm again with my partner and our children, immersed in nature, growing our own food, and being only a few minutes from the sea and beach life.

I love exercise and used to compete in bodybuilding and powerlifting before learning some tough lessons on over training. I'm taking it more gently this time around, and have a morning practice of Qi Gong in our beautiful garden. I also really enjoy coastal bush walks, with Mauao still being one of my favourites!

Pip Webb

Kia ora koutou. Tuwharetoa me Ngati Ruahine aku iwi.

My name is Pip. I was born in Mangakino, went to primary school here in Rotorua and have lived all over the country since. I have come back to Rotorua with my partner Trent to settle and be near whanau. Collectively, we have four children and almost five grandies. There is nothing we like better than hosting a big noisy Sunday lunch and we are pretty happy when they all go home afterwards.



I have a degree in Education and have been a teacher, a librarian and had a short stint milking cows in the Far North. I have spent the last ten years working for the New Zealand Customs Service. I am making my way back into the workforce after a diagnosis of a chronic pain syndrome and six months of recovery and management of my condition. I am passionate about service, people and the well-being of our communities.

I look forward to being a positive and hard-working addition to the team at CCI Support. I hope to meet you all soon, to share our collective stories and experiences with the view to living the best lives we can.

New Board Member Sarah Davey

We extend a warm welcome to our new board member, Sarah Davey. Sarah has a long connection with the Bay of Plenty having grown up in Tauranga.

Her initial career practicing law in New Zealand and internationally provided a solid foundation for the next 20 plus years developing health and disability services at senior management and governance levels.

She is currently the Service Development Manager, Planning and Funding at the Bay of Plenty District Health Board. With her husband Trevor, she is also a Director of Latitude Surveying Limited, a Tauranga based land surveying firm.



Trevor and Sarah have three children.

Whakatane Gets the Message Out

The staff at Hospice Whakatane are always keen to support the community and like to have group displays in their large windows, so they were very happy when we asked to have our display up.

The display is a symbolic one. It features actual shoes from people in our community here who live daily with M.E./C.F.S. The shoes represent the lives that they are missing. Those shoes are not out there walking or jogging. Their soles are not worn.

And each personal story of how this feels for them, the effect on their lives, is summed up on paper tied to the shoelaces.

Examples are:



"I used to be a nurse and I loved running. For more than 20 years I have not been able to do either."

"I miss being able to garden as much as I want. I became unwell in 1969 and still live with the symptoms daily."



"Where do I start? I feel like I have missed so much..."

"Each night the pain in my legs feels like lightning. The pain of movement makes me nauseous. Dancing is now impossible."

Poignant indeed.

Since the article and display Elizabeth McGougan, our Eastern Bay Field Officer, has received several enquiries about our services which is very encouraging.

Greetings from the East!



May has been a busy month, with a newspaper article and a display in the main street of Whakatane for ME/CFS Awareness month. Our membership has been learning about tools to calm the stress response and I have been following up on some research into Restorative Movement.

Last year at the ANZMES conference, Auckland physiotherapist **Erin Holland**, who works with and has an interest in ME/CFS clients, spoke to us about the research of **Peter Rowe** and his study (*Neuromuscular Strain Increases Symptom Intensity in CFS, 2016*) which showed the impact of movement on our bodies.

They found that when they subjected ME/CFS patients to the straight leg neuromuscular strain manoeuvre (SLR) this was capable of increasing symptom intensity in individuals for up to 24 hours.

This means that increased sensitivity may be a contributing factor to this condition i.e. putting physical strain on our body's nerves and soft tissues causes more symptoms like cognitive issues, light headedness, orthostatic stress and pain.

The SLR is the raising of the legs from a lying flat position, this puts the hip at a right angle. This position is similar to sitting in bed with the body propped up with pillows, or sitting while driving with the arms outstretched. This means that sitting like this for a period of time, even at rest, can cause mechanical tension on our soft tissue

and nerves and may increase our symptoms, so ways of resting, driving etc may actually be increasing our symptoms.

As I often mention, each of us is very different physically and our experiences are different, but for me this knowledge makes a lot of sense for my body, which I have often found to be more painful after sitting/resting for long periods of time.

Erin Holland says that our nervous system is so sensitive that doing many normal physiotherapy manoeuvres may make us more symptomatic. She works on the body's movement restrictions first (stiff or extremely tight areas), as per the Rowe study, to desensitize the body before moving on to other movement/ exercise.

She says that she always does less physiotherapy treatments to a person with ME/CFS and with time and care they can come right, but it takes MUCH longer than normal.

She suggests:

- Start to desensitize the nervous system (by calming it and gently moving it)
- Work on our breath
- Find and then set our baseline
- Have achievable goals (she has found that we tend to set our goals too high)
- Commit to retraining our bodies and minds to a very slow process.

I have found this research very interesting and it is great to see this type of work being done and then used by New Zealand practitioners.

If you want to read the full paper it can be found at <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0159386#sec010>

Man says to his wife one evening

" What would you do if I won Lotto ?"

" That's easy " she says " I'll take half, and then leave you. "

" Sounds fair " he replied. " Well, I won \$12.00 last week. Here's \$6.00. Keep in touch."



Suzanne's Story "Asking For help"

In November **Suzanne Riesterer** finally realised she needed to ask for help. She had spent the last few years focused solely on helping her family cope with their own health issues: cancer, stroke, brain damage, Alzheimer's, and she had recently lost her husband of 40 years to cancer.

Suzanne had been battling her own health issues for many years. This was not an option any more. Her brother gave her the contact number for local charity Complex Chronic Illness Support and she knew she had found the answer.



"Just talking with Elizabeth, the CCIS Field Officer, made me realise 'Oh this is Chronic Fatigue Syndrome', which I had never been diagnosed with before. It was a huge turning point for me. I knew my next step was to see Doctor Vallings," says Suzanne.

Suzanne saw Auckland based **Dr Ros Vallings**, the leading physician for ME/CFS in New Zealand. She was able to diagnose Suzanne and give her some help on managing this complex illness.

For Suzanne this means she has more understanding of her illness. *"It has made me finally feel really settled. I am not struggling to understand what is wrong with me anymore. I know there is help out there, I have found my journey and I know that I am on the right road."*

Like many others living with conditions like ME/CFS in the Eastern Bay, Suzanne battled on for years even though she was suffering serious symptoms. Suzanne says *"I kept on pushing, working, being a mum, pushing and pushing. I remember walking down the road with Bryan and I could not lift my legs - they were just stuck. Bryan had to get the car and pick me up. I went to hospital several times because I was so unwell that I could not get out of bed. I could not walk, but at the hospital I got no answers. Eventually I stopped going and managed the best that I could at home for three years."*

Myalgic Encephalomyelitis aka **Chronic Fatigue Syndrome** (ME/CFS) is a condition which is thought to affect **20,000 - 25,000** people in New Zealand. Its defining symptom is **post-exertional malaise** (PEM) which means that after doing an activity, pain, fatigue, and cognitive symptoms can become very severe. This can last for days, months or years. Other symptoms include gastrointestinal upset, orthostatic intolerance, unrefreshing sleep, heart arrhythmias, and a number of other symptoms that are common amongst ME/CFS patients. It's not just about fatigue.

Suzanne has found that she is able to manage her condition with careful pacing, an eye on her diet, some supplementation and medication, and a focus on rest. She is able to work part time, be a grandmother to her wonderful mokopuna and be a part of the Opotiki community which her family has been at the centre of for many years.

During May's ME/CFS International Awareness week, Suzanne said:

"I just want to shine a light on this condition and tell people that there is help for them. I have met some great people who just get it. They understand what I am going through. You don't have to be alone."

Contact local Complex Chronic Illness Support Field Officer **Elizabeth McGougan** on **021 838 217** or visit **www.ccisupport.org.nz**

Social Media - Where does it fit in the process of recovery?

Source: Some information taken from Alex Howard's facebook OHC Live Ep 079:

'Use technology, don't let it use you'

When it comes to using technology/social media, is it better to become like a nun or monk and abstain totally in order to achieve better health? There is no black and white answer but instead, many shades of grey!

Alex Howard of the Optimum Health Clinic, London, points out that several years ago when he was on the recovery path, it was much harder to access information. He had to look for it in books in the library! So on that front, we are much more fortunate these days, with access to a wealth of information that can help us on our recovery journey – and for most of us, we don't even have to leave our home to access it!

Technology helps to counter the isolation that many with ME/CFS/FM can experience. It enables us to connect with the outside world when our physical ability to do that is compromised. As well as facilitating our connection with friends and family, we can connect with others on the recovery path to give and receive support.

There is, however, a downside to technology/social media. It can be very easy to get caught up in mindless content on social media. It is a good practice to ask yourself as you check out the endless posts– Is this helpful? Is this inspiring?

To assess whether your relationship with technology is healthy, ask yourself the following:

'Could I go a day without it?'

'Am I using social media to 'numb out' - to avoid my own thoughts and feelings / issues going on in my own life?'

(There is a place for occasional 'numbing out' but consistently distracting yourself in this way is not helpful).

The answers to these questions should provide you with some clues!

Taken to extremes, interaction with technology/social media can potentially become an addiction – as much of an addiction as the more acknowledged forms of addiction involving drugs, alcohol, gambling for example.

The key is to choose consciously your level of engagement with technology/social media, and to be discerning. For example, don't have too many news alerts. Remember, the news is



biased towards the negative and the dramatic, and is not an accurate report of the most important things that have happened that day.

Also, we are all different in terms of sensitivity when it comes to noise, exposure to screens, etc. Try to avoid over-stimulating your nervous system and bringing on that 'tired and wired' state. Turn off devices an hour or so before bedtime and preferably keep them out of the bedroom.

The last words on the topic of social media go to Ashok Gupta, ME/CFS recoveree and creator of the Amygdala Retraining Programme. He has also created a free meditation app www.themeaningoflife.tv/ to help people discover more happiness in their lives.

He reminds us that, in general, we see the best 1% of people's lives posted on social media. If, as people affected by ME/CFS/FM, we are constantly comparing our current reality with what we see on social media, we are far more likely to become discouraged, even depressed.

So, to summarise, technology itself is neither good nor bad, but the way we engage with it has the potential to help or hinder our recovery. The choice lies in our hands.

Scientists say they're closer to possible blood test for Chronic Fatigue Syndrome (CFS)

Source: <https://www.nbcnews.com/health/health-news/scientists-say-they-re-closer-possible-blood-test-chronic-fatigue-n999766>

NB: This article has been abridged.

Scientists in the United States say they have taken a step towards developing a possible diagnostic test for CFS, a condition characterised by exhaustion and other debilitating symptoms.

ME/ CFS (also known as myalgic encephalomyelitis) is estimated to affect some 2.5 million people in the US and as many as 17 million worldwide.



Researchers at Stanford University School of Medicine said a pilot study of 40 people, half of whom were healthy and half of whom had CFS, showed their potential biomarker test correctly identified those who were ill.

The research, published in the journal, *Proceedings of the National Academy of Sciences* recently, analysed blood samples from trial volunteers using a 'nanoelectronic assay'

– a test that measures changes in amounts of energy as a proxy for the health of immune cells and blood plasma.

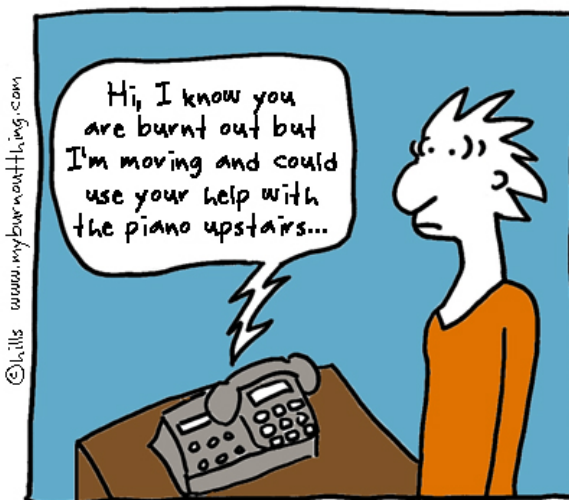
The scientists 'stressed' the blood samples using salt and then compared the responses. The results, they said, showed that all the CFS patients' blood samples created a clear spike, while those from healthy controls remained relatively stable.

'We don't know exactly why the cells and plasma are acting this way, or even what they're doing,' said Ron Davis, a professor of biochemistry and genetics, who led the study. *'But we clearly see a difference in the way healthy and CFS immune cells process stress.'*

Other experts not involved directly in this work have cautioned, however, that there is still a long way to go before a biomarker is found that can establish a definitive CFS diagnosis.

Andrew Lloyd, an infectious disease doctor professor at the School of Medical Sciences, University of New South Wales, Sydney, Australia, said it's premature to make broad conclusions about the study results as the sample size was only 20 CFS patients and 20 healthy control subjects.

Watch this space! ...



Some light relief.....

An aeroplane was about to crash. There were 4 passengers on board, but only 3 parachutes. The first passenger said, "I am Stephen Curry, the best NBA basketball player. The Warriors and my millions of fans need me, and I can't afford to die." So he took the first pack and left the plane.

The second passenger, Donald Trump, said, "I am the newly-elected US President, and I am the smartest President in American history, so my people don't want me to die." He took the second pack and jumped out of the plane.

The third passenger, the Pope, said to the fourth passenger, a 10-year-old schoolboy, "My son, I am old and don't have many years left; you have more years ahead so I will sacrifice my life and let you have the last parachute."

The young boy said, "That's okay Your Holiness, there's a parachute left for you. America's smartest President took my schoolbag."



Chicken miso

Ever used miso apart from in soup?

Be bold, give this a try. It's good for you, especially those of us with sensitive digestive systems.

Because miso is a fermented food, it is high in nutrients; it increases helpful bacteria in the gut aiding digestion and it improves the immune system. Miso adds a salty, sweet, earthy flavour which works particularly well with baked chicken - wings, legs, even chicken nibbles. For this recipe a barley miso is used, but you can use any kind of miso, which usually comes in a form of paste. Rice vinegar can be substituted with white vinegar. It's simple to prepare too.

Ingredients:

- 500g chicken pieces
- 2 tbsp of barley miso
- 1 tbsp rice wine vinegar
- 1 tbsp light soy sauce
- 1 tsp of finely grated ginger



- In a large non-metallic bowl, place all the ingredients together with the chicken and mix well.
- Allow to marinate for a few hours or ideally overnight.
- Place the chicken on a baking tray and cook for about 20 minutes at 180 degrees C.
- Check the meat is completely cooked by piercing the flesh. If the juice runs clear, it is cooked.

Enjoy.

ref: www.shescookin.com

Library

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

Check that the office is open before you come. If you are on the internet you can access the titles from our website www.ccisupport.org.nz

Can We Email Your Newsletter?

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

Acknowledgement

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

Action for ME, UK

ME/CFS Group (Canterbury)

MEISS (Dunedin)

ME Association, UK

DR Ros Vallings

ANZMES

Nelson Bays ME/CFS & FM Support Group

Appreciation to our Funders

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



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

Group Meetings Calendar

CCI Support meetings held 2nd Wed of the month **10:30am** contact 027 625 4449

Eastern Bay Group meets 2nd Wed of the month **1:30pm** contact Elizabeth 021 838 217

Tauranga Coffee Group meets 3rd Wed of the month **10:30am** contact 027 625 4449

Young Members meetings held 3rd Thurs of the month **12pm** contact Matt 021 276 2446

June 2019	July 2019	August 2019
Wednesday June 12th Support meeting at 56 Christopher Street, 10.30am – 12.00pm Open discussion/Q & A Ph Tina: 027 625 4449	Wednesday July 10th Support meeting at 56 Christopher Street 10.30am – 12.00pm Topic to be advised Ph 027 625 4449	Wednesday August 14th Support meeting at 56 Christopher Street 10.30am – 12.00pm Topic to be advised Ph 027 625 4449
Wednesday June 12th Eastern Bay group - 1.30pm Topic: Nutrition Little Orchard Activity Room, Whakatane Library Ph Elizabeth: 021 838 217	Wednesday July 10th Eastern Bay group - 1.30pm Topic: Restorative Movement Venue to be advised Ph Elizabeth: 021 838 217	Wednesday August 14th Eastern Bay group - 1.30pm Topic: Sleep Little Orchard Activity Room Whakatane Library Ph Elizabeth: 021 838 217
Wednesday June 19th Coffee morning 10:30am at Mitre 10 Mega Café, 1066 Cameron Rd, Gate Pa	Wednesday July 17th Coffee morning 10.30am at Mitre 10 Mega Café, 1066 Cameron Rd, Gate Pa	Wednesday August 21st Coffee morning 10.30am at Mitre 10 Mega Café, 1066 Cameron Rd, Gate Pa
Thursday June 20th Young members' meeting 56 Christopher Street at Midday 12pm Ph 021 276 2446	Thursday July 18th Young members' meeting 56 Christopher Street at Midday 12pm Ph 021 276 2446	Thursday August 22nd Young members' meeting 56 Christopher Street at Midday 12pm Ph 021 276 2446
Rotorua coffee mornings & Support meetings. To be advised	To be advised	To be advised

PLEASE NOTE

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

**Formed
1981**

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

**Incorporated
1986**

Board of Management

President (acting) Jacqui Bassett
Vice-President (acting) Matt Appleton
Treasurer Keith Appleton
Board Members Barbara Whitton
Steve Napier
Sarah Davey

Staff

Operations Coordinator Julie Cross
Field Officer Dorotka Wisniewski
Field Officer Joanna Delamere
EBoP Field Officer Elizabeth McGougan
Rotorua Field Officer Pip Webb
Newsletter Jan Morrison

10% Discount Stores

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

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

Want to call in or write to us?

We are at
56 Christopher St, Tauranga 3112
Admin: ph (07) 2811 481
Email: info@ccisupport.org.nz
Website: www.ccisupport.org.nz

SUBSCRIPTIONS and DONATIONS

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

Subscriptions and donations can be direct credited to our bank account if that is convenient. Our bank account is: Kiwibank A/c No: 38 9014 0140507 00
Please enter your 'name' and 'ME Sub' and/or 'donation' in the reference and email us if you would like a receipt.
OR..... deposits can be made in person to Kiwibank if you go in with our account number.

BEQUESTS

Including a bequest to Complex Chronic Illness Support in your will is also an option you may consider. ACORN Foundation can assist you to arrange a bequest to CCI Support. Donations can be made to our endowment fund with ACORN ph 07 579 9839, internet banking on the Acorn website : www.acornfoundation.org.nz or cheque made out to Acorn Foundation, PO Box 13604, Tauranga 3141



.....
Cut here if sending by post

Yes, I would like to make a donation / pay my subscription to Complex Chronic Illness Support.

Please find enclosed my donation of \$.....

Please find enclosed my annual subscription of \$20.00

☐

*Tick the boxes
which apply*

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Please send receipt to:

Name:

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