



M.E. - Myalgic Encephalomyelitis

(CFS – Chronic Fatigue Syndrome)

Our mission is to offer moral support, to provide relevant information, and to encourage research regarding M.E.

Support Group Meetings

Everyone is welcome to our Support Group Meetings:
Patients, family, friends, and supporters.

The M.E. Society of Edmonton Support Group Meetings are now held over the Internet! Everyone is welcome, registration is not required and there is no fee to join. These groups are a safe place to share your life, receive support and learn more about ME/CFS. Talking with people who have similar struggles to you is often comforting. All of our support groups are strictly confidential, and recordings and screen shots of the meetings are not permitted. We hope you can join us!

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FOR EDUCATIONAL PURPOSES ONLY

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Please submit articles or feedback for the newsletter to newsletter@mesocietyedmonton.org or contact our office.

Support Group Meetings Cont'd

We use "Go To Meeting" to host our online meetings. You can log in to our meetings using the link below. Type the Access Code for the Support Group you are attending in the white box and then click join. Dates and login information for our Support Group is also on our website and Facebook page. There will always be plenty of time to discuss any subject even if there is a topic for the meeting. If you want any further information about our Support Group, please do not hesitate to contact us.

<https://www.gotomeeting.com/en-ca/meeting/join-meeting>

Sat, Nov 20, 2021 1:00 PM - 2:30 PM MST Access Code:
132-966-181

Topic: Doctor Appointments

Sat, Dec 18, 2021 1:00 PM - 2:30 PM MST Access Code:
724-101-245

Topic: Pacing During the Holiday

M.E Board Meetings

Our Meetings are open to the public, and you are welcome to join us without becoming a Board member. We are always in need of new board members, so please consider helping the M.E. Society of Edmonton by joining our volunteer Board. If you wish to attend a Board Meeting, send us an email to receive login information at general.info@mesocietyedmonton.org

The M.E. Society of Edmonton Board Meetings are now held online! We meet from 1-3 PM, usually on the first Saturday of each month. Dates for our meetings are listed on our website, or contact us for further information.

Telus Internet for Good Now Available for People with Disabilities

"Having access to reliable internet is increasingly essential. But for people with disabilities, obtaining this connectivity can be a challenging. Internet for Good helps by offering low-cost internet connectivity to Canadians who receive the British Columbia Persons with Disability (PWD) benefit, the Alberta Assured Income for Severely Handicapped (AISH) benefit, or the Canada Pension Plan Disability Benefit (CPPD)."

"TELUS" Internet for Good program provides high speed at home only \$9.95 (plus taxes) per month."

Read more about this program on the Telus' website:

<https://www.telus.com/en/social-impact/connecting-canada/people-with-disabilities/application?linktype=subnav>

M.E. Association from United Kingdom

Looking for Survey International Participants



People that struggle with chronic illness know only too well what "isolation" is, let alone surviving through a pandemic! A person with CFS/FM dealing with isolation is often the norm, that is something the rest of the world has had to deal with through the Covid lockdowns or experiencing Covid. Particularly due to Covid 19 which creates even more fatigue, pain and many other symptoms. For those that can comprehend reading and research it gives us even more time on our hands to explore.

M.E. Association from the UK have been looking for international participants for a study on heart rate monitoring to avoid Post Exertional Malaise. If this interests you please check out this site:

<http://meassociation.org.uk/2021/10/physios-for-me-survey-on-heart-rate-monitoring-in-me-cfs/>

As a way of validation from "Health Rising" website, a persons experience that used both heart rate monitoring & heart rate variability protocols:

<https://www.healthrising.org/blog/2021/03/04/hannah-pacing-heart-rate-monitoring-chronic-fatigue-syndrome/>

Submitted by a fellow M.E. Society Board Member





Mary Fox Pottery



This is a story of pure "HOPE" and Resilience, especially when a person is dealing with M.E. / CFS. I first met Mary Fox in the Spring of 2021 in Ladysmith B.C.

I had just read an article of her newly released book "My Life as a Potter". She told me she was afflicted with M.E. in 1989. In her book, she tells the story that she and her friend Heather were heading out to the "Vancouver Folk Festival" in July 1989. They both became very sick with the worst flu ever, Heather couldn't walk and Mary could barely walk. For the next 6 weeks they were both flat on their back and housebound!

Mary, at the time was involved in her pottery and her work was being taken seriously, she had invitation to exhibit her work. Heather had been working at B.C. Tel at a temporary job, at the time. Heather wanted to go back to work but, Mary was concerned about her decision. Heather headed off in her car, twenty minutes later Mary got a frantic call! Heather had made it only two blocks and needed to be picked up, she had forgotten how to drive. She never left the house unattended again. The doctor was taken aback by what had happened to them. Their water supply was tested, they were advised to move out of their house for a couple of weeks to rule out environmental problems. Work was out of the question for both young women, both needed help with the simplest tasks. Friends helped with groceries and designed a plan to care for them. After a year of routine help, it was time to apply for home support.

Mary was horrified, she was 30 years old! Another year went by, it was time to apply for "Canada Disability Pensions". The worst financial hurdle was housing, as renting in Vancouver was expensive. Mary's father talked to the girls about scrapping up enough money to buy a miner's cabin in Ladysmith on Vancouver Island. They moved to their new home in 1991.

Sadly, Heather never recovered, she was very ill and needed Homecare. Eventually, Heather went into a Carehome and died in 2007. Mary remained devoted to her friend and also looked forward to her future, as a artist with determination to create! Through the years, Mary though still affected with M.E. was able to renew her interest in pottery & sculpture ... she works on a part time basis in her home / shop. The miner's cabin became her studio, as a inspirational artist. Today, her work is recognized internationally.

More information is available on Mary Fox Pottery website.

Long Covid Gains Official Recognition

"The World Health Organization's case definition aims to help doctors across the world to assess and diagnose long Covid. This was developed as a collaborative effort by key stakeholders, including both patients themselves as well as patients who are researchers, highlighting the importance of including those with a lived-experience of having had COVID-19 and the associated persisting condition. The illness effects more than 1 in 3 people who have had Covid 19 disease."

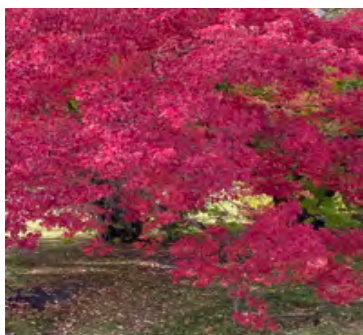
"Post Covid-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of Covid-19 with symptoms and that last more than 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have more impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from initial illness. Symptoms may also fluctuate over time." ... from the [World Health Organization](https://www.who.int/news-room/feature-stories/long-covid) website

Anzmes Press Release of October 8, 2021

"We hope that by having a clinician case definition, that more patients will be listened to, and taken seriously when they seek the medical care they so desperately need. It is incredibly distressing to hear that many of those that meet the criteria often give up seeking medical care due to being 'gas-it', or dismissed by their doctors.

This in part, may also be due to the similarities the Long Covid has with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS), another poorly-understood and often dismissed condition that can occur following viral infection. ME/CFS is also known as a sister disease to Long Covid. It is interesting to note, Long COVID can also occur following a breakthrough symptomatic infection. This seems to be a lost opportunity that would benefit not only those suffering from post COVID 19 condition - but, also those suffering with ME/CFS - who for many years have been out of the spotlight and largely ignored, despite their estimated numbers world wide being equivalent currently to the predicted to have post-COVID 19 syndrome - about 20 million people world wide ME/CFS is very briefly mentioned under the little-used name "Systemic Exercise Intolerance Syndrome", which has little public or even patient use"

October 8, 2021 Anzmes Media Release <https://anzmes.org.nz/category/news>



Open Medicine Foundation Ron Davis issues a statement on the NICE guidelines

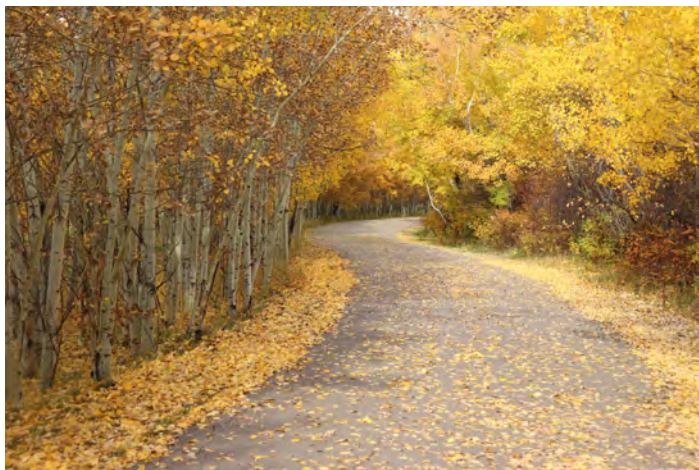
"People with ME/CFS are urging the National Institute for Health and Care Excellence (NICE) to publish finalized guidelines for ME/CFS that ensure accurate diagnosis, appropriate symptom management, and access to the best support available. However, medical Royal Colleges have informed NICE they will not implement these improved guidelines, and that graded exercise therapy (GET) will remain a recommended treatment, despite the evidence of this treatment harming people with ME/CFS.

Ronald W. Davis PhD, Chair of Open Medicine Foundation's Scientific Advisory Board, has issued a powerful statement regarding the detrimental pause of NICE guidelines: NICE has abruptly paused the publication of its new guidelines for ME/CFS, arguing that those who are treating patients need to agree with the guidelines. This is a false argument. Medical advice must follow the evidence and not personal beliefs or political positions. If doctors treating ME/CFS patients do not agree with evidence based guidelines, they shouldn't be treating patients. This is why we have guidelines.

When guidelines contain treatments that don't work, or are harmful, then the guidelines should be rejected. We must have faith that the guidelines are in the best interest of the patient. NICE has completed their objective scientific review. It's a travesty that NICE is being influenced by people with vested interest in maintaining their beliefs in treatments that have long been shown to lack evidence supporting them and have been shown to be harmful to patients. If NICE does not stick to their mission of unbiased evidence based guidelines, then it will lose its credibility.

It's time for the UK to join the rest of the scientific community and publish guidelines that are consistent with the evidence. Their influence is crucial, and every day that old guidelines stand, physicians all over the world continue to recommend inappropriate and harmful treatment for ME/CFS patients."

Update: The NICE guidelines for ME/CFS were finally published on Oct. 29, 2021



Funnies

And so it begins...

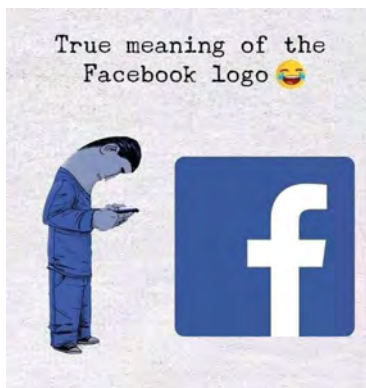


A duck was about to cross the
road when a chicken
looked at him and said....



"DONT DO IT MAN.... YOU WILL
NEVER HEAR THE END OF IT!"

True meaning of the
Facebook logo 😂



The word queue is
ironic.

It's just a 'q' with a
bunch of silent
letters waiting in a
line.

I finally remember what Zoom
meetings remind me of.



Christmas Hampers

We will be handing out Christmas Hampers to those in need this December. This year the hampers will include a gift card from Sobey's or Superstore. Please contact Kristine at kristine.miles@mesocietyedmonton.org or contact our office at 780-944-0809 before December 10th to reserve your Christmas Hamper.



RESOURCES

Here is a Canadian Government Page for People with Disabilities, providing Information about the various Services you can apply for. Maybe you can pull the information on this site apart under specific titles of each benefit available in a Newsletter sometime.

<https://www.canada.ca/en/services/benefits/disability>

M.E. Society of Edmonton

Phone: (780) 944-0809

#7, 11630 Kingsway Avenue NW Edmonton,
AB T5G 0X5

Hours: By appointment, only. Please call and
leave a message to schedule an appointment

(Closed July, August and holidays)

general.info@mesocietyedmonton.org

www.mesocietyedmonton.org



Annual Memberships

Memberships can be purchased at any time,
especially for newcomers!

Thank you for your support.

For more helpful resources
check out our website:

<http://www.mesocietyedmonton.org/resources.html>

Our office administrator is

Kristine Miles

kristine.miles@mesocietyedmonton.org

**Feeling hopeless?
Thinking about suicide?
Help is available 24hrs/7d a week**

Crisis Support Centre

Distress Line:

(780) 482-4357

Crisis Response Team:

(780) 342-7777