



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's 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 a similar struggle to you is often comforting. We hope you can join us!

We use "Go To Meeting" to host our online meetings. You can log in to our meeting 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. If you want more information about our Support Group, email us at

general.info@mesocietyedmonton.org

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

Saturday, March 20, 2021 1:00 PM – 3:00 PM (MDT)
Access Code: 735-525-277

Saturday, April 17, 2021 1:00 PM – 3:00 PM (MDT)
Access Code: 121-962-925

Saturday, May 15, 2021 1:00 PM – 3:00 PM (MDT)
Access Code: 329-783-405

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FOR EDUCATIONAL PURPOSES ONLY

Disclaimer: Our newsletter is published by the M.E. Society of Edmonton. It is a cooperative effort of volunteers. The Society's executive, board of directors, and newsletter editors do not accept responsibility, legal or otherwise, for the opinions and content of articles printed in their newsletter. We do not endorse any healthcare professionals, products, or medical treatments that may be mentioned in any of the articles and personal stories in our newsletters or at our meetings. They are provided to demonstrate the wide range of treatments that individuals have tried. Every individual has unique health concerns. It is recommended that anyone wishing to start/stop treatments mentioned in our newsletters do so under the close supervision of a healthcare professional.

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

International ME/CFS Awareness Day

On May 12th, the High Level Bridge in Edmonton will be once again be lit up in blue from 10 minutes before sunset until midnight! With so many Covid 19 restrictions in place around the world, the usual celebrations will be reduced.

Let's Celebrate as a community but keep it smart & apart, as recommended by the ME Association! This year we're encouraging everyone taking part to keep our celebration of "Florence Nightingale's" birthday safe & six metres apart. If you are house bound, think of blue ways to celebrate like ... make a blue cake, blue nails, blue hair or/and wear something blue that day! Dream up something you can do in the comfort of your own home!



Living with M.E. (ME/CFS) Education. Recognition. Hope.

What is it

- Education session for M.E. (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome). Developed and presented by *Patients Helping Patients*, a group of ME Patients with direction from Medical Advisor Dr. Eleanor Stein.
- Topics include signs & symptoms of M.E. (ME/CFS), strategies for symptom management, keeping hope alive and excellent resources.

Who Can Attend:

- Patients, Caregivers, Friends, Family and Healthcare Providers – ALL are welcome!

Where & When:

Online Presentations

2 Hours starting at: 11:00 am PT, 12:00 pm MT, 1:00 pm CT, 2:00 pm ET, 3:00 AT

Tues, April 20, 2021 Register at: <https://us02web.zoom.us/webinar/register/April>

Tues, June 15, 2021 Register at: <https://us02web.zoom.us/webinar/register/June>

Tues, September 28, 2021 Register at: <https://us02web.zoom.us/webinar/register/Sep>

Tues, November 9, 2021 Register at: <https://us02web.zoom.us/webinar/register/Nov>

Florence Nightingale Award – 2019

Anita Gonzales is the recipient of The ME Society of Edmonton “Florence Nightingale Award” for 2019. Anita has volunteered as an accountant for The ME Society since 2008. She quietly & patiently works in the background completing our fiscal year end, taxes and AGLC financial paperwork.

We are sincerely grateful for all the work she has done for The ME Society of Edmonton We would be lost without her help with our finances. It is an absolute delight to work with Anita.



M.E. Board Meetings

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.

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 the login information at general.info@mesocietyedmonton.org



From the Editor's Desk of Madness

Due to unforeseen circumstances, 2020 has been filled with a lot of trying times as we progress through the Covid-19 challenges!

In addition, our last dedicated newsletter editor has regrettably retired from duties and we are so grateful for job well done.

We are still searching for someone that could perform these duties on a full-time basis. If you are aware of anyone that could help out the ME Society, please let us know. It would be greatly appreciated. In the meantime, an interim board member is pitch hitting in an attempt to bring you a lifeline that so many of you need!

I also wanted you all to know that our office is still active but, on a much-reduced scale. We are here to give you all as much support as possible and to provide help to new members.

United States News

How COVID-19 Could Reveal the Secrets of Chronic Fatigue Syndrome

Columbia scientists say the pandemic may offer valuable insights.

By David J. Craig Fall 2020

Reprinted with Permission by "Columbia Magazine",
more articles available at <http://www.magazine.columbia.edu>

Physicians have seen it before: in the aftermath of a viral epidemic, survivors complain of a crushing lethargy, mental foggy, sleep difficulty, and muscle pain. Many are eventually diagnosed with myalgic encephalomyelitis, also called chronic fatigue syndrome (ME/CFS), a poorly understood condition that has no FDA – approved treatment and that often leaves people debilitated for life. It has happened after outbreaks of SARS, MERS, West Nile fever, Epstein-Barr viral infections, and Ebola. and now experts fear, it could happen again on a much larger scale with Covid 19.

Many people who have Covid-19 and recovered from their respiratory symptoms are now experiencing health problems that we often see in the early stages of ME/CFS says Mady Horning, a Columbia immunologist and an expert on Neurological disease

While it is too early to know how many COVID-19 patients may develop ME/CFS, past studies indicate that 10 percent or more of people who become seriously ill as a result of a viral infection may subsequently be diagnosed with the condition. If those numbers hold for COVID-19, Horning says, millions of people worldwide could be at risk.

"We could be looking at an unprecedented wave of ME/CFS over the next few years, with profound societal costs," says Horning, adding that an estimated three million Americans already suffer from the disorder. And yet with this crisis comes an opportunity: Horning and other ME/CFS experts see the pandemic as their best chance to date to investigate the physiological roots of the disease and develop treatments. ME/CFS which

usually occurs when a viral, bacterial, or fungal infection causes lasting damage to the immune, nervous, and metabolic systems, is often diagnosed years after the original infection, limiting researchers' ability to piece together how it develops and evolves. But now that a viral infection suspected of triggering ME/CFS is spreading so aggressively, scientists say they have an opportunity to conduct larger, more statistically powerful studies.

"This could help us determine exactly what is different about people who fully recover from an infection like COVID-19 and those who suffer lingering problems," says Hornig, who is an associate professor of epidemiology at the Mailman School of Public Health.

Hornig is now undertaking several studies that aim to identify risk factors for ME/CFS among COVID-19 patients and to lay the groundwork for new prevention and treatment strategies. In collaboration with scientists at the LA-based research and advocacy organization Solve ME, for example, she is planning to follow large numbers of people who have recovered from COVID-19 to find out how many develop the syndrome and, hopefully, why.

"One of the interesting things we've seen so far is that some COVID-19 patients who initially seem to be on the path to developing ME/CFS actually start to feel better after four or five months," she says. "We think that looking closely at these people and comparing them to others who eventually do get diagnosed with ME/CFS could yield valuable insights. Might there be something distinct about their immune systems that makes them resilient? That could be the kind of discovery that opens up new possibilities for treatment."

International News

COVID-19 Vaccine eligibility, safety and ME/CFS What we know so far ...

**By Dr Charles Shepard, Medical Advisor, ME Association
Reprinted with Permission December 10, 2020**

With the start of Vaccination against COVID-19 occurring this week, we are receiving queries about where people with ME/CFS will be on the priority list.

The joint Committee on Vaccination and Immunisation (JCVI) has produced a list of different groups of people in the order that they are going to be offered one of the new COVID-19 vaccines.

At the top of the list are people who are living and working in care homes, health workers, the very elderly (i.e. those over 80 years of age) and people who are extremely vulnerable to COVID-19 - because they have a very significant risk of developing serious or life-threatening complications if they catch COVID-19. Which is fair enough....

And while anecdotal evidence that people with ME/CFS are likely to suffer an exacerbation or relapse of their ME/CFS symptoms if they catch COVID-19, there is no evidence to indicate that they are at significantly increased risk of developing serious or life-threatening complications.

So, it will be an uphill struggle to get ME/CFS onto the very high priority list. There is then a group of people with what are termed by the JCVI as having underlying health conditions that also make them vulnerable in relation to COVID-19. This list includes people with chronic neurological conditions. ME/CFS should be included in the

'underlying health conditions' list – as it is classified as a neurological disease by both WHO and NHS England; HERE. And COVID-19 will almost certainly exacerbate pre-existing ME-CFS symptoms or cause a relapse of ME/CFS.

However, it looks as though people on this list will only become high priority once the over-65 age group has been vaccinated. So, it seems unlikely that people below the age of 65 will be offered a COVID-19 vaccine until March or April next year – but it could be sooner if supplies of the Oxford/Astra Zeneca vaccine are approved and released.

We will continue to update you on what is happening in relation to all aspects of COVID-19 vaccines and ME/CFS. In the mean time there is no point in contacting your GP to see if you can have a COVID-19 vaccine – unless you in one of the high priority groups who are going to be given the vaccine over the coming weeks.

How safe are these COVID-19 vaccines for people with ME/CFS?

The safety data so far on all three vaccines indicates that they all have a potential to cause short-lived side-effects- i.e. sore arm, fatigue, slight fever – that are found with any other vaccine.

There is no indication at present of any serious side-effects with any of these vaccines. However, two cases of transverse myelitis have been reported in relation to the Astra Zeneca vaccine.

So as the other vaccine, it is possible that COVID-19 vaccines will also cause a temporary exacerbation of flu-like ME/CFS symptoms. And there is also a possibility that they could trigger a more significant exacerbation of ME-CFS symptoms.

At present, we have no data from the clinical trials as to happens to people with ME-CFS with any of these vaccines – and I suspect that nobody with ME/CFS has taken part in any of the clinical trials. This is data that is only going to come from patient evidence once people with ME/CFS start having the vaccine in 2021 So everyone is going to have to make a personal judgement that involves:

1. A definite risk of some ME/CFS symptoms being exacerbated
2. A much lower risk of a more significant exacerbation of ME/CFS symptoms
3. The possibility that once very large numbers of people have been vaccinated, we will learn about some rare but serious side effect
4. A fairly high degree of protection from COVID-19 in return for taking these risks.

Life is full of risks and on a personal basis I will almost certainly be having a COVID-19 vaccine when I become eligible in 2021.



Funnies

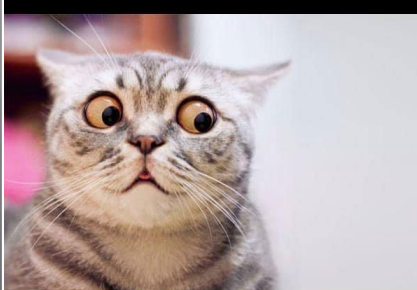
The longer I stay home, the more homeless I look

Don't get me started, my brakes went out a long time ago.

I'm bored of being bored.



The stupid moment when you have your pill bottle in front of you but you can't remember if you already took it or not.



Monday Morning after Daylight Savings starts



When I was a child, I thought nap time was a punishment,



Now as a grown up, Nap time feels like a Vacation.

Blursday

noun

Because you never know what day it is.

When you realize
2020 is followed by 2021
2020 won...



WALKING PAST PEOPLE



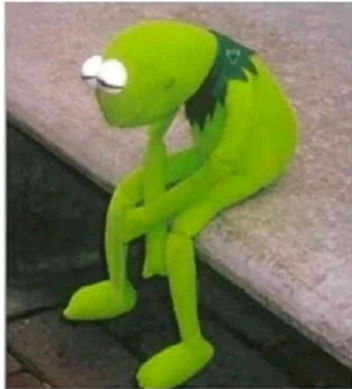
IN THE GROCERY STORE

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>

I feel like I am already tired tomorrow.



M.E. Society of Edmonton

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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