



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. These meetings are offered free of charge, and you do not need to sign up or register, just drop in and join us for the afternoon.

Please refrain from wearing scented products.

Support Group Meetings are held on Saturdays at the **Central Lions Senior Recreation Centre**. This facility at 11113 -113 Street is handicapped accessible and has plenty of free parking. In severe weather, please call the office at 780-944-0809 and listen to the message to check for cancellations.

Saturday, March 16 (1-3 pm)

Topic: Socializing While Ill

Saturday, April 20 (1-3 pm)

Topic: Coping with Limited Energy

No support group in May

(May 11 - Retirement Party)

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Photo by E. Jolicœur

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.

Upcoming Events and News

Retirement Party

Saturday, May 11
1-3 PM
Central Lions Senior Recreation Centre
(11113 - 113 Street)

Please join us for the afternoon to help us thank John Wodak for his years of service.

If you would like to write a letter of "thank you" to John, please email it to michele.schuler@mesocietyedmonton.org subject "JOHN WODAK". We will be printing each of them out on nice paper and compiling into a keepsake book for him.



ME/CFS Information Session Facilitators Needed

Workshop facilitators are needed to assist with local ME/CFS Information Sessions. Training will be provided. Position Requirements:

- 5-10 years of workshop facilitation experience
- Life skills certificate, BBA, and/or equivalent education/training
- Excellent communication skills
- Experience with Google Docs, GoToMeeting, PowerPoint, Word, email and texting
- Must have ME or live with someone with ME
- Available for the occasional weekday information session - usually scheduled from 12:30-2:30 or 1-3 pm.

If interested, please send resume and contact information to Judy-Anne Wilson, Education and Awareness Coordinator, ME Society of Edmonton - JudyAnne.Wilson@mesocietyedmonton.org

Office Administrator Position News

We have had another change in the office! Susan decided to leave shortly after hiring, but we were fortunate enough to have Michele Schuler join us. Michele lives in Mundare and started Feb. 20.

Her previous experience with non-profit boards and processes with funding from Alberta Gaming will provide excellent support to the Board.

Welcome Michele!



Photo by E. Jolicoeur

Board Meetings

Board meetings of M.E. Society of Edmonton are open to the public, so everyone is invited and welcome to attend.

Meetings are held in the Conference room, please note that we are not wheelchair accessible. We are located in the Adtel Building at 11630 Kingsway Avenue NW, Edmonton.

We meet from **1:00-3:00 p.m. on the first Saturday of each month.**

Please consider attending. Contact our office at 780-944-0809 or michele.schuler@mesocietyedmonton.org to arrange and be advised of any changes.

In consideration of attendees with chemical sensitivities, please do not wear any scented products to our meetings.

An Important message from Diane Ching, President of the M.E. Society of Edmonton (CFS)

At the end of June 2019, **I will be stepping down as president** of the M.E. Society. I have been on the board since 2007; 2 x 2 years stints as president, 1 year as past president and 8 years as secretary. Serving as an executive board member carries responsibilities and at times, can be stressful. After twelve years, it is time for me to step aside and focus on my own health. I passionately believe in the mandate of the M.E. Society and the good work it has done and continues to do. **In order for the Society to progress into the future, I would like to apprise you of the current state of the board.**

We desperately need new Board members if we are to continue next year.

Our current Board is comprised of dedicated volunteers:

Lynn – joined 2007; Support Group Coordinator; will continue as regular board member

Helga – Board member for over 25 years (turns 80 this year)

Judy-Anne – joined 2014; Treasurer and Education; stepping down from Board to focus on M.E. Education

Gabe – joined 2017; now returned to work f/t

Chuck – previous president/vice president; not returning; remains our office IT consultant

Jan – joined 2016; health prevents her from participating fully

Karen – joined 2017; Secretary but health prevents her from participating fully

About the Board:

- A minimum of 6 Board meetings held each year; attend in person or via the web; 1st Saturday of each month; no meeting in January, July or August; requires Police record check
- Term limit for President is 2 years; prevents burn out; keeps things fresh
- *Only* Executive members can be signing authority on cheques (two to sign)
- Executive members: President, Vice-President, Secretary, and Treasurer
- Executive positions can be job-shared (except Treasurer and Past President)
- Treasurer position is minimal, office administrator does bookkeeping, we have a volunteer accountant
- Regular Board members attend meetings, read reports and help make decisions

Planning for Succession

- In existence for 35 years because of a long line of individuals that have volunteered for a time.
- Offering to serve should not be a life long commitment. The Society is more than one or two people, and requires a continual injection of new Board members to learn the processes to stay viable.
- We all have health issues that we try to balance with our Board duties.

What will be lost if we do not have Board members next term?

- Website/Facebook/Newsletter
- Support groups
- Personal point of contact for information (books/booklets/brochures/information)
- Social events and Christmas hampers
- Funding for an advocate to assist with AISH, CPP-D applications and tribunals
- Financial support for education program currently being delivered through “Alberta Healthy Living”
- Financial support for National ME/FM Network
- Efforts to incorporate ME/CFS in curriculum at U of A medical school, and encourage and support research of ME/CFS at the U of A

No Board = No Funds = No Society

Contact us if you are able to serve or have any questions. Executive Board members are elected at the Annual General Meeting in June. Regular Board members may join at any time.

Canadian News

Dr. Eleanor Stein has posted February 2019 and December 2018 newsletters at <http://eleanorsteinmd.ca/newsletters/>

Margaret Parlor, President of the National ME/FM Action Network, reports that on December 13, 2018, Member of Parliament Anita Vandenbeld made a very powerful statement recognizing the difficulties facing the ME/FM community in Canada. You can watch it at: <https://youtu.be/kyhA5qyu54M> or on her Facebook page. (Feel free to let her know how good it feels to be recognized at: anita.vandenbeld@parl.gc.ca.)
<https://www.facebook.com/AnitaVandenbeldMP/videos/1032484150295348/>.



United States News

The National Academy of Medicine has announced an art contest around the theme of health equity. It is open to people aged between 5 and 26 <https://nam.edu/programs/culture-of-health/young-leaders-visualize-health-equity/>

The Open Medicine Foundation has announced a contest focusing on poetry and art for ME/CFS. You can submit, and you can view and vote on the submissions at <https://www.omf.ngo/poetry-submission/>

Elizabeth Unger, MD, PhD, posted a CDC Expert Commentary on Medscape on February 25 "Chronic Fatigue Syndrome: It's Real, and We Need To Do Better".
<https://www.medscape.com/viewarticle/908622>

Cort Johnson put together a summary of ME/CFS on Health Rising on Dec 10, 2018, called "The Basics: A Guide to Learning, Sharing and Making a Difference in Chronic Fatigue Syndrome (ME/CFS)". <https://www.healthrising.org/blog/2018/12/10/the-basics-a-guide-to-learning-sharing-and-making-a-difference-in-chronic-fatigue-syndrome-me-cfs/>

A video (12 min) with David Kaufman MD is available (Oct 16, 2018) on Diagnosis and Management of Myalgic Encephalomyelitis and Chronic Fatigue Syndrome at:
https://www.youtube.com/watch?v=RC9TjgE_PIU&feature=youtu.be

Charles Lapp MD published a good article (free) that introduces primary care physicians to the unique and challenging aspects of initially diagnosing and managing ME/CFS called "Initiating Care of a Patient With Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)". *Front Pediatr.* 2019;6:415. Published 2019 Jan 23,
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6357921/>



International News

For the latest news from around the world, check out <https://www.meaction.net/news/>

The ME Association in the UK had released a free high-quality Factsheet and Research Summary in their quicklinks section of their home page at <https://www.meassociation.org.uk/>. They also have new videos weekly on their MESHown <https://www.meassociation.org.uk/themeshow/>

The December 22 issue of the ME Global Chronicle is available at <https://let-me.be/download/48/>

ME/CFS Alert posted a new video, Episode 103 called Inflammation, Neural Function and ME/CFS with Ronald G. Tompkins, M.D., Sc.D. on Jan. 14 (24 min). <https://www.youtube.com/watch?v=3VPFJsNJS88>

There was a debate on ME in the UK House of Commons on January 24, 2019. For more information see <https://www.meaction.net/2019/01/25/historic-parliamentary-debate-shaped-by-people-with-me/>

From New Zealand, the ANZMES group released a summary on Dec. 17 of the National Centre for Neuroimmunology and Emerging Diseases CFS/ME International Conference in November in Queensland, Australia: <https://anzmes.org.nz/>.

At that conference, Stafford Fox Medical Research Foundation announced the funding of two full Professorial Research Fellowships for four years (<http://bit.ly/2QtbVtv>). The fellowships, worth \$2 Million, are for the advancement of biomedical and clinical research into the treatment of Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME).



Disability and Taxes: Gaining Certainty on Tax Credits and Deductions

By James McKenzie. This article originally appeared on Action CIND at <https://www.actioncind.org/> Sep 15, 2018.
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Have you ever heard of the Disability Tax Credit (DTC)? If you are suffering from a long term disability, or are caring for someone who is, chances are you have. And if you've ever tried applying for this particular benefit, you probably know how tedious and frustrating the process can be. So it's no surprise that only forty percent of Canadians with severe disabilities have successfully claimed the Disability Tax Credit. Other reasons include: low awareness of the tax credit, a complicated test, and the exclusion of many types of disabilities such as mental disabilities. Also, many medical practitioners do not understand the criteria or application process.

So Why Apply?

Despite the challenges surrounding the application process, you can benefit a lot from the Disability Tax Credit. Some of these benefits include: a reduction in your household's tax burden, more disposable income, and access to other government benefits such as the Registered Disability Savings Plan. In this article, we will break down the application process as well as the qualification criteria.

Activities of Daily Living

One of the biggest criteria for determining whether you qualify for the Disability Tax Credit is your level of restriction in activities of daily living. Applicants must be markedly or significantly restricted in at least one or two of the basic activities of daily living respectively. These activities are: speaking, hearing, walking, eliminating (toilet use), feeding, dressing and mental functions necessary for everyday life. People who are blind or need life sustaining therapy may also qualify. Whatever your impairments are, they must be prolonged (at least 12 months) and be present 90 percent of the time.

Markedly Restricted vs Significantly Restricted

People are considered markedly restricted if they take an inordinate amount of time to perform an activity of daily living. This is usually three times the average time taken by someone without the impairment. People who are significantly restricted cannot perform at least two activities of daily living even with the appropriate therapy, devices or medication at least 90 percent of the time.

It is imperative that you prove your restriction in the application process, because this is the main criteria for qualification. It should be noted that the cumulative effect of at least two or more significant restrictions can be the equivalent to being markedly restricted in one activity of daily living.

If you are on life sustaining therapy, the therapy must support a vital function and must be undertaken at least three times per week for at least fourteen hours. Note that the fourteen hours does not include activities prior to and after the therapy, such as travel time. Also, the therapy must take time away from everyday activity.

The Application Process

The Disability Tax Credit application form is known as the T2201 and is available on the CRA website. The form is divided into part A and part B. Part A is to be completed by

the applicant or tax payer. The applicant must provide details on the person with the disability as well as the claimant (if different from the person with the disability). If you are completing the form on behalf of the person with the disability, then you must specify your relationship with that person as well as detailed information how you provide regular and consistent support to the said person.

Part B (pages 2-5) must be completed by the medical practitioner (usually a doctor or nurse). However, the said medical practitioner can complete the entire form. If your medical practitioner is someone other than a nurse or doctor, then he/she may only complete parts of the form that are relevant to their field of expertise. Practitioners other than a nurse or doctor who are qualified to complete the form are: optometrist, occupational therapist, audiologist, physiotherapist, psychologist and speech-language pathologist. You or your medical practitioner can attach additional sheets if needed.

Send the completed T2201 to the Disability Tax Credit Unit of the tax centre for your region by mail. The mailing address can be found on page 6 of the form. You must send the original signed copy (so be sure to keep another copy for yourself).

You've Applied, So Now What?

Once the CRA has received your application they will notify you of their decision. Should they require additional information they will contact you or your medical practitioner. The CRA will send you a notice of determination which informs you whether you have been approved or denied. If you are approved, the notice will specify what year (s) you are eligible for the Disability Tax Credit. Unless requested to do so, you do not need to submit an application to the CRA every year. You will also be informed about other programs you are eligible for. If your condition improves, you must notify the CRA.

If your application is denied, the determination form usually provides a reason for the denial. If you disagree with the decision, you can write to the tax centre to ask them to review their decision. It is recommended that you consult with your medical practitioner before writing the letter. Be sure to refer to the information you put in your original application (this is where the copy comes in handy) if it contradicts the reasons given for the denial. Alternatively you can file an appeal with the Tax Court of Canada within a period of 90 days. Be aware that due to a backlog of cases facing the Tax Court the process can be lengthy.

Applying for the Disability Tax Credit can be a tedious and frustrating process, but for those who qualify it is worthwhile. In order to save you (and others) time and effort, you should do your best to determine whether or not you qualify before you begin the application process. If you feel your personal circumstances make you eligible then you should apply. Good luck!

If you have any questions, concerns, or would like to share your personal experience with the application process, please reach out to us at info@actioncind.org.

Massage, Yoga, and More

The web site /blog at: <https://www.verywellhealth.com/fibromyalgia-and-chronic-fatigue-4014724> called "Very Well Health" has posted a number of articles over the past year summarizing a number of integrative therapies and forms of gentle exercise or movement for ME/CFS and fibromyalgia, including:

Massage, Rolfing, and Other Bodywork for Fibro. <https://www.verywellhealth.com/massage-rolfing-other-bodywork-715645>

Does Myofascial Release Work for Fibromyalgia? <https://www.verywellhealth.com/myofascial-release-for-fibromyalgia-715642>

Does Cupping Bring Relief for Fibromyalgia? <https://www.verywellhealth.com/cupping-for-fibromyalgia-4072097>

Acupuncture for Fibromyalgia <https://www.verywellhealth.com/acupuncture-for-fibromyalgia-does-it-work-715649>

Acupuncture for Chronic Fatigue Syndrome <https://www.verywellhealth.com/acupuncture-for-chronic-fatigue-syndrome-715648>

Yoga for Chronic Fatigue Syndrome (CFS) <https://www.verywellhealth.com/yoga-for-chronic-fatigue-syndrome-715790>

Pilates for Fibromyalgia and CFS <https://www.verywellhealth.com/pilates-for-fibromyalgia-chronic-fatigue-syndrome-715779>

Tai Chi for Fibromyalgia and CFS <https://www.verywellhealth.com/tai-chi-for-fibromyalgia-chronic-fatigue-syndrome-715780>

The Benefits of Yoga for People With Fibromyalgia <https://www.verywellhealth.com/yoga-for-fibromyalgia-715782>

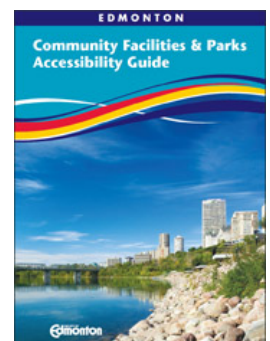
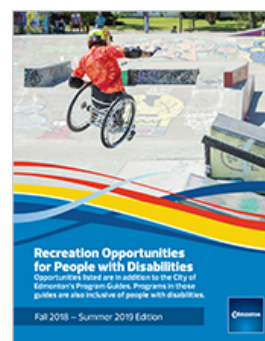
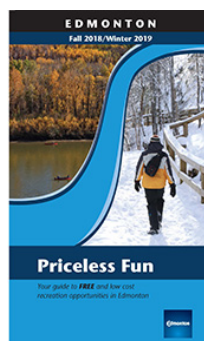
Qigong for Fibromyalgia and CFS <https://www.verywellhealth.com/qigong-for-fibromyalgia-chronic-fatigue-syndrome-715788>

Note for those with limited or no insurance benefits, you can get student massages at reduced rates, at <https://makamicollege.com/student-massages>, <https://acmt.ca/student-clinic/student-clinic-bookings/>, <https://www.macewan.ca/wcm/SchoolsFaculties/HCS/Programs/MassageTherapy/MassageClinic/index.htm> and others. Note that Makami College will soon be relocating from Capilano Mall to Bonnie Doon Mall.

There are booklets with information about recreation activities in the Edmonton area that may be useful, such as "Priceless Fun (Your guide to FREE and low cost recreation opportunities in Edmonton)" and "Recreation Opportunities for People with Disabilities". You can pick up copies at your local library, or online at: https://www.edmonton.ca/activities_parks_recreation/program-guides.aspx.

The City of Edmonton **Leisure Access Program** allows eligible low-income Edmontonians to access participating City of Edmonton recreation facilities and attractions through a (free) annual pass or a subsidized monthly pass. You can find more information at <http://www.edmonton.ca/lap> or by calling 311. Applicants are automatically considered for the Ride Transit Program as well, for discounted transit passes.

Do you have a favourite location in the Edmonton area that is a peaceful place to recharge and feel better? Let us know at newsletter@mesocietyedmonton.org and we'll try to feature it in our upcoming issues.



I know I don't have to be sarcastic, but the world has given me so much material to work with ... I would hate to be wasteful.

Happiness is using an ATM and finding a receipt left by someone with an account balance lower than yours.

The trouble with living alone is that it's always my turn to do the dishes.

I have way more conversations in my head than I do in real life.

I'm not sure if life is passing me by, or trying to run me over.

I want to be 14 again and ruin my life differently. I have new ideas.

I've been hiding from exercise. I'm in the fitness protection program.

I'm multitasking ... I can listen, ignore and forget all at the same time.

Dealing with vertigo is about as relaxing as showering with cats.

Somebody told me I'm horrible with names.

I got called 'pretty' today! Well actually, the full statement was "You're pretty annoying" but I only focus on positive things.

I had my patience tested. I'm negative.

**PRESUMABLY GOOD AT
HELPING PEOPLE STAY ALIVE**



How you view that one medication that finally works for you after years of trial and error



I despise spelling errors. You mix up two letters and your whole post is urined.

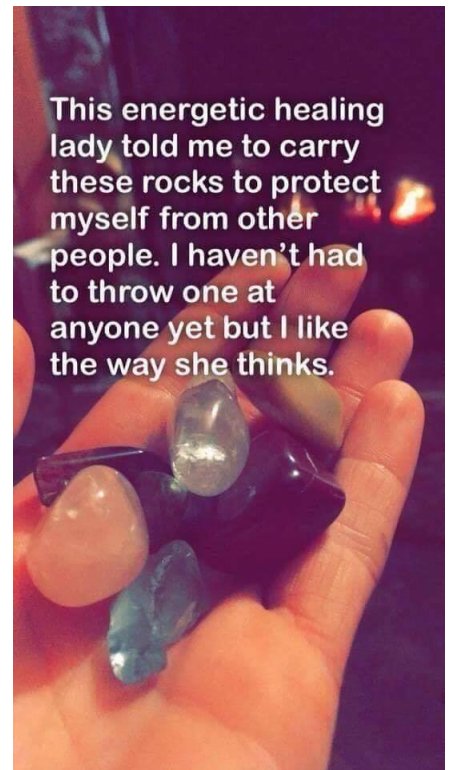
I thought there was a bug on the floor, but it was just some yarn. It's dead yarn now, though.

If you're arguing loudly on your phone in public, please put it on speaker; I need to hear both sides of the story.

It's important to be thankful for the little things in life. Like the fact that farts don't poof out in colourful clouds.

Isn't it funny how I don't look sick and you don't look dumb?

This energetic healing lady told me to carry these rocks to protect myself from other people. I haven't had to throw one at anyone yet but I like the way she thinks.

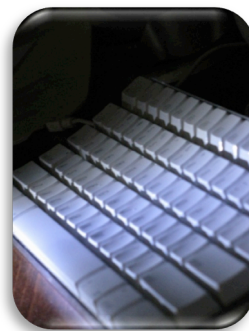


RESOURCES

Tax return assistance

If you need help completing your Canadian income tax return and you cannot afford an accountant or commercial income tax preparation service, take advantage of free tax clinics offered by the Canada Revenue Agency. Trained volunteers can help you with your taxes if you have a straightforward income tax return and your income is low. The program has basic eligibility requirements so check with the individual clinic.

<https://www.canada.ca/en/revenue-agency/services/tax/individuals/community-volunteer-income-tax-program/need-a-hand-complete-your-tax-return.html>



Disability deductions and credits

Find information on the most common deductions and credits that can be claimed for someone with an impairment in physical or mental functions. This includes yourself, your spouse or common-law partner, and other eligible dependants. (Note that criteria changed last year (2017 tax year) making it easier for caregivers to claim tax credits in Alberta).

<https://www.canada.ca/en/services/taxes/income-tax/personal-income-tax.html>

Check out: Disability Deductions and Credits, Services and information section

https://www.canada.ca/en/revenue-agency/services/tax/individuals/topics/about-your-tax-return/tax-return/completing-a-tax-return/deductions-credits-expenses/disability-deductions-credits.html?fbclid=IwAR1nb240pte_RVrYvS-b3SBZVjFMY6JpNpoywtDO72GkqhLP6HO99kt54Uk

As well as: What can persons with disabilities claim as a deduction or credit?

https://www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/what-persons-disabilities-claim-a-deduction-credit.html?fbclid=IwAR3jnRUuYyNHNDIH8AeJTjKDgTNzeD-oMaJFMyr3Lm_hgMR0umWqDhf19j4



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:

www.mesocietyedmonton.org/resources.html

Our new office administrator is

Michele Schuler

michele.schuler@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**