NATIONAL ME/FM ACTION NETWORK
SINCE 1993

Quest
Newsletter

www.mefmaction.com
Quest 140, Winter 2024
mefminfo@mefmaction.com

Dear Friends

There are many special people with ME/FM in Canada. We lost one of them in December, Teresa Craig Morgan. The cause was a heart valve issue that had not been detected. Yes, there were symptoms, but it was easy to assume that the symptoms were part of her ME/FM condition.

Our best wishes go out to her husband Ken Morgan. Ken travelled the ME/FM road with Teresa for many years. Ken is an illustrator and put Teresa's experiences into a poster which we are including on page 5. Ken wants us to share the following message with you:

If you have unexplained symptoms, do not assume that they are part of ME/FM. Get them checked out.

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We heard from another special person who was having problems with her medication but did not realize for quite a while that her medication was the cause of her problems. She wants to share the following message with you:

If you get a new medication or a change in your dosage, talk to your doctor and pharmacist about what it is supposed to do, what the side effects might be, and what is the best way to take the medication. Check back with you doctor and pharmacist from time to time because there could be new information about the medication, new alternatives to the medication, or new factors to consider.

Contents

2024 Federal Budget Submission

Every year, the federal government asks the public what it would like to see in the budget for the next fiscal year. When we think of budgets, we think of a ledger sheet full of figures. But behind the government's ledger sheet are documents from their departments and agencies describing their plans and priorities for the fiscal year. We want some departments and agencies to be thinking hard about ME and FM in the next fiscal year. This includes Health Canada, the Public Health Agency, Canadian Institutes of Health Research, Social Development, and Statistics Canada. Here is what we wrote.

January 10, 2024
To: Budget2024@fin.gc.ca

Including Health and Disability Issues Experienced by Canadians with ME and FM in Canada's 2024 budget

The National ME/FM Action Network has been working on behalf of Canadians with Myalgic Encephalomyelitis (also referred to as chronic fatigue syndrome) and Fibromyalgia since 1993. Nearly 1 million Canadians had a diagnosis of one or both conditions in 2019. Most were of working age. Most were women. ME and FM are frequently triggered by infection so we are expecting a surge in new cases as a result of Covid.

The health and disability systems have not paid attention to ME and FM for decades. This has resulted in poor health outcomes. People with these conditions have unnecessarily high rates of distress, seen in variables like unmet health care needs, poverty, food insecurity and social isolation. This has also resulted in the health and disability systems being unprepared for the Covid related surge in cases. Everyone deserves better.

To address gaps in the health and disability systems, we recommend that the following items be included in the government's plans and priorities for the 2024-25 fiscal year:

- Make up-to-date health information about ME and FM available on government websites. If ME and FM are on the Health Canada website, they are extremely well hidden. Out of about 250 health conditions on the Public Health Agency of Canada website, ME is the only condition whose information is labelled as "archived".
- Make statistical information about ME and FM available to the public so that policy issues can be identified and discussed.
- Provide fair funding for ME and FM research, taking into account the burden of illness and the many years of neglect.
- Implement the Canada Disability Benefit to address the very serious issue of working-age disability poverty. Develop fair, inclusive eligibility criteria for the Canada Disability Benefit before it is introduced.
- Review the disability statistics program in time for the 2026 Census and the 2027 Canadian Survey on Disability.
- Review disability training programs for public servants to ensure that all types of disability, including chronic disabling illnesses, are covered.

copies to the ministers responsible for health, disabilities and Statistics Canada

Canada Disability Benefit Submission

We discussed the proposed new Canada Disability Benefit in our last newsletter. The CDB would make payments to low-income working-aged people with disabilities. The government is now starting to write the regulations and has asked for input from the disability community. The National ME/FM Action Network made the following submission.

Submission to the Consultation on the Canada Disability Benefit Act regulations

By the National ME/FM Action Network (mefminfo@mefmaction.com)

On behalf of persons with Myalgic Encephalomyelitis (ME) and/or Fibromyalgia (FM)

Date: December 9, 2023

Thank you for the opportunity to comment on the Canada Disability Benefit Act regulations.

There were an estimated 125,000 working age people with family income below $20k who had a diagnosis of ME (chronic fatigue syndrome), FM or both, according to the Canadian Community Health Survey 2015/16.

The National ME/FM Action Network was founded in 1993. Over the years, we have become very familiar with working-age disability poverty. ME and FM often strike people when they are young or of working age and they often interfere with the person's ability to pursue substantially gainful employment, leaving many in poverty. We are pleased that working-age disability poverty is getting attention. It is a very serious issue.

We have looked at the legislation. We have written about the CDB in our latest newsletter, Quest 139. Our president was a speaker on a webinar organized by Osgoode Professional Development.

We have identified three high-level issues:

1. What is meant by disability? Too often, disability criteria leave out people with ME, FM or both. This program is extremely important for our people. Please ensure that they are not left out of it.
2. How much money is involved? Funding should be allocated in the 2024-25 federal budget so that this poverty is addressed quickly. Therefore, estimates need to be developed as soon as possible.
3. How does this program fit in with other financial support programs? A very real concern is that other programs will claw back the income or will charge more for their services.

It is necessary for these issues to be resolved to guide the development of the regulations.

Letter to Mnister of Health - Addressing Long-COVID

January 19, 2024

To: The Honourable Mark Holland, Minister of Health
hcminister.ministresc@hc-sc.gc.ca

Re: Addressing Long-COVID

The joint Statistics Canada / Public Health Agency of Canada report cited below made a number of findings about the long-term effects of COVID-19. As of June 2023:

- 2.1M Canadian age 18+ were experiencing long-term symptoms following COVID-19.
- 49.7% of them said that they had not seen any improvement in symptoms over time.
- Fatigue and brain fog were the most reported symptoms.
- About 14.5M days of work or school have been missed by Canadians age 18+ due to long-term symptoms following COVID-19.
- About 100k Canadians age 18+ have been unable to return to work or school because of their symptoms.
- Only 1 in 8 Canadians age 18+ who sought help for their long-term symptoms felt they received adequate care.

The report concludes that: “Considering these findings, protection against COVID-19 infections including reinfections and the development of long-term symptoms is paramount.”

That is a good suggestion but it does not help people who already have long-term symptoms or the people who will develop long-term symptoms in the future. These people need help and Canada needs their contributions.

Our organization has been working on the topic of post-infectious illnesses for three decades. Our advice is to build on the work currently being done around Myalgic Encephalomyelitis.

ME (which is often referred to as chronic fatigue syndrome) is often acquired following infection. A number of different infectious agents have been found to trigger ME. Symptoms of ME include fatigue and brain fog - the two most reported long term symptoms following COVID infections.

Despite a lack of support from the health and disability systems over recent decades, a top-class international ME community has formed with expertise in research, clinical care and disability issues. It is from this community that many of the long-COVID answers are likely to emerge. But the ME community needs your support to make this happen.

We would be pleased to meet with you or your staff to discuss how to move forward. We would like to see these ideas reflected in the 2024-25 plans and priorities of the health portfolio.

Margaret Parlor

President

Copies to Deputy Minister - Health Canada, President - Public Health Agency of Candada, Chief Public Health Officer, Acting President - CIHR

See “Experiences of Canadians with long-term symptoms following COVID-19”
published December 2023 by Statistics Canada and the Public Health Agency of Canada.
https://www150.statcan.gc.ca/n1/pub/75-006-x/2023001/article/00015-eng.htm

Some of the effects of

Myalgic Encephalomyelitis (M.E.)

sense of purpose

taking a walk

a social gathering

a doctor's appointment

self esteem

circle of friends

M.E. *steals your quality of life*

Poster by Ken Morgan

The WASF3 Protein

The US National Institutes of Health was studying a rare genetic cancer. One women with the cancer had ME/CFS while other members of the family did not. This led the NIH researchers down some interesting paths.

Medical News Bulletin, a Canadian online magazine, reached out to us for comment on this fascinating story. We are pleased to reprint their article, with permission.

The story was originally posted here:
https://medicalnewsbulletin.com/nih-scientists-discover-biological-basis-for-me-cfs-symptoms/

You can also see related articles here:

Full explanation of the research paper
https://medicalnewsbulletin.com/journal-club-wasf3-disrupts-mitochondrial-respiration-and-may-mediate-exercise-intolerance-in-myalgic-encephalomyelitis-chronic-fatigue-syndrome/

Interview with the Principal Investigator
https://medicalnewsbulletin.com/ask-the-expert-the-me-cfs-mystery/

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Medical News Bulletin - NIH Scientists Discover Biological Basis for ME/CFS Symptoms

Andrea Romeo RN BN

A new study published in Proceedings of the National Academy of Science sheds some light on the role of a protein that may prevent ME/CFS patients from generating normal amounts of cellular energy.

A Medical Mystery

ME/CFS has no known cause and is not well understood, even by medical professionals. The condition is characterized by extreme fatigue and the inability to recover normally after exertion. Symptoms can last for years and include neurological concerns such as dizziness, memory problems, and difficulty concentrating. Many sufferers are unable to return to work or perform normal daily activities the way they did before becoming ill.

This medical mystery may be closer to being solved thanks to scientists from the U.S. National Institutes of Health (NIH) and their investigation into the WASF3 protein.

A Plea for Recognition

ME/CFS often arises following a viral infection such as flu or a respiratory virus. It is unknown why some people never fully recover from the initial infection and go on to develop the long-term symptoms of ME/CFS. There is no medical test for ME/CFS. Doctors can only diagnose ME/CFS by systematically ruling out other possible causes, a process that can sometimes take months or even years.

Adding insult to injury, many doctors have historically misunderstood ME/CFS--even doubting its existence entirely. Routine tests often come back normal, and many sufferers have had their symptoms dismissed by healthcare providers as being “all in their head”. For decades, physicians prescribed psychotherapy or exercise programs that were inappropriate or actively harmful to their condition.

Advocates have struggled for many years for better recognition of ME/CFS in the international medical community. The U.S. Institute of Medicine finally acknowledged ME/CFS as a physical illness in 2015 and made recommendations to standardize the way it is diagnosed. These criteria were adopted in the U.S., but other countries have been slower to get on board. The UK, for example, did not officially recognize ME/CFS until 2021.

Speaking Out

Margaret Parlor, president of the Canadian advocacy group, The National ME/FM Action Network, told us “Society in general, and the health and social service systems in particular, have been reluctant to acknowledge ME. This attitude has tremendous consequences for people who are genuinely energy impaired, and who often do not receive the respect they deserve and the support they need. They may not receive quick and accurate diagnosis and advice which can lead to worse outcomes. Anecdotal and statistical evidence shows that they are dealing frequently with issues like poverty, food insecurity, and social isolation.”

“Kerri”, a British woman living with ME/CFS, explained to Medical News Bulletin that she had to leave university and was bedridden for two years after developing the condition. She shared how her illness is often dismissed as a psychiatric issue, “You see a change in the doctor’s approach as soon as you mention ME. There is a huge bias in the medical community, and we are in a fight against that every time we need to seek treatment.”

This slow adoption of new information by government and medical institutions has had a material effect on the quality of life for ME/CFS patients, and support for research.

New Clues

The hallmark of ME/CFS is post-exertional malaise. It is normal to feel tired after exercise, but healthy people regain their energy with rest. In contrast, people with ME/CFS experience an extreme and abnormal inability to recover after exercise. You could say they run down their batteries and can't recharge them.

Dr. Paul Hwang, who led the study, and his team uncovered an important clue as to why people with ME/CFS can't refill their batteries. They found abnormal amounts of a protein called WASF3 in the mitochondria of patients with ME/CFS.

Known as the "powerhouse of the cell", mitochondria create energy for every cell in the body by converting oxygen and glucose into a molecule called ATP. When your muscles work, they use ATP as fuel to make each muscle cell contract.

If you can't make ATP in large quantities and fast, you don't have enough fuel to operate your muscles, so you feel weak or tired.

Dr. Hwang explains, "When people with ME/CFS exercise, they don't use up as much oxygen from their blood as normal people. They also make more lactic acid, which is a marker of poor oxygen utilization." In other words—people with ME/CFS feel exhausted because their cells have trouble generating and using energy effectively.

Researchers in the ME/CFS field have long suspected that something is wrong in the mitochondria of patients with ME/CFS. The findings of Dr. Hwang and his team add strength to this theory and excitingly, point the way for further investigation.

A Role for WASF3 in ME/CFS

Dr. Hwang described the discovery as a prepared accident. Setting out to study the mitochondria of patients with genetic cancer called Li-Fraumeni Syndrome, they found a discrepancy in one patient who also had chronic fatigue. They detected excess WASF3 in the mitochondria of this patient and felt obligated to investigate further.

The researchers compared the muscle cells of the patient with ME/CFS to the muscle cells of a sibling (brother or sister) who did not have the disease. They found abnormal amounts of WASF3 in the muscle cells of the patient with ME/CFS, but not in the healthy sibling. When tested, the muscle cells with abnormal amounts of WASF3 did not recover as quickly from exercise, leading the researchers to wonder if surplus WASF3 was causing exercise intolerance in the patients with ME/CFS.

The team tested this intriguing hypothesis on mice genetically modified to overproduce the WASF3 protein. The mice that overproduced WASF3 were able to run half as long on a treadmill compared to normal, wild-type mice.

The group then compared several muscle tissue samples from patients with ME/CFS to healthy volunteers. They found significantly higher WASF3 levels in the samples from people with ME/CFS.

Together, these findings suggest a connection between too much WASF3 and ME/CFS symptoms.

Cellular Stress

An intriguing aspect of this finding was that WASF3 protein levels were driven by cellular stress.Scientists are now discovering links between cellular stress and mitochondrial damage in many chronic conditions e.g. rheumatoid arthritis and cardiovascular disease. Researchers believe that by exposure to certain viruses, including COVID-19 can cause mitochondrial dysfunction.

The authors hope their research will provide insights, not only into ME/CFS, but into other disorders associated with fatigue such as rheumatic arthritis and long COVID.

What's next for WASF3?

This work is in its early stages, it will be some time before clinical tests can be developed for WASF3. In the meantime, the NIH researchers hope other research groups will validate their work- confirming their results and gathering more test subjects.

Dr Hwang acknowledges that this study involves a sample size of only 14 patients. WASF3 levels in muscle tissue may explain fatigue in only some ME/CFS patients. The next stage of this research will be testing how closely extra WASF3 correlates to abnormal fatigue.

He tells us, "We do not believe that WASF3 is the cause of ME/CFS, but rather is one of the factors mediating energy deficiency in muscle. We need to see if we can target WASF3 in ME/CFS patients and fix the bioenergetic defect that we have described."

He continues, “Having identified WASF3 in the mitochondria, we are now very interested in studying its role in ME/CFS. In our lab we are working on finding the best that we can, realizing that treatment is a priority.”

Looking to the Future

Margaret Parlor of the National ME/FM Action Network was cautiously optimistic about the study. She stated that the results add credibility to the growing understanding that the symptoms of ME/CFS have a biological foundation. However, she points out, that there is a need for increased national attention and funding for ongoing research.

A 2020 study of disease funding by the U.S. National Institutes of Health (NIH) found the disease burden of ME/CFS is double that of HIV/AIDS and over half that of breast cancer. To be proportionate with the disease burden, the study found that funding for ME/CFS research would need to increase roughly 14-fold.

Further research, credibility with medical professionals, and meaningful treatment options cannot come soon enough for people like “Kerri”, “It would be amazing if we could have some small steps towards change. Studies like this need more exposure and international recognition. We need to turn the tide of public and medical perception of the illness.”

To find out more about WASF3 check out our interview with Dr Paul Hwang.

Want to get to grips with the science behind the story? Join us at MNB:Journal Club for a translation of the original research article.

References

Centers for Disease Control and Prevention (2023).
Myalgic encephalomyelitis/chronic fatigue syndrome.
Accessed September 7, 2023,
https://www.cdc.gov/me-cfs/about/index.html.

Komaroff (2019). Advances in Understanding the Pathophysiology of Chronic Fatigue Syndrome. JAMA. 322 (6):499–500. doi:10.1001/jama.2019.8312

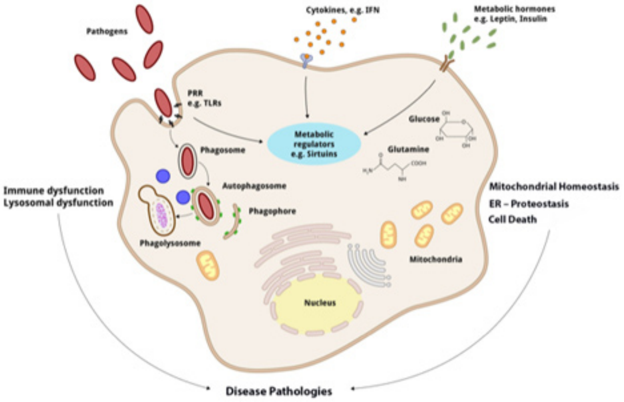
Lim, E. J., Ahn, Y. C., Jang, E. S., Lee, S. W., Lee, S. H., & Son, C. G. (2020). Systematic review and meta-analysis of the prevalence of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). Journal of translational medicine, 18(1), 100. https://doi.org/10.1186/s12967-020-02269-0

Mirin, A. A., Dimmock, M. E. & Jason, L. A. (2020). Research update: The relation between ME/CFS disease burden and research funding in the USA. Work. 66(2), 277—282. *https://doi.org/10.3233/WOR-203173*

Cellular Stress Described

Cells are constantly exposed to several internal (metabolites, damaged macromolecules such as proteins and lipids) and external stimuli (e.g. microbes, radiations, temperature and chemicals) which stress the cells. A successful survival of an organism depends on how well it adapts to different stress. Cells survive these insults by mounting specific repair mechanisms such as oxidative stress response, unfolded protein response (UPR), and DNA damage response (DDR) which aid in regaining normal physiology. When they fail to restore homeostasis, they undergo cell death or they survive in a maladaptive phase resulting in pathologies such as malignancies, neurodegenerative, cardiovascular, and metabolic disorders.

from: *https://www.centreforcancerbiology.org.au/research/cellular-stress-and-immune-response-laboratory/*



US ME/CFS Prevalence Statistics

The US included ME/CFS on its 2021-2022 National Health Interview Survey. ME/CFS status was based on a yes response to both of the following survey questions: "Have you ever been told by a doctor or other health professional that you had Chronic Fatigue Syndrome (CFS) or Myalgic Encephalomyelitis (ME)?" and "Do you still have Chronic Fatigue Syndrome (CFS) or ME?"

This survey found that there were 3.3 million US adults diagnosed with ME/CFS. More specifically, the report stated that:

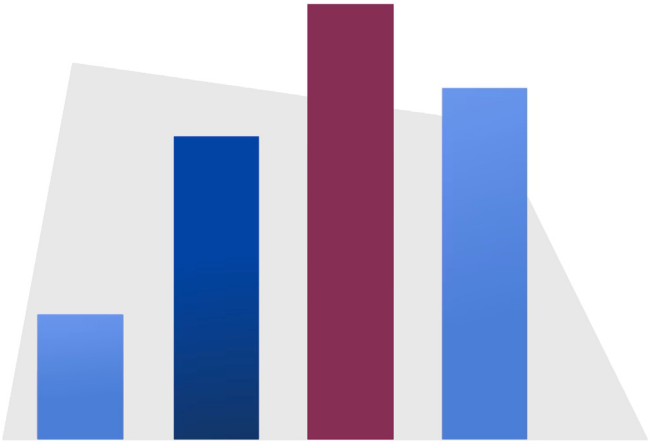
- 1.3% of adults had myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).
- Women (1.7%) were more likely than men (0.9%) to have ME/CFS.
- The percentage of adults who had ME/CFS increased with age through ages 60–69 and then declined among those age 70 and older.
- White non-Hispanic (1.5%) adults were more likely to have ME/CFS compared with Asian non-Hispanic (0.7%) and Hispanic (0.8%) adults.
- Adults with a family income less than 100% of the federal poverty level (2.0%) were more likely to have ME/CFS, followed by those at 100–199% (1.7%), and those at or above 200% (1.1%).
- The percentage of adults who had ME/CFS increased with increasing rurality of their place of residence.

https://www.cdc.gov/nchs/data/databriefs/db488.pdf

To quote one news report: "this number is larger than previous studies have suggested, and is likely boosted by some of the patients with long COVID. The condition clearly "is not a rare illness," said the CDC's Dr. Elizabeth Unger, one of the report's co-authors."

https://www.pbs.org/newshour/health/chronic-fatigue-syndrome-is-more-common-than-previously-understood-cdc-says

The US survey question is very similar to the question which has been on the Canadian Community Health Survey questionnaire a number of times since 2001. Based on Canadian data, here are some observations.



While the US found the 1.3%prevalence to be surprisingly high, this rate is slightly lower than what we have been seeing in Canada. The higher rate in Canada might reflect broader access to health care in Canada compared to the US. Access to health care might also explain the racial differences in the US figures – people of colour may have less access.

Here in Canada, we don't see the drop-off in prevalence in the senior years. ME/CFS is more usually diagnosed in non-seniors. It is likely that Canada has been diagnosing ME/CFS longer than the US has and many of the Canadians with a diagnosis have become seniors.

We agree that long-Covid is likely to lead to an increase in the prevalence of ME/CFS and FM, but we question whethervery many people with long-Covid would have been diagnosed with ME/CFS when the survey was run in 2021-22.

We have definitely seen that people with ME/CFS have higher rates of poverty. The question is causality – does ME/CFS cause poverty or does poverty cause ME/CFS. We know that ME/CFS can impact earning potential. But it is also possible that poverty can raise one's vulnerability to ME/CFS.

We have not looked at the question of urban/rurality here in Canada. We do not understand why rural residents would have higher rates of ME/CFS.

Note that we are comparing the US 2021-2022 figures to pre-Covid Canadian figures. We have asked Statistics Canada for more recent data.

Three Articles on Coping

The first article, out of Europe, is aimed primarily at psychotherapists and talks about a role psychotherapy can play in the care of patients with ME/CFS. The authors state:

"According to the current state of research, psychotherapy and psychosomatic rehabilitation have no curative effect in the treatment of ME/CFS. Nevertheless, we see numerous patients in practices and outpatient clinics who suffer severely as a result of their illness and whose mental well-being and coping strategies would benefit from psychotherapeutic help."

In discussing what help psychotherapists can provide, the authors zero in on post-exertional malaise and the need for pacing. They are very clear that "pacing is a way of trying to prevent symptom exacerbation and relapses. It is not a treatment..." But they say that psychotherapy can help patients to understand pacing, to implement pacing, to deal with the social pressures to push oneself, and to cope with the frustration of having to pace.

The authors refer to further issues that can arise including uncertainty of diagnosis and cooperation with physicians, plus the difficulty holding sessions with people who have limited energy. The authors do not discuss these issues in detail.

Note that this article is talking about ongoing care rather than the care for someone in a crisis situation, like contemplating suicide or considering medical assistance in dying.

https://pubmed.ncbi.nlm.nih.gov/37109676/#full-view-affiliation

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The second article is written by three authors from the US and Dr Eleanor Stein from Calgary. The article is written for "outpatient medical professionals" to help them identify when someone with ME is considering suicide and to guide them on how to respond. By outpatient medical professionals, they mean people who do not specialize in psychology or psychiatry and do not work in a mental health setting, but they see patients about physical health conditions and should be able to identify mental health issues and arrange help.

The article concludes:

"Like other chronic, debilitating illnesses, ME/CFS places individuals at an increased risk of death by suicide. Several characteristics prominent in ME/CFS exacerbate this risk and make diagnosis and management of suicidality demanding. These include absence of any disease-modifying treatments, severe functional limitations confining sizable numbers of patients at home, and symptoms (e.g., PEM, medication sensitivities, cognitive dysfunction) limiting certain therapies. Decades-long misattribution of ME/CFS to physical deconditioning or irrational, hypochondriacal beliefs combined with conflation of ME/CFS with depression or anxiety have also resulted in an uneducated healthcare workforce at best and a skeptical, dismissive one at worst. Severity of impairment is often not acknowledged. Consequently, some patients are reluctant to engage in psychiatric/psychological care despite sometimes desperately needing it. Lack of proper recognition by medical professionals and authorities in turn has meant an absence and scarcity of resources targeted or available to patients, whether medical/psychiatric/psychological care, social support from family members or friends, or disability benefits.

Outpatient medical professionals play a vital role in ameliorating this cascade of effects. We have provided a framework for identifying and managing adult suicidal patients afflicted by ME/CFS through adapting current recommendations to this neglected population. Through both applying evidence-based interventions aimed at all suicidal patients and tailoring interventions specific to an individual patient's circumstances, we believe that suffering and suicidality can be alleviated."

This article is extremely comprehensive and would be an ideal foundation for workshops for outpatient medical professionals.

https://www.mdpi.com/2227-9032/9/6/629 This article is included in the book on severe and very severe ME.

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The third article appeared in the January 2024 issues of the journal Canadian Family Physician / Le Médecin de famille canadien. It is entitled "Patient experiences with requests for medical assistance in dying, perspectives of those with complex chronic conditions". Examples of complex chronic conditions include chronic pain syndrome, FM and ME. The article was summarized very well by the editor/rédacteur.

https://www.cfp.ca/content/70/1/41

Editor’s key points

- In a small qualitative study of Canadian patients (N=16) with complex chronic conditions, long-lasting suffering that had led to poor quality of life was the most common reason patients gave for having requested medical assistance in dying (MAID). The most common diagnoses patients reported were chronic pain syndromes (13 of 16 patients).
- Receiving approval for MAID was viewed as validation of patients’ suffering and provided some with a sense of having regained control over their lives, which contributed to some patients deciding to delay receiving MAID.
- Survey participants indicated MAID was preferable to suicide as it was more certain, more socially acceptable, and more peaceful; and because of fears of negative outcomes resulting from unsuccessful suicide.
- Unlike previously reported experiences of MAID applicants whose natural deaths were reasonably foreseeable, many survey participants reported having unmet health care needs. Opportunities may exist for family physicians to explore different ways to help patients with complex chronic conditions and to better understand their experiences.

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The three articles are sending the same message – that the health system needs to do better and the information is available whereby it can do better.

Points de repère du rédacteur

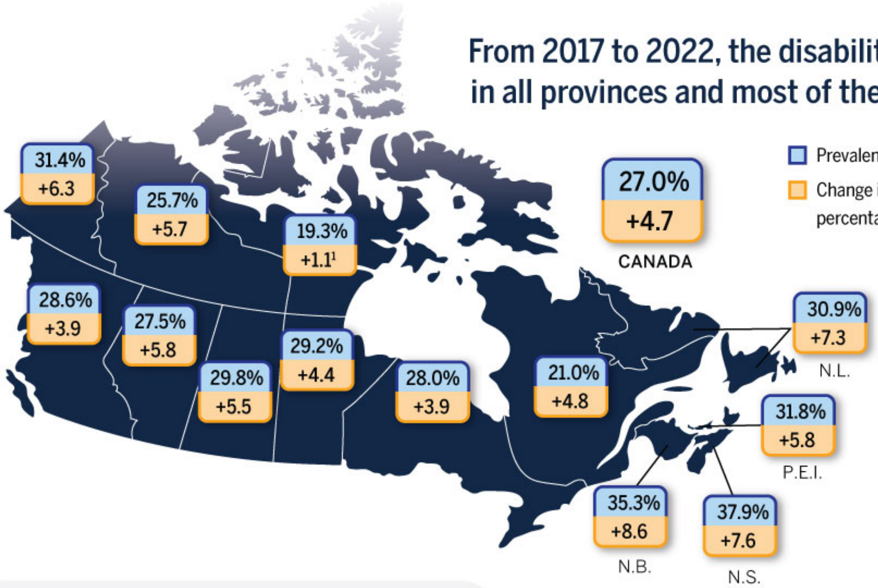
- Dans une petite étude qualitative auprès de patients canadiens (N=16) souffrant de problèmes chroniques complexes, des souffrances de longue date qui ont entraîné une mauvaise qualité de vie étaient la raison la plus fréquente qu’ont exprimée les patients pour avoir demandé l’aide médicale à mourir (AMM). Les diagnostics les plus courants qu’ont signalés les patients étaient des syndromes de douleur chronique (13 des 16 patients).
- L’approbation de l’AMM était considérée par les patients comme une validation de leurs souffrances et a suscité chez certains le sentiment d’avoir regagné le contrôle de leur vie, incitant certains d’entre eux à décider de retarder l’administration de l’AMM.
- Les participants au sondage ont indiqué que l’AMM était préférable au suicide, parce qu’elle est plus certaine, plus acceptable socialement et plus paisible, et aussi parce qu’ils craignaient des issues défavorables à la suite d’un suicide raté.
- Contrairement à des expériences rapportées antérieurement par des demandeurs d’AMM dont la mort naturelle était raisonnablement prévisible, plusieurs participants au sondage ont signalé que leurs besoins en soins de santé n’avaient pas été satisfaits. Certaines possibilités pourraient s’offrir aux médecins de famille pour explorer différentes façons d’aider les patients souffrant de problèmes chroniques complexes et mieux comprendre leurs expériences.

NEW DATA ON DISABILITY

in Canada, 2022

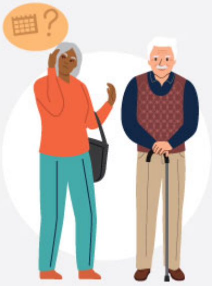
In 2022, **27.0%** of Canadians aged 15 and older, or **8.0 million** people, had at least one disability. This represents an **increase of 4.7** percentage points from 2017.

From 2017 to 2022, the disability rate rose in all provinces and most of the territories

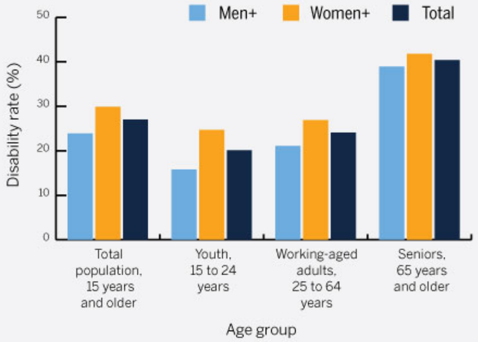


🟦 Prevalence, 2022

🟧 Change in rate from 2017, in percentage points



The disability rate increases with age. Growth of Canada's senior population between 2017 and 2022 contributed to the overall increase in the disability rate.



Women of all ages are more likely than men to have a disability[2]

From 2017 to 2022, **mental health-related, pain-related,** and **seeing** disabilities had the largest increases, contributing the most to the rise in the Canadian disability rate.

🟦 Prevalence among the total Canadian population, 2022

🟧 Change in rate from 2017, in percentage points

Mental health-related	10.4%	+3.2
Pain-related	16.7%	+2.2
Seeing	7.4%	+2.0
Learning	5.6%	+1.6
Memory	4.9%	+1.1
Mobility	10.6%	+1.0
Flexibility	10.9%	+0.9
* Hearing	5.6%	+0.8
* Dexterity	5.0%	+0.4
Developmental	1.5%	+0.4
Unknown	0.8%	+0.2

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*Updated image

[1] The change observed since 2017 is not statistically significant at a 5% significance level, meaning that it is likely due to sampling variability.

[2] The category "Women+" includes women and some non-binary persons, while the category "Men+" includes men and some non-binary persons. Given the small size of the non-binary population, data aggregation to a two-category gender variable is most of the time necessary to protect the confidentiality of the responses provided.

Source: Statistics Canada, Canadian Survey on Disability, 2022.

Canadian Disability Statistics

Findings from the 2022 Canadian Survey on Disability (CSD) were released recently and are summarized in the infographic on page 12.

Canada's Census of Population is run every five years (2021, 2026 etc). A section on the Census long-form asks Canadians if they have difficulty with "activities of daily living" starting with seeing, hearing and walking. The Canadian Survey on Disability is conducted in the following year (2022, 2027 etc.) Statistics Canada interviews a sample of people who reported difficulties with activities of daily living on the Census. The CSD then tests whether the difficulties are severe and frequent enough to qualify as disabling for CSD purposes.

The US Census is also run every five years (2020, 2025 etc). The US 2020 Census had a section that was similar though not identical to the section on the Canadian Census.

Content for any Census has to be confirmed at least a year in advance to allow time for programs, forms and manuals to be prepared. The US announced very recently that it is changing this section on the 2025 Census. In making this decision, it tested the old set of questions against a somewhat different set of questions. The old set of questions were yes/no questions. The new set had four levels of difficulty.

In the US test, the old set of questions resulted in a disability rate of 13.9%. The new set of questions resulted in a rate of 8.1% when using "a lot of difficulty" and "cannot do at all". The rate jumped to 31.7% when "some difficulty" was included as well. This shows that disability rates are very sensitive to the questions asked and the scoring system used.

https://www2.census.gov/about/partners/cac/sac/meetings/2023-09/presentation-2022-acs-content-test-results.pdf Slides 11 and 12.

In a different study, researchers compared two sets of questions with each other but also checked how well the questions identified people with disabilities. The study found that the sets of questions missed a lot of disabled people and that they "performed especially poorly in capturing respondents with psychiatric disabilities or chronic health conditions". *https://www.healthaffairs.org/doi/10.1377/hlthaff.2022.00395*

Leaving people out affects the statistical results but there is another implication. The Census long-form is seen by many Canadians and it leaves the impression that this is what disability is about.

The National ME/FM Action Network would like to see a complete review of disability statistics in Canada. We recognize that disability is a conceptually difficult area. The World Health Organization's International Classification of Functioning, Disability and Health (ICF) says that functioning depends on one's body's ability to do the combination of activities that are needed for participation in society. It also says that this chain (from body functions and structures to activities to participation) is affected by health factors, personal factors and environmental factors. The CRPD puts an obligation on governments to fix the environment factors where it is possible for them to do so. We believe that the ICF and CRPD are key starting points for the review.

If changes are going to be made to the 2027 CSD, work has to begin very soon.

Articles on Severe and Very Severe ME/CFS

In 2020 and 2021, a journal Healthcare published a series of articles on severe and very severe ME/CFS. These articles have now been compiled into a book. You can purchase the book or you can download the whole book for free. *https://www.mdpi.com/books/book/8496-me-cfs-the-severely-and-very-severely-affected*

If you want a couple of the articles and don't have access to a computer and printer, just give us a call and we will print and mail the articles to you. Here is a list of the authors and titles.

Whitney Dafoe
Extremely Severe ME/CFS—A Personal Account

Victoria Strassheim, Julia L. Newton and Tracy Collins
Experiences of Living with Severe Chronic Fatigue Syndrome/Myalgic Encephalomyelitis

Rachel K. Straub and Christopher M. Powers
Chronic Fatigue Syndrome: A Case Report Highlighting Diagnosing and Treatment Challenges and the Possibility of Jarisch–Herxheimer Reactions If High Infectious Loads Are Present

Leah R. Williams and Carol Isaacson-Barash
Three Cases of Severe ME/CFS in Adults

Nigel Speight
Severe ME in Children

Anthony L. Komaroff
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: When Suffering Is Multiplied

Chia-Jung Chang, Li-Yuan Hung, Andreas M. Kogelnik, David Kaufman, Raeka S. Aiyar, Angela M. Chu, et al.
A Comprehensive Examination of Severely Ill ME/CFS Patients

C (Linda) M. C. van Campen, Peter C. Rowe and Frans C. Visser
Two-Day Cardiopulmonary Exercise Testing in Females with a Severe Grade of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Comparison with Patients with Mild and Moderate Disease

Karl Conroy, Shaun Bhatia, Mohammed Islam and Leonard A. Jason
Homebound versus Bedridden Status among Those with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Yo-Chan Ahn, Jin-Seok Lee and Chang-Gue Son
Reliability and Validity of the Modified Korean Version of the Chalder Fatigue Scale (mKCFQ11)

Per Ole Iversen, Thomas Gero von Lueder, Kristin Reimers Kardel and Katarina Lien
Cardiac Dimensions and Function are Not Altered among Females with the Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

C (Linda) M.C. van Campen, Peter C. Rowe and Frans C. Visser
Cerebral Blood Flow Is Reduced in Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patients During Mild Orthostatic Stress Testing: An Exploratory Study at 20 Degrees of Head-Up Tilt Testing

Rebekah Maksoud, Natalie Eaton-Fitch, Michael Matula, Hélène Cabanas, Donald Staines and Sonya Marshall-Gradisnik
Systematic Review of Sleep Characteristics in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

C. (Linda) M. C. van Campen, Peter C. Rowe and Frans C. Visser
Validation of the Severity of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome by Other Measures than History: Activity Bracelet, Cardiopulmonary Exercise Testing and a Validated Activity Questionnaire: SF-36

C (Linda) MC van Campen, Peter C. Rowe and Frans C Visser
Reductions in Cerebral Blood Flow Can Be Provoked by Sitting in Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patients

Helen Brownlie and Nigel Speight
Back to the Future? Immunoglobulin Therapy for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Lily Chu, Meghan Elliott, Eleanor Stein and Leonard A. Jason
Identifying and Managing Suicidality in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Helen Baxter, Nigel Speight and William Weir
Life-Threatening Malnutrition in Very Severe ME/CFS

Jose G. Montoya, Theresa G. Dowell, Amy E. Mooney, Mary E. Dimmock and Lily Chu
Caring for the Patient with Severe or Very Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Caroline Kingdon, Dionysius Giotas, Luis Nacul and Eliana Lacerda
Health Care Responsibility and Compassion-Visiting the Housebound Patient Severely Affected by ME/CFS

Patricia A. Fennell, Nancy Dorr and Shane S. George
Elements of Suffering in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: The Experience of Loss, Grief, Stigma, and Trauma in the Severely and Very Severely Affected

William Weir and Nigel Speight
ME/CFS: Past, Present and Future

Samir Boulazreg and Ami Rokach
The Lonely, Isolating, and Alienating Implications of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Faith R. Newton
The Impact of Severe ME/CFS on Student Learning and K–12 Educational Limitations

Derek F.H. Pheby, Diana Araja, Uldis Berkis, Elenka Brenna, John Cullinan, Jean-Dominique de Korwin, et al.
The Development of a Consistent Europe-Wide Approach to Investigating the Economic Impact of Myalgic Encephalomyelitis (ME/CFS): A Report from the European Network on ME/CFS (EUROMENE)

http://mefmaction.com

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