NATIONAL ME/FM ACTION NETWORK
SINCE 1993

Quest
Newsletter

www.mefmaction.com
Quest 133, Summer 2022
mefminfo@mefmaction.com

Dedication - Dr Lynn Marshall

We would like to dedicate this issue of Quest to Dr Lynn Marshall, July 15, 1942 – April 14, 2022.

Some of you will have encountered Lynn at the Environmental Health Clinic at Women's College Hospital which serves Ontarians with ME, FM and MCS. She assisted in the founding of the clinic in 1996. She was a staff physician for many years, serving as Medical Director for several of those years.

All of you will have benefitted from her work. Two of her important products, co-written with Dr. Alison Bested, are the Functional Capacity Scale, found in many documents including our CPP-Disability Guide, and the Clinicians Review of ME/CFS. Both these documents can be found on our website.

I remember Lynn for her kindness. She was a truly gentle, wise and supportive individual.

Contents

Another Reflection on the Pandemic

In our last newsletter, three people shared their reflections on the pandemic. Just after our last newsletter was released, we received a message from one of our readers. She said that she was having a much harder time with the pandemic than the three people who wrote. She said that she had been planning to write about her experiences but had not had time to do so, saying that "living with CFS is too hard." We are sharing her reflections in this newsletter which show both humour and cutting insight.

The Pandemic and Me

Background: I have been disabled by ME/CFS since 1990 and unable to work all that time. I live alone. I have no publicly supported help and no family help. Getting vaccinated was a victory for me but it is not enough. I seriously need to not catch Covid-19 at all. Even a bad flu could be catastrophic since there is no one to help.

Perhaps the best thing about the pandemic was that it is less noisy. Not fully quiet - the construction noise never ended - but the other noises diminished. It was wonderful. I wish it had lasted.

In the first part of the pandemic, New Zealand news was my beacon of hope proving that it was possible to look this crisis bravely in the face and make difficult decisions designed to save lives and protect health. The NZ Director General of Health Dr. Ashley Bloomfield didn't get everything right, but he got a lot right and was constantly learning. He stood up in front of his people and explained things. A lot of what I know I learned from him. He explained over and over how effective the Pfizer-BioNTech vaccine was and how few side effects it had. He helped to give me the courage to get it. Kudos also to a wonderful Kiwi Scientist Dr. Siouxsie Wiles who put out endless bits of accessible information on how the vaccines (and other public health measures) work. And I learned a lot about effective hand-washing from the CBC who did a few articles and videos on it.

The first part of the pandemic was inconvenient because so many things suddenly stopped. For me this included a window replacement project. I was left with a boarded-over window and scaffolding that interfered with access to my door. After many weeks, the work started up again. While that part was finished, other work was left undone, and remains undone. My car is overdue for an oil change My furnace did not get its fall check-up, which meant that I couldn't use the humidifier all of last winter which added to my discomfort.

In those first months my regular chiropractic and massage therapy treatments came to a sudden halt. My health deteriorated as a result. This led to my falling on the stairs, which in turn meant I was unable to walk for almost 2 months. It was very painful, and I had to move about the house by scooting on a walker ... which in turn damaged walls and doorways and furniture. Why on earth do these things have protruding bolts seemingly designed to cause as much damage as possible?

When services became available again, my chiropractor made the choice to retire. He relented when it became evident that his patients had no other options. His possible re-retirement hung over me. Every visit had me wondering if it would be the last. Yes, he has retired now. Finding someone new seems an impossible task.

My dentist quit last summer. My handyman quit the winter before that. I used to pay a friend to give me a few precious hours of help each week. That has been reduced, completely interrupted a few times, and is now unlikely to resume on a weekly basis. She is burnt out from her regular job. Along with having less help, I also have lost a big part of my small support network.

Before the pandemic, I would pay someone once a year to drive me out of the city. It hugely helped my mental health. This is no longer possible.

Ordering items online has been a particular problem. Orders have been lost. Items have been missing. Items have turned out to be stale-dated or not as advertised. While the stores say I can return the items, there is no way to do so safely and within my energy budget. Also dealing with customer service is utterly exhausting.

People, at least in the city, seem more rude and angry. And they don't seem to care as much about doing things well. So it takes that much more energy to accomplish anything, and that is emotionally draining.

Last summer, when Covid rates were somewhat down, I decided it was safe enough to catch up on my postponed health needs of doctor, dentist and optometrist. But they all required that I phone from the parking lot. I had to buy a cell phone just so that I could access care. That is an ongoing expense.

I got vaccinated. Back in the 1990s there were some people claiming a link between CFS and polio vaccines. As I got ill in 1990 shortly after receiving my polio booster shot, this seemed credible to me. Like so much else in the world of ME/CFS, this was never followed up and either debunked or proven true. But I have not had any kind of vaccination for the 30+ years since. Until last year when I got the Pfizer vaccine for Covid-19.

I panicked after making my first appointment and cancelled it. Then a kind angel offered to go through the process with me, picking me up, standing by me through the appointment, taking me home. This involved over an hour of waiting in slow moving lines outside in stifling heat, and more time waiting while they sorted out the mistakes the doctor had made. There was no accommodation for people who had other health problems. Thank goodness I had my walker to sit on and someone to drive me home! I slept 16 hours per day for over a week afterward. It was kind of nice since the quality of the sleep was so deep. Not so good in terms of keeping myself fed etc. The second shot was much easier, no waiting, better doctor. And the booster easier yet. I even managed to do the booster on my own.

It seems that people with "Long Covid" don't want to be associated with ME/CFS. The research into Long Covid often ignores hard won learnings from ME/CFS. I do have some hope that research for Long Covid will lead to some help for people with ME/CFS. However, I have to note that ME/CFS research has received little support over 30 years while Long-Covid is getting more fairly quickly, which adds to my sense that people with ME/FM have not received adequate attention and support, are generally dismissed and are not considered worth helping.

This is the worst part of the pandemic for me: having it ground into me over and over how I do not matter, even the tiniest little bit.

*

Overall, my biggest issues are around people and rules that do not take Covid-19 seriously. As I said earlier, I seriously need not to catch Covid-19, even after having been vaccinated. I find that a lot of people want to ignore Covid and some of the public health measures don't factor in the needs of vulnerable people. This puts vulnerable people more at risk which means that we have to take more precautions which restricts our lives even more than previously.

The people across the street put up a lawn sign protesting public health measures. They and another set of neighbours chose to flout the rules, refusing to wear masks and they held gatherings despite restrictions. I can and do wear a mask, but it only moderately reduces my risk if others aren't also wearing one. I would hear people complaining about wearing a mask as if it were some existential crisis for them. I frequently imagine a golden scale of justice with a simple mask on one side, and a coffin on the other side. How can such a small inconvenience have been elevated to such importance? Why is there so little acknowledgement of the dangers it mitigates?

Our "leaders" only seem to care about preventing our health system from being overwhelmed. And especially now that so many are vaccinated, they just seem to expect everyone to get Covid, and as long as they don't end up in hospital it is deemed enough.

"Endemic" is represented as a good thing! It is NOT. Polio used to be endemic and it continued to kill and cripple children every year. Covid-19 becoming endemic just means that it is never going away. We missed that chance of eradicating it. Now it will be with us for the foreseeable future.

There is wide spread belief that dropping of public health measures and 'rules' means either that the pandemic is over or that we are somehow safe now without them. The pandemic is not even close to over. Don't believe me? Ask the World Health Organization.

Reducing people's access to Covid testing has consequences. At one level, people don't know whether they have Covid. On another level, I don't feel that I have the information that would truly help me judge how bad things are and how safe it is to leave the house. It also means that we may well miss the next dangerous variant until it is well entrenched.

*

In some ways my life hasn't changed very much with the pandemic. I have mostly stayed home and not socialized for over 30 years. It is somewhat affirming to realize how difficult others find it. But, with the new and added threat of Covid-19, my life has become more complicated and lonelier.

There have been some bright spots. I would like to recognize a neighbour who includes a few groceries for me in her weekly curb-side pick-up order. I would also like to recognize my massage therapist who has suddenly had a series of scheduling conflicts requiring him to make home visits ... when he sneaks in a bit of household help for me! I am incredibly grateful for gestures like these.

CHRC Statement on MAiD

CTV featured a story about an individual in a wheelchair who has Multiple Chemical Sensitivities. She could not find a place to live despite concerted efforts, so she applied for Medical Assistance in Dying and was approved. This sparked a reaction from Marie-Claude Landry, the head of the Canadian Human Rights Commission (CHRC). Nobody, Ms Landry states, should be forced into that situation.

As a follow-up, money was raised and suitable housing was found. The MAID process has been put on hold. *https://www.ctvnews.ca/health/woman-with-disabilities-approved-for-medically-assisted-death-relocated-thanks-to-inspiring-support-1.5921893*

Here is the statement from the Canadian Human Rights Commission.

MAiD cannot be an answer to systemic inequality

Following recent reports of an individual accessing Medical Assistance in Dying, because they were unable to find housing that accommodated their disability, Chief Commissioner Marie-Claude Landry of the Canadian Human Rights Commission releases the following statement:

Medical Assistance in Dying is intended to allow people the ability to die with dignity when science and medicine can offer no better alternative to alleviate unbearable suffering. Leaving people to make this choice because the state is failing to fulfill their fundamental human rights is unacceptable.

For many people with disabilities, systemic inequality results in inadequate access to services, which means that their fundamental rights continue to be denied and their dignity diminished. They cannot get the health care they need because of where they live. They cannot live in their community because the housing they need is not accessible. They cannot afford crucial medication.

In many instances, people with disabilities see ending their life as the only option. We must do more to fight for those who continue to be denied the fundamental human rights to which we are all entitled.

Social and economic rights – the right to an adequate standard of living, the right to adequate housing, the right to healthcare and the right to accessible services – are

L'aide médicale à mourir ne peut être la réponse à l'inégalité sociale

Suite à de récents rapports d'un individu ayant accédé à l'aide médicale à mourir à défaut de ne pas avoir trouvé un logement afin d'accommoder son handicap, la présidente de la Commission canadienne des droits de la personne, Marie-Claude Landry, publie la déclaration suivante :

L'aide médicale à mourir a pour but de permettre aux personnes de mourir dans la dignité lorsque la science et la médecine ne peuvent offrir de meilleures solutions de rechange pour soulager des souffrances insupportables. Laisser une personne faire ce choix parce que l'État ne respecte pas leurs droits fondamentaux est inacceptable.

Pour de nombreuses personnes handicapées, l'inégalité systémique est le résultat d'un manque d'accès aux services sociaux, ce qui signifie que leurs droits de la personne continuent d'être bafoués et leur dignité diminuée. Elles ne peuvent pas obtenir les soins de santé dont elles ont besoin en raison du lieu de leur résidence. Elles ne peuvent pas vivre en communauté parce que le logement dont elles ont besoin n'est pas accessible. Elles ne peuvent pas se payer les médicaments qui leur sont indispensables.

Dans de nombreux cas, les personnes handicapées considèrent que mettre fin à leur vie est la seule option possible. Nous devons faire plus afin de lutter pour les personnes qui continuent d'être privées de ces droits fondamentaux auxquels nous avons tous et toutes droit.

Les droits sociaux et économiques – le droit à un niveau de vie suffisant, le droit à un logement adéquat, le droit aux soins de santé et le droit à des services accessibles – sont des droits de la personne fondamentaux. Ils sont fundamental human rights. They are essential to living a life of dignity. Without access to social and economic rights, our other rights have little meaning.

Canada has an obligation to ensure that everyone can live with full enjoyment of these rights. Social and economic rights – fundamental human rights – should be enshrined in law. This would give people recourse when they are being denied an adequate place to live, or are unable to find healthcare or are excluded from receiving a service. It would provide access to justice. It would provide options beyond ending one's life.

Medical Assistance in Dying cannot be a default for Canada's failure to fulfill its human rights obligations.

In an era where we recognize the right to die with dignity, we must do more to guarantee the right to live with dignity.

essentiels pour vivre une vie dans la dignité. Sans accès aux droits sociaux et économiques, nos autres droits ont peu de sens.

Le Canada a l'obligation de veiller à ce que chacun et chacune puisse vivre et jouir pleinement de ces droits. Les droits sociaux et économiques – droits de la personne fondamentaux – devraient être enchâssés dans la loi. Cela permettrait aux personnes d'avoir un recours lorsqu'elles se voient refuser un lieu de vie adéquat, lorsqu'elles sont incapables de trouver des soins de santé ou lorsqu'elles se voient refuser un service. Cela donnerait accès à la justice. Cela offrirait d'autres options que de mettre fin à sa vie.

L'aide médicale à mourir ne peut être un substitut lorsque le Canada manque à remplir ses obligations en matière de droits de la personne.

À une époque où nous reconnaissons le droit de mourir dans la dignité, nous devons faire davantage pour garantir le droit de vivre dans la dignité.

To Canada Revenue Agency

Sent: June 2, 2022

The National ME/FM Action Network welcomes the Canada Revenue Agency (CRA) initiative to develop an accessibility plan for Canadians with disabilities.

We work on behalf of Canadians with Myalgic Encephalomyelitis (ME, often called Chronic Fatigue Syndrome), Fibromyalgia (FM), or both. According to a Statistics Canada survey, nearly 1 million Canadians have been diagnosed with one or both of these complex, chronic, disabling conditions. Many are women. Many are of working age.

ME and FM are poorly served. One consequence is that many people have bad experiences with the health and disability systems. Another consequence is that, with little infrastructure, the ME/FM community becomes a hard-to-reach population.

We received your request to circulate your survey. We decided instead to ask people to write to us about their experiences with CRA. We sensed that your survey did not cover some of the disability issues experienced by our community. The responses we received discussed the physical, mental and emotional energy needed to interact with CRA. The responses also raised the difficulty qualifying for the Disability Tax Credit. These issues are not covered in the survey.

A key symptom of ME and FM is reduced physical activity levels. People usually have 14 to 16 usable hours in a day. Someone with mild ME or FM might have 8 usable hours. Someone with more severe ME or FM would have even fewer. The reduction in activity levels has at least two consequences for this discussion:

- 4 hours spent completing a tax return or 1 hour spent on hold looking for tax information may be inconvenient for most people, but it can be onerous for someone with few usable hours per day.
- With few usable hours, people often have to cut back or drop employment, meaning that they are often low income.

Not only is physical activity affected, mental activity is affected as well. This is referred to as cognitive fatigue or brain fog. A person pointed to a reduction in “communication capacity”, adding that problems could arise unpredictably. This made it very difficult to communicate with CRA. One person reported that on some days she could not even organize her documents. She added that the brain fog made her so prone to errors that she did not trust herself to complete her return and therefore turned to a professional.

Our respondents mentioned two provisions made for low income Canadians with simple tax returns – tax clinics and free software. These are very much appreciated. One person reported that she had PTSD from dealing with the health and disability systems and had lost confidence in institutions. She did, however, trust a tax service offered by a small nonprofit agency.

But there are problems with the free services. One person mentioned that the free software got stuck in an infinite loop so she could not complete the return herself and had to hire an accountant. Another person did not think that she qualified for a free service because she had qualified for the Disability Tax Credit which would make her tax return somewhat complex. A very interesting response came from someone who has been on provincial disability since she became ill years ago. Because her income is so low, she needs to supplement it. She cannot work regularly enough to be an employee so she created a micro-business where she can put in an hour or two from time to time. She was told she needed a business account. Because she has a business account, she does not qualify for the free tax clinics or free software.

One person mentioned the complexity of completing the tax return because of multiple medical deductions.

Our respondents talked about calling the telephone help line. They talked about long waits. They talked about the first person not being able to answer their question or just reciting back information available on the website. Good information was generally available, but it could take multiple referrals. One very low income person said that she hired a professional service which she could ill afford because it provided advice more quickly.

The issue of the Disability Tax Credit also came up often. The eligibility criteria were developed around traditional impairments and do not consider how disabling physical, mental and emotional energy impairment can be. Our organization has raised this issue many times. Our people want it raised yet again. Some talked about the energy and expense of applying, appealing and reapplying (if they even qualified in the first place). We know CRA's position – it simply administers the legislation. Our community does not consider that an adequate answer.

Finally, someone asked two questions that we cannot answer. Why are CPP-Disability payments so low and why are they taxed when the contributions were taxed originally?

We hope that this information will open up discussion on CRA accessibility. We would be pleased to discuss these issues in more depth. This discussion is particularly relevant in light of yesterday's auditor-general's report discussing CRA's responsibility toward hard-to-reach populations.

An Introduction to Myalgic Encephalomyelitis and Fibromyalgia For Employers

Overview

Myalgic Encephalomyelitis (which used to be called chronic fatigue syndrome) and Fibromyalgia are acquired chronic conditions. The symptoms that come with ME and/or FM can make it difficult for people to participate in the workforce.

Canadian society expects people of working age to participate in the workforce. The workplace provides meaning, social connections and income to individuals. In return, workers provide value to employers.

Over half a million Canadians of working age have a diagnosis of ME (CFS), FM or both. That is about 1 in 40 people in this age category. Employers are therefore very likely to encounter cases.

Employers are not responsible for diagnosing or treating ME or FM, but employers can have a substantial impact on an affected worker's well-being. This document outlines basic vocabulary and basic concepts. It is intended to improve understanding between employers and affected workers.

Defining ME and FM

Myalgic Encephalomyelitis” is a term first used in the UK in the 1950's. “Chronic fatigue syndrome” is a term introduced in the US in the 1980's for the same condition. The name “chronic fatigue syndrome” has misled people into thinking that the individuals affected were malingering or deconditioned and afraid to do more. As the seriousness of ME is becoming more apparent, the name “chronic fatigue syndrome” is being retired. Do not trust advice that suggests that people can push their way though ME. They can't.

Two complementary descriptions of ME are shown on the next page.

The first definition was published in 2003 by an international group of experts appointed here in Canada. It outlines seven requirements, starting with pathological fatigue and post-exertional malaise. It provides a list of symptoms that people can experience. It is important to know that ME is complex and that any of the listed symptoms is possible.

In 2015, the United States asked an expert group at their Institute of Medicine to look at how to diagnose ME. They liked the Canadian definition but were concerned that the amount of detail could delay diagnosis. They picked five symptoms to focus on. That is the list on the right side of the chart. If you go to the US based Job Accommodation Network (askjan.org) and ask for ME, you will see the website starts with the simplified US list but adds in symptoms from the Canadian list that could also be present and relevant to employers.

In 1990, the American College of Rheumatology defined FM based on widespread pain and tenderpoints. A Canadian expert panel on FM published a report in 2003 that accepted this definition but noted that symptoms such as fatigue, cognitive difficulties, sleep disturbances and gastrointestinal issues were often present adding to the illness burden. New definitions have been proposed incorporating the associated symptoms. Some health providers use the 1990 definition while others prefer later definitions.

As you can see, ME and FM are different diagnoses but their symptoms overlap to a large extent. In theory, FM is more associated with pain while ME is more associated with exertion intolerance. In practice, we don't know how rigourously health care professionals apply the criteria and how well they distinguish between ME and FM. This becomes a particular issue for people with a diagnosis of FM-only. Some of them should have a diagnosis of ME instead or as well, and should be extremely careful of exertion.

ME/CFS:
2003 Canadian Clinical Working Case Definition

☐ **Pathological Fatigue**
A significant degree of new onset, unexplained, persistent or recurrent physical and/or mental fatigue that substantially reduces activity levels and which is not the result of ongoing exertion and is not relieved by rest

☐ **Post-exertional Malaise and Worsening of Symptoms**
Mild exertion or even normal activity is followed by malaise: the loss of physical and mental stamina and/or worsening of other symptoms. Recovery is delayed, taking more than 24 hours

☐ **Sleep Dysfunction**
Sleep is un-refreshing: disturbed quantity - daytime hypersomnia or nighttime insomnia and/or disturbed rhythm - day/night reversal. Rarely, there is no sleep problem.

☐ **Pain**
Pain is widespread, migratory or localized: myalgia; arthralgia (without signs of inflammation); and/or headache - a new type, pattern or severity. Rarely, there is no pain

☐ **Neurocognitive Manifestations (2 or more)**
- ☐ confusion
- ☐ impaired concentration
- ☐ short-term memory
- ☐ disorientation
- ☐ categorizing and word retrieval
- ☐ perceptual and sensory disturbances
- ☐ ataxia
- ☐ muscle weakness
- ☐ fasciculation
- ☐ cognitive overload
- ☐ emotional overload
- ☐ hypersensitivity to light or sound

☐ **At least one symptom from two of the following categories**

Autonomic Manifestations
- ☐ orthostatic intolerance–neurally mediated hypotension (NMH)
- ☐ postural orthostatic tachycardia syndrome (POTS)
- ☐ delayed postural hypotension
- ☐ light-headedness
- ☐ extreme pallor
- ☐ nausea and IBS
- ☐ urinary frequency and bladder dysfunction
- ☐ palpitations with or without cardiac arrhythmias
- ☐ exertional dyspnea.

.

Neuroendocrine Manifestations
- ☐ loss of thermostatic stability–subnormal body temp; marked diurnal fluctuation
- ☐ sweating episodes
- ☐ recurrent feelings of feverishness
- ☐ cold extremities
- ☐ intolerance heat and cold
- ☐ marked weight change
- ☐ anorexia or abnormal appetite
- ☐ loss of adaptability and worsening of symptoms with stress

Immune Manifestations
- ☐ tender lymph nodes
- ☐ recurrent sore throat
- ☐ recurrent flu-like symptoms
- ☐ general malaise
- ☐ new sensitivities to food, medications and/or chemicals.

☐ **The illness has persisted for at least 6 months**

SEID:
2015 Institute of Medicine Diagnostic Criteria

Diagnosis requires the following three symptoms:

☐ A substantial reduction or impairment in the ability to engage in pre-illness levels of occupational, educational, social, or personal activities, that persists for more than 6 months and is accompanied by **Fatigue**, which is often profound, is of new or definite onset (not lifelong), is not the result of ongoing excessive exertion, and is not substantially alleviated by rest, and

☐ **Post-exertional Malaise*** and

☐ **Unrefreshing Sleep***

At least one of the two following:

☐ **Cognitive Impairment*** or

☐ **Orthostatic Intolerance**

* Frequency and severity of symptoms should be assessed. The diagnosis of ME/CFS/SEID should be questioned if patients do not have these symptoms at least half of the time with moderate, substantial, or severe intensity.

Onset and Progression

ME and FM are acquired illnesses. Many cases have followed infections such as mononeucleosis, HHV6, SARS and MERS. The ME/FM community anticipated that cases would follow COVID. The emergence of “long-haulers” supports this prediction. (To clarify, not all long-Covid cases will meet the criteria for ME or FM but some will.) There are other triggers besides infections, such as vehicle collisions. In some cases the trigger is not obvious.

The key is that people do not return to their previous health as expected. It is not understood why this happens. It does not appear to be a result of continuing infection. Hypotheses include damage to the neuro-immune system or the inability of the immune system to turn itself off.

Nobody can predict the course of ME or FM with certainty, but there are some general principles. ME and FM are not considered progressive or life-threatening. Early recognition and intervention are desirable. At later stages, full recovery is relatively rare but not impossible and people are generally working for functional improvement, not necessarily for a return to previous health.

The underlying impairment has not been identified, but there may be help for individual symptoms. Currently, the best strategy for overall improvement is pacing since exertion can cause setbacks and setbacks can be serious. Thus, exertion should be avoided.

As their ME and FM continue, people adapt. Their reduced health becomes their new-normal. They learn how their body responds and how to manage. Having said that, there can be better or worse days or periods of time, something that is true for everyone.

The Disabling Aspects of ME and FM

The primary disabling aspect of ME and FM is reduced physical and cognitive activity levels.

When thinking of reduced activity levels, it is useful to think of a flashlight with a weak battery. It does not cast a continuous dim beam. Instead, the flashlight may cast a strong beam for a reduced period of time before fading. The length of time tells you how weak the battery is. The user will save the flashlight for priority situations.

Similarly, people with ME and FM may be able to function for periods of time but not be able to sustain activity because they run out of physical and cognitive energy. (Physical and cognive activity draw from the same energy source.) Getting more sleep does not solve the problem.

The amount of activity people can do reflects the severity of their condition. People will allocate their energy to priority activities. People use energy for self-care, household chores, family and household duties, school or work, and social and recreational pursuits in roughly that order of priority. The Functional Capacity Scale looks at how much an individual can do. The scale runs from zero (bedbound and dependent) to ten (fully active). At level 7, people can look after themselves and do a bit of housework, employment or school, but have given up outside activities.

Exceeding one’s capacity has been shown to be harmful for people with ME. This adverse reaction is referred to as post-exertional malaise (PEM). Because of PEM, people with ME are advised to “stay within their energy envelope”. This is referred to as pacing. Having realistic expectations, employing energy conservation techniques and alternating activity with rest are important pacing strategies. People with FM are generally more tolerant of exertion but pacing is still advised for them.

Orthostatic Intolerance (OI) may also be present. OI happens when there is difficulty pumping blood upwards when standing or sitting still. The lack of blood flow to the brain leads to dizziness or cognitive dysfunction. People with OI instinctively want to move around, put their feet up or lie down.

Some of the other disabling aspects of ME and/or FM include sensitivity to light or sound, sensitivity to food, medications and/or chemicals, and temperature dysregulation.

The Health System Situation

ME and FM are not well served by the health care system. There is a lack of training in medical school. There is no official specialty that covers them. (Rheumatology used to look after FM but dropped it.) Waiting lists for the few ME/FM focused clinics in Canada are years long. Through no fault of their own, people have a hard time finding medical advice or getting documentation for disability applications.

Managing Workers at Onset

Onset can be a very vulnerable time. A flu-like illness starts and everyone expects that life will go back to normal and yet it does not. Home and family activities may be seriously disrupted. Social and recreational activities may not be possible. Attendance at work or school may suffer.

There is a tendency for others (including family, friends, managers, supervisors and co-workers) to think that the individual is malingering. There is a tendency for the individual to try to ignore or push though the situation, which can have negative long-term health consequences.

Here are some principles to keep in mind:

- The worker may not understand what it happening and may be in denial. Employers might notice a change in the employee's work patterns.
- This is a time of uncertainty and medical advice and documentation may be difficult to obtain.
- If ME or FM is developing, rest is important. This could mean reducing hours of work. It could mean using sick or disability leave.

Managing workers at later stages

The functional capacity scale (referred to earlier) was developed in a return-to-work context. Patients were telling the doctors that they were doing "better". The doctors were sending them back to work. Many were failing. Then the doctors realized that "better" might not equal "well enough to work". Functional capacity needed to be considered. Someone at a level 6 would be able to do minimal work while a person at a consitent level 8 could consider working full time.

If a person is not well enough to work, disability supports need to be considered. Applying can be difficult. One helpful document is our guide to applying for CPP-Disability. While focused on CPP-D, the principles apply to other disability supports.

If a person with ME or FM is well enough to work, it is very important that the demands of the job respect the worker's functional capacity. Reduced hours and flexible hours could be considered. Periods of increased demand or pressure should be avoided. Energy conservation techniques should be considered, such as working from home or being assigned a close parking space. The work environment should be restful, without bright lights, excessive noise or smells. There should be opportunities for rest breaks. The worker should be able to work with his/her feet raised, especially if dysautonomia is involved. A comprehensive list of possible accommodations can be found at the Job Accommodation Network website.

References

The Functional Capacity Scale can be found in a number of documents including on page 42 of our Guide to applying for CPP-Disability
http://mefmaction.com/index.php?option=com_content&view=article&id=425&Itemid=364

The definition sheet was developed by the Complex Chronic Diseases Program of British Columbia and can be found at
http://www.bcwomens.ca/Specialized-Services-Site/Documents/Complex Chronic Diseases (CCDP)/ME_CFS_SEID Diagnostic Criteria.pdf

The Job Accommodation Network is found at *https://askjan.org/*

More information on ME and FM can be found on the National ME/FM Action Network website *mefmaction.com*

Note: This is the first version of this document. Feedback from employers and workers is welcome.

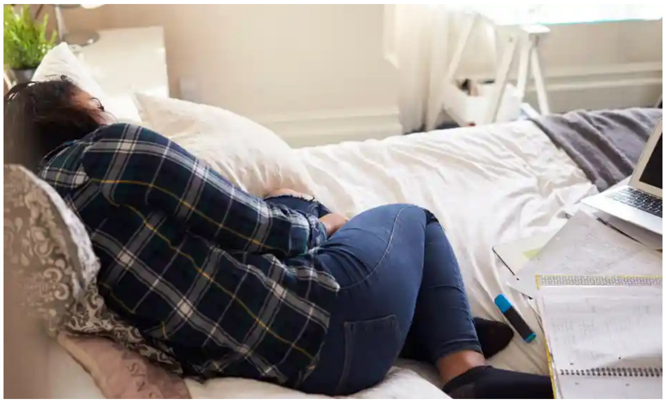
National ME/FM Action Network
512, 33 Banner Road
Nepean, ON K2H 8V7Canada
MEFMAction.com

Loneliness, Isolation and ME/FM

Loneliness is the subjective feeling that you are lacking the social connections that you need. It can feel like being stranded, abandoned, or cut off from the people with whom you belong – even if you are surrounded by other people. What is missing when you are lonely is the feeling of closeness, trust, and the affection of genuine friends, loved ones, and community.

Researchers refer to three dimensions of loneliness to reflect the particular type of relationships that are missing.

- Intimate or emotional loneliness is the longing for an intimate partner or close confidantes, someone or several people with whom you share a deep mutual bond of affection and trust.
- Relational or social loneliness is the yearning for quality friendships and social companionship and support.
- Collective loneliness is the hunger for a network or community of people who share your sense of purpose and interests.



The lack of relationships in any of these dimensions can make someone lonely. So, for example, someone can have a supportive marriage and yet still feel lonely for friends and community.

Unlike the feeling of loneliness, which is subjective, isolation describes the objective state of being alone and out of touch with other people. Isolation is a risk factor for loneliness simply because you are more likely to feel lonely if you rarely interact with others. But being alone does not necessarily translate into the emotional experience of loneliness. One can enjoy solitude. What defines loneliness is the internal comfort level.

While isolation is a risk factor for loneliness, ME/FM is a risk factor for isolation. The lack of public understanding, the stigma and the disbelief of ME/FM can makes it hard to interact with people. With lack of available energy, it can be hard to maintain existing relationships or build new ones. And, as pointed out in the reflection, the concern about catching Covid adds to the difficulty.

The Canadian Community Health survey tells us that Canadians with ME/CFS or Fibromyalgia experience high rates of having a very weak sense of community belonging compared to other chronic condition groups and even compared to the elderly. Having a weak sense of community belonging is not quite the same thing as being lonely (because one can recognize weak community links and not be upset by it), but it does indicate that ME/FM presents a major problem.

What can be done to reduce ME/FM loneliness? Well, in the long run, better health care, more understanding, and more supports will make a big difference. In the shorter term, recognizing the chain from ME/FM to isolation to loneliness will help. Recognize that ME/FM can be a factor in having fewer social contacts, and recognize that having fewer social contacts does not mean that you have to feel lonely. Do what you can to take care of the social contacts you have. Don't be hard on yourself.

Post-Exertional Malaise (PEM)

From the Canadian Consensus Criteria by Carruthers et al.

Post-Exertional Malaise and/or Fatigue: There is an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, post exertional malaise and/or fatigue and/or pain and a tendency for other associated symptoms within the patient's cluster of symptoms to worsen. There is a pathologically slow recovery period–usually 24 hours or longer.
http://mefmaction.com/images/stories/Medical/ME-CFS-Consensus-Document.pdf

From the U.S. Center for Disease Control & Prevention (CDC) webite

Post-exertional malaise (PEM) is the worsening of symptoms following even minor physical or mental exertion, with symptoms typically worsening 12 to 48

hours after activity and lasting for days or even weeks. PEM can be mitigated by activity management (pacing). The goal is to avoid PEM flare-ups and illness relapses by balancing rest and activity.
https://www.cdc.gov/me-cfs/healthcare-providers/clinical-care-patients-mecfs/treating-most-disruptive-symptoms.html

From Beyond Myalgic Encephalomyelits, Clinicians Guide, National Academy of Medicine

Questions to ask concerning post exertional malaise

All questions should explore frequency and severity

- What happens to you as you engage in normal physical or mental exertion? Or after?
- How much activity does it take you to feel ill?
- What symptoms develop from standing or exertion?
- How long does it take to recover from physical or mental effort?
- If you go beyond your limits, what are the later consequences?
- What types of activities do you avoid because of what will happen if you do them?

PEM may be delayed related to the trigger. Consider asking patients to keep a diary for a week or two, documenting act
https://nap.nationalacademies.org/resource/19012/MECFScliniciansguide.pdf

From people with ME (we asked for descriptions on Facebook)

Like your battery is depleted. You cannot get up to do things even if you wanted to. Limbs feel very heavy. Then you need to rest until you charge it up again.

For me the exhaustion can make it so that I can’t breathe out against my CPAP airflow. Even when I don’t use the CPAP I can feel like I can’t breathe, that my ribs ache.

I feel that the exhaustion is so intense as if there are weights on each one of my body parts, including my head. Even trying to eat becomes a challenge.

I liken it to the gravity being turned up making it hard to move. Walking feels like I am walking on the floor of a bouncy castle, or through waist deep water.

To me it feels like a complete shut down of physical, mental and emotional function. I compare it to the worst flu or hang over anyone has had. Even a near death experience. Something you will never recover from. The waiting to return can be a lonely journey.

It’s more a feeling of being very very sick than just fatigue. It feels like when you have the flu and you feel so sick and fatigued and in pain everywhere that you can hardly think, hardly move.

The other day I painted a bench. Doesn’t seem like a difficult thing to do. I felt okay during the exercise but within an hour afterwards I felt weighed down like there was an excesses of gravity. Then my muscles began to tighten and within 2 hours of painting that bench I was in pain from head to toe. Extreme fatigue also, to the point that thinking clearly is difficult. I felt that way for about 36 hours. The day after painting the bench, I was nearly useless from such fatigue and pain. It’s not possible to push through that kind of malaise. One can only endure it and hope it doesn’t last too long.

It’s horrid. Like every inch of my body is betraying me. Crying out to move because it’s stiff but screaming if I do dare to move. Like I have weights strapped to my limbs and heavy elastic bands dragging me to the floor.
Keeping my eyes open is impossible. What’s worse is you lay there, needing to eat to get some energy to move but having no energy to get food.
Taking so long to eat its always cold, unable to chew because the muscles in your face are too tired.
But I think the worst is the phychological pain after when your able to move and see people. They just don’t understand the complete devastation you have been to. ‘I’m tired too’ .. ‘but you’re ok now?’ Noone sees you at your lowest so it has to be described to them and words never ever do it justice.

It is as if the life force has been sucked out of your bones.

I call PEM my “limp noodle” days. Like if you were to throw cold, cooked spaghetti against a wall and it slowly succumbs to gravity. The days that a bathroom is too far. That flexing your muscles to get out of bed is a monumental task.

Like you are not sure there is enough energy in your body to keep your heart beating.

PEM - When my heart rate is 20-40 bpm faster while laying down, my lungs are ‘grabbing’ for air, I feel prickles under my skin all over, sparkles in my vision & my urine turns white. Any movement is done slowly & carefully on a ‘must be done’ basis only.

All of the above, six decades.

It’s like I have been poisoned and I’m slowly dying. Reasoning and desision making become so difficult. I lose focus on myself and start to spiral round the “Black hole” which is constantly tugging me in.

Nausea and dizziness combined with sudden narcolepsy and along with a cold clammy feeling.

Kind of like what I imagine severe altitude sickness feels like - which I understand is actually a good analogy for what’s happening on a biological level. Crushing exhaustion, nausea, struggling for air, struggling to coordinate one’s body, body temperature going wild, incredibly foggy/confused like one’s been drugged, and exerting oneself or trying to “push through it” makes it so much worse.

It’s like someone turned on a tap and drained all the energy out of your body to the point where you can hardly move or not move at all because you are so weak and your body feels so heavy.

Zip stamina for brain or muscle
My gut issues flare and can’t string a thought together
Need earplugs and eye mask and quiet, no motion

It’s like someone has poured lead into my blood stream. Everything is too heavy to lift: arms, legs, head, even eyelids. Every finger aches, and every toe. Propping myself up enough to sip some water without choking takes so much effort and causes so much pain, that I collapse back down afterwards, panting.

Sometimes it feels like someone drugged me while I was sleeping. My whole body feels heavy - like gravity is stronger. And that’s not even touching on the mental aspect of the fatigue.

Bone deep exhaustion joins brain fuzziness, body wide bruise ache/burning, any input of touch, light or sound is painfully overwhelming with nausea to top it off.

Some people in my circle had a bad few days after having the COVID-19 vaccine. I tell them it’s like that, but every day.

Soul sucking

International Fibromyalgia Conference 2022

The 4th annual Controversies in Fibromyalgia Conference was held virtually in May. Over 100 people from at least 25 countries attended.

The third conference, which was discussed in Quest 129, focused on central sensitization as the cause of FM pain. Within days of that conference, a study found that injecting IgG from someone with FM into mice resulted in mice having FM pain. This implied that the immune system is involved in FM. At the 4th conference, immune issues were included. This ties in with FM overlapping to some extent with long-Covid.

The concept of catastophizing came up too many times. The idea is that people are over-concerned about their pain and the over-concern makes the pain worse. A patient rep pointed out that society often does not acknowledge that an individual with FM is in pain, forcing them to over-state the pain to get the needed attention.

The Israeli patient group talked about going to court to get FM built into their health and disability system. The Brazilian group talked about persuading their health and disability systems to include FM. The European Network of Fibromyalgia Associations asked national organizations whether their countries produced FM statistics, had FM guidelines for clinicians, and included FM in their disability coverage. To quote the report:

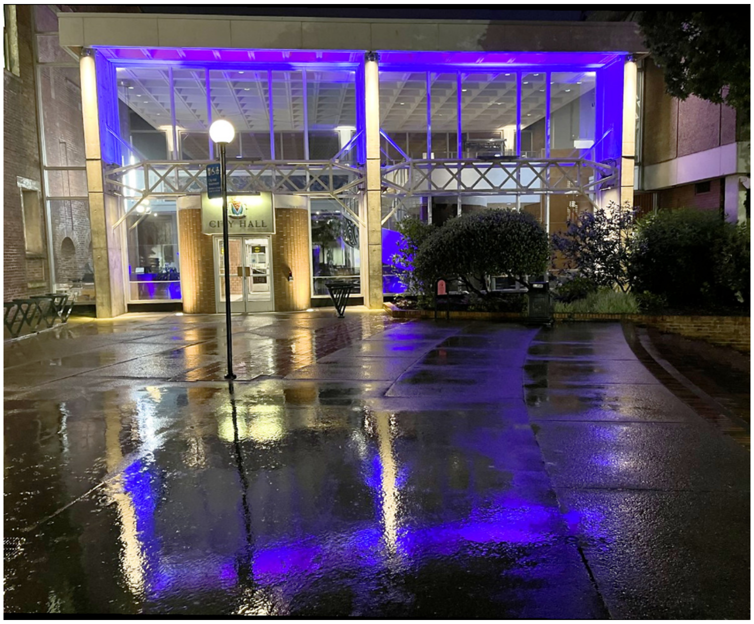
Through the study we can see how there is a lack of knowledge among national politicians and the profession and a consequence of this is a substandard national European health insurance system and an insufficient individual patient care. These shortcomings in society cause profound deterioration for people/patients with FM which affects working life, the family and provides a low quality of life. In addition, with enormous costs for the European countries.

https://drive.google.com/file/d/1DaBUFJo3XIfH0iaU4P2k7SHZPsXnfdSL/view

ME/FM International Awareness Day 2022 - Victoria, BC

MEVA Sponsored a City of Victoria ME/CFS and FM Proclamation and Requested the Legislature Grounds Light Up in Blue for ME.

Victoria City Hall was Lit Up in Purple for FM.



Your Housing Experiences

Housing has become a topic of interest for the federal government.

We would like to bring forward housing issues important to the ME/FM community.

Could you help us? Email, write or phone us about your housing experiences, or put something on our Facebook page. We will compile the information and share it with government. We will also include the information in our fall newsletter.

http://mefmaction.com

http://www.facebook.com/MEFMActionNetwork

NATIONAL
ME/FM
ACTION NETWORK
SINCE 1993

NEW MEMBERSHIP or RENEWAL fees

ANNUAL MEMBERSHIP FEE :
$30.00 per year including quarterly newsletter Quest

IN ADDITION, I would like to donate *$____________
to help with the many projects of the National ME/FM Action Network.
**Tax Receipt issued for all donations*

TOTAL PAYMENT:

$______________________

PAYMENT OPTIONS

☐ Cheque
Please make Cheque Payable to the:
NATIONAL ME/FM ACTION NETWORK

☐ VISA

☐ Master Card

☐ Other ________________

Card Number:

____

Expiry Date:

month ______ year ________

CVV________ (3 digit code on back of card)

Name on Card:

____

Signature:

____

☐ I would like to be a member.
Please waive the annual fee.

MEMBERSHIP APPLICATION or RENEWAL FORM

For online application and renewals go to MEFMaction.com

Date: ____________________

Name / Organization

____

Contact Name ___________________________________

Address ____

____

City ____

Province/State ____________Postal Code/Zip ____________

Country ____

Email ____

Phone ____

Website ____

☐ Please send news updates to my email address

☐ **Do not** send news updates to my email address

____

☐ Please send an electronic version of the Quest newsletter

☐ Please send the Quest newsletter to my mailing address

MAIL FORM & PAYMENT TO:

NATIONAL ME/FM ACTION NETWORK
512-33 Banner Road
Nepean, ON K2H 8V7

THANK YOU FOR YOUR SUPPORT!

CREDIT CARD TRANSACTIONS CAN BE FAXED TO 613-829-8518

Our phone number is 613-829-6667