www.mefmaction.com Quest 117, Winter 2018 mefminfo@mefmaction.com

Reflecting the Public Interest

Thanks to Lydia for looking after the last issue of Quest, giving me some time off this summer.

It was good to have a rest because it has been a busy autumn. We have been communicating with the federal officials in a number of areas, including:

- with CIHR about research funding
- with CPP-Disability about their new forms and guidelines
- with the House of Commons committee about the new Accessibility Legislation
- with Statistics Canada about upcoming statistics
- with the Minister of Health's office about ME/FM needs

We have been hitting barriers, especially in the area of research funding. That is why we are looking at a different approach – suggesting that our members and supporters talk directly to Members of Parliament. The job of MP's is to reflect the public interest.

This is a perfect time to talk to them. Every autumn, the government asks for ideas for the next budget. We think that funding for ME/FM research is a priority. But research cannot operate in a vacuum. Research needs awareness and it needs clinicians. So we put together a proposal that combines these priorities.

While the federal government has responsibility for aspects of healthcare, provinces and organizations have roles as well. One very important initiative is the Ontario Task Force. We were thrilled to learn that the Task Force, which had been suspended when the election was called last May, is back up and running, with a report due in early 2019.

Some Canadian Contributions to ME/FM Over the Last 25 years

A compilation of studies on ME/CFS published in 1993 by Dr Byron Hyde. Lydia Neilson had a major role in putting the book together.

The publication of the Canadian Clinical Criteria for ME/CFS and for FM in 2003. Lydia spearheaded the projects, and Canadians figured prominently on the expert panels.

The publication of statistics from the Canadian Community Health Survey by our organization, increasing understanding of the experiences of patients and the impact of ME/CFS, FM and MCS.

The conference hosted by Dr Stein (Calgary 2008), the international research and clinical conference hosted by our organization (Ottawa 2011) and May's research conference in Montreal.

Specialty clinics in Vancouver, Toronto and Halifax.

The development of information for clinicians and patients by Dr Bested, Dr Stein, Valerie Free, our organization and others.

The 2017 report of the Ontario Task Force on Environmental Health which outlined the needs of patients with ME, FM and MCS and steps needed to move forward. Also very important are the reports that persuaded the Ontario government to establish the Task Force.

Research from Canadian universities into the pathogenesis of ME in areas including epigenetics, micro-RNA, and immunology.

Contents

Book Review

CLASSIC PACING For a better life with ME

By: Ingebjorg Midsem Dahl

Review by Lydia Neilson

Hardback $42.73 Canadian

Spiral bound $28.90 Canadian

Ingebjorg lives and was born in Oslo, Norway in 1979. She contracted ME (Myalgic Encephalomyelitis) in 1983 and became interested in coping and management of her illness as there was no medical treatment for ME at that time. At 18 Ingebjorg wrote her first article on pacing and was published in five countries.

Her illness started to deteriorate drastically in her late teens and she had to give up her university studies. Her focus became getting her ME under control. By trial and error, she got to know what made her illness better or worse by pacing. Once she got that under control for herself, she published a book on pacing in Denmark to help others. It has now been translated into English.

The first thing I noticed about the Spiral bound book was how easy it is to turn the pages and keep it lying flat. The writing itself is easy to read, well-spaced and therefore the pages don't look overwhelming. It is immediately obvious that she understands what ME is like. Quoting Ingebjorg about what Rest means, for example, "For a healthy person things like watching TV, listening to music or reading, are forms of resting. For people with ME that have less energy to use, those sorts of things must be counted as activities."

Ingebjorg covers all aspects of ME and explains how to manage and cope with everything that a person goes through. Her observations are right on target and worthwhile following. I can't think of anything she left out. It is a very impressive strategy for coping.

This book can be purchased at Book Depository located in the United Kingdom online but can also be purchased via Amazon.

https://www.bookdepository.com/Classic-Pacing-for-Better-Life-with-ME-INGEBJORG-DAHL/9781999641818

Understanding CIHR

The failure of CIHR to fund ME/FM research is a serious issues that need to be discussed openly.

Six years ago, the National ME/FM Action Network told CIHR that, based on the prevalence and impact of ME, our estimate of fair CIHR research funding would be around $10M per year, and that this did not take into account retroactive entitlement for all the years ME had not been funded to that level. We gave another $10M/year estimate for Fibromyalgia, again pointing out that this estimate does not include retroactive entitlement.

Just to clarify, our goal is research, not money per se. The dollar figure is to give an idea of the scope of the research need. We are not talking about one or two studies. We are looking for a suite of studies looking at different aspects of ME and FM, in the same way that there are a suite of studies for areas like Multiple Sclerosis, HIV/AIDS or Autism.

Further, nobody has a greater interest in good science than the patient-caregiver community. Having said that, we do not believe that every project will be fully successful and every dollar will be spent optimally. This does not happen in any area of research.

In the latest fiscal year, there is not a single funded study listed for ME and only two small studies listed for FM.

The people at CIHR have been very nice. So why can't they get research programs going? As I ponder that question, my mind turns back to a conversation I had with a CIHR employee some years ago.

When I arrived at the CIHR reception desk, I had to show identification and sign in. The person I was meeting was called to meet me at reception She came out from a locked area, then took me back in through locked doors. Why the security? I asked.

She explained that CIHR funds only a small percentage of the amount requested – something like 10 or 15 percent. Funding decisions are serious decisions that can affect the careers and lives of researchers.

In 1992, she went on, a researcher was unhappy and had a meeting with NSERC, one of the three main federal funding agencies. (CIHR funds health research, NSERC funds science and engineering research and SSHRC funds social science research). Several days later, he shot and killed four of his colleagues at Concordia University's computer science department and injured someone else. He is still in jail. And his complaints about research funding were found to have some substance.

Maybe I am putting too much emphasis on this event, but it seems to me that it had a major impact on the culture at CIHR. It seems that CIHR wants to make sure that its decisions will be broadly acceptable to the research community and won't antagonize anyone.

The CIHR culture is reminiscent of the culture of a country club where individuals have to meet the approval of existing members in order to join, have to start as junior members and work their way up, and are expected to accept the way things are done without rocking the boat, where the club is friendly but a little out of touch with the wider community.

The problem is that CIHR is allocating public money – over $800M this fiscal year. This money is being allocated with the objective of keeping peace in the research community, but does this reflect the public interest? In most circumstances, public and researcher interests would more or less line up. But they don't line up for ME and FM. The pubic interest says that ME and FM need major funding, while many researcher do not see ME/FM as valid research areas. Further, researchers might see that funding for ME/FM could take away funding from their preferred health area.

So how is this impasse going to be resolved?

We can continue to play by the existing rules, applying for junior membership and hoping to work up from there. We are learning more about CIHR is looking for and CIHR is making small adjustments recognizing the challenges that the ME/FM area face. Realistically, however, this could take years and the ME/FM community should not have to wait.

Alternately, someone can take the bull by the horns and designate funding, perhaps the Minister of Health or perhaps CIHR leadership. ME/FM research is a valid research area that has been so badly served that designated funding is warranted.

We only hope that a fair and meaningful research program is put in place as soon as possible.

Pre-budget Submission

Every autumn, the Government of Canada asks Canadians what they would like to see in the next federal budget.

We are sure that everyone in the ME/FM community would like to see investment in ME/FM research.

As we were writing up a submission around research funding, it quickly became clear that research cannot proceed without clinical services or awareness. So we expanded the submission to include all three.

The work of the National ME/FM Action Network would be a lot simpler if we dealt with only ME or only FM. However, we believe that the two are closely related despite their different histories. We struggled with how to balance ME and FM in the submission. We chose to focus on ME because it is more ready-to-go, especially with international initiative getting underway. We have not forgotten FM, and we will not forget FM as we move forward. In the same way that research can't go far without clinical services and awareness, the work around ME will not be able to go far without examining and addressing the related illnesses.

We are attaching the pre-budget submission in English and French. We have asked you to take copies of the submission, write a note on the back, sign the note with your name and address and forward it to the Minister of Health, the Minister of Finance and your local member of Parliament.

Snail mail is more effective than email, but email was more effective than not sending anything.

A signed letter is more effective than an anonymous letter but if you are not ready to go public, then an anonymous letter is better than no letter at all.

We are also attaching letters already sent by two of our supporters. They gave us permission to use their names, but asked that we remove their address. You can use these letters as models. Please don't feel that you have to write as much or as eloquently as they did or even cover the same content. What is important is that you write from your heart.

The sooner the better, but please send this by mid-January because the budget decisions are finalized then.

Address for the Minister of Health

Hon. Ginette Petitpas Taylor
House of Commons
Ottawa, Ontario
K1A 0A6

Email:Ginette.PetitpasTaylor@parl.gc.ca

Address for the Minister of Finance

Hon. Bill Morneau
House of Commons
Ottawa, Ontario
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Email:Bill.Morneau@parl.gc.ca

Address the envelope to your MP as follows:

[Your local MP]
House of Commons
Ottawa, Ontario
K1A 0A6

You can look up your MP's name here https://www.ourcommons.ca/Parliamentarians/en/members

Enter your postal code on the right side of the page just above the first row of photos.

For digital copies of the submission in English and French go to our website at :

http://mefmaction.com/index.php?option=com_content&view=article&id=549

Please let us know what you hear back from the Ministers and your MP. Thank you!

NATIONAL
ME/FM
ACTION NETWORK

Government of Canada Pre-budget 2019/20 Consultations

Myalgic Encephalomyelitis: Addressing a blind spot in the health care system

Prepared by National ME/FM Action Network
A registered charity working on behalf of
Canadians with Myalgic Encephalomyelitis and/or Fibromyalgia since 1993

From time to time the health care system develops blind spots. It did so with Autism, ascribing it to poor mothering rather than accepting it as a health condition. It did so with Multiple Sclerosis, ascribing it to hysteria rather than accepting it as a health condition. And it has done so with Myalgic Encephalomelitis (ME). Thirty years ago, ME was given the trivializing name Chronic Fatigue Syndrome. Shortly thereafter ME was ascribed to being out of shape and being afraid of exercise. In other words, ME was considered to be inconsequential and the patient's fault rather than a health condition.

The idea that the patient is to blame for ME has finally been rejected internationally. Science is showing ME to be a chronic multi-system disease which includes impairment of the aerobic energy production cycle, meaning that people cannot generate the energy they need. Pushing oneself makes symptoms worse, leading the top US medical organization to refer to ME as Systemic Exertion Intolerance Disease.

The lack of recognition, respect, services and research for ME has had a devastating effect. The ME community - over half a million Canadians at last count - is dealing with poor health, poverty, food insecurity, social isolation and suicidal thoughts. ME occurs more frequently in women than men, which is likely a factor in its troubled history. ME occurs at all ages including young people, but it disproportionately affects people at the time of life when they would be raising families and active in the workforce. The burden of disease for ME is substantial, a little higher than the burden of disease for autism or MS according to a US study.

Canadian society and the economy are paying a very high price by ignoring ME. Government leadership and funding are needed to overcome the lack of recognition, respect, services and research. We recommend that the government aggressively pursue three parallel activities and that funding for these be included in the 2019/20 budget:

Fill the research void: CIHR has allocated $800M+ to 6,000+ research studies this fiscal year and not one of the study descriptions even mentions ME. Government needs to commit to substantial, dedicated, long-term funding to entice researchers into this area so that research into cause and treatment can take place.

Fill the gap in health services: A government priority is ensuring that Canadians have access to appropriate and effective health services. When ME is included on the Canadian Community Health Survey, it almost always has the highest rate of unmet health care needs among the chronic health conditions surveyed. Action is needed to address these unmet needs.

Raise awareness: Action is needed to overcome the widespread stigma and misrepresentation that surrounds ME. Awareness is needed among health professionals so that they recognize cases and give patients sound advice. Awareness is needed among social support providers since supports like income replacement or home care are key to allowing people to look after their health. Awareness is needed among employers, schools, family members, colleagues and the public so that patients are understood and not pushed or isolated.

Note: Fibromyalgia is another neglected area in the health care system. FM frequently overlaps with ME. Many of the initiatives taken to address ME issues could apply to FM as well.

November 2018

Budget 2019-20 – Consultations prébudgétaires du gouvernement du Canada

Encéphalomyélite myalgique : combler un trou dans le système de santé

Préparé par le National ME/FM Action Network
Organisme de bienfaisance enregistré qui depuis 1993 a pour mission
l'assistance aux malades du Canada souffrant d'encéphalomyélite myalgique et/ou de fibromyalgie

Il arrive qu'il se creuse des trous dans le système de santé. Pensons à l'autisme, attribué à des défauts du maternage plutôt qu'accepté comme un problème de santé. Ou à la sclérose en plaques, attribuée à l'hystérie plutôt qu'acceptée comme un problème de santé. C'est aussi le cas de l'encéphalomyélite myalgique (EM). Il y a 30 ans, on lui a donné le nom trivialisant de *syndrome de fatigue chronique*. Presque dès l'origine, on l'a expliquée par la méforme physique et la crainte de l'exercice. Autrement dit, une maladie de peu d'importance et imputable aux malades plutôt qu'un problème de santé.

À l'international, on a finalement rejeté le concept de la responsabilité des malades. La science a montré que l'EM est une maladie chronique multisystémique où le cycle de production de l'énergie aérobie est attaqué : les malades sont incapables de suffire à leurs besoins en énergie. Tenter de dépasser ses forces aggrave les symptômes, ce qui a amené le plus important organisme médical américain à y référer comme la *maladie de l'intolérance systémique à l'effort*.

Le manque de reconnaissance, de respect, de services et de recherche a eu un effet dévastateur. Les malades – plus d'un demi-million au Canada, au dernier décompte – composent avec des problèmes de santé, pauvreté, insécurité alimentaire, isolement social et pensées suicidaires. L'EM touche davantage les femmes, probablement un facteur de sa difficile histoire. Elle affecte des gens de tout âge, y compris des jeunes ; de façon disproportionnée, cependant, elle frappe des gens sur le marché du travail, en train d'élever leur famille. Selon une étude américaine, son fardeau est considérable, légèrement supérieur à ceux de l'autisme ou de la sclérose en plaques.

La société et l'économie canadiennes paient chèrement cette ignorance. Pallier le manque de reconnaissance, de respect, de services et de recherche passe par le leadership et les fonds du gouvernement. Nous recommandons trois voies parallèles où mener des actions dynamiques et en inclure le financement au budget 2019-20 :

Combler le vide de la recherche – Lors du présent exercice fiscal, les IRSC ont alloué plus de 800 millions à plus de 6000 études, dont aucune ne faisait seulement mention de l'EM. Le gouvernement doit garantir un financement substantiel spécifique à long terme pour aviver l'intérêt du sujet pour la recherche, de façon à ce que s'effectuent des études sur les causes et le traitement de la maladie.

Combler les trous des services de santé – L'une des priorités du gouvernement est l'accès de la population canadienne à des services de santé adéquats et efficaces. Quand l'*Enquête sur la santé dans les collectivités canadiennes* inclut l'EM, cette maladie est presque toujours la maladie chronique dont les besoins en soins de santé sont les moins comblés. Pour combler ces besoins, il importe d'agir.

Agir pour sensibiliser – Il faut agir pour vaincre la stigmatisation et la méconnaissance entourant l'EM. Il faut sensibiliser le monde de la santé, pour que la maladie soit décelée et que les malades reçoivent des conseils adéquats. Il faut sensibiliser le monde du soutien social, car les mesures d'assistance comme le remplacement du revenu ou les soins à domicile sont essentielles pour permettre aux malades de voir à leur propre santé. Il faut sensibiliser le monde de l'emploi et de l'éducation, les familles, les collègues et le grand public, pour entourer les malades de compréhension plutôt que de les rejeter ou les isoler.

Note – La fibromyalgie est elle aussi en butte à la négligence du système de santé. Les deux maladies se recoupent souvent. Beaucoup d'initiatives pour remédier aux problèmes de l'EM pourraient aussi s'appliquer à la FM.

Novembre 2018

November 8, 2018

Hon. Ginette Petitpas Taylor
Minister of Health
House of Commons
Ottawa, ON K1A 0A6

Re: Pre-Budget 2019/20 Consultation Input

Dear Minister:

I want to draw your attention to a pre-budget consultation proposal by the National ME/FM Action Network (attached) and request that you include some amount of new funding in this area during the 2019/20 budget cycle.

The proposal highlights the need to commit long-term funding to research on Myalgic Encephalomyelitis (ME) and Fibromyalgia (FM), address the unmet health care needs of people living with these diseases, and to raise awareness and reduce stigma associated with these diseases.

This proposal is vitally important to me as a person living with FM and many like me. I also have Parkinson's Disease and can equivocally say that FM is misunderstood and the available support pales in comparison to that available for people living with Parkinson's. There is still significant stigma associated with the disease which has been considered trivial and "all in the head" of the patient – just like Multiple Sclerosis and Autism were considered in the past. FM experts know better now and must ensure health providers make good treatment recommendations, just as patients need the hope that comes from research toward a cure! The announcement of dedicated funding would fill a significant need and perhaps reduce the burden of this illness on the healthcare system.

While I have already forwarded a similar letter to the Minister of Finance and my local M.P., I would ask that if possible you encourage your Deputy Minister and policy staff to include dedicated ME/FM funding in the upcoming budget.

Thank you in advance for your consideration.

Sincerely,

Dorothy L. Mercer

Dorothy Mercer

November 8, 2018

Hon. Ginette Petitpas Taylor
Minister of Health
Confederation Building 356
House of Commons
Ottawa, ON K1A 0A6

Since the annual federal budget will be considered soon, you are in a position to help an estimated 1 million fellow Canadians who suffer as I do from ME/FM (commonly known as Chronic Fatigue Syndrome – CFS - or Myalegia Encephalomyeletis) and Fibro Myalgia) by supporting research and health services.

This is not an airy-fairy disease, a figment of our imaginations as some medical professionals and politicians used to believe. It has a panoply of painful and debilitating symptoms that incapacitate us from supporting ourselves as contributing citizens not to mention destroying the quality of life for ourselves and our families.

I attended a national conference on ME/FM in New York City and learned a great deal about the global outlook on this illness. While interest has grown during the 25+ years that I have suffered from ME/FM, we Canadians are not even close to achieving a level of acceptable care and knowledge.

Funding research is important because:

1. Research on ME is at a potential breakthrough point regarding causes and treatments
2. Research on FM is in its infancy but shows promise to be as treatable as other inflammatory nerve conditions such as rheumatoid arthritis
3. Several European nations especially Sweden are learning apace so research information needs to be better developed here and better shared

Funding health services is important because:

- The lack of appropriate care here compared to New York City, where I recently moved from, is considerable. It took me 17 months of living here (as a Canadian citizen) to find even the minimum of necessary care to prevent my total relapse.
- Apart from me personally, about 5% of the Canadian population has already been diagnosed with this illness – and untold thousands as yet remain undiagnosed.
- Research on people with disabilities shows that about half of all people diagnosed with ME/FM are too disabled to look after themselves. There is unnecessary cost to patients, their families and to society when they lack proper medical treatment.

Funding to promote awareness is important because:

- Social support providers need to be better informed so as to provide appropriate support that is more efficient and ultimately can reduce costs
- Medical professionals need to become more aware how to treat patients, as I unfortunately found out – delays in my treatment have caused unnecessary costs to address my symptoms separately instead of getting at the root causes
- Patients like me suffer from social stigma even from our own families, which reduces the emotional support that we need to recover and thrive.

I would appreciate being informed on budget hearings and/or receiving relevant information on progress being made on these issues.

Thank you! Merci!

Sincerely,
Carolyn J. Curran

Dr Alain Moreau from the University of Montreal and Dr Ron Davis from the Open Medicine Foundation were speakers at the Second Annual Community Symposium on the Molecular Basis of ME/CFS at Stanford University

Why does my accent become more pronounced with a Migraine?

Along with ME/CFS, I started getting migraines in 1986. I should be able to recognize the warning signs before the migraine and cope with them by now. The funny thing is, each time a migraine happens, it is as if it is for the first time.

Once the full-blown migraine shows its ugly head, I get enlightened and know the other symptoms are related to the migraine. For some reason I can't get it to my head it is the migraine until it actually arrives.

With me, a few days before, my eyes have even more trouble coping with lights and noise, I start to have difficulty completing thoughts, I stumble over my words and my thinking process slows down. I always have to absorb conversations before they seem to hit my brain and I can respond. Difficult enough, and now I started noticing my Dutch accent which is not too noticeable until I am coming down with a migraine. Why is that?

I usually don't notice how I speak but when the migraine appears, I become very conscious of the fact that, although I don't sound like I just arrived, I certainly don't sound like I've been here a long time. This may not seem important to some people but I find it utterly frustrating and embarrassing. I try to avoid conversations wherever I possibly can and come across as an unusually great listener.

Lydia

20 'weird' requests that help people manage their Fibromyalgia

For people with Fibromyalgia, these requests might not seem weird at all.

Thanks to the website the Mighty and author Paige Wyant

1. "Do not tickle me. Tickling me is excruciating, never fun and it's literally made me avoid certain friends. Not because I was trying to be petty, but if I specifically (and often emphatically) had asked someone not do it, and I've said 'it hurts, badly,' and they do it anyway… I have had to do it unless I want a flare-up because I'd hung out with them. My husband is credited with never once in 20 years trying to tickle me, which seems like a small request, but something I greatly appreciate." – Nina H.
2. "[I ask] not to startle me out of sleep because it's a guaranteed flare." – Sarah M.
3. "Don't judge me if I don't want to sleep anywhere else but home… I need my 10 pillows to buffer every pain point at night… and no, I'm not being over-dramatic. If you want me to stay out prepare to take me to the ER in the morning because of the pain and all my joints locking." – Jenna-Lee E.
4. "Please put the windows up in the car, the light breeze you are enjoying is excruciating on my skin and the noise is making it impossible to think." – Jayne D.
5. "[I ask] people to please turn down the TV or radio because sound is too much to handle. Also, asking that the curtains stay closed so I don't get too much light and end up with sensory overload. Everyone except for my husband looks at me like I'm 'insane'… Yet, these issues can become physically painful very quickly." – Diana E.P.
6. "I always ask for a booth at restaurants because they hurt less to sit at for longer periods of time. At home we eat on the couch because regular chairs hurt or are uncomfortable to sit at." – Krystina K.F.
7. "I have asked people to let me finish my sentence. With my fibro I get migraines. My migraines causes a severe stutter almost every day. People think they are helping me by finishing my words or sentences when really it can get frustrating because I feel like I'm incapable of speaking." – Mackenzie P.

8. “When I’m in the kitchen my roommate can’t be. It’s too small to avoid bumps.” – Brody L.
9. “[I ask] to be moved to the ‘freezing’ patient room at the doctor’s office, which is too cold for everyone else but is perfect for me because I always feel like I’m burning up. Being in a 70-degree room is too hot for me – I sweat, and get more dizzy and nauseous than I already am on a daily basis.” – Gwendolyn C.R.L.
10. “I have to ask that we keep the heat down in the winter and the air at a low temperature in the summer because it is easier on me to regulate my body temperature this way. I have to keep popsicles or ice cream on hand so I can have one after a hot shower. Otherwise I will not be able to cool down.” – Vinnie B.
11. “I always insist on sitting in the middle of the theater, in the middle of the row (middle middle) so I don’t have to sit with my neck at any odd angles. Partially due to mild cranial-cervical instability due to being born with EDS and partially due to FMS chronic pain. It got really bad after I was rear ended in junior high.” – Eileen H.
12. “[I ask] for a blanket to wrap myself up in when it’s 32°C [89.6°F]. I can’t regulate my body temperature – I’m either freezing or boiling, and the outside weather never really dictates which one.” – Alexandria P.
13. “[I ask] for a handshake instead of a hug from friends or loved ones. Or instead we do ‘gentle hugs’ which tend to come off a smidge awkward because people then are concerned about me/didn’t actually realize I was in pain.” – Geena D.
14. “I only will get a vehicle if it has heated seats now because they make driving tolerable. Some people think it’s weird that I won’t buy a car if it doesn’t have heated seats.” – Krystina K.F.
15. “[I ask] people to chill out because their hostility is stressing me, leading to a flare.” – Sarah N.
16. “[I ask] coworkers to turn off the lights to avoid migraines during meetings. And being bundled up all year at my desk and asking people to [not] ask me questions about it.” – Courtney F.
17. “[Please don’t] use the vacuum around me or at the very least allow me to insert ear plugs before you try. The low tone overwhelms me and makes me cry (like nails on a chalkboard).” – Toni C.B.
18. “[Don’t] wear/use a certain scent that will trigger my migraines.” – Terri D.
19. “‘Can you pull my legs or arms please?’ I find if someone pulls my limbs it eases the pain mostly or causes a crack that eases the pain for a bit. Usually [I ask] my partner but I’m not shy on asking friends or work colleagues.” – Kirsty A.
20. “Always text me before you call me. I’ll tell you if I have the strength for a convo.” – Toni C.B.

https://themighty.com/2018/11/questions-requests-people-with-fibromyalgia-make/?utm_source=newsletter_fibromyalgia&utm_medium=email&utm_campaign=newsletter_fibromyalgia_2018-11-08

New Accessibility Legislation

The federal government introduced Bill-81, new accessibility legislation, this autumn and it is winding its way through Parliament.

We often talk about access to health care or access to education. When talking about disability issues, the word “access” or “accessibility” is often given a narrow interpretation. As a friend explained, if a hospital offers a service but you can’t get in the door because there is no ramp for your wheelchair or you cannot communicate with the doctor because you are deaf and there is no sign language interpretation, that is an access issue. If the hospital does not offer a particular service, that is a health care issue, not an access issue.

When you look at the Bill-81, the proposed Accessibility Act, you will see that its provisions are about access to buildings or websites or television or workplaces. You will not see provisions about modifying the Disability Tax Credit, adding health services, dealing with poverty, or increasing awareness which are changes to the services themselves, not access issues. You also will also not see provisions that are the responsibility of provinces or the private sector. The legislation is limited to matters within federal jurisdiction.

The National ME/FM Action Network wrote the House of Commons committee looking at the legislation expressing appreciation for what was included in the legislation and disappointment around what was not included.

Statistics Canada

Statistics Canada has advised us that the Canadian Community Health Survey for 2019 and 2020 will ask respondents if they have been diagnosed with Chronic Fatigue Syndrome and if they have been diagnosed with Fibromyalgia. It will not ask about Multiple Chemical Sensitivities.

The Canadian Community Health Survey has been an incredibly helpful source of information for us. It has provided evidence that people with a diagnosis of CFS and FM are dealing with serious disability, disadvantage and unmet needs. We therefore ask that, if you are contacted to participate in the survey, please do so.

We are well aware that many people would prefer that Statistics Canada use the term Myalgic Encephalomyelitis rather than Chronic Fatigue Syndrome. The problem is that not many Canadians use this term so ME would be dropped from the survey and we would be left without statistics. It is far preferable to have CFS statistics, then call for studies to determine how the diagnosis is made and what it means.

New CPP-D Application Processes

A new version of the Canada Pension Plan-Disability application form was released in August 2018. The purpose of the form is

- to collect administrative information about the applicant,
- to collect information to determine whether the applicant has made sufficient contributions to the plan to meet the eligibility requirements, and
- to collect information to help determine whether the applicant has a disability that is severe and prolonged as described in the legislation.

Two additional revised documents were released at the same time. The medical form asks for additional information to be used to determine whether the disability is severe and prolonged. The adjudication tool is a guide to the public and adjudicators describing how decisions around disability eligibility are made.

The new application form has done a very good job in collecting administrative information and the information to determine whether sufficient CPP contributions have been made. The National ME/FM Action Network is, however, concerned about the collection of information to determine whether the disability is severe and profound. We have outlined our concerns in the letter below, asking for a meeting to discuss our concerns. In a nutshell, we don’t think that they are asking the right questions.

For anyone in the process of applying using the new form, we suggest that you read chapter 4 of our CPP-D Application Guide very carefully and include any information that you think will help explain your disability, whether or not the information is directly requested on the application form. This could include the worksheets in the Guide, written descriptions of the problems you are encountering, and statements from family and colleagues.

Here is a letter sent to the Minister:

To: The Honourable Jean-Yves Duclos,
Minister of Families, Children and Social Development

The new CPP-Disability Application processes incorporate many improvements, but there are still problems for Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and/or Fibromyalgia.

The National ME/FM Action Network is a registered charity working on behalf of Canadians with ME/CFS and/or FM since 1993. Nearly a million Canadians have a diagnosis of ME/CFS, FM or both. These illnesses have high prevalence among people of working age and can be very disabling. Many people with ME/CFS and/or FM find themselves in the position of applying for CPP-Disability.

People with these illnesses should not be at a disadvantage in qualifying for CPP-D. The new CPP-D adjudication framework specifically identifies the adjudication of FM and ME/CFS cases as challenging, signalling that they are indeed at a disadvantage. We are recommending that a special meeting be held this winter to discuss the challenges.

Chronic Pain Syndrome is also identified as challenging. Chronic pain is a common symptom of these illnesses, but chronic pain can arise from other sources. We are copying the Chronic Pain Association of Canada and we would welcome their participation at this meeting.

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The National ME/FM Action Network believes that the CPP-D income should be available to every Canadian who has contributed to the plan and who meets the eligibility criteria. CPP-D payments are an important component of medical support. Many people have told us that they cannot concentrate on their health until their financial issues are resolved.

We also believe that CPP-D should be available to all eligible Canadians on an equal basis. It should not be slower, harder or more burdensome for people with ME/CFS and/or FM to qualify for CPP-D than it is for people with other types of impairment.

ME/CFS and FM have been seriously overlooked by the health services and health research systems. In the absence of validated diagnostic tests, diagnosis is currently based on clinical observation. Unfortunately, many health professionals are unfamiliar or even skeptical of these illnesses. However "It is the capacity to work and not the diagnosis or the disease description that determines the severity of the disability under the CPP." Klabouch v. Canada (Minister of Social Development) 2008 FCA 33, so medical opinion should not be determinative.

The CPP-D program released a new application form, a new medical form, and a new adjudication framework in August 2018. There are many good points about the new material. Our concerns relate to the information collected to determine whether the disability is severe and prolonged

The adjudication framework specifically identifies "Fibromyalgia, Chronic Pain Syndrome and Chronic Fatigue Syndrome" as problems.

... some conditions, such as Fibromyalgia, Chronic Pain Syndrome and Chronic Fatigue Syndrome will not have the traditional objective tests available to determine whether the person meets or continues to meet the "severe and prolonged" criteria. The adjudication of these cases can be a challenge.

This challenge can discourage applicants from applying and health care professionals from completing their form. It can also discourage adjudicators from approving applications, leaving applicants the choice of appealing or dropping their claim. FM, CPS and ME/CFS applications are at an immediate disadvantage.

The adjudication framework continues

In these conditions, evidence can be obtained from other sources, such as a vocational rehabilitation consultant, an occupational therapist, a physiotherapist, an employer, etc.

The people most familiar with the situation could be family, friends, former co-workers or supervisors, community members or homecare workers. Nowhere does the application form invite applicants to list names of people who are familiar with their experience and nowhere does it invite statements from these people.

The list of abilities on the new application form is confusing for people with ME/CFS and/or FM. The questions do not necessarily reflect workplace situations. For example, a person may be able to walk a block relatively well on most days if that is all the person had to do, but may not be able to walk sufficiently to get ready for work, get to work, walk around the workplace, and return home. Likewise, a person may be able to stare at a computer screen for 20 minutes in isolation, but may not be able use a computer even that long in a noisy workplace with frequent interruptions.

It surprises us that the functional capacity scale was not included as part of the application. The ME/FM community has found it to be a very useful tool in assessing disability.

While we appreciate the specific mention of fibromyalgia and fatigue in the textual examples, the examples do not fully link to work. Reading novels, washing hair and driving kids to sports activities are generally not work activities, though organizing thoughts, finding words and seeing clients certainly can be.

We are concerned about the evidence being elicited to determine whether the disability is prolonged. An optimistic doctor forecast could be wishful thinking on the doctor's part or an attempt to give hope to the applicant rather than a realistic prognosis.

We believe that these issues need discussion. Our suggestion is that a meeting be organized this winter consisting of patients, advocates and medical professionals familiar with ME/FM issues along with CPP-D staff. The goal would be to suggest fair, non-burdensome strategies for collecting the information needed to determine CPP-D eligibility. The discussions would be of benefit to both applicants and adjudicators. We can suggest the names of participants. You may wish to consider including the Chronic Pain Society of Canada as well.

On a different note: When reassessing eligibility, we understand that the onus is on the medical adjudicator to show that the recipient has improved and no longer meets the eligibility criteria. The adjudication framework suggests that the test is whether the person would qualify if this were a new application.

Margaret Parlor
President
National ME/FM Action Network

Local woman raises awareness of debilitating disease

The following article was published on Nov. 14, 2018. Thank you to Richard McGuire and the Osoyoos Times (BC), for allowing us to reprint it.

Some years ago, when Hilary Robertson was suffering from extreme exhaustion and continuous pain, she visited a medical specialist to try to pinpoint what was wrong.

"You're almost 70," he told Robertson, who was then actually 62. "Get on with your life. There's nothing wrong with you."

Since that time, Robertson has been diagnosed with myalgic encephalomyelitis (ME), a condition commonly referred to as chronic fatigue syndrome (CFS).

And she's become an advocate for people with this condition, which is still misunderstood in popular culture.

"There were jokes even on Jimmy Kimmel about yuppie flu and 'oh, I just don't feel like going to work today,'" Robertson said earlier this year in a talk to the Rotary Club of Osoyoos.

And while popular culture and even some medical professionals still see those with ME as malingerers, there is now widespread medical recognition that ME is a real and serious condition.

"It's a neurological disease that occurs in sporadic and endemic forms and affects over 560,000 Canadians," said Robertson. "The cause of the disease is unknown."

Some researchers believe it is caused by a virus that results in some, but not all, people developing the condition.

Robertson suspects that in her case it resulted from a viral infection that she and a group of others with her picked up in Victoria some years ago.

"Three of us were hospitalized," she said. "They could never figure out what we had, but in my view, that was the beginning of my disease journey."

After the specialist told her to get on with her life, Robertson gave it a try.

"That summer I pushed myself really hard thinking, 'maybe I'm crazy,'" she said. "This is not an unusual reaction for any patient. That's actually when I pushed all of my systems into what I would call 'under drive' instead of 'overdrive.'"

ME results in a continuous state of fatigue.

"No matter how long you sleep or how well you sleep, you wake up feeling exhausted," said Robertson. "You don't feel refreshed."

Sleep patterns are disrupted with patients often experiencing hypersomnia, or excessive sleepiness, during the day and insomnia at night.

"We sometimes say in the ME community that we have a battery and we never get it to charge to 100 per cent," said Robertson. "And when we take it down to five per cent, we don't just lie down. It can take three or four days, even a week or two, to bring yourself back up to maybe 60 per cent."

During that time, there is a cascading effect of symptoms, though not everybody experiences the same ones. Even mild exertion activities such as taking a shower or standing for a period of time can result in exhaustion.

Pain can be experienced in muscles and joints and it's often widespread and migratory in nature.

"It can be where you feel like you've got shooting knives all over you or it can be deep bone and aching muscles," she said.

There is neurological and cognitive impairment.

"We get very spastic, our legs don't necessarily work, our muscles go into spasms," she said.

When Robertson talked to the Rotarians, she sometimes had difficulty speaking due to irritable larynx syndrome triggered by the disease.

She acknowledged her talk would likely drain her battery, but she said it was important to get the word out.

"I will probably be at home for the next couple of days from this," she told the Rotarians. "I make choices about where I spend my energy, because I only have a certain amount of energy every month."

That can mean showering or cooking dinner instead of going for coffee with a friend or walking more than a block with the dogs.

While ME itself isn't fatal, it can contribute to cardiac conditions such as arrhythmia that might be. And it can lead some people to take their own lives.

The disease can affect all ages and both genders, but it tends to be predominant in women. And, for an unknown reason, it is more prevalent in people who are "type A," high achieving, quite fit and very active.

"You're going full tilt as I was with the expectations of life and work and community and it just stops you in your tracks," said Robertson, who was a university professor.

"I went from snowshoeing up on (Mount) Baldy for 10 km on the sides of those mountains to not being able to walk more than half a block," said Robertson. "I now can walk four blocks."

Obviously this disease, which can take years to diagnose and lasts for years, has a huge impact not just on the patients, but also on their families.

"It affects both John and me and all of our families," she said, referring to her husband, an active Rotarian.

And there are feelings of loss for the active life that is gone.

"I often find myself filled with grief on seeing a person running along the canal, playing pickleball, hiking the trails, walking their dogs and even planning vacations," Robertson says. "So often the response is, 'you are looking so well. You are getting better!' when in fact I am simply managing myself to a better degree."

A Canadian ME advocacy group calls itself Millions Missing Canada. Robertson said the term applies to the millions of people around the world with ME who are missing from their community, their life and family. But it also applies to the severe lack of research funding in relation to other diseases.

Robertson says that the Canadian Institutes of Health Research typically provides $158.58 per person for research funding for chronic diseases. ME gets 11 cents per patient, compared to $575 per patient for HIV research, she said.

It's taking time for awareness of ME to become more widespread, but Robertson sees signs of progress.

"My doctor has been phenomenal," she said referring to Dr. Elzaan de Witt. "She knew nothing about this disease when it first started, so it's been a learning journey for her also."

Other doctors are also becoming more aware.

Robertson points to the 2017 release of a documentary by Jennifer Brea called "Unrest" that documents Brea's own battle with ME that transformed her from a Harvard PhD student to someone who couldn't even sit in a wheelchair.

Robertson and her husband plan a showing of the film in their attempt to raise awareness.

And she's finding a new role as an ME advocate.

"It's funny, when one door closes another opens," she said. "I was teaching university, loved it, but couldn't do it any longer. I said to my doctor that maybe my next job is to become an advocate for this disease and so it's funny how that has been happening."

She's been receiving calls from such places as Smithers, Vancouver and locally from people waiting to be diagnosed or waiting to get into the Complex Chronic Diseases Program at BC Women's Hospital.

"My doctor has referred some to me (for conversation)," she said. "It is a very isolating, very lonely disease. It's a very confusing disease. But the world is getting smarter."

RICHARD McGUIRE

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