We are very excited that a ME/CFS research conference will be held in Montreal in May. The list of people speaking is amazing. There are researchers from six countries, clinicians that have contributed to many important documents, and patient leaders from various parts of Canada.

As one of the events, the National ME/FM Action Network will be holding an afternoon workshop. The topic of the workshop is addressing unmet needs for ME/CFS and FM. We will use the first report of the Ontario Task Force on Environmental Health as a starting point and are delighted that the Chair of the Ontario Task Force will join us. Another starting point is a survey of Canadian rheumatologists on their attitudes toward FM and FM management.

To support the workshop, we would like to draw on your experience. We have put a questionnaire into this newsletter asking about how you were originally diagnosed, whether people with FM have post-exertional malaise, about your experiences with specialists, and about research you would like to see. Send us your answers in any way that works for you.

We think that the Ontario Task Force report has a lot to offer. We would like to see services offered all across Canada. Therefor, we have created our on task force to expand on Ontario's work and to share their findings.

Elections are coming, and we encourage everyone to vote. We point out different ways of voting if you can't get to the regular polls. The Minister of Finance has written us with valuable information on how to complete Disability Tax Credit applications. And we thank lawyer Brent Handel for his article on dealing with disability insurers.

Disability Tax Credit Developments

A person can qualify for the federal government's Disability Tax Credit (DTC) in three ways

- by being markedly restricted in at least one of eight specified activities.
- by being significantly restricted in at least two of the eight specified activities (the cumulative effects provision)
- by needing life sustaining therapy.

The eight specified activities are seeing, hearing, speaking, thinking, dressing, feeding, walking and eliminating bodily waste.

A person with ME/CFS or FM will usually apply for the DTC under the cumulative provision. That means we have to figure out what is meant by significant restrictions. Marked restrictions are defined, but significant restrictions are not.

A person may be completely unable to walk. Alternately, the person may have difficulty walking. The person may walk slowly, have poor balance while walking, be limited in how much walking is possible, have pain while walking, or have after-effects of walking.

Marked restrictions in walking is defined as being unable to walk or walking very slowly. The other difficulties are not listed in the definition of marked restrictions. However, based on a letter we received from an official in the office of the Minister of Finance (who is responsible for the legislation), it appears that you can use the other difficulties as evidence of significant restrictions.

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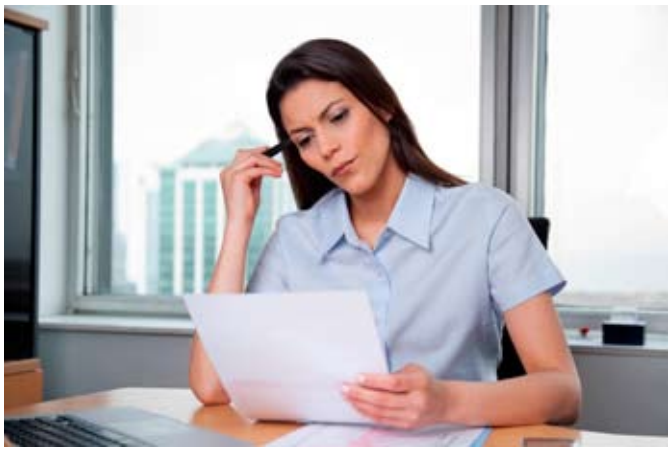
Specifically, the letter provides the example of someone who can walk but then must take time to recuperate and can think but for only a short period of time. Many people with ME/CFS or FM would relate to that situation. People with ME/CFS or FM might also be able to argue that they can dress or feed themselves, but that they can do these activities for only short periods of time and/or they need to recuperate afterwards.

This interpretation of the significantly restricted is not clear on the T2201 form so we will be asking for the form to be changed.



In the meantime, if you are applying for the DTC consider whether you have to walk, think, dress, or feed yourself in short segments and consider whether you need time to recuperate after doing these activities. If so, we suggest that you describe your difficulties on your application this way, that you show the letter from the Minister of Finance to your health provider and that you attach a copy of the letter to your application form with the relevant paragraphs highlighted.

The letter is posted here:

http://mefmaction.com/images/stories/News/NetworkNews/DTC-MinisterofFinance-0218.pdf

Research Conference, Montreal, May 2018

This conference is a result of a planning grant provided by the Canadian Institutes of Health Research. The principal investigator on the grant application was Dr Alain Moreau of Montreal. Co-investigators on the grant application include several researchers, several clinicians, and patient representatives from the National ME/FM Action Network, the Quebec ME Association AQEM and Action CIND.

The primary purpose of the conference is to strengthen US-Canadian collaboration in the search for the causes and mechanisms of ME/CFS and the search for biomarkers. Many important researchers from inside and outside Canada will be attending the conference. The goal is to build bridges between these researchers and to explore how to grow this research area. They will meet for presentations on Friday May 4. The patient representative co-applicants will be invited to join them. The researchers will meet for discussions on the morning of Saturday May 5 along with some patient group leaders.

The general patient community is invited on Friday May 4. The patients will start off with presentations jointly with researchers, then split off for special presentations and discussions, then come back together with researchers late in the day for more joint presentations.

In addition, the National ME/FM Action Network is planning a pre-conference on the afternoon of Thursday May 3 to discuss the challenges of building research and services for ME/CFS and FM patients. Patients are welcome to participate!

Finally, it should be noted that Dr Moreau is taking advantage of the expertise coming to Montreal to hold a medical education event for health providers in Quebec. This will take place on Thursday May 3. This event is not aimed at patients.

While there is a desire to record or webcast parts of the conference, it is not yet clear to what extent this will be possible if at all.

A website for the conference is here:

https://www.fourwav.es/view/647/info/

Registration for the conference closes on April 30.

Montréal 2018
Conférence sur l'EM/SFC

ME/CFS Conference
Montreal 2018

We must thank Dr Moreau and his team for the work they have done putting this conference together and thank CIHR for providing the grant which makes this possible.

Sponsors:

National ME/FM Action Network
Canadian Institutes of Health Research
Sibylla Hesse Foundation
Association Québécoise de l'Encéphalomyélite Myalgique (AQEM)
ME/FM Society of BC
Women's College Hospital
BC Women's Hospital and Health Centre
Nova Scotia Health Authority
Fonds de recherche Santé
Open Medicine Foundation
Action CIND
Millions Missing Canada
M. E. Victoria Association
TransMedTech Institute

In summary:

Day 1: (Thursday May 3)

Medical Education Conference – for Quebec health professionals only – all day

Workshop on meeting unmet needs – open to everyone – 1:15 - 5:00 pm

Day 2: (Friday May 4)

Research conference – all day

Patient conference – all day

Note that there are shared meetings at the beginning and the end of the day.

Day 3: (Saturday May 5)

Roundtable for researchers and patient leaders – morning only

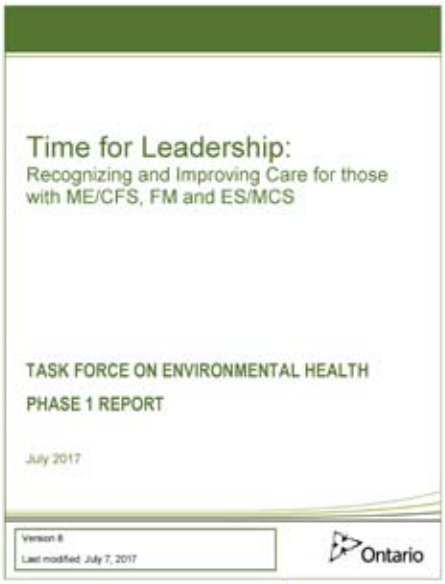
Pre-conference Workshop

Introduction

With patients and patient representatives coming from across Canada, we want to take advantage of the opportunity to talk about how to best serve the Canadian ME/FM community. The health and social systems could function much better for patients! But first there are important issues that need to be discussed and worked through.

Task Force Recommendations

To start our discussion, we will look at the Ontario Task Force report. Recall that the Task Force was appointed by the Minister of Health and Long Term Care with a three years mandate to figure out how to provide services to Ontarians with ME/CFS, FM and MCS. Task Force members include health administrators, academics, clinicians and people with lived experience.



We listed their year 1 recommendations to the Minister in Quest 113 but here is a very brief summary: make a formal public statement, fund academics, ensure fee codes, come to consensus on clinical case definitions and clinical practice guidelines, develop clinical care pathways, make hospitals safe, make long term homes safe and continue the fellowship program for clinical residents.

Important issues to discuss at the workshop are diagnosis and treatment criteria and who will provide care. We will also look for issues that are missing from the year 1 recommendations and we will talk about bringing urgency and openness to the process.

Link: *http://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2017/task_force_on_environmental_health_report.pdf*

Also available in French

The Survey of Canadian Rheumatologists

When we are discussing diagnostic and treatment protocols and care pathways, we will look at a survey of Canadian rheumatologists that was conducted in late 2016 and published recently. The survey was undertaken to explore the attitudes of rheumatologists toward FM and FM management in order to inform an update of the "2012 Canadian Fibromyalgia Guidelines".

The survey was aimed at members of the Canadian Rheumatology Association. The surveyors were unable to find contact information for some, some were ruled out of scope (e.g. pediatric, trainee and non-practicing rheumatologists), some refused to participate, and some simply did not return their forms. Of the 552 members of the CRA, 140 rheumatologists responded. This group may or may not represent overall attitudes. It is also important to keep in mind that rheumatology is letting go of FM. Only twelve of the rheumatologists responding to the survey said that more than 10% of their patients had primary FM. This raises questions around the purpose and validity of conducting a survey of rheumatologists.

For many of the questions, respondents are asked if they strongly agree, agree, are undecided, disagree, or strongly disagree. In the following analysis, agree and strongly agree are combined, while disagree and strongly disagree are combined.

Attitudes Toward and Management of Fibromyalgia, A National Survey of Canadian Rheumatologists and Critical Appraisal of Guidelines, Arnav Agarwal, BHSC, Yvgeniy Oparin, BHSc, Lauren Glick, BSc, Mary-Ann Fitzcharles, MD, Jonathan D. Adachi, MD, Matthew D. Cooper, MD, Lucas Gallo, Laura Wong, BHSc, and Jason W. Busse, DC, PhD

https://www.researchgate.net/profile/Arnav_Agarwal/publication/322090138

Diagnosis and Treatment

For ME/CFS

The battle around diagnostic and treatment protocols for ME/CFS should be over. The US Centers for Disease Control website has dropped the Fukuda definition, Graded Exercise Therapy and Cognitive Behaviour Therapy. The CDC has adopted the 2015 report of the Institute of Medicine (IOM) as well as the IACFS/ME Primer and the new Pediatric Primer. These documents are all based on Canadian Consensus Criteria principles – they are all components of the CCC toolkit.

The IOM report was written to help family doctors recognize ME/CFS in undiagnosed patients. The IOM asks clinicians to look for people with 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". The person must also experience post-exertional malaise, unrefreshing sleep, and cognitive impairment and/or orthostatic tolerance.

While the IOM report helps doctors screen for ME/CFS cases, it does not discuss treatment. Those come from the Primers. The Primers were written respectfully, recognizing the complexity and seriousness of the illness. Health providers are advised to clarify the medical issues by checking for alternate explanations of the symptoms as well as by checking for co-existing conditions. Treatment and support approaches are then suggested. The recommended treatments at this time are chronic disease management strategies. With better understanding of causality, more fundamental treatment strategies are expected to emerge and be incorporated into practice.

The Primers are not clinical practice guidelines in the strict sense. Clinical practice guidelines are based on published literature. The CDC has recognized that the literature around ME/CFS is both incomplete and too contaminated to support literature-based clinical practice guidelines.

For FM

In 1990, the American College of Rheumatology developed guidelines for the diagnosis of FM based on widespread pain and tender points. In 2003, the expert panel appointed by Health Canada essentially endorsed the criteria, but noted that it was important to consider additional signs and symptoms which add to the burden of illness such as activity reduction, cognitive difficulty and sleep dysfunction. In 2010, an international group suggested criteria which incorporated these signs and symptoms but dropped the tender point requirement. (The criteria were modified in 2011 and 2016.) In 2012, a Canadian group (led by a Canadian rheumatologist who was a co-author of the 2010 suggested definition) published guidelines for FM recommending the 2010 definition and a number of treatment strategies.

The National ME/FM Action Network has concerns about those guidelines including their underestimation of the effects of FM on people, their endorsement of graded exercise therapy without checking for post-exertional malaise, their assignment of responsibility for FM management to family doctors, and their psychosocial flavour. The guidelines do not acknowledge the work of the expert panel appointed by Health Canada which we find disappointing. The survey results show that there is some basis for our concerns.

Survey respondents were asked if FM is primarily a psychosocial condition. 31% agreed 44% disagreed and 26% were undecided.

They were asked if FM is often a work-disabling condition warranting the receipt of disability payments. 37% agreed, 49% disagreed and 23% were undecided.

It should be reasonable expect that diagnostic and treatment criteria for an illness take the position that the illness is real and be respectful of its seriousness.

It is important to check people with FM for co-existing ME/CFS because post-exertional malaise is fundamental to determining treatment. A person without PEM can be treated with graded exercise. A person with PEM cannot. It is very interesting to read in the survey report that "while physical activity has been shown to be effective in fibromyalgia management, many studies report high dropout rates due to initial pain resulting from exercise." A possibility is that people with ME/CFS were included in the studies and were the ones dropping out.

The rheumatologists were not impressed with the effectiveness of treatment strategies. The 2012 guidelines suggest around a dozen strategies. Only 47% of respondents thought patient education was effective, only 1% thought that complementary and alternative medicine was effective, and the other strategies were in between those two figures. This points to the need for research and clinical trials.

Who Provides Follow-up Care

As soon as ME/CFS or FM is suspected, the clinician should immediately provide basic information to the patient, assess functional capacity and determine if the patient needs accommodation or other disability supports, start testing for related and exclusionary conditions and make provisions for follow-up care.

Who should provide the follow-up care? Should it be the family doctor, should it be a specialist, or should it be a multi-disciplinary program? Is the answer the same for ME/CFS and FM? These are fundamental issues is determining care pathways.

While no speciality ever adopted ME/CFS, rheumatology did adopt FM. However, rheumatology is withdrawing from FM management. The reasons given are because FM is not a musculoskeletal process and because specialists do not see themselves as providing value-added. In the article's words, "there is no evidence linking specialist care to improved outcomes".

Rheumatologists were asked about their role in the management of FM. Only 4% said that rheumatologists have a primary role, 41% said that they were there to provide guidance to general practitioners, 51% said they were there only to detect and exclude inflammatory conditions, and 5% said they had no role at all.

They were asked if they were confident that they had the clinical skills to effectively manage patients with FM. 53% agreed, 27% disagreed and 21% were undecided.

They were asked if they may refuse referrals for consultation from patients with a reported diagnosis of FM. 50% agreed, 39% disagreed and 11% were undecided.

This tells us that delivering medical treatments with tangible benefits motivates specialists. In areas like ME/CFS and FM where the benefits of treatments are not as evident, where does the motivation come from?

The care pathways also have to consider the diversity of people needing services. This includes young people, people who are homebound or bedbound, and people living in rural and remote areas.

Missing Recommendations

The Task Force made many important recommendations, but building infrastructure to serve this large and complicated group of people is very complex. Here are gaps we have identified and there may be more.

Research: It is surprising that the Task Force did not call for a much larger research program

Alert on PEM: While society generally encourages people to increase activity levels, this is contraindicated for people with exertion intolerance. Because of the public health implications, this message should be widely disseminated.

Home Care: Many people with ME/CFS and/or FM are finding it difficult to qualify for home care. The eligibility criteria need to be reviewed.

Disability: Many disability programs do not acknowledge the functional limitations that come with ME/CFS and FM. A prime example is the special education system in Ontario.

Health care education: The Task Force recommends continuing residency fellowships, but additional education is needed – for practising doctors, nurses, physical therapists, occupational therapist, and first responders as well as students in all these areas.

Support groups: The lay community will be called upon to provide peer support. Existing groups need recognition and ways need to be found to expand lay services.

Translation: Some important documents such as the IOM report are not available in French.

Urgency and Openness

The Task Force report brought a sense of urgency to the area, but that urgency does not seem to have been transmitted to officials. This needs attention.

The Task Force has been operating behind a barrier of confidentially. We wonder why this amount of confidentiality is required.

Feedback Questionnaire

We are wondering how good the IOM criteria will be in screening for cases of ME/CFS. We are also wondering if the criteria could be adapted by replacing "fatigue" with "widespread pain" to screen for cases of FM.

Think back to when you were searching for a diagnosis. What told you that you needed to go to a doctor, not simply go to bed?

How did you describe your illness before your diagnosis of ME/CFS or FM?

Do you think you might have been identified with ME/CFS sooner if the health system had used these criteria as a screening tool? Why or why not?

"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".

Do you think you might have been identified with FM sooner if the health system had used those criteria as a screening tool with "widespread pain" replacing "fatigue"? Why or why not?

**

For people with a diagnosis of FM but not ME/CFS, do you think you have post-exertional malaise? What happens to you as you engage in normal physical or mental exertion? Or after? If you go beyond your limits, are there later consequences?

Do you think that family doctors can meet the needs of ME/CFS and FM patients?

Rheumatologists question whether they provide value to patients. In your experience, do specialists provide value to patient? How?

What kind of ME/FM research would you consider to be priorities?

Are there issues that should be added to the Ontario Task Force list?

Other comments

Thank you for your help. You can mail, email or fax your form to us, or even phone in your answers.

Email: MEFMinfo@mefmaction.com

Mail: National ME/FM Action Network
512, 33 Banner Road
Nepean, ON K2H 8V7Canada

Phone: 613-829-6667 Fax: 613-829-8518

Government Response Misses the Mark

Sent to a member of parliament

When we met on Friday, we touched on the House of Commons e-petition #734 which asked the federal government to commit to a concerted effort to address the needs of Canadians with Myalgic Encephalomyelits/ Chronic Fatigue Syndrome, Fibromyalgia and/or Multiple Chemical Sensitivities.

https://petitions.ourcommons.ca/en/Petition/Details?Petition=e-734

Let me paraphrase the document that the government submitted in response to the e-petition:

- *We have funded one ME/CFS research project (for a total of $100k) and we put a statement in a newsletter to researchers saying that more research is needed.*

- *We set up a group to talk about what Fibromyalgia research would be nice. (The response neglected to mention two studies being funded for total of about $150k that year).*

- *We don't have anything to report about Multiple Chemical Sensitivities.*

Now assume that the same petition was about Autism, Multiple Sclerosis and HIV/AIDS rather than ME/CFS, FM and MCS. Substitute Autism, Multiple Sclerosis and HIV/AIDs in place of ME/CFS, Fibromyalgia and Multiple Chemical Sensitivities in the three statements above. Between them, they receive around $40M in funding per year. Would they be impressed?

We chose Autism, Multiple Sclerosis and HIV/AIDS because research has found that each of these illnesses has a disease burden that is roughly the same as (actually a bit less than) the disease burden of ME/CFS.

http://www.oatext.com/Estimating-the-disease-burden-of-MECFS-in-the-United-States-and-its-relation-to-research-funding.php

We are not aware of any studies estimating the burden of illness for Fibromyalgia or Multiple Chemical Sensitivities. However, considering their prevalence, age distribution and degree of disability (information available from the Canadian Community Health Survey), their disease burden would be roughly the same as for ME/CFS and therefore MS, Autism and HIV/AIDS as well.

Here is a preferable response to the e-petition:

"We know there are major problems with services to the ME/FM/MCS community and we have made fixing the problems a government priority. Because we want to see more research in these areas, we have established a project team (or new institute) to encourage research and we have committed long term funding (in the 10's of millions a year) knowing that researchers will follow the money. Meanwhile, we have asked the Public Health Agency of Canada to increase surveillance (statistical activities). We have also asked PHAC to look at messaging around activity and exercise – it has promoted exercise but this message must be nuanced so that Canadians understand that exercise can be harmful to people who are exertion intolerant. We have asked the health human resources team at Health Canada to look at what is required to build ME/CFS, FM and MCS into the health care system as quickly as possible. We are also asking staff who are working in the areas of chronic pain, opioid use, food security and home care to consider ME/FM/MCS issues. We know that the disability area of government is looking at disability issues affecting the ME/FM/MCS commuity. Meanwhile, recognizing the importance of good communication and the expertise that exists outside government, we are appointing an advisory committee to report jointly to the Minister of health and the Minster responsible for persons with disabilities. The committee secretariat will have an important role in coordinating activities in government to address these issues."

Thank you to Mr Handel of Alberta for submitting this article.

DISABILITY INSURANCE and ME/CFS or Fibromyagia - Stacking the Odds for Success

by Brent L. Handel J.D., Q.C.

Disability insurance provides partial income replacement if you are disabled/unemployable because of any type of illness including ME/CFS or Fibromyalgia (FM). You may have disability insurance through a group insurance plan offered through your employer, union or association. You also may have purchased an individual disability insurance plan and paid the premiums yourself.

CONTRACT LAW

It is important to understand disability insurance is under the broad heading of law called "contract law". Contract law is governed by the terms of the contract entered between the two parties. Disability insurance is thus a simple contract and therefore it is extremely important you review the terms of the policy for guidance as to what the insurance company can and cannot do. Many disability insurance policies are written in "plain language" and so you may be able to read the policy yourself to ascertain most of the terms. If it is not in plain language or if you are having any difficulty in understanding the important legal terms, consult a lawyer. This article is not a substitute for legal advice in your contractual situation, but this article will give you some helpful tips to stack the odds in obtaining disability insurance when you have ME/CFS or FM.

SHORT-TERM DISABILITY (STD) vs. LONG-TERM DISABILITY (LTD)

Short-term disability pays a percentage of your normal earnings – for example 70% - up to only a certain amount of time such as 15 weeks or 26 weeks or even up to 52 weeks, then it automatically runs out as the name "short-term disability" implies. Once short-term disability expires, long-term disability benefits may be applicable and typically pays 60-70% of your normal income but with often a maximum dollar amount. Long-term disability benefits are usually paid for up to two years if you are unable to perform your regular occupation. After two years many long-term disability contracts will only pay disability benefits if you are disabled from performing any occupation. This highlights the importance of reviewing your disability insurance contract to determine your rights. Many disability policies for professionals will maintain the "your regular occupation" stipulation past two years even to age 70, which makes maintaining disability payments long term much easier.

COURT OF LAW CONSIDERATIONS

It is important to remember that in a court of law the issue is NOT what causes ME/CFS or FM or whether you have ME/CFS or FM. Rather the issue is what effect does the condition (whatever you call it) have on this person and does it disable this person from their occupation, or any occupation. Indeed, even if a diagnostic test for ME/CFS or FM became available tomorrow, it would not change disability insurance litigation very much as the issue is not simply identifying an illness, rather it is determining the functionality and thus employability of a person. This should give you encouragement to apply for disability insurance if you have ME/CFS or FM, even with the current medical uncertainty surrounding the disease, as this is not as important in a court of law as it is in medical research.

This cannot be emphasized enough: the test is not one of "disability", rather the test in a disability insurance dispute is employability. Employability requires regularity as regularity is the essence of employability. As well, if you must give up all your social, recreational, and family activities and sleep all off work hours to maintain your job, then you are likely unemployable as a court will not force you to give up everything in your life except work.

FILING A CLAIM – STACKING THE ODDS IN YOUR FAVOUR

A. Pay attention to your medical records. From the moment you realize you are sick with the terrible disease of ME/CFS or FM, it is important for you to understand that all of your medical records and doctor's reports will be read by your lawyer and the insurance company to reconstruct a history of your illness. Thus, when speaking to your doctor it is important that you specify clearly to the doctor what you are able and what you are not able to do. Outline the specific tasks which exacerbate your symptoms versus which tasks you can do. This will help your doctor keep better chart records and write a better medical report for the insurance company. Note, however, despite your doctor completing a medical report the insurance company has the right to have you examined

by a doctor chosen by the insurance company. Do not worry too much what this doctor says about you as these medical opinions are often quite easily discredited on cross-examination.

B. Attend all medical appointments. As your case is ongoing it is important that you attend all medical appointments you book. The medical records/charts will be produced as indicated above and if there are "no show" appointments without an explanation this will be used against you by the insurance company to argue that you did not obtain proper medical treatment.

C. Adhere to recommended treatment plans. Related to above it is important that you vigilantly adhere to recommended treatments plans (assuming they are not harmful to you such as an uninformed physician recommending exercise). From a legal point of view, you must only follow one treatment plan recommended by one professional, not all the treatment plans recommended by all the doctors you have seen. This is important in a disease such as ME/CFS or FM where there are many different opinions about what would be helpful treatment. From a legal point of view, you need only follow one. Note following the "advice" of medical forums will not suffice in a court room.

D. Keep a medical diary. There are conflicting opinions in the legal world about keeping a medical diary to record your symptoms of pain and fatigue. The writer believes a medical diary - if it is consistently kept throughout the time that you are sick - can be helpful as it allows you to articulate exactly what went on over the years as time goes on. However, if you start keeping a medical diary and then stop part way through this can hurt your case as adverse inferences may be drawn from you stopping keeping a medical diary. Whether this is valid or not to draw an adverse inference is of course up to debate but the insurance company will attempt to argue that since you stopped keeping a medical diary you must have had a substantial improvement in your condition.

E. Don't overstate or understate your condition. Never embellish your situation to your medical doctor or to any healthcare treating professional. At the same time, it is important not to minimize your situation to healthcare professionals. It is important to attempt to be as objective as you can in articulating exactly how you feel so that the people who are seeing you or treating you can understand your true situation. Many health care professionals do not realize how devastating ME/CFS or FM can be and so it is important to articulate specific things that you can and cannot do and for how long etc. But at the same time avoid embellishing or using adjectives that are hyperbole as that will not be helpful in a review of your claim.

F. Be aware of private investigators. Related to the above aspect of honesty you should be aware that insurance companies will hire private investigators to attempt to videotape you engaging in activities that you have previously claimed you are unable to do. This is important in a case such as ME/CFS or FM where the credibility of the applicant is crucial. Thus, from a legal point of view a judge adjudicating on your credibility in a positive way will make the fundamental difference in your case. For example, does the judge believe you when you say you have fatigue and believe you when you say you can only engage in two hours of activities per day. On the other hand, if there is videotape evidence that is clearly contrary to your previous statements or testimony at a deposition about what you can and cannot do, then your case will be very difficult, not only for the insurance company to accept, but also for a judge to accept.

Therefore, we recommend that if you want to test your condition to see if you are getting better that you never perform such a test in public where other people can see it because it may end up being the one time when you are being videotaped which could then come back to be problematic. Bottom line, always be honest and straightforward.

G. Be cautious around social media. Social media such as Facebook and Instagram have become fertile areas for disability insurance company lawyers to review for evidence of you being able to perform more than your stated capacity. This is outlined in the article *Facebook and Other Social Media Evidence and Personal Injury Litigation Cases*. Social media suffers from the "highlight reel" problem in that we all like to post our best moments on Facebook or Instagram. However, this leads to an inaccurate picture of your true condition if you are simply only posting your best pictures.

It is best to stop engaging in Facebook and Instagram and any other social media if you have ME/CFS or FM and are pursuing a disability insurance claim. Social media has the potential to create problems and could very well result in a denial of your claim if there are documents posted which show you engaging in activities that you have said you are unable to engage in.

H. Ensure your application package is complete. This is perhaps the most common mistake unrepresented people make in applying for disability insurance. Make a persuasive first impression by making sure there are not any missing pieces of information, whether medical or general, so that the disability insurance company can obtain an accurate picture of how sick you really are. At the time, it will seem like a lot of work to initiate the application thoroughly and completely but it is well worth it so that the insurance company can grant you disability coverage without having to go to litigation and then later providing the missing information.

Common gaps in information include:

Providing an incomplete list of functional limitations;

Providing incomplete medical charts or completely omitting medical charts from a doctor you have seen;

Leaving out medical diagnosis if there are conflicting medical diagnoses. It is better to include all diagnoses and provide explanations of differences;

No providing explanatory information from co-workers or family member;

Providing an incomplete work history.

CONCLUSION

Stacking the odds in your favour in applying for disability insurance requires attention to detail and stamina to complete the application thoroughly. Unfortunately, people with ME/CFS or FM do not have stamina so often applications are incomplete and thus unconvincing. It requires a great deal of work to assemble all the required documentation, and this is even more difficult, if not impossible, when you suffer from ME/CFS or FM. It would not be good management of your medical condition to push through the application and further impair your health. Thus, it may be beneficial to enlist a family member or hire a disability agent or lawyer to assemble the required documents properly and completely for you to avoid an initial denial and to avoid having to go to court.

Brent L. Handel, J.D., Q.C. is a lawyer in Alberta, Canada. Further helpful information about disability insurance may be found in blog posts at *www.helpandhope.ca*.

Leading ME/CFS US Clinicians Meet

Dr Bateman, Dr Kaufman, Dr Lapp, Dr Bested

On March 2-3, 2018, the Bateman Horne Center hosted an exciting summit of leading U.S. ME/CFS clinicians who came together to share their pearls of wisdom on diagnosis and treatment in order to improve ME/CFS clinical care and refine more precise research targets.

https://batemanhornecenter.org/consensus-driven-cfs-clinician-coalition-takes-shape/

Voting in Elections

It looks like three provinces will hold elections in 2018 (Ontario June 7), New Brunswick (September 24) and Quebec (October 1). There will be a number of municipal elections as well.

We encourage everyone who is eligible to vote to do so. Voting says that you want your voice to be heard.

For people with ME/CFS and/or FM, voting can be difficult. Fortunately, there are options for casting your vote above and beyond the usual method of voting at the regular poll or at an advance poll. Each province writes its own rules. I will describe the options available in Ontario. These options may or may not be available in other provinces. Contact your election officials for further information in your area.

In Ontario, there are some dates to keep in mind:

- Local election offices open on May 9th
- Nominations close on May 17th
- The election itself is on June 7th
- Special voting has to be complete by 6pm on June 6th

Here are three special options available in Ontario that can help people with ME/CFS or FM:

- Voting at home
- Voting by mail
- Voting at the local elections office.

If you want to vote from home, contact your local elections office on or after May 9th and ask for an appointment. Two people will come to your house and do the paperwork. They will show you the list of candidates in your riding. You will write your choice on the ballot in secret and seal it up. They will take your ballot when they leave and put it in a special ballot box to be counted after the polls close.

Some special points to note:

- You might want your appointment to be after May 17th so the names of all the candidates are known. If your preferred candidate is already known, you don't have to wait.
- Let the elections office know if it takes you time to answer the door.
- A caregiver can vote at the same time as long as the caregiver lives in the same electoral district.

Another choice is to vote by mail. You need to complete an application form which you can obtain on-line or by contacting your elections office. When elections officials receive the completed form, they will courier you a voting package. The completed voting package must be received before polling day.

If you can get out occasionally, you can vote at your local elections office any time it is open. Do remember to take identification!

The phone number for Elections Ontario is 1-888 668-8683

The phone number for Elections Quebec is 1-888-ÉLECTION (1-888-353-2846)

The phone number for Elections New Brunswick is 1-888-858-8683 (VOTE)

Benefit Concert for the ME/FM Society of BC

Mariposa's sixth annual awareness show for ME/CFS & FM

Saturday, June 16, 2018 @ 7:30 pm

Marpole United Church (1296 West 67th Ave. Vancouver)

Join the award-winning artists of Opera Mariposa and the Mariposa Theatre Wing for a gala concert in support of a great cause! In Mariposa's sixth annual charity benefit show, acclaimed soprano Jacqueline Ko, pianist Nina Horvath and friends perform opera, Broadway and more to raise funds and awareness for chronic neuroimmune diseases and the ME/FM Society of BC. This one-night-only concert event also includes a reception and a prize raffle, so you won't want to miss the uplifting new show from the singer that critics rave "knows exactly what to do with an absolutely gorgeous voice" (Review Vancouver)!

Featuring:

Jacqueline Ko, soprano

Brittony LeFever, mezzo-soprano

Lyndon Ladeur, tenor

Nina Horvath, piano

New Index of ME/CFS Published Research

For people interested in ME/CFS research, the ME Association of the UK now has an index of published research which is plans to update monthly. A very valuable resource.

Thank you to Charles Shepherd, and Dr Abhijit Chaudhuri.

http://www.meassociation.org.uk/wp-content/uploads/ME-Association-Index-of-MECFS-Published-Research-28.02.18.pdf


http://mefmaction.com


http://twitter.com/mefmaction


http://www.facebook.com/MEFMActionNetwork

NATIONAL ME/FM ACTION NETWORK

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Email: mefminfo@mefmaction.com • www.mefmaction.com

(BN) 89183 3642 RR0001

Resources

Item	Qty	Total
Membership Fee $30		
ME/CFS Brochure (Eng)		*free*
ME/CFS Brochure (Fr)		*free*
FM Brochure (Eng)		*free*
FM Brochure (Fr)		*free*
ME/CFS Overview $7		
FM Overview $7		
TEACH-ME (Eng) $25		
TEACH-ME (Fr) $25		
CPP Disability Guide $10		
Primer-Bilingual Edition $25		
SUB TOTAL		

Please transfer the above "sub total" onto the front, to tally in to the total payment being made.
Thank You

THE NATIONAL ME/FM ACTION NETWORK RESOURCES

Quest Newsletter—Free with annual membership of $30.00

When you become a member of the National ME/FM Action Network, you receive our quarterly newsletter QUEST. We keep you informed about medical research, disability and legal issues and on developments affecting the ME/FM community in Canada and internationally.

ME/CFS and FM Brochures - FREE

Coloured pamphlets on ME/CFS and FM are available in English and French. You can view them on our website

Consensus Documents for ME/CFS and FM

- Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols [Journal of Chronic Fatigue Syndrome, Vol. 11, No. 1, 2003. Haworth Press 2003/2004 ISBN:0-7890-2207 9]
- The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners [Haworth Press, 2004 (Soft cover book) ISBN 0-7890-2574-4]

The consensus documents are available at Amazon.ca or at Chapters.ca or view them on our website.

ME/CFS and FM Overviews - $7.00

The ME/CFS and FM Overviews are summaries of the Canadian Consensus documents.

- You can view the ME/CFS Overview in English, French, Spanish, German, Italian and Dutch on our website. English versions of the ME/CFS Overviews are available for purchase from the National ME/FM Action Network. French versions of the ME/CFS Overview are available for purchase from Quebce Association for ME, AQEM (aqem.ca)- call (514) 369-0386 or 1-855-369-0386 or email info@aqem.ca.
- You can view the FM Overview in English, French, Spanish and Italian on our website. English versions of the FM Overview are available for purchase from the National ME/FM Action Network.

TEACH-ME (Second Edition) - $25.00

Our TEACH-ME Source Book is for Parents and Teachers of children and youth with ME/CFS and/or FM. This document is available in English and French.

CANADA PENSION PLAN DISABILITY GUIDE 2015 Edition- $10.00

A Guide designed for those who are disabled and wish to apply for Canada Pension Plan Disability Benefits. It outlines the various steps in the process.

Chronic Fatigue Syndrome / Myalgic Encephalomyelitis - Primer for Clinical Practitioners
Syndrome de fatigue chronique Encéphalomyélite myalgique - Petit guide pour la médecine clinique - $25.00

The ME/CFS Primer was produced by the International Association for Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (IACFS/ME). It was translated into French by the National ME/FM Action Network. You can view both the English and the French on our website. Bilingual versions are available for purchase from the National ME/FM Action Network.

All of the above resources can be viewed on the
National ME/FM Action Network website at http://mefmaction.com

NATIONAL ME/FM ACTION NETWORK

NEW MEMBERSHIP or RENEWAL fees

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

Resources $_____
Please see reverse

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*

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Please see reverse for available network resources.

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THANK YOU FOR YOUR SUPPORT!

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