NATIONAL ME/FM ACTION NETWORK

Quest

Newsletter

www.mefmaction.com Quest 106, Spring 2016 mefminfo@mefmaction.com

February 25, 2016

The Honourable Carla Qualtrough

Minister of Sport and Persons with Disabilities

Dear Minister Qualtrough,

RE Follow-up from February 22, 2016 meeting

Thank you for our meeting on Monday, February 22, 2016 to discuss issues faced by Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and/or Fibromyalgia (FM). Also in attendance were James Van Raalte, Director-General of the Office of Disability Issues and Jude Welch, your Director of Parliamentary Affairs.

Statistics Canada's Canadian Community Health Survey estimates that there are 800,000 Canadians with a diagnosis of Chronic Fatigue Syndrome, Fibromyalgia, or both. (This figure goes up to 1.4 million if you include Multiple Chemical Sensitivities, a condition that often overlaps.) The survey data shows that these Canadians have a high degree of disability, disadvantage, and unmet needs.

While ME/CFS and FM are most prevalent among people of working age, they can affect seniors and young people as well. Our organization, the National ME/FM Action Network, prepared and published a Sourcebook for Teachers discussing issues affecting young people. It is available for free in English and French on our website.

My first ME/FM advocacy work fifteen years ago involved asking the Ontario education system to address the needs of students who, for health reasons, could not attend school full time. Frustratingly, the issues have never been satisfactorily addressed, leaving students who need part-time or home-bound schooling poorly served and in some cases unserved. No explanation was ever provided for the inaction, but obviously the system calculated that these students were not deserving enough to warrant a change to the status quo.

This is one illustration of the resistance and lack of cooperation that the ME/FM community has encountered. Dr James Coyne, a professor of psychology with over 350 publications, has just published a blog touching on the topic. He recently became interested in the controversy about the "PACE" study which supposedly justifies the use of behavioural therapy and exercise in treating ME/CFS. Patients have criticized the study on many grounds including poor participant selection criteria, the change of success criteria in the middle of the study, and the failure to declare competing interests. Dr Coyne asked the study authors for anonymized individual data in order to test their findings. He was rebuffed. Here are his observations.

> *"Peter White and the PACE investigators' crude, personal, and unprofessional response to my request for data was reflexive. They are accustomed to receiving those requests from patients in a culture where patients should be seen and not heard. They were responding as if I was somehow below them in the hierarchy in which their views should be uncritically accepted with all the deference that colonialists are due. How vexatious of me to challenge the interpretations of their data that they were putting forth…*
>
> *"Once I was cast among the patients, I was subject to the usual smearing and collective punishment for real and imaginary hostile actions of a few patients in a*

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> *familiar narrative crafted by Simon Wessely's Science Media Centre. Although I have a stronger publication record than any of the PACE investigators, concerns were raised about releasing data to those who are incapable of analyzing it.*
>
> *"Over time, I've gotten to know some of the individuals who have previously requested data, although I have never met them. They impress me as amply qualified to analyze data, and they often analyze data that I report in my blogs, with them asking for no credit. Many of them have been academics or have had other professional achievements. Others were progressing well along in their educational pathways before they were struck by their illness. Still others become citizen-scientists with the capacity to publish peer reviewed letters to the editor as a result of struggling to deal with their misunderstood medical condition.*
>
> *"There is something ugly, pernicious going on here, more fundamental than the question of data sharing. Being a patient with chronic fatigue syndrome/ myalgic encephalomyelitis is what sociologists like Erving Goffman would call a spoiled identity. Being a patient means being stripped of all other significant social identities and being reduced to a common denominator, stigmatized role."*

The talent and goodwill that exists in the ME/FM community needs to be recognized while the uncooperative and disrespectful way the ME/FM community is treated needs to be addressed.

Meanwhile, in our first letter to you, our organization identified five federal disability programs that need to be examined from a ME/FM perspective.

Attached are descriptions of the six projects that flow from our meeting – the five disability programs plus building a healthy relationship with the community. Our organization will work with the public service through the Office of Disability Issues to move forward in these six areas. I indicated my intention of updating this report every few months and you indicated a real interest in receiving these updates. That is very appreciated.

Thank you again for the opportunity to describe to you the situation facing Canadians with ME/CFS and FM.

Yours truly,

Margaret Parlor
President
National ME/FM Action Network

Attachment to Letter:

Disability Action Items
Description and Status Report
National ME/FM Action Network
February 25, 2016

Building a healthy relationship

Background

The ME/FM community has encountered stigma and lack of cooperation. It has received little help in overcoming these challenges.

Action to date

Need identified

Next Step

Develop action plan in collaboration with ODI

CPP-Disability

Background

ME/CFS and FM often strike people in the workforce, robbing them of their ability to work and their financial security. The CPP-Disability program was designed for this situation. However, people with ME/CFS often have difficulty qualifying. Our organization has published a guide to help people through the process, but the problems go much deeper. We have identified a key goal "to ensure that people with ME/CFS and Fibromyalgia who meet the eligibility requirements, having sufficient contributions and being regularly incapable of pursuing any substantial gainful occupation, are approved in the first round." We should have added "without undue effort, cost, or delay."

Action to date

Met with Kris Johnson, Director-General of the program on January 19, 2016. He advised us that CPP-D medical staff would be reviewing the adjudication of ME/CFS and FM cases.

Followed up with a letter dated February 3, 2016 making a number of recommendations to improve the current situation.

The Auditor-General of Canada released an audit of the CPP-D program on February 2 which found that the application process is long and complex and also found that many of the applications sent to the Social Security Tribunal could have been approved earlier. A stakeholder meeting was held on February 17 to review broad issues. The National ME/FM Action Network was represented at that meeting.

Next step

Response from CPP-D.

Disability Tax Credit

Background

The DTC is a program which provides tax relief to qualified individuals. It has also been expanded to be the entry point into other benefits such as the Registered Disability Savings Plan. The qualification criteria are outlined in the Income Tax Act. The application form (Form 2201) is filled out by the applicant and must be signed by a designated health professional.

From our point of view, the application form does not "speak the language" of ME/FM applicants, the process in cumbersome, doctors are unsure how to complete the form, and many forms are being sent back to doctors for more information. We would like to work with the program to find solutions so that people with ME/CFS and FM who are deserving of the credit can receive it without undue effort, cost and delay.

Action to Date

February 16, 2016 - Asked ODI whom we should be contacting

Next step

Response from ODI

Home care

Background

Statistics Canada's Canadian Community Health Survey show that people with ME/CFS and FM report high levels of unmet home care needs compared to people with other chronic conditions or even to the elderly. Expanding home care is a Liberal priority. We want to ensure that people with ME/CFS and FM are not left out.

Action to date

Need identified

Next step

We are trying to figure out whom to contact

Work Accommodation Initiatives

Background

For patients with moderate or severe symptoms, employment would be contra-indicated, but for patients with stable, mild symptoms, some employment may be possible. The ME/FM community has developed a Functional Capacity Scale (which has been validated) that runs from 0 (completely bedbound) to 10 (very healthy and active). The rule of thumb is that a person has to be consistently at a level 6 before part time flexible work is even considered and consistently at level 7 before full time work is even considered. Other factors would come into play such as how strenuous the work is and how accommodating the workplace is. There is little research into ME/FM workplace issues and we are not aware of any ME/FM-specific employment support services. This is a topic that needs to be developed.

Action to date

February 16, 2016 – requested a meeting with ODI staff.

Next step

Response from ODI

Elections Canada – At-home voting

Background

Some people in the ME/FM community are home-bound and cannot cope with administration, but would still like to participate in the election process. We discovered that Elections Canada will come to private homes on request, look after the administrative matters, hand over a ballot package, and take away the completed ballot. The problem is that this service is not advertised. We are asking specifically that this service be readily apparent on the Elections Canada website.

Action to date

Contacted Elections Canada on August 6, 2015, September 9, 2015, and January 21, 2016

Next step

Response from Elections Canada

Abbreviations used in this newsletter:

CPP-D: Canada Pension Plan-Disability
CRPD: United Nations Convention on the Rights of Persons with Disabilities
DTC: Disability Tax Credit
ICD: International Classification of Diseases
ICF: International Classification of Functioning, Disability and Health
ODI: Federal government Office of Disability Issues
UK: United Kingdom
UN: United Nations
WHO: World Health Organization

Focus on Disability

Models of Disability

Academics have developed dozens of “models of disability”. They look at how disability is portrayed and who is responsible for dealing with disabilities.

Two leading models are the medical model and the social model. The **medical model** portrays disability as a medical problem within the individual. The challenge becomes caring for the individuals and finding a cure. The **social model** portrays disability as a societal problem. Under this model, the problem lies not with the person but rather with a society that hasn’t recognized the diversity that comes as part of nature. The medical model looks at people who cannot climb stairs while the social model asks why the stairs are blocking the way. The medical model looks at people who cannot work a 40 hour work-week, while the social model expects the length of the work-week to be tailored to the individual.

Under the **human rights model**, individuals with a disability have the right to accommodation and service providers have an obligation to respect the needs of the person with disabilities (up to the point of undue hardship).

The **charity (or philanthropy) model** calls on the public to support work on behalf of people with disabilities. People with disabilities are looked upon as recipients of benevolence, and the amount they receive depends on their perceived worthiness.

There are several models that throw responsibility back onto the individual with disabilities. The **moral model** attributes disability onset to evil thought or acts, meaning that the disabled people deserve their fate. The **eugenics model** considers people with disabilities to be genetically inferior. I even saw joking reference to an **insurance model** under which the insurance industry has a role in ensuring that motivational factors such as secondary gain and financial incentives do not encourage disability.

The International Classification of Functioning, Disability and Health (ICF) claims to use a **biopsychosocial model** because it tries to bring together the biological, individual and social perspectives.

The CRPD

The United Nations (UN) Convention on the Rights of Persons with Disabilities, referred to as the CRPD, has nations placing responsibility on nations to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity." In the case of Canada, responsibility for fulfilling the obligations falls on both the federal and provincial governments.

The preamble of the CRPD states that "*disability is an evolving concept and ... disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.*" Section 1 states that "*Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*"

Here is a poster developed by a US disability organization celebrating the CRPD. Interestingly, the poster does not feature the obligation on governments to provide to access to health services (article 25) which is an extremely important service for the ME/FM community. Most recognized disabilities have moved beyond the stage where accessing health service is an important issue.

THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (CRPD)

ACCESSIBILITY

FULL AND EFFECTIVE PARTICIPATION

ARTICLE 16: FREEDOM FROM EXPLOITATION, VIOLENCE AND ABUSE

INDEPENDENCE OF PERSONS

ARTICLE 21: FREEDOM OF EXPRESSION AND OPINION, AND ACCESS TO INFORMATION

ARTICLE 19: LIVING INDEPENDENTLY AND BEING INCLUDED IN THE COMMUNITY

EQUALITY OF OPPORTUNITY

ARTICLE 28: ADEQUATE STANDARD OF LIVING AND SOCIAL PROTECTION

FULL INCLUSION IN SOCIETY

ARTICLE 27: WORK AND EMPLOYMENT

EQUALITY BETWEEN MEN AND WOMEN

ARTICLE 30: PARTICIPATION IN CULTURAL LIFE, RECREATION, LEISURE AND SPORT

RESPECT FOR INHERENT DIGNITY

ARTICLE 23: RESPECT FOR HOME AND THE FAMILY

NON-DISCRIMINATION

NOTHING ABOUT US, WITHOUT US!

USICD is a non-profit membership organization that works to catalyze the energy, expertise and resources of the US disability community and US government to help improve the lives and circumstances of people with disabilities worldwide. www.usicd.org

Analyzing Disability

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) defines disability as follows: **"*Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*"**

Impairments. Barriers. Participation. What do these words mean?

You have undoubtedly heard of the ICD, the World Health Organization's (WHO) International Classification of Diseases. The WHO has a companion document which has a much lower profile, the International Classification of Functioning, Disability and Health, referred to as the ICF. The ICF, approved by the WHO in 2001, is based on this diagram.

Functioning refers to all body functions, activities and participation.
Body functions and structures can have **impairments**.
Activities are tasks or actions executed by the individual. Examples are watching, listening, speaking, grasping, lifting, walking, driving, cooking, cleaning, and dressing. Activities can be **limited**.
Participation is involvement in a life situation such as going to school, working, being part of a family or being part of a social group. Participation can be **restricted**.
Disability is an umbrella term for body function impairments, activity limitations and participation restrictions.
Environmental factors and **personal factors** can be facilitators or barriers.

The ICF provides codes for various body structures, body functions, activities and participation and environmental factors. Health conditions are coded in the ICD. There is no coding structure for personal factors.

Here is a simple case study applying the model. A knee is a body structure which is used for mobility, a body function. Jody has a tear of her cartilage which causes a lack of stability in her knee (impairment of body function). This affects her ability to walk, kneel, climb and carry objects (activity limitations). This inability affects Jody's ability to play with grandchildren or do housework (participation restrictions). She has crutches, does physiotherapy and has access to pain medications (environmental facilitators) but she lives in a home with stairs, her medications have side effects, and the sidewalk outside is covered in ice (environmental barriers). She is conscientious about doing her physiotherapy exercises (personal facilitator).

When ME/CFS or FM starts, people will notice symptoms like pain, fatigue and brain fog (impairments of body functions). Occasional illness is normal and society accommodates it. When participation restrictions become excessive (e.g. not being able to keep up with work/school, family and social life), the situation moves to a different dimension.

For help in articulating ME/FM impairments, activity limitations and participation restrictions in a work context, see Chapter 6 and the worksheets in the CPP-D Applications and Appeals Guide. This document lists symptoms [impairments] of ME/CFS and FM, activities that are part of normal living, and requirements for participating in the workplace. You can identify where problems exist and then draw linkages between the impairments, the activities limitations and participation restrictions.

Environmental Factors:

- Products and technology (drugs, assistive devices, building design...)
- Natural environment and human-made changes to the environment (climate, air quality, light, sound...)
- Support and relationships (family, friends, acquaintances, professionals, pets...)
- Attitudes
  - family,
  - friends,
  - care providers,
  - health professionals,
  - societal attitudes,
  - social norms, practices and ideologies
- Services, systems and policies

There are three problems with the ICF model as far as ME/CFS and FM are concerned.

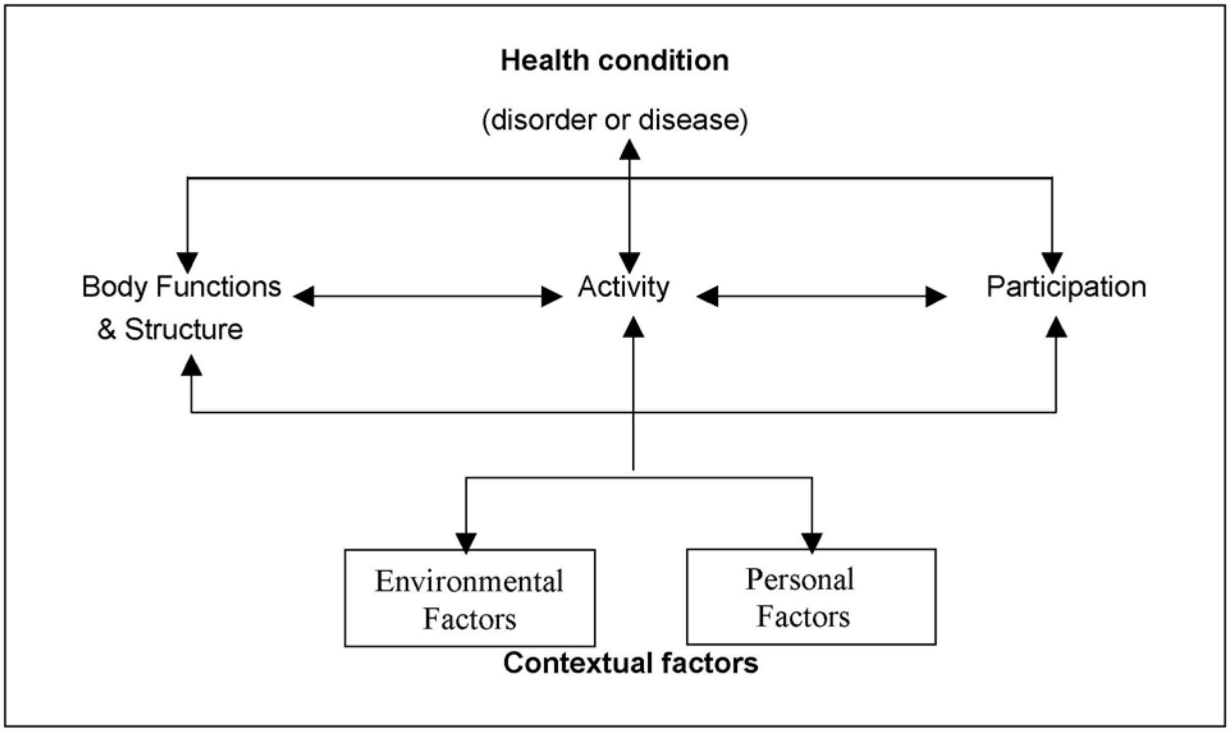
* The activity limitations that come with ME/CFS and FM are widespread. It isn't any one particular activity that is the problem, it is the across-the-board reduction in activities. Thus, looking at each individual activity in the ICF may fail to convey the big picture. In contrast to the ICF, the Functional Capacity Scale looks at the cumulative effects of ME/CFS and FM. We have featured it on pages 8-12. The ICF would do well to build the Functional Capacity Scale into its model.

* The mechanisms through which ME/CFS and FM cause activity limitations and participation restrictions have not been explained though it is known that a number of body systems are involved. How do disability programs react to this uncertainty? There are several approaches:

- by treating the uncertainty of causation as irrelevant and focusing on the impact. Elections Saskatchewan simply says that if a person can't get to the voting place, the voting place will come to the person. The reason the person cannot get out to vote does not matter.
- by pretending that ME/CFS and FM don't exist. We see this with the Royal College of Physicians and Surgeons of Canada which does not have a specialty for ME/FM, with the Canadian Institutes of Health Research which funds almost no ME/FM research, and with the Ontario special education system which provides services for recognized conditions but ignores the needs of ME/FM students.
- by treating ME/FM applicants with suspicion. This was brought to light in the UK survey on home care where a third of respondents felt that ME/CFS was not being accepted as genuine. We noted it in the instructions to adjudicators in the CPP-Disability program.

In tying disability so closely to body structure, the ICF is leaving unexplained illnesses very vulnerable to being ignored or being disbelieved.

* The ICF model shows personal factors as having an impact on body functions, activities and participation. However, the ICF provides little guidance on the relationship. This leaves people very vulnerable to being blamed for their situation especially in the case of unexplained illnesses.



Stigma

Stigma is related to the ICF's environmental factor - attitudes. Positive attitudes are facilitating while negative attitudes are barriers. Stigma is about negative societal attitudes. The implications of stigma can spill over from societal attitudes (public stigma) into interpersonal relationships and into public policy (structural stigma). Stigma can even affect a person's attitude toward him/herself (self stigma). In fact, it is hard to ascertain societal attitudes except through individual attitudes and policy decisions.

"The Stigma of Diseases and Disability, Understanding Causes and Overcoming Injustices" is a 2014 publication of the American Psychological Association. Various chapters look at stigma related to mental illness, substance abuse, intellectual disabilities, infectious diseases, Alzheimer's, etc. While ME/CFS and FM are not specifically covered, the book still provides interesting perspectives. The book is surprisingly readable for a compilation of academic articles.

Here are key some points from the book. [I have added a few thoughts in square brackets.]

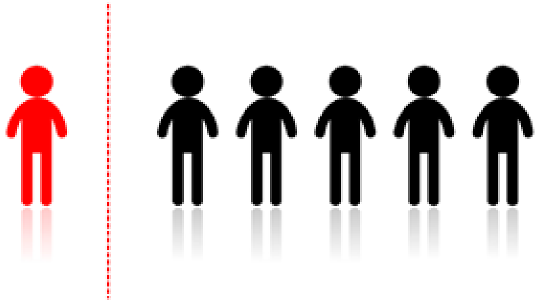
Disease and disability strike with a double whammy: Not only do they cause pain, distress and loss, but they also trigger a social reaction, and the prejudice and discrimination that often accompany illness can be as limiting as the condition itself. (p3)

The impact of stigma varies by disease and disability. (p4)

Health care providers have made great strides in understanding and treating diseases, and social scientists have likewise made advances in explaining a frequent corollary of illness, stigma. (p3) Sociology has historically focused on mental illness, criminality, disability and chronic illnesses such as HIV/AIDS, while social psychology has focused on race, gender and sexual orientation. (p12)

Studies looked at strategies in overcoming mental health stigma. They found that protests might fix the immediate problem but cause backlash, while general education has limited benefits. The most effective strategy was contact – targeted personal interactions with specific goals.(ch2)

Types of stigma include public stigma (public attitudes absorb negative stereotypes and discriminate against the stereotyped group), self-stigma (a stigmatized person is aware of the stigma, agrees with it and applies it to him/herself), label avoidance (individuals are careful not to acquire the stigmatized label), and structural stigma (having stereotypes incorporated into services, systems and policies.) (p18) [The second half of this newsletter looks at structural stigma.]



Stigma can extend to family members. (ch 14). [Stigma can also extend to supporters, like sympathetic clinicians and researchers.]

Three social purposes have been proposed for stigma: exploitation and dominance, avoidance of disease, and enforcement of social norms. (p65) [The social norm being protected in ME/FM stigma is hard-work and productivity. Dominance is at play when the health care system blames, mistreats or ignores patients to protect its favoured status.]

Activity Logs - Functional Capacity Scale

We are including activity logs and the functional capacity scale because these are very important tools for people with ME/CFS and FM in determining and documenting disability levels!

ACTIVITY LOG

Name: ___________________________________ Date Commencing: _______________________

DAY	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
SLEEP: Write number of hours slept and quality 1 = very poor 2 = poor 3 = fair 4 = good 5 = very good							
Functional Capacity Scale: Record your energy rating every hour using the scale 1 - 10. **Activities** (please specify)							
6 a.m.							
7 a.m.							
8 a.m.							
9 a.m.							
10 a.m.							
11 a.m.							
12 p.m.							
1 p.m.							
2 p.m.							
3 p.m.							
4 p.m.							
5 p.m.							
6 p.m.							
7 p.m.							
8 p.m.							
9 p.m.							
10 p.m.							
11 p.m.							
# of minutes walked							
# of usable hours / day							

NUMBER OF USABLE HOURS / DAY = Number of hours NOT asleep or resting/meditating with eyes closed.

Activity log:

- Keep it in a handy place
- Complete it every day
- Take your completed logs to your doctor/other health care provider at follow-up visits
- Your logs assist your doctor/other health care provider to adjust your treatment plan as needed
- Completed logs may reassure your insurance company of your active ongoing participation in your treatment.

Completing activity log:

- You may change the times on the left hand side of the log to suit your usual schedule (e.g. if you usually get up at 10:00 a.m. and go to bed at 2:00 a.m., write 10:00 a.m. in as the first time, and adjust the other times accordingly).
- Please note your activities with one or two word(s) in the appropriate time slots (e.g. dressed, made bed, nap).
- Rest is defined as lying down, eyes shut, meditating or sleeping.
- To better identify activity patterns coloring the log based on activity levels e.g. red for exercise, yellow for sedentary activity, blue for sleep, will help patients identify which activity pattern works best for them.

FUNCTIONAL CAPACITY SCALE

The Functional Capacity Scale incorporates energy rating, symptom severity, and activity level. The description after each scale number can be used to rate functional capacity

0 = No energy, severe symptoms including very poor concentration; bed ridden all day; cannot do self-care (e.g. need bed bath to be given).
1 = Severe symptoms at rest, including very poor concentration; in bed most of the day; need assistance with self-care activities (bathing).
2 = Severe symptoms at rest, including poor concentration; frequent rests or naps; need some assistance with limited self-care activities (can wash face at the sink) and need rest afterwards for severe post exertional fatigue.
3 = Moderate symptoms at rest, including poor concentration; need frequent rests or naps; can do independent self-care (can wash standing at the sink for a few minutes) but have severe post exertion fatigue and need rest.
4 = Moderate symptoms at rest, including some difficulty concentrating; need frequent rests throughout the day; can do independent self-care (can take a shower) and limited activities of daily living (e.g. light housework, laundry); can walk for a few minutes per day.
5 = Mild symptoms at rest with fairly good concentration for short periods (15 minutes); need a.m. and p.m. rest; can do independent self-care and moderate activities of daily living, but have slight post exertion fatigue; can walk 10-20 minutes per day.
6 = Mild or no symptoms at rest with fairly good concentration for up to 45 minutes; cannot multitask; need afternoon rest; can do most activities of daily living except vacuuming; can walk 20-30 minutes per day; can do volunteer work – maximum total time 4 hours per week, with flexible hours.
7 = Mild or no symptoms at rest with good concentration for up to ½ day; can do more intense activities of daily living (e.g. grocery shopping, vacuuming), but may get post exertion fatigue if 'overdo'; can walk 30 minutes per day; can work limited hours, less than 25 hours per week; no or minimal social life.
8 = Mild intermittent symptoms with good concentration; can do full self-care, work 40 hours per week, enjoy a social life, do moderate vigorous exercise three times per week.
9 = No symptoms; very good concentration; full work and social life; can do vigorous exercise three to five times a week.
10 = No symptoms; excellent concentration; over achiever (sometimes may require less sleep than average person).

JOURNAL D'ACTIVITÉ

Nom : ____ Date de début : ____________________

JOUR	Lundi	Mardi	Mercredi	Jeudi	Vendredi	Samedi	Dimanche
SOMMEIL : Inscrire durée en heures et qualité du sommeil 1 = très faible 2 = faible 3 = moyen 4 = bon 5 = très bon							
Échelle de capacité fonctionnelle: Sur une échelle de 1 à 10, indiquer le niveau d'énergie pour chaque heure. **Activités** (préciser)							
6 h							
7 h							
8 h							
9 h							
10 h							
11 h							
12 h							
13 h							
14 h							
15 h							
16 h							
17 h							
18 h							
19 h							
20 h							
21 h							
22 h							
23 h							
n^{bre} de min. de marche							
n^{bre} d'hres utili-sables ce jour							

N^{bre} D'HEURES UTILISABLES DE CE JOUR = nombre d'heures NON de sommeil ou de repos ou de méditation les yeux fermés.

Journal d’activité :

- Le garder à portée de la main.
- Le tenir chaque jour.
- L’apporter aux visites de suivi, médecin ou autre thérapeute.
- Bon moyen d’aider votre médecin ou thérapeute à ajuster le plan de soin au besoin.
- Bon moyen de démontrer à votre assureur que vous participez activement à votre propre traitement.

Comment tenir votre journal d’activité :

- Vous pouvez modifier les heures (à gauche) pour les adapter à votre propre horaire (par ex. si vous avez l’habitude de vous lever à 10 h et de vous coucher à 2 h, faites commencer l’horaire à 10 h et modifiez le reste en conséquence).
- Dans chaque case horaire, inscrire l’activité en quelques mots (déjeuner, faire lit, sieste, etc.)
- Par repos, on entend s’étendre les yeux fermés, et dormir ou méditer.
- Pour mieux analyser les patterns d’activité, colorer les cases selon le niveau d’activité (par ex. bleu = repos - rouge = exercice - jaune = activité sédentaire), ce qui permet à chaque malade de reconnaître le ou les patterns les plus appropriés à sa situation.

ÉCHELLE DE CAPACITÉ FONCTIONNELLE

L’échelle de capacité fonctionnelle permet d’évaluer l’énergie, la gravité des symptômes et le niveau d’activité. Se référer à la description de chaque niveau pour évaluer la capacité fonctionnelle.

0 = Zéro énergie, symptômes graves, avec capacité de concentration très faible ; incapable de quitter le lit de la journée, incapable d’effectuer des activités de soins personnels (ex. besoin de se faire donner un bain).

1 = Symptômes graves au repos, avec capacité de concentration très faible ; journée presque entière au lit ; besoin d’aide pour les activités de soins personnels (se laver).

2 = Symptômes graves au repos, avec capacité de concentration faible ; pauses ou siestes fré-quentes ; besoin d’une certaine aide pour des activités réduites de soins personnels (capable de se débarbouiller devant l’évier) et besoin de repos ensuite car fatigue après effort grave.

3 = Symptômes modérés au repos, avec capacité de concentration faible ; besoin de pauses ou siestes fréquentes ; capable d’effectuer certaines activités de soins personnels sans aide (se laver debout à l’évier quelques minutes) mais fatigue après effort grave et besoin de repos.

4 = Symptômes modérés au repos, avec une certaine difficulté à se concentrer ; besoin de pauses fréquentes toute la journée ; capable d’effectuer sans aide certaines activités de soins personnels (douche) et de la vie quotidienne (par ex. travaux ménagers légers, lessive) ; capable de marcher quelques minutes par jour.

5 = Symptômes légers au repos, avec courtes périodes d’assez bonne capacité de concentration (15 minutes) ; besoin de se reposer le matin et l’après-midi ; capable d’effectuer sans aide des activités de soins personnels et de la vie quotidienne, mais avec fatigue après effort légère ; capable de marcher de 10 à 20 minutes par jour.

6 = Symptômes légers ou absents au repos, avec assez bonne capacité de concentration jusqu’à 45 minutes ; incapable d’effectuer plus d’une tâche à la fois, besoin de pause en après-midi, capable d’effectuer la plupart des activités de la vie quotidienne excepté passer l’aspirateur ; capable de marcher de 20 à 30 minutes par jour ; capable d’effectuer des activités bénévoles au maximum 4 heures par semaine, avec horaire flexible.

7 = Symptômes légers ou absents au repos, avec bonne capacité de concentration jusqu’à une demi-journée ; capable d’effectuer des activités de la vie quotidienne plus intenses (par ex. faire l’épicerie, passer l’aspirateur), mais peut ensuite éprouver de la fatigue après effort en cas d’en avoir « trop fait » ; capable de marcher 30 minutes par jour, capable de travailler un nombre d’heures limité, maximum 25 par semaine ; vie sociale inexistante ou réduite.

8 = Symptômes intermittents légers, avec bonne capacité de concentration ; capable d’effectuer toutes les activités de soins personnels, de travailler 40 heures par semaine, d’avoir des activités sociales, de faire de l’exercice de modéré à vigoureux trois fois par semaine.

9 = Aucun symptôme ; très bonne capacité de concentration ; vie personnelle et sociale active ; capable de faire de l’exercice vigoureux de 3 à 5 fois par semaine.

10 = Aucun symptôme ; capacité de concentration excellente ; perfectionniste (besoin de sommeil parfois inférieur à la moyenne).

Evaluating Disability Programs

When evaluating disability programs from a ME/FM perspective, here are some questions to consider:

To what extent is the particular service that is needed by people with ME/FM available and in place? People with ME/FM need income replacement when they can't work, home care when they can't manage household activities, part-time and home-bound schooling when they can't manage full time school, and medical support to help manage their illness.

How well is the service needed by people with ME/FM advertised and explained? The UK study of home care found that many people did not know the qualification criteria or procedures. Elections Canada makes at-home voting available, but it is hard to find the service on its website.

Is the service's application process easy to use for people with ME/FM? The UK study of home care pointed out how hard it was to apply for services because of the concentration and stamina required. A recent report of Canada's Auditor-General's talked about the general complexity of the CPP-D application process where the application kit contains eight documents totalling 42 pages. We are finding that many doctors charge money for completing DTC forms.

Is the service's eligibility test fair and reasonable and ME/FM sensitive? CPP-D asks if the person has a severe and prolonged mental or physical disability and clarifies that severe means that the person is incapable regularly of pursuing any substantially gainful occupation. Special education (Ontario) asks if the student meets one of a listed exceptionality. The DTC asks if the person is legally blind or restricted in one or more of a list of activities.

Is the service's adjudication process fair to people with ME/FM? The UK home care study found that adjudicators were not fully believing of ME/CFS applicants. The CPP-D adjudication process identifies ME/CFS and FM cases as challenging, implicitly granting permission to adjudicators to turn down the application.

Special Education (Ontario)

Special education is under provincial jurisdiction. The National ME/FM Action Network focuses on national issues, so special education should not be in this newsletter. It is included because special education is an important disability support and because it can be used to demonstrate two ways that good intentions can be badly implemented.

The Ontario Education Act and the Ontario Human Rights Code promise all children the right to a public education. So far so good.

Bad implementation 1: Re-defining the eligibility criteria and leaving people out:

While the special education provisions are intended to apply to any student who cannot access the mainstream system, the Ministry of Education re-defines eligibility using traditional disability categories – deaf/hard-of-hearing, blind/low-vision, autistic etc. This leaves out students with non-traditional disabilities, including the disabilities that come with ME/CFS and FM. Yes, school boards can offer ME/FM students special services, but at their discretion. Note that the US special education legislation includes a category "other health impaired" which covers ME/FM students.

Bad implementation 2: Writing procedures based on administrative and financial considerations rather client rights:

The UK Ministry for Education got this one right. Their guidelines say: "If your child's going to be away for a long time, the [school board] **will make sure** they get as normal an education as possible...This could include arranging home teaching...The [school board] **must make sure** your child continues to get **a full time education - unless** part time is better for their health needs. The [school board] should also ...**make sure your child isn't without access to education for more than 15 school days [and] arrange education from the start of your child's absence if it's clear they're going to be away from school for long and recurring periods."**

The Ontario Ministry of Education got this one wrong. Their guidelines for home teaching say that it is at the discretion of the principal and supervisory officer and that medical evidence is required to qualify. One local school board posts its implementation procedures which makes home teaching subject to available resources, calls for nine weeks of absence before home teaching starts, limits the service to five hours per week and six months per school year, require paperwork, and reiterates that the service discretionary.

For help dealing with school issues, do not forget our Teach-ME Sourcebook. You can purchase a hardcopy (in English or French) or download a copy for free from our website.

Home Care (UK)

Statistics from the Canadian Community Health Survey 2005 and 2010 show that Canadians with Chronic Fatigue Syndrome and Fibromyalgia had high rates of unmet homecare needs. Indeed, they were double the rates of Canadians over 80 years of age whose applications seem to be taken much more seriously. Expanding home care is a commitment of the new Canadian federal government. It is important to ensure that home care is available to non-seniors who are disabled as well as to seniors.

The charity Action for M.E. looked at issues of home care (referred to as social care) in the United Kingdom (UK). 850 people with ME/CFS took part in their survey. Their findings were published in "Close to collapse: an interim report on access to social care and advocacy for people with ME/CFS". What they found is very relevant as Canada moves forward.

There is a shocking gap between support needs and service provision.

- *A staggering 97% of respondents told us they experience two or more difficulties with daily living activities listed in the Care Act 2014 for England.*
- *However, just 16% had received social care assessments*
- *Of these [850 people], only 6% had been awarded a care package.*

The benefits of social care can be significant. The main benefits of having a care package, for the 6% who had one, were:

- *reduction of the burden of caring on family members and on informal carers (60% of respondents)*
- *being better able to manage symptoms (50% of respondents), which can either be a foundation for improvement or prevent deterioration in health.*

The report examined why the care gap exists and put forward these explanations:

- *Cognitive difficulties – severe limitations on concentration span and profound mental fatigue – in M.E./CFS are a major barrier to self-representation in the complex processes of social care.*
- *The acute levels of multiple disabilities that M.E./CFS can cause often make the processes of assessment and planning too strenuous for those most in need of help. A quarter of respondents said they were too ill to deal with social care services and many gave up asking for help out of sheer exhaustion because the assessment and planning system was not adjusted to their needs.*
- *Lack of information about entitlements and poor signposting to social care services were a major barrier to access*
- *There appears to be misinformation and continuing stigma attached to the label of M.E./CFS despite the strong evidence base that should mitigate this. This may affect the outcome of assessments and the provision of appropriate care and also seems to deter people with M.E./CFS from asking for help or support. One third of respondents felt the disability resulting from their illness was not accepted as genuine.*

Action for M.E. has published a self-advocacy toolkit for patients. They are conducting a further study in the hopes of influencing the home care program, and they are asking for funding of a national advocacy service, having found that *Three quarters of respondents believed their situation would be "a little better" (25%) or "a lot better" (50%) if they had someone to represent them. There was a high level of satisfaction amongst those who had used advocacy but nearly four in five respondents had not accessed advocacy.*

At-Home Voting

Voting is important, but how do you vote if you are housebound? We checked the websites of Elections Canada and the ten provincial election agencies to see if an at-home voting service was advertised. Lo and behold, five provinces said that they offer this service and six (including Elections Canada) didn't say so. We sent a joint letter to all of them, thanking the five, and asking the others to review their position.

This memo was sent to Elections Canada and provincial election agencies

Date: January 18, 2016

Re: Voting by home-visit – an important service for accessibility

The National ME/FM Action Network is a registered charity that has been working on behalf of Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia since 1993. These are surprisingly common conditions that can be very disabling. Some people with ME/CFS or FM are housebound while others are bedbound.

During the recent federal election, we asked ourselves how people who are housebound or bedbound could vote.

The federal website showed four ways of voting – at a regular poll, at an advance poll, at an Elections Canada office, or by mail. The first three options are not suitable for people who are housebound, so we investigated voting by mail. The voter has to obtain an application form, fill it in, get it to an Elections Canada office, receive a voting package, follow the instructions, and get that package back to an Elections Canada office by the deadline. Some of our people could handle all this but it would be too difficult for others.

When we asked the right questions, we learned that there is another service available – voting at home. The voter simply has to contact Elections Canada who will send officials to the house. The officials will complete the application process, hand over a voting package, and take the completed voting package back to the office. This option makes voting accessible for some people who would not otherwise be able to vote.

The home-visit option is not advertised on the Elections Canada website. Even if it were, the information may not reach those who need it most (many of whom do not have internet), but it would be a good start.

We then looked at the election websites for the ten provinces to see if we could easily find information on voting by home-visit (looking under ways to vote or accessibility.)

We found that people can arrange home visits simply by contacting the provincial election agencies in Saskatchewan, Manitoba, Ontario, New Brunswick and Nova Scotia. We would like to convey our appreciation to the election agencies of these provinces for making this service available and, moreover, making it known that this service is available.

We found that Quebec also offers home-visits, but it must be initiated by a written request. Requiring a written request is a barrier. We ask that this requirement be removed.

We could not find any information about voting by home-visit in British Columbia, Alberta, Prince Edward Island or Newfoundland and Labrador. We do not know whether this option is not available or whether it simply is not documented on the website. We ask that the election agencies in these provinces (and Elections Canada) ensure that this option is available and that it’s availability is made apparent on your website.

Thank you

- ☆ Elections Alberta wrote us back and said that their legislation prevents election officials from going to homes, but the legislation is being reviewed. They told us how to make a submission to the review committee. We have made a submission. Wow – hope for change.
- ☆ Elections Quebec wrote us back and explained that they do come to homes but legislation requires a written application for the service. They went on to say that they had forwarded our letter to the legislature suggesting that the written requirement be dropped. Wow - hope for change.
- ☆ Elections Saskatchewan advertised the service, but they still replied immediately.

  Thank you for your kind letter. We are pleased to be able to offer homebound voting for the April 4 provincial election. As you’ve seen, our information on this is here on our website: http://www.elections.sk.ca/voters/ways-to-vote/ Also information on homebound voting is in our voters guide and in the voter information card package that will be mailed to all registered voters in Saskatchewan after the election is called in early March. Please feel free to forward this information on to your contacts and clients in Saskatchewan who may benefit from this voting option.

  Wow - Elections Saskatchewan is an organization that is enthusiastic and creative about reaching out to people that need help!

Canada Pension Plan-Disability

<u>This letter was sent to a senior public servant in the CPP-D program:</u>

February 3, 2016

Thank you for the opportunity to meet on Tuesday January 19, 2016. The focus of discussion was the first-stage adjudication of CPP-Disability cases involving Myalgia Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia.

Here are some key points:

- ME/CFS and Fibromyalgia bring with them a high degree of disability. Both qualitative and quantitative research support this statement.
- People with ME/CFS and Fibromyalgia report very high rates of unmet health care needs. There has never been an official medical specialty for ME/CFS and that there is no longer a specialty for Fibromyalgia since rheumatologist are abandoning the field. These are complex conditions for primary care physicians to be handling, especially as medical schools have provided little or no training in the area.
- Lack of information and misinformation in the medical community are huge problems. One myth is that Graded Exercise Therapy is curative for ME/CFS. In fact, studies show that over-exertion can cause damage to patients, leading to the conclusion that patients should not push their limits.
- "Chronic fatigue syndrome" was a poor choice of names. ME/CFS is a multi-system illness and is about much more than chronic fatigue. Likewise, Fibromyalgia is about much more than chronic pain.
- Too many people with ME/CFS and Fibromyalgia are having their application turned down at the first stage. This has enormous human cost. People tell us that they cannot focus on their health until their financial situation is stabilized.
- The CPP-D adjudication framework identifies ME/CFS and Fibromyalgia as challenging to adjudicate.

The National ME/FM Action Network was pleased to hear that CPP-D has asked medical staff to review the policy and procedures concerning ME/CFS and Fibromyalgia. A key goal should be to ensure that people with ME/CFS and Fibromyalgia who meet the eligibility requirements, having sufficient contributions and being regularly incapable of pursuing any substantial gainful occupation, are approved in the first round. These illnesses are prolonged. We have a number of recommendations on how to improve the current situation:

- Since these conditions are considered a challenge, CPP-D should assign experienced well-trained adjudicators to these applications and CPP-D should ensure that these adjudicators are kept up-to-date in this quickly evolving area.
- CPP-D should articulate what it wants to see in the medical submission. The medical documentation should include:
  - the Clinical Diagnostic Worksheet found in the Canadian Consensus Criteria for ME/CFS or the Clinical Diagnostic Worksheet found in the Canadian Consensus Criteria for Fibromyagia, or both worksheets,
  - Activity Logs and an assessment of them using the Functional Capacity Scale, and
  - The RAND questionnaire.
- These submission requirements need to be communicated to health professionals across the country.
- CPP-D should remember that ME/CFS and Fibromyalgia patients are not well served by the health care system. Applications should not be denied on the basis of an incomplete medical file that is not the applicant's fault. If medical information is missing, the adjudicator could contact the health professional or the applicant for additional information or to request specific medical documentation as outlined above, commission an independent assessment, or base the decision on the non-medical evidence.
- CPP-D should recognize that there are often conflicting medical opinions on file. Some health professionals are not familiar with ME/CFS and Fibromyalgia while a few even deny their existence. Applicants should be adjudicated on the basis of their disability and no application should be denied on the basis of an uninformed or biased medical opinion.
- A rejection of an application for non-compliance with treatment requires an understanding of the benefits of the treatment and an understanding of the challenges that patients face. Generally, treatments for ME/CFS and Fibromyalgia have at best slow, incremental

benefits while patients face large challenges (financial constraints, limited stamina, limited concentration, side effects of treatments, etc) Therefore, a rejection on the basis of non-compliance or even for failing to pursue a particular treatment option should be a rare event.

- Payment to health professionals should reflect the effort that goes into providing the necessary information. This payment may be higher for ME/CFS and Fibromyalgia than for other standard conditions since more time is needed to collect and document the complexity of these illnesses.
- Statistics should be kept on decisions (approval rates, time taken, reasons for refusal, etc.) by type of application. Patterns and trends should identified and corrective action taken when problems are noted. Statistics should be published on a regular basis to ensure that there is system transparency.

We note the Auditor-General's report on CPP-D released yesterday and believe that our recommendations are very consistent with their recommendations dealing with the initial application/adjudication stage.

We are willing to discuss any of these points with you and your staff.

Thank you again for the opportunity to put these issues on the table to ensure that Canadians with ME/CFS and Fibromyalgia have equitable access to CPP-D benefits.

Disability Tax Credit

Thanks to everyone who has shared with us your experience with the DTC. If you have experience with DTC and have not submitted your story, we would still like to hear from you.

The Network has asked to meet with DTC to get clarification on the application form. We hope to be able to provide you with guidance soon.

If you are applying or re-applying for DTC in the meantime, you should know that other people with ME/FM have indeed qualified. Severe cases may be able to qualify under a single category while more moderate cases will likely use the cumulative provisions. Categories which appear to be used most often by people with ME/FM are mental functions, walking, dressing, feeding and elimination.

Correspondence With the Lancet

The following are exerts from emails sent to/from Dr. Richard Horton, Editor in Chief of the Lancet regarding the publication of the PACE trial findings.The full correspondance is posted on our facebook page.

From National ME/FM Action Network

...In February 2011, The Lancet published an article called “Comparison of adaptive pacing therapy, cognitive behavior therapy, and graded exercise therapy” This was an unblinded trial for treating ME/CFS (PACE), a randomized trial. The article stated it was an effective treatment for ME/CFS.

An open letter was sent to you on November 13, 2015 by Vincent R. Racaniello, PhD, Professor of Microbiology and Immunology together with five of his colleagues. This letter was resent to you on February 10, 2016 with 36 additional signatories of leading scientists and researchers requesting that an independent re-analysis of the individual-level PACE trial data be done...

It is important for The Lancet to have an unbiased voice and by not obtaining an independent analysis of the data of the PACE trial, it does not live up to its commitment and mandate for furthering science and the ME/CFS and FM communities.

From the executive assistant of the editor of the Lancet

...Dr Horton is currently travelling and I am confirming receipt of your email on his behalf.

From the National ME/FM Action Network

...In all due respect, although Dr. Horton is travelling, it does not stand in the way of getting a proper re-analysis done on the PACE data. This is not only in the interest of science and the ME/CFS and FM communities across the globe but also for The Lancet whose reputation and credibility is being questioned.

CPP-D - Notice of Readiness Form CAUTION

If your appeal is at the Social Security Tribunal and you are currently waiting for a hearing - you would have likely received a Notice of Readiness form in the mail.

This form is very important - as once you complete this form and return it to the Social Security Tribunal it means that you are stating that there **are no more documents you wish to file in support of your appeal**. Many people will be keen to get the Appeal heard, but we strongly recommend that you consult an expert to ensure that you are indeed ready to proceed before you sign the form.

http://mefmaction.com http://twitter.com/mefmaction http://www.facebook.com/MEFMActionNetwork

NATIONAL
ME/FM
ACTION NETWORK

512-33 Banner Road, Nepean, ON K2H 8V7 Canada
Phone: 613-829-6667 • Fax: 613-829-8518
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**

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