

On January 17, 2012, representatives of the National

ME/FM Action Network met with officials of the Canada

Pension Plan Disability program. This is a letter following up on that meeting.

We would like to thank you and your three colleagues for meeting with us on January 17, 2012, to discuss the issue of CPP disability benefits for people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and/or Fibromyalgia.

CPP-D is an important issue in the ME/FM community. These illnesses frequently strike people of working age and impact on their ability to participate in the workforce. We find in general that people are slow to recognize the serious and prolonged nature of their illness and they try to continue to work as long as possible. They may have difficulty finding a doctor to diagnose and treat these conditions and to support their CPP-D application. It is only with great reluctance that patients acknowledge the disabling nature of these illnesses and consider applying for CPP-D. Even then they may have to figure out how to do this. There is little support for CFS or FM patients in working through the application process. For example, we received a call recently from a patient asking us for the name of a lawyer – her doctor had asked her to find one to explain to him how to complete the forms. If you are familiar with the concept of capability maturity models, the system for CFS and FM patients is at Level 1, the lowest level, and struggling to move to Level 2 (with Level 5 being the highest level).

The National ME/FM Action Network has put together a Guide to help people through the application process – a component of moving to Level 2. We currently reviewing the document. While the technical steps of applying are straight-forward, we are having great difficulty explaining what information the adjudicators are looking for to support a finding of severe and prolonged disability. We suspect that is because the CPP-D program itself is uncertain about how to judge these cases.

Chronic Fatigue Syndrome and Fibromyalgia receive special attention in the CPP-D Adjudication Framework. Let me quote from the document:

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Written by Administrator

Tuesday, 24 January 2012 00:00 - Last Updated Tuesday, 24 January 2012 08:54

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

CPP-D staff have prepared an "Adjudication Tool" to guide adjudicators in their review of FM, CPS, CFS and Multiple Chemical Sensitivities cases. This Adjudication Tool is not available on the CPP-D website but was provided to our organization on request. There is another Adjudication Tool to guide adjudicators when a patient does not comply with medical advice. Thank you for forwarding this document after our meeting.

Even if the adjudication of CFS and FM cases "can be a challenge", fairness dictates that patients with these conditions should not have more difficulty qualifying for disability benefits than patients with the same degree of disability as a result of other medical conditions. Patients with CFS and FM should have a level playing field. There are a number of issues that need to be addressed in order to create a level playing field. Broad issues include equitable access to medical support and to advocates who can assist in the application process. But much more specifically, we would like to get clarification on how decisions are made.

We believe that the Adjudication Tool for FM/CFS/MCS/CPS needs review. We have a number of concerns with this document including:

- - the definitions and descriptions do not reflect the latest information
- - the Tool implicitly assumes that the medical system knows what is best for patients even though reality is more complex
- - the adjudication appears to be based on the dynamics between the patient and the medical system rather than on the degree of disability
- - while we recognize the need for nuance, the Tool is nuanced to the point that decisions seem arbitrary.

We put forward a functional capacity scale as a foundation for decision-making. The scale is based on the Karnofsky model and was adapted for use with ME/CFS, FM and MCS patients by two outstanding doctors at the Environmental Health Clinic of Ontario. The patient completes an activity log over a period of time and the score is based on that, meaning that there is evidence

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to back up the score. In our opinion, the scale aligns extremely well with the criteria for severe disability. A consistent score of 6 or lower would suggest the inability to work, while a consistent score of 8 or higher would suggest the potential to be in the workforce. We are not suggesting that the score completely replace the expertise of an adjudicator – there could be special circumstances that need to be considered. However, we believe the score is important information for the adjudicator and should be an important factor in the decision.

You agreed to discuss the possibility of a review of the Adjudication Tool with your Director-General. We would really encourage this project. It would make the application process much easier for patients and health professionals in the ME/FM community. There would have more certainty around outcome, which would relieve stress and help planning. New adjudication guidelines would also benefit the program itself, making the adjudication process more efficient and credible.

We would be happy to put forward the names of patient advocates and medical experts familiar with ME/CFS and FM who could provide valuable input to a revision exercise. We can also connect you to people working in the areas of Chronic Pain and Multiple Chemical Sensitivities.

Let me also remind you of two topics we covered at the meeting:

1) The National ME/FM Action Network is a registered charity founded in 1993 to provide support to Canadians with ME/CFS and/or FM. We provide information through newsletters, a website and an answering service. We also carry out special projects that are important to the patient community. Special projects have included:

- - spearheading the development of diagnostic and treatment protocols for ME/CFS (2003) and Fibromyalgia (2004),
- - intervening in court cases, including a human rights case at the Supreme Court of Canada
- - hosting the 2011 biennial conference of the International Association for CFS/ME. The conference was held here in Ottawa last September.
- - publishing a Guide for educators on teaching students with ME/CFS and FM
- - publishing a Guide for patients on how to apply for CPP-Disability benefits.

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The National ME/FM Action network is the national organization for ME/CFS and FM patients. We do not have provincial affiliates as part of our legal structure but we work closely with provincial, local and international groups. We “represent” patients in a broad sense and not in the sense representing individual applicants for CPP-D. We do not have the resources help patients with their individual applications.

2) The Canadian Community Health Survey, a major survey conducted by Statistics Canada, has provided valuable insight into the situation facing Canadians with CFS, FM or both. The survey showed that:

- - an estimated 756,000 Canadians had a diagnosis of CFS, FM or both in 2010.
- - Canadians with these illnesses experience a high degree of disability (difficulty with tasks, difficulty in social situations, permanently unable to work.)
- - Canadians with these illnesses experience a high degree of disadvantage (low income, food insecurity, social isolation)
- - Canadians with these illnesses experience a high level of unmet needs (health care, home care)

We provided you copies of our Quest newsletter containing the 2005 and 2010 data. The newsletter with 2005 data is posted on our website: http://www.mefmaction.com/images/stories/quest_newsletters/Quest80springsummer2009.pdf

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We would be very interested in seeing statistics on the number of people applying for CPP-D on the basis of CFS or FM, and we would be interested in statistics on processing times and outcomes of these applications.

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We look forward to hearing the results of your discussions with your Director-General.

Margaret Parlor

President

National ME/FM Action Network

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