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July 5, 2017

The Honourable Carla Qualtrough  
Minister of Sport and Persons with Disabilities  
[hon.carla.qualtrough@canada.ca](mailto:hon.carla.qualtrough@canada.ca)

Dear Minister Qualtrough

The primary impairment that comes with ME/CFS and/or FM is a reduction in physical and mental energy available for use in everyday life. People must adjust their life to balance their energy usage with their energy availability. Reduced functional capacity can be very disabling.

There are four major ways that the Canadian government communicates what it means by disability: through the human rights route, the CPP-Disability program, the Disability Tax Credit (DTC) program, and the Canadian Disability Survey. The human rights system recognizes reduced functional capacity as a disability. The CPP-D program conceptually recognizes this disability and is struggling to operationalize the concept. Neither the DTC program nor the Canadian Disability Survey conceptually recognizes reduced functional capacity as a disability.

To address the non-recognition by the DTC program, we have just written the Minister of Finance asking that functional capacity necessary for everyday life be added to the DTC list of "basic activities of daily living". A copy of the correspondence is attached.

We hope that we will have your full support in working through the DTC issues with Finance Canada and more generally in building recognition for this oft-overlooked group of disabled Canadians.

Yours truly

Margaret Parlor  
President

c.c. Anita Vandenbeld M.P., Ottawa West-Nepean



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July 5, 2017

The Honourable Bill Morneau  
Minister of Finance  
[bill.morneau@canada.ca](mailto:bill.morneau@canada.ca)

Dear Sir:

**Re: Fixing the Disability Tax Credit (DTC) for Canadians with ME/CFS and/or FM**

There are Canadians who have health impairments that reduce the physical and mental energy available to them. They reduce their participation in work, school, family, recreational, social and civic life to compensate and they struggle to function and support themselves financially. Even so, they have great difficulty qualifying for the Disability Tax Credit (DTC). The test for the DTC focuses on specific activities (eg feeding and dressing) or functions (eg seeing and speaking). People with reduced energy may be able to do each of the activities or functions when looked at in isolation.

We are asking for a change to the DTC criteria to recognize that functional capacity is critical to participation in society and that reduced functional capacity is a form of disability. In the attached document, we describe the problem and propose how the DTC program could be changed.

We hope that you will consider our proposal and fix this gap in the DTC quickly. We would be pleased to work with you to accomplish this goal.

Yours truly,

Margaret Parlor  
President

c.c. Anita Vandenbeld M.P., Ottawa West-Nepean



## **Fixing the Disability Tax Credit (DTC) for Canadians with ME/CFS and/or FM**

Prepared by: National ME/FM Action Network  
A registered charity working on behalf of Canadians with  
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)  
and/or Fibromyalgia (FM)

July 2017

## Summary

The Disability Tax Credit (DTC) was originally developed as a program to provide tax relief for blind Canadians in recognition of the extra costs involved in their disability. It has evolved in two directions since then. Firstly, it has expanded in recognition of other impairments besides vision impairment. Secondly, it has become the gateway for other disability supports such as the disability savings plan and home renovation expense deductions; to qualify for these supports, one must first qualify for the DTC.

Symbolically, the DTC is a very important federal government statement on what is meant by disability.

The DTC expanded in a piecemeal fashion as various impairments were incorporated into the program. The impairment experienced by the ME/FM community, reduced functional capacity which is also referred to as loss of physical and mental stamina, has not been incorporated. As a result, people with ME/CFS and/or FM do not have full and fair access to the DTC program itself or to the supports associated with the DTC program. Further, the government is signaling that people with reduced functional capacity are not really disabled.

We ask that you immediately add a new category to the T2201 form to recognize restrictions in functional capacity necessary for everyday life. It appears that this could be done quickly and easily without amending the Income Tax Act. Adding this category to the form would go a long way toward addressing the unfairness experienced by the ME/FM community, although there are additional issues that would still need to be discussed.

## The DTC Criteria

Form T2201 uses eight specific “basic activities of daily living” (vision, speaking, hearing, walking, feeding, dressing, elimination, and mental functions necessary for everyday life). Disability is based on being *markedly* restricted in one or more of these categories, or being *significantly* restricted in two or more of the categories.

We have put the term “basic activities of daily living” in quotations for two reasons. Firstly, the categories on the DTC list are a combination of activities (eg dressing and feeding) and functions (eg hearing and seeing). Secondly, the same term is used in a social service context but is defined differently and this could lead to confusion.

What is important to note is that the DTC list is highly selective and does not provide a complete and comprehensive test of disability. It does not look at the whole package of activities and abilities that people need to be able to do to live independently and to participate in the community. People who are not significantly restricted in the DTC categories may still be unable to live independently or participate fully in Canadian society. They could still have additional costs and could still be financially unable to support themselves. Catherine, who has ME/CFS, told us that she and a friend reviewed form T2201 and felt that she didn't qualify for the DTC because she could do all the particular bits and pieces. Amazingly, she had qualified to live in an assisted care facility and was assigned a care attendant.

## DTC problems for the ME/CFS community

The National ME/FM Action Network has been working on behalf of Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and/or Fibromyalgia (FM) since its founding in 1993. We have found and the Canadian Community Health Survey confirms that people with ME/CFS and/or FM experience a high level of disability, unemployment, poverty, food insecurity, feelings of social isolation, and unmet health care needs. A link to a statistical report can be found at the end of this document.

When it comes to the DTC, we are hearing confusion, frustration and despair from our community. People are highly disabled and struggling to participate in society, and yet they find it very difficult to qualify for the DTC. They do not understand why they should not get the tax relief and other supports offered to other disabled Canadians.

The test for each category is described in stringent ways, usually being unable or taking an inordinate amount of time to do that “activity”. Taking extra time is not the only way people adapt to functional impairment. They simplify tasks or avoid them instead. They wear track suits as opposed to buttoned apparel or stay in pajamas all day. They open canned goods rather than preparing nutritious fresh meals. We heard from Louise who was turned down for the DTC. She did not apply under the feeding category. We asked her what she eats. She told us that she was too tired to fix meals so she always phones out to have meals delivered. She was adjusting to her inability, not recognizing it.

To qualify under the cumulative provision, someone doesn't have to be “markedly restricted” in a single activity, only “significantly restricted” in two or more activities such that this is equivalent to being markedly restricted in a single activity. While some people with ME/CFS and/or FM have been successful under this provision, the whole concept is difficult to understand or apply.

Even if people with ME/CFS and /or FM think that they might qualify for the DTC, they can have difficulty finding the energy to apply or finding a medical doctor to complete the form. Doctors often do not think that people qualify. Doctors do not know how to present the information. Louise's doctor missed the fact that she was not preparing meals herself. Doctors often charge fees for completing forms, another barrier to applying.

Ensuring that people with ME/CFS and/or FM have full and fair access to the DTC is important because

- disabled people who fail to qualify are not receiving the tax credit they deserve,
- disabled people who fail to qualify do not have access to disability programs that require DTC eligibility such as the disability savings plan, and
- the DTC is one of the most important federal government statement on what disability means and it overlooks this sizable and needy group of disabled Canadians.

## **Impairment in Functional Capacity**

The DTC program's underlying model of disability does not include the essential impairment encountered by people with ME/CFS and/or FM – reduced functional capacity, also referred to as loss of physical and mental stamina.

Science around ME/CFS is showing impairment of energy production and availability. The prestigious US Institute of Medicine dubbed ME/CFS as “systemic exertion intolerance disease”. The same studies have not yet been done for FM, but similar findings are likely.

Compare cell phones with good batteries to cell phones with defective batteries. Cell phones with good batteries will function fully and reliably all day. They can be charged up overnight and be ready to go the next day. Cell phones with defective batteries won't function fully and reliably all day and they won't recharge properly. The problems will differ depending on the extent of the battery defect. Some cell phones might function reasonably well but not for the full day. Some might function poorly when they function. If you have a cell phone with a defective battery, you would accommodate by recharging it more often or turning off the phone for part of the day to save it for important times.

In a similar vein, people with ME/CFS and/or FM do not function fully and reliably for full days and they don't find that sleep recharges their batteries. Trying to push themselves can backfire by making their symptoms worse. People end up reducing their activities to balance their energy usage with their energy availability. Finding that balance can be very difficult since energy availability may not be consistent from day to day. They rest frequently and focus on priority activities.

The community uses a functional capacity scale to judge how serious the functional impairment is. The scale runs from 10 (an over-achiever) and 9 (a regular person with normal energy) down to 0 (someone completely bedridden). As you go down the scale, you will see activities being dropped, generally starting with recreational and social activities, then work and school activities, then household management, and finally self-care. This means that people have given up a huge portion of their life before they begin to qualify for the DTC since the DTC focuses on things that people give up last.

People at level 7 can consistently function physically and mentally around half a day. They have cut out most social activities and if they are still working they have cut back to part time. They are making

many accommodations in activities of daily living to reduce their energy expenditure – shopping at corner stores, buying processed foods, taking taxis rather than walking. They have a housekeeper if they can afford one. Thus, people at this level are already incurring additional expenses and have reduced ability to support themselves financially, which are important issues that DTC eligibility is supposed to address. Thus, we would argue that people at functional level 7 should be eligible for the DTC.

People at level 4 need frequent rests throughout the day. They can do independent self-care and limited activities at home (eg a bit of light housework and laundry). They can walk for a few minutes per day. They are not working and they have no social, recreational or civic life. They find it difficult to do tasks that require mental energy like paying a bill. They are housebound. They are incredibly disabled, yet they may be able to do all the bits and pieces on the T2201 form – vision, speaking, hearing, walking, feeding, dressing, elimination, and mental functions necessary for everyday life. They may think that they don't qualify or even be told that they don't qualify for the DTC. It is wrong that people who are so disabled might not qualify.

## **Our Recommendation**

The National ME/FM Action Network recommends that impairment in functional capacity necessary for everyday life be immediately added as a new category of “basic activity of daily life” on form T2201. We recommend that it be used in conjunction with the Functional Capacity Scale, and our position is that people who are not functioning consistently and reliably at level 8 or above on this scale should qualify.

We note that elimination is a category on the T2201 form but not in the Income Tax Act and therefore we believe that a new category could be added to form T2201 without amending the legislation. The limitation would be that only medical doctors would be allowed to certify the category.

We recommend that this category of impairment be effective from the date of onset of the impairment rather than from the date the T2201 form is amended.

## **Longer Term Suggestions**

- ✓ Consider who besides medical doctors could certify functional capacity restrictions.
- ✓ Automatically qualify people for DTC who have already qualified for CPP-D or provincial/territorial disability supports. These people have gone through a rigorous process of demonstrating that they are disabled and have reduced ability to support themselves financially.
- ✓ Reimburse health professionals for completing form T2201. Non-disabled people do not have to complete these forms. Thus, the payments to health professionals is a tax on disabled people.
- ✓ Provide more information to medical professionals on the purpose of the DTC and the information that the program is looking for.
- ✓ Make the DTC refundable so that it benefits people with little or no income.
- ✓ Identify what expenses people with functional capacity limitations incur and add these to the list of deductible expenses
- ✓ Consider the implications of the UN Convention on the Rights of Persons with Disabilities (CRPD) on disability programs. Under the CRPD, disability is based on participation, impairment and environmental factors, whereas programs like DTC were developed in an impairment-focused era.

## PROPOSED ADDITION TO FORM T2201

### **Functional capacity necessary for everyday life**

Your patient is considered markedly restricted in functional capacity necessary for everyday life if, for a prolonged period of time, your patient's physical and mental stamina to participate in home, school/work, social, recreational and civic life is markedly less than it was prior to becoming impaired or is markedly less than that which would be expected of someone of the same age. No treatable cause has been found for the reduced stamina and/or symptom treatment has had limited effect.

Note: Please attach an activity log (two week minimum). Estimate a functional capacity scale score for each day – see the IACFS/ME Primer Appendix C.

Note: Caution should be used in prescribing activity and exercise because people with reduced stamina may be intolerant of exertion.

Examples of markedly restricted in functional capacity necessary for everyday life (examples are not exhaustive).

- Your patient worked full time and had an active family and social life. Your patient became ill nine months ago and continues to report fatigue, pain, and concentration difficulties. For these health reasons, your patient has significantly reduced work hours, has dropped social and recreational activities, and is doing many fewer household tasks than before. Several treatment strategies have been tried without appreciable effect.
- Your patient, whom you did not know pre-impairment, reports having experienced pain, fatigue and concentration difficulties over the last two years. Your patient, who lives alone, is working part time and looking after some household chores but has dropped virtually all outside activities. In your office, your patient shows signs of reduced physical and mental stamina, speaking quietly, responding slowly, and not always following your questions. You have been provided with a diary for the previous two week period that shows limited activities followed by rest periods. You have been told that this is typical for the past two years. This is markedly less physical and mental activity than you would expect from a 40-year-old.



## **Additional Information**

The National ME/FM Action Network is a registered charity that has been working on behalf of Canadians with ME/CFS, FM or both since 1993. Our website is [www.mefmaction.com](http://www.mefmaction.com)

For a quick introduction to ME/CFS and FM, see our information sheets which can be found here: [http://mefmaction.com/index.php?option=com\\_content&view=article&id=160&Itemid=207](http://mefmaction.com/index.php?option=com_content&view=article&id=160&Itemid=207)

Over 800,000 Canadians reported a diagnosis of CFS, FM or both in 2014, according to a major Statistics Canada survey. These people are dealing with disability, unemployment, poverty, food insecurity, social isolation and unmet needs. We have published an easy-to-read document outlining these statistics:

English: [http://mefmaction.com/docs/CCHS\\_Stats\\_2014.pdf](http://mefmaction.com/docs/CCHS_Stats_2014.pdf)

French: [http://mefmaction.com/docs/CCHS\\_Stats\\_2014\\_Fr.pdf](http://mefmaction.com/docs/CCHS_Stats_2014_Fr.pdf)

The Functional Capacity Scale and activity logs can be found in Appendix C of this document:

English: [http://iacfsme.org/portals/0/pdf/Primer\\_Post\\_2014\\_conference.pdf](http://iacfsme.org/portals/0/pdf/Primer_Post_2014_conference.pdf)

French: [http://mefmaction.com/images/stories/conferences/IACFS\\_Primer\\_2014\\_French.pdf](http://mefmaction.com/images/stories/conferences/IACFS_Primer_2014_French.pdf)

The Institute of Medicine report which refers to ME/CFS as “systemic exertion intolerance disease” can be found here: <https://www.ncbi.nlm.nih.gov/books/NBK274235/>