

# Information for People Struggling to Recover from COVID-19

Even though your COVID-19 is officially gone, your health is not bouncing back the way you think it should. This is having an impact on your overall life. One possible reason for your slow recovery is that you are developing Myalgic Encephalomyelitis (ME), Fibromyalgia (FM) or both. We cannot provide medical advice. You will need a health care professional to help you sort out your medical issues. However, as patients and caregivers who have experience with ME and FM, we can share with you some of what we have learned.

Many people with existing ME or FM found that their health problems started after having a virus. Continuing infection does not seem to explain the ongoing

symptoms. One possible explanation is that the virus turned on the immune system, the virus left, and the immune system couldn't turn itself off. (When you feel bad with a virus, you are feeling your immune system response rather than the virus itself.) Another possible explanation is that the virus damaged the autonomic nervous system which controls many bodily functions.

ME (formerly referred to as chronic fatigue syndrome) and FM are complex chronic disabling diseases. At last count, around 900,000 Canadians had been diagnosed with one or both conditions. They are more prevalent in women than men. They can affect young and old but are most often found in people of working age.

## Diagnosing ME and FM

Two decades ago, there was little guidance to clinicians on how to diagnose and treat ME and FM. Our organization found doctors to draft guidelines. We worked with Health Canada to appoint panels of Canadian and international experts to review the drafts. We facilitated the work of the two panels. The results were published in peer review journals in 2003. The ME diagnostic criteria have become the world standard. The FM guideline changed thinking about FM, moving the focus from pain to a broader range of symptoms.

In the absence of known biomarkers, ME and FM are diagnosed based on a pattern of symptoms. These include reduced activity levels, cognitive problems, sleep problems, and pain. The main difference is that ME requires post-exertional malaise (referred to as PEM) while FM does not.

Most people can push themselves, and the next day they are able to push themselves as far or farther. Their bodies respond to challenges by become fitter. People with PEM do worse the second day, suggesting that

exertion actually harms their aerobic energy system. If you have PEM, exertion can be harmful. It can be hard to convince patients with PEM and those around them that backing away from activity can be a better strategy than pushing forward. You will see advice to people with ME to try Graded Exercise Therapy (GET) which is about trying to do a little more every day. Be aware that this therapy has been discredited for ME patients.

The leading organization for US clinicians is the Institute of Medicine (now called the National Academy of Medicine). In a 2015 report on ME, they addressed a specific problem. Many people with ME were undiagnosed and health care providers had limited time to meet with patients. How could potential cases of ME be recognized in a few minutes? They recommended that the health care provider look for reduced activity levels, PEM, sleep disorders, and either cognitive problems or orthostatic intolerance. These are some of the elements in the 2003 clinical guidelines for ME, so think of the IOM report as a useful screening tool for ME cases.



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## Diagnosing ME and FM (continued)

Most people can look after themselves and their home, participate in school or work, maintain a social life and do some physical activity. When chronic illness intervenes, they find themselves cutting back on these activities a little or a lot, depending on the severity of the chronic illness. To discuss activity levels with your health care provider, it is very helpful to keep a diary and then apply the functional capacity scale (FCS) which is shown on the next page. The FCS runs from zero (completely bedbound) through 7 (can do some part time work) to 10 (athlete). Your level of function can vary from day to day, but you are trying to find a level that you can sustain and build from. A diary is also useful in identifying PEM and in documenting disability applications if required.

Orthostatic Intolerance (OI) has to do with getting blood to your brain. If you are lying down, you are pumping along the flat. If you are walking around, the movement helps you pump. If your body (ortho) is standing still (static), then you have to rely on your pulse and blood pressure. If these aren't working properly you may feel faint or dizzy and you may lose concentration (intolerance). People with OI might be able to walk around a grocery store but have trouble wait-

ing in line to pay. People with OI have trouble taking showers, especially washing hair where they have to pump blood up to their arms and head. People with OI have trouble standing at a stove to stir food. One measure to use when describing OI is HUA - hours of upright activity. Count how much of the day you are standing or sitting with your feet on the floor, versus sitting with your feet raised or lying down.

Cognitive problems are very common with ME and FM and this can be the most frustrating symptom. They may be related to OI or to running out of energy. Be aware that you have limited energy reserves that are shared between physical, mental and emotional activity.

If you discuss a FM diagnosis, your health provider has choices on what criteria to use. We suggest looking at the Overview of the 2003 FM report. In that report, the FM criteria is based on widespread pain and the existence of tenderpoints, and then health providers are asked to consider additional related symptoms like reduced activity levels, sleep problems and cognitive difficulties. Nowadays, some health providers are inclined to give less attention to tenderpoints and more attention to additional symptoms.

### Pacing

If you are experiencing Post Exertional Malaise (PEM), it is important to manage your activity levels. It will take some time, but you can figure out what level of exertion will cause an exacerbation of symptoms. Remember that exertion can be mental, physical or emotional. If you do too much you may not feel the effect right away. It may be the next day and it could last for days or weeks. People often find it better to do activities in short stints with breaks rather than all at once.

## FUNCTIONAL CAPACITY SCALE:

The Functional Capacity Scale incorporates energy rating, symptom severity, and activity level. The description after each scale number should help you to rate your functional capacity at the beginning and end of each day.

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).

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

# Talking to Your Health Care Provider

Now we come to a delicate but important topic. As you go through the health system, we hope you are treated seriously and with respect, but, unfortunately, this doesn't always happen. ME and FM are complex diseases that the health system has difficulty explaining and treating. The health system has not confronted this challenge; instead it has set it aside. You may encounter health care providers who step forward and offer support, others who ignore ME and FM and others who will blame you. Don't take the negative reactions personally. They say more about the health care providers and their training than they say about you. But it does leave you in the difficult situation of figuring out how to get the help you need.

Focus on your priorities. This will include understanding what is wrong with you and how you can protect and rebuild your health. It may also include dealing with difficulties at work or school and financial stress. Let us also raise another priority, so obvious it is often overlooked. Be aware that your ongoing health issues affect your relationships with family and friends.

Spend time at the diagnostic stage so that you understand fully what you are dealing with. Be sure to check for overlapping and differential diagnoses.

We cannot see what your health will be in the future, but we do know that, regardless of your health condition, you can still have a beautiful and meaningful life.

## Resources to get started:

For overviews of the Canadian Consensus Documents

*Myalgic Encephalomyelitis (available in English, French, Spanish, German, Italian and Dutch)*

[http://mefmaction.com/index.php?option=com\\_content&view=article&id=214&Itemid=263](http://mefmaction.com/index.php?option=com_content&view=article&id=214&Itemid=263)

*Fibromyalgia (available in English, French and Spanish)*

[http://mefmaction.com/index.php?option=com\\_content&view=article&id=214&Itemid=263](http://mefmaction.com/index.php?option=com_content&view=article&id=214&Itemid=263)

For clinical guidance on how to diagnose ME (including a discussion of differential and overlapping diagnoses) and how to treat ME:

*The International Association Primer (available in English and French)*

[http://mefmaction.com/index.php?option=com\\_content&view=article&id=508:mecfs-primer-for-clinicalpractitioners-2014-revision&catid=88](http://mefmaction.com/index.php?option=com_content&view=article&id=508:mecfs-primer-for-clinicalpractitioners-2014-revision&catid=88)

*The Pediatric Primer (available in English and French)*

[http://mefmaction.com/index.php?option=com\\_content&view=article&id=541:mecfs-diagnosis-and-management-in-young-people&catid=67&Itemid=376](http://mefmaction.com/index.php?option=com_content&view=article&id=541:mecfs-diagnosis-and-management-in-young-people&catid=67&Itemid=376)

*For the Institute of Medicine Clinicians Guide which confirms the medical basis of ME and provides screening criteria (available in English only)*

<https://www.nap.edu/resource/19012/MECFSciniciansguide.pdf>

Many more resources are available on our website at [www.mefmaction.com](http://www.mefmaction.com)



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