NATIONAL ME/FM ACTION NETWORK
SINCE 1993

Quest
Newsletter

www.mefmaction.com
Quest 128, Spring 2021
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Focus on Fibromyalgia

Introduction

The National ME/FM Action Network is committed to helping Canadians with ME, FM or both. FM has received less attention than ME in recent years. This newsletter puts a focus back on FM.

In the first part of the article, we question whether FM and ME belong together. We conclude that there are very good reasons to look at their relationship: because the symptoms of FM and ME overlap, because both FM and ME patients need to consider their tolerance of exertion, and because things learned in one area could benefit the other. In the second part, we look at what is needed to move FM forward.

Here are some indicators of the situation around FM in Canada today.

- While the 2019 Canadian Community Health Survey (CCHS) showed that 572k Canadians have a diagnosis of FM, there is little infrastructure within the health care system to address it.
- While Canada's health research funding agency allocated over $1.3 Billion in research funding in 2020-21, only $161,667 went to FM research.
- While people with FM can be very disabled, it can be hard to qualify for supports. As a consequence, people with FM have high levels of unmet home care needs, unemployment, poverty, food insecurity and social isolation.
- While a study showed that a number of people who contracted SARS in 2003 went on to develop FM-type symptoms, there has been little recognition that FM might result from COVID.

Commonly Used Abbreviations

There are many abbreviations in common use around ME and FM. Being familiar with them will make it easier to read this newsletter. See how many of these you recognize. Answers are on page 14.

ACR
CBT
CCC
CCHS
CDC
CIHR
CNS
CPP-D
DTC
FM
FMS
GET
IACFS/ME

ICD
IMHA
IOM
LTD
MCS
MCS/ES
ME
ME/CFS
NAM
NIH
PEM
SEID
WHO

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Focus on Fibromyalgia

FM and ME: Do they belong together?

When Sherri Todd founded the MEFM Society of BC in 1988, she chose to cover both FM and ME. When Lydia Neilson founded the National ME/FM Action Network in 1993, she also chose to cover both FM and ME. Somehow, both Lydia and Sherri sensed, even three decades ago, that FM and ME belonged together. Sherri had received a diagnosis of FM followed several years later by a diagnosis of ME. She thought of the two together. Lydia volunteered with a doctor who treated FM and ME cases. When she talked to patients, she noticed that the two groups were telling the same stories, leading her to think of FM and ME as variations on the same theme.

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Historically, rheumatology adopted FM and the International Classification of Diseases (ICD) placed FM as a musculoskeletal condition. By 2010, rheumatologists were becoming frustrated with FM cases and wanted to let go of them. Also around this time, several drugs were approved for FM care, providing rheumatology with the opportunity to suggest that family doctors could handle FM cases without their help. In 2012, a Canadian group led by a rheumatologist proposed FM treatment guidelines which gave responsibility for FM care to family doctors. Rheumatologists were not given any role. The American College of Rheumatology (ACR) website currently states:

> *Fibromyalgia is not a form of arthritis (joint disease). It does not cause inflammation or damage to joints, muscles or other tissues. However, because fibromyalgia can cause chronic pain and fatigue similar to arthritis, some people may advise you to see a rheumatologist. As a result, often a rheumatologist detects this disease (and rules out rheumatic diseases). For long term care, you do not need to follow with a rheumatologist. Your primary care physician can provide all the other care and treatment of fibromyalgia that you need.*

It is one thing to suggest that rheumatology is not the right specialty to oversee FM. It is another thing to say that FM doesn't need a specialty at all. This minimizes the seriousness of the condition.

In the latest version of the ICD, FM was moved out of the musculoskeletal section to a chronic pain area.

While rheumatology is relinquishing ownership of FM, FM still appears on the website of the organizations like the Canadian Arthritis Society (which offers FM workshops) and FM is still under the purview of the Institute of Musculoskeletal Health and Arthritis (IMHA) at the Canadian Institutes of Health Research (CIHR). The severance of FM from rheumatology is not quite complete.

Chronic pain is expressing an interest in FM based on the fact that chronic pain is a key symptom of FM. There are two arguments against assigning FM to chronic pain. Firstly, chronic pain is only one of the symptoms of FM as will be discussed below. Lessons can be learned from the ME area where chronic fatigue was seen as the essence of ME and that delayed progress for years. Secondly, the Canadian Community Health Survey for 2015/16 tells us that only 15% of the people with serious chronic pain had a diagnosis of FM, so FM might not be a major item on the chronic pain agenda. Having said that, chronic pain specialists could have an important role to play in FM care and chronic pain research could yield valuable insights.

The ME area has claimed interest in FM. Our organization is one example, but not the only one. There are three specialty clinics (Vancouver, Toronto and Halifax) that cover FM as well as ME. In addition, the international association for ME (the IACFS/ME) includes FM in its mission statement.

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In a narrow sense, a diagnosis is made when a clinician, using clinical judgment, finds that a patient meets established criteria. Yes the patient meets the criteria or no the patient does not. In a broader sense, a diagnosis describes the medical situation an individual is facing. The broader diagnostic process would exclude alternate causes for the symptoms (though some criteria require the clinician to exclude other causes), would describe symptom patterns and severity, and would document co-morbidities.

In 1990, the American College of Rheumatology (ACR) published research criteria for FM based on chronic widespread pain and the existence of tender points.

In 2003, an international expert panel appointed by Health Canada accepted the 1990 criteria for diagnosis, but went on to say that additional symptoms were often present and had to be taken into account when assessing the burden of illness. These additional symptoms are summarized on our info-sheet for FM (page 7-10).

In 2010, a group of rheumatologists proposed new diagnostic criteria for FM based on widespread pain and some of those additional symptoms, notably reduced activity levels, sleep dysfunction and cognitive difficulties. The tender point requirement was dropped, partly because it was not well known and partly because it missed many FM cases in men. The 2010 FM definition was slightly modified in 2011 and again in 2016. The 2016 version is summarized in the chart on page 4.

All these criteria are in use. The US Social Security Agency gives applicants a choice of using either the 1990 or the 2010 criteria. Some clinicians prefer the 2016 criteria. It is important to know which criteria is being used because different diagnoses convey different information.

When it comes to ME, there is currently a fairly strong international consensus to use the Canadian Consensus Criteria (CCC) for diagnosis. The IOM criteria were designed for quick identification of potential CCC cases. The CCC and the IOM criteria are nicely summarized in a document found on the BC clinic website (page 5). The IOM criteria require four symptoms – activity reduction, post exertional malaise, sleep problems and cognitive problem and/or orthostatic intolerance. Pain is almost certainly present in ME, but the IOM decided that ME pain was hard to distinguish from other kinds of pain so pain does not make a good screening question. If you meet the IOM criteria you have “Systemic Exertion Intolerance Disease” (SEID). The CCC provides a fuller description of symptoms of ME than the IOM criteria do. The CCC also requires the clinician to exclude other conditions that could explain the symptoms. (These are not shown on page 5).

If you look closely, you can see that the FM criteria might also be used as a screening tool for possible ME cases. FM criteria look for pain, activity reduction, sleep difficulties and cognitive problems. People that qualify for a diagnosis of FM might qualify for a diagnosis of ME as well. Likewise, people who qualify for a diagnosis of ME might qualify for a diagnosis of FM as well.

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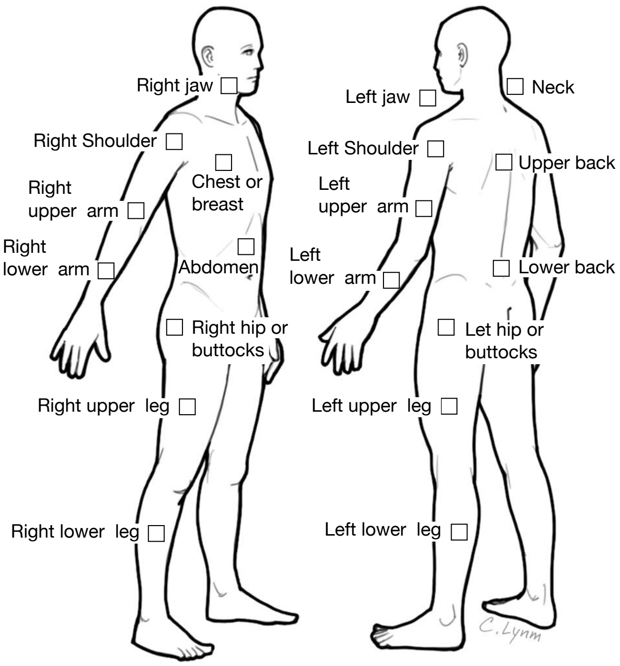
2016 Revised Fibromyalgia Diagnostic Criteria

Seminars in Arthritis and Rheumatism 46 (2016) 319 - 329

① Widespread Pain Index (WPI score range 0 - 19)

Pain and tenderness *during the past week*

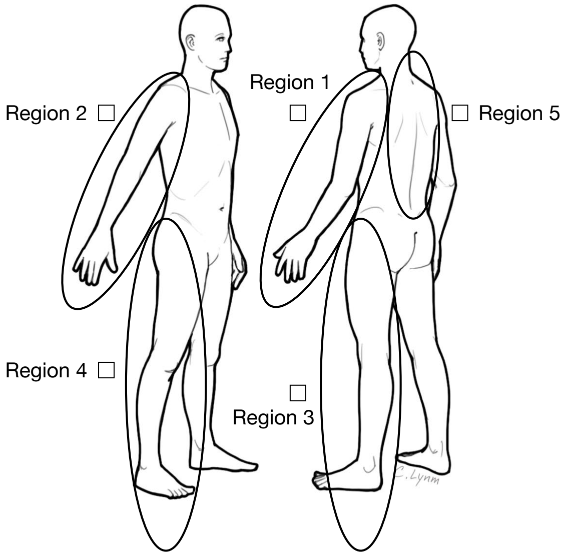


Widespread Pain Index Total (maximum 19) _____

All of the following criteria must be met to make a diagnosis of Fibromyalgia

1. WPI ≥ 7 and SSS ≥ 5 OR WPI 4 to 6 and SSS ≥ 9	☐ No	☐ Yes
2. Generalized pain: at least 4/5 regions	☐ No	☐ Yes
3. Have the symptoms in section 3 and pain been present at a similar clinical level for **at least 3 months**?	☐ No	☐ Yes
Fulfills all diagnostic criteria for FM	☐ No	☐ Yes

② Generalized pain - do not count jaws, chest, or abdomen



Generalized Pain Total (maximum 5) _____

③ Symptom Severity Score (SSS score range 0 - 12)

Over the past week:
No problem
Slight or mild problem: genrally mild or intermittent
Moderate problem: considerable problems; often present and/or at a moderate level
Severe problem: continuous, life-disturbing

	No problem	**Slight/mild**	**Moderate**	**Severe**
• Fatigue	☐ = 0	☐ = 1	☐ = 2	☐ = 3
• Trouble thinking or remembering	☐ = 0	☐ = 1	☐ = 2	☐ = 3
• Waking up tired (unrefreshed)	☐ = 0	☐ = 1	☐ = 2	☐ = 3

During the past 6 months:

• Pain or cramps in the abdomen	☐ No = 0	☐ Yes = 1
• Depression	☐ No = 0	☐ Yes = 1
• Headache	☐ No = 0	☐ Yes = 1

Symptom Severity Score Total (maximum 12) _____

ME/CFS:
2003 Canadian Clinical Working Case Definition

☐ **Pathological Fatigue**
A significant degree of new onset, unexplained, persistent or recurrent physical and/or mental fatigue that substantially reduces activity levels and which is not the result of ongoing exertion and is not relieved by rest

☐ **Post-exertional Malaise and Worsening of Symptoms**
Mild exertion or even normal activity is followed by malaise: the loss of physical and mental stamina and/or worsening of other symptoms. Recovery is delayed, taking more than 24 hours

☐ **Sleep Dysfunction**
Sleep is un-refreshing: disturbed quantity - daytime hypersomnia or nighttime insomnia and/or disturbed rhythm - day/night reversal. Rarely, there is no sleep problem.

☐ **Pain**
Pain is widespread, migratory or localized: myalgia; arthralgia (without signs of inflammation); and/or headache - a new type, pattern or severity. Rarely, there is no pain

☐ **Neurocognitive Manifestations (2 or more)**
☐ confusion
☐ impaired concentration
☐ short-term memory
☐ disorientation
☐ categorizing and word retrieval
☐ perceptual and sensory disturbances
☐ ataxia
☐ muscle weakness
☐ fasciculation
☐ cognitive overload
☐ emotional overload
☐ hypersensitivity to light or sound

☐ **At least one symptom from two of the folowing categories:**

Autonomic Manifestations
☐ orthostatic intolerance–neurally mediated hypotension (NMH)
☐ postural orthostatic tachycardia syndrome (POTS)
☐ delayed postural hypotension
☐ light-headedness
☐ extreme pallor
☐ nausea and IBS
☐ urinary frequency and bladder dysfunction
☐ palpitations with or without cardiac arrhythmias
☐ exertional dyspnea.

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Neuroendocrine Manifestations
☐ loss of thermostatic stability–subnormal body temp; marked diurnal fluctuation
☐ sweating episodes
☐ recurrent feelings of feverishness
☐ cold extremities
☐ intolerance heat and cold
☐ marked weight change
☐ anorexia or abnormal appetite
☐ loss of adaptability and worsening of symptoms with stress

Immune Manifestations
☐ tender lymph nodes
☐ recurrent sore throat
☐ recurrent flu-like symptoms
☐ general malaise
☐ new sensitivities to food, medications and/or chemicals.

☐ **The illness has persisted for at least 6 months**

SEID:
2015 Institute of Medicine Diagnostic Criteria

Diagnosis requires the following three symptoms:

☐ A substantial reduction or impairment in the ability to engage in pre-illness levels of occupational, educational, social, or personal activities, that persists for more than 6 months and is accompanied by **Fatigue**, which is often profound, is of new or definite onset (not lifelong), is not the result of ongoing excessive exertion, and is not substantially alleviated by rest, and

☐ **Post-exertional Malaise*** and

☐ **Unrefreshing Sleep***

At least one of the two following:

☐ **Cognitive Impairment*** or

☐ **Orthostatic Intolerance**

* Frequency and severity of symptoms should be assessed. The diagnosis of ME/CFS/SEID should be questioned if patients do not have these symptoms at least half of the time with moderate, substantial, or severe intensity.

When it comes to treatment of ME, one group recommended Graded Exercise Therapy (GET) and Cognitive behavioural Therapy (CBT). Not so fast, said a second group. People with ME experience post exertional malaise (PEM), so exertion should not be forced through GET. Pacing and staying within one's energy envelope are preferable strategies, not so much that they are curative but rather that they prevent the situation from getting worse. Further, in the same way CBT may help a patient cope with cancer, CBT may help a patient deal with ME. But CBT does not cure cancer and should not be expected to cure ME. The first group prevailed for several decades. The second groups is prevailing now.

The FM community should be paying close attention. Treatment protocols for FM generally encourage exercise, but some FM protocols do not look for exertion intolerance. FM patients may be embarking on exercise regimes which are ill advised. Note that the 2003 FM report paid a lot of attention to safe exercise, saying that "[a]s much care must be taken in prescribing exercise programs as in prescribing pharmaceuticals." CBT may help an individual patient cope with FM, but to think of it as curative is a stretch.

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How do FM and ME differ? A discussion of the differences is found in the 2003 Canadian Consensus Criteria for ME.

> *A syndrome may be delineated by means of a criterion that reflects a cutoff point on a continuum of symptoms and dysfunctions. Thus ME/CFS and fibromyalgia syndrome (FMS) can be differentiated on the basis of symptom balance in what many believe are variants of the same or similar disease pathogeneses. By criterial definition, pain is the major feature of FMS whereas post exertional malaise and fatigue are the major symptoms of ME/CFS. However the latter often involves significant cognitive dysfunction and pain, and overlap situations are common where both pain and fatigue are of similar prominence. Some FMS patients have complex symptomatology that is often indistinguishable from ME/CFS. Indeed many patients are diagnosed with both ME/CFS and FMS. Approximately 75% of ME/CFS patients also meet the criteria for FMS. Some patients have a syndrome pattern that changes from one to the other. For example, FMS can evolve into ME/CFS and visa versa.*

> *Although it may sometimes be difficult to distinguish between ME/CFS and FMS on the basis of symptomology, ME/CFS cases are commonly triggered by a viral infection, whereas physical trauma as well as other initiating events, trigger many FMS cases. Another important difference is in the response to exercise. Patients with mild FMS may be better able to tolerate aerobic exercise whereas it often aggravates the symptoms in ME/CFS patients, who may need alternate forms of exercise and a gentler progression. The possibility of overlap with ME/CFS may give rise to confusion as different situations may require different approaches to exercise.*

The key messages from this document are:

- FM and ME may have the same disease pathogenesis.
- FM and ME have overlapping symptoms. The question is symptom balance. Pain is prominent in FM while post exertional malaise and fatigue are prominent in ME.
- ME is often triggered by infection while FM is often triggered by physical trauma.
- FM and ME respond differently to exercise.
- A person can be diagnosed with both FM and ME. FM can evolve into ME, and ME can evolve into FM.

Almost 20 years after this was written, we still don't know the pathogenesis of FM or ME. FM research seems to be focusing on the central nervous system while ME research is exploring a greater range of systems and even down to the cellular level. Both approaches have value. What is important is that what is learned on one side be considered by the other.

Response to exercise is important because it decides whether exercise (or any effort for that matter) should be encouraged (FM) or managed (ME). This means that checking for exertion tolerance is important. Because cases can evolve from FM to ME to FM, exertion intolerance should be checked on an ongoing basis.

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Fibromyalgia

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What is Fibromyalgia?

Imagine feeling like you've been hit by a truck. Your neck and shoulder muscles are tight and contracted and feel like they are pulling on your joints. Your arms are tingling as if pins and needles are stuck in. Your brain seems wrapped in cotton batting. You try to move but your muscles are stiff and the slightest touch makes you wince. You are tired, but sleep does not come easily and it isn't refreshing.

Such is life for people with Fibromyalgia. Fibromyalgia is a complex physical illness characterized by chronic widespread pain of the muscles, ligaments, and tendons and generally accompanied by other signs and symptoms.

Who Can Get Fibromyalgia?

Fibromyalgia affects all age groups, including children, all racial/ethnic groups, and all socioeconomic strata. As in many painful conditions, such as arthritis, there is a higher prevalence of Fibromyalgia in females. Many people, particularly men, may go undiagnosed.

According to the Canadian Community Health Survey of 2016, about 520,000 Canadians have been diagnosed with Fibromyalgia. The illness is still not well known but this is changing.

What Causes Fibromyalgia?

Most of the research findings point to a malfunctioning of the central nervous system (CNS), which includes the brain and spinal cord, with resulting pain amplification. Peripheral systems (soft tissue/muscles and nerves) also demonstrate some abnormalities. Body-wide symptoms may result from a dysfunctional interplay between the CNS and peripheral systems.

Various triggering events may precipitate the onset of Fibromyalgia including infection, trauma (e.g., physical injury, automobile accident, surgery, emotional trauma) or the development of another disorder, such as rheumatoid arthritis. It is now thought that these triggering events awaken rather than cause an existing physiological abnormality.

Abnormal pain processing has been demonstrated in brain scans. The systems involved are complex which may explain the individualized response to medication and other treatments.

Research studies are investigating a wide range of issues including genetic components, the role of stress hormones (e.g. cortisol) and neuro-chemical imbalances. Other studies are searching for biomarkers and diagnostic tests.

How is Fibromyalgia Diagnosed?

You must have:

- Widespread pain that lasts at least 3 months. Widespread means that there is pain above and below the waist, and on both sides of the body.
- 11 or more of the 18 defined tender points. Tender points are specific, distinctive points on the body. When they are touched with a force that is not painful to healthy people, the tender points produce pain in Fibromyalgia patients. Many of the tender points are where ligaments, tendons, or muscles attach to bones.

There are additional clinical symptoms & signs that can contribute importantly to the patient's burden of illness. Some of the signs and symptoms are listed below.
Refer to publication no. 1 on the back for a more complete list of possible symptoms.

- Neurological Manifestations: Numbness and tingling in the muscles, cramps, muscle weakness, headaches, generalized weakness, sensitivity to light and sound
- Neurocognitive Manifestations: Poor concentration and short-term memory loss, impaired speed of performance, inability to multi-task, and/or cognitive overload
- Fatigue: There is persistent and reactive fatigue accompanied by reduced physical and mental stamina.
- Sleep Dysfunction: Sleep is unrefreshing. There may be disturbance in sleep quantity or rhythm including daytime hypersomnia or nighttime insomnia.
- Autonomic and/or Neuroendocrine Manifestations: irregular heartbeat, dizziness, heat/cold intolerance, respiratory disturbances, intestinal and bladder disturbances, stress intolerance, blunted emotions and/or reactive depression
- Stiffness: It is common to have generalized or regional stiffness that is most severe upon awakening and typically lasts for hours. Stiffness can return during periods of inactivity during the day.

Some health professionals are using different criteria to diagnose Fibromyalgia. Under the alternate criteria, diagnosis is based on the number of areas of the body experiencing pain combined with a measure of activity reduction, sleep problems, cognitive difficulties and other somatic symptoms.

Treatment / Management

Symptoms as well as "functional capacity" vary widely among Fibromyalgia patients. While some are very disabled, some can function at a limited level and some are able work part or full time but have limited activities beyond work.

In spite of ongoing research, there is no cure for Fibromyalgia. The objectives of your treatment strategy are to reduce symptoms and improve quality of life. Discuss each symptom with your health care practitioner. Managing your illness involves a combination of pharmaceuticals, natural remedies, self-management strategies and lifestyle adjustments.

Improving Sleep

Even small improvements in sleep will help to improve your symptoms. Try to find techniques that will improve sleep time and quality. Establish a routine; create a quiet environment; avoid getting overtired; try herbal remedies. Many find it helpful to take medication to assist sleep. It may be helpful to consult a sleep specialist.

Nutrition

It can be difficult to prepare meals when dealing with chronic pain but a good balanced diet is essential. Do not forget to eat as your body needs fuel to function. Many Fibromyalgia patients suffer from food sensitivities and irritable bowel syndrome. Patients get symptom relief when they eliminate offending foods from their diet. It will require trial and error to find which foods bother you but some common sensitivities include wheat, dairy, corn and refined sugar.

Pain Management / Lifestyle adjustments

Talk to your doctor. There are over-the-counter medications that will help with sleep and pain. A few drugs have been approved specifically for Fibromyalgia. As each individual responds differently to medications, your doctor may suggest other medications not specifically designed for Fibromyalgia. People with Fibromyalgia are often sensitive to medications and it may be necessary to start with a lower than recommended dose and increase gradually, monitoring the effects carefully.

Alternative therapies such as acupuncture, massage and hydrotherapy can be helpful for some but their effectiveness varies amongst individuals. Consider including a naturopathic doctor as part of your health care team.

Many studies have shown that exercise is effective in improving some symptoms. However, you should approach exercise with caution. Begin slowly and be careful not to aggravate your symptoms.

You will find that you don't have the same capacity for activity as you once did. It is essential that you manage your energy levels. You will need to pace your activities so that you can be as active as you are able without aggravating your symptoms. Listen to your body and respect what it is telling you. Plan ahead, know your limits, stop before you reach them. Do not push yourself.

Managing your illness will require lifestyle adjustments. You may need to reduce your daily activities but over time you will accomplish more with less pain.

Mind and Body

As in any illness, it is important to understand there is a connection between the mind and the body. While they will not cure your Fibromyalgia, many therapies are available that help to reduce stress, induce relaxation, generate positive thinking and gain a sense of control. Before starting any therapy ensure your therapist fully understands that your illness is real and serious and that they are using a collaborative approach.

You may benefit from activities such as meditation, breathing exercises, yoga and Tai Chi or from therapeutic activities such as writing and art.

Get Support

One of the biggest challenges people with Fibromyalgia face is a lack of understanding from friends, family and even the medical community. Fibromyalgia can be very isolating and people with it may feel they are alone.

- It is important that friends, family, colleagues and caregivers are understanding and supportive. They too can become knowledgeable about Fibromyalgia.
- Look for and join a support group in your area or online.

THE NATIONAL ME/FM ACTION NETWORK
is a Canadian, registered, nonprofit organization dedicated to advancing the recognition and understanding of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia through education, support and research.

The network celebrated its 25th anniversary in 2018. By becoming a member, you can stay up to date on news and events while supporting our efforts.

View these publications on our website:

1. **Fibromyalgia Syndrome: A Clinical Case Definition and Guidelines for Medical Practitioners. An Overview of the Canadian Consensus Document.** *Carruthers BM & van de Sande MI. 2005/2006.*
2. **TEACH-ME A Sourcebook for Teachers of Young People With Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia Syndrome (FMS).** *Bell DS, Carruthers BM and the TEACH-ME Task Force. 2nd Edition 2005*
3. **Canada Pension Plan Disability Application & Appeals Guide for Canadians with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia Syndrome (FMS).** *Neilson LE, Parlor M, Wodak J. 2020*

Other Recommended Reading:

Bested AC, Logan, AC Howe R. **Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia.** *2nd ed. Cumberland House 2008*

Stein E. **Let Your Light Shine Through.** *Stein 2012*
Available at http://EleanorsteinMD.ca

LA FIBROMYALGIE

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La fibromyalgie, c'est quoi ?

Imaginez qu'un camion vous est passé dessus. Vos muscles du cou et des épaules sont tendus et contractés, on dirait qu'ils tirent sur vos articulations. Vos bras fourmillent de piqûres d'épingle. Votre cerveau est dans la ouate. Quand vous bougez, vos muscles sont raides ; un simple toucher vous arrache une grimace. Malgré la fatigue, le sommeil ne vient pas et vous ne récupérez pas.

Voilà ce que c'est que vivre avec la fibromyalgie, une maladie physique complexe, caractérisée par la douleur chronique disséminée des muscles, des ligaments et des tendons, qui s'accompagne généralement d'autres signes et symptômes.

La fibromyalgie, qui en souffre ?

La maladie frappe tous les groupes d'âge y compris les enfants, tous les groupes raciaux ou ethniques et tous les niveaux socioéconomiques. Comme de nombreuses conditions douloureuses, par exemple l'arthrite, on la retrouve davantage chez les femmes. Elle reste souvent non diagnostiquée, surtout chez les hommes.

Selon l'Enquête sur la santé dans les collectivités canadiennes 2016, environ 520 000 personnes ont reçu un diagnostic de fibromyalgie. On ne connaît pas toujours pas bien cette maladie, mais la situation est en train de changer.

Quelles sont les causes de la fibromyalgie ?

La plus grande partie des résultats des recherches indiquent un dysfonctionnement du système nerveux central (cerveau et moelle épinière), qui cause une amplification de la douleur. Certains systèmes periphery ques (tissus mous/muscles et nerfs) présentent aussi des anomalies. Affectant tout le corps, les symptômes pourraient provenir d'une interaction dysfonctionnelle entre ces systèmes.

Une variété d'événements déclencheurs peut favoriser l'apparition de la fibromyalgie : une infection, un traumatisme (blessure physique, accident d'automobile, opération chirurgicale, traumatisme émotionnel, etc.) ou le développement d'une autre condition comme la polyarthrite rhumatoïde. On croit maintenant que ces déclencheurs ne causent pas l'anomalie physiologique existante mais l'éveillent.

Des scans du cerveau ont montré qu'il traite la douleur de façon anormale. Les systèmes reliés à la maladie sont complexes, ce qui pourrait expliquer que les réactions aux médicaments et aux traitements varient selon les individus.

Il s'effectue des recherches sur de nombreuses questions comme les composantes génétiques, le rôle des hormones de stress (comme le cortisol), les déséquilibres neuro-chimiques, ou encore les biomarqueurs et les tests diagnostiques.

Comment diagnose-t-on la fibromyalgie ?

Symptômes que vous devez présenter :

- douleur disséminée depuis au moins 3 mois – par disséminée, on entend en haut et en bas de la taille, et des deux côtés du corps.
- 11 ou plus des 18 points douloureux reconnus – par points douloureux, on entend des points spécifiques du corps qui génèrent de la douleur lors d'une pression qui n'affecte pas une personne normale. Plusieurs sont situés aux points d'attaches entre les os et les ligaments, tendons ou muscles.

D'autres symptômes et signes cliniques peuvent beaucoup aggraver le fardeau de la maladie, voir liste ci-dessous.

** Consulter le document n° 1 (voir verso du présent dépliant), qui donne une liste plus complète des symptômes possibles.*

- Manifestations neurologiques : engourdissement et fourmillement musculaire, crampes, faiblesse musculaire, maux de tête, faiblesse généralisée, sensibilité à la lumière et au bruit
- Manifestations neurocognitives : difficulté de concentration, perte de la mémoire à court terme, baisse de la vitesse de rendement, fonctionnement multitâche impossible, surcharge cognitive
- Fatigue : fatigue persistante et réactionnelle, accompagnée d'une réduction de l'endurance physique et mentale
- Troubles du sommeil : sommeil non réparateur, problèmes de quantité ou de rythme du sommeil, comme l'hypersomnie le jour ou l'insomnie la nuit
- Manifestations du système autonome ou neuroendocrinien : irrégularité du rythme cardiaque, étourdissement, intolérance au chaud ou au froid, troubles de la respiration, troubles de l'intestin ou de la vessie, intolérance au stress, affect émoussé, dépression réactionnelle
- Raideur : fréquente raideur localisée ou généralisée très marquée au réveil, qui dure souvent des heures, et qui peut réapparaître plus tard à la suite d'une période d'inactivité

D'autres critères de diagnostic sont parfois utilisés, basés sur le nombre de régions du corps affectées par la douleur, en combinaison avec l'évaluation de la réduction de l'activité, des troubles du sommeil, des difficultés cognitives et autres symptômes somatiques.

Gestion et traitement

Les symptômes et la « capacité fonctionnelle » varient grandement selon les malades. Pour un certain nombre, le handicap est très grave, d'autres peuvent fonctionner à un niveau restreint, d'autres encore peuvent occuper un emploi à temps partiel ou plein mais avec des loisirs très limités.

Malgré les recherches qui se poursuivent, on ne connaît pas de remède à la fibromyalgie. Les objectifs de votre stratégie de traitement sont de réduire vos symptômes et d'améliorer votre qualité de vie. Discutez de chacun de vos symptômes avec votre médecin. Gérer votre maladie passe par la conjugaison de produits pharmaceutiques, de remèdes naturels, de stratégies d'auto-gestion et de modifications de votre régime de vie.

Améliorer le sommeil

EUne amélioration même légère du sommeil contribue à réduire les symptômes. Essayez de trouver des techniques pour améliorer la durée et la qualité de votre sommeil. Suivez une routine, créez un environnement calme, évitez de trop vous fatiguer ; essayez des remèdes à base d'herbe. Envisagez la prise de somnifère ou la consultation auprès de spécialiste du sommeil.

Nutrition

La douleur chronique rend la préparation des repas pénible mais un régime équilibré est essentiel. N'oubliez pas de manger : votre organisme ne fonctionnera pas à vide. Beaucoup de malades souffrent d'hypersensibilités alimentaires ou du syndrome de l'intestin ou du côlon irritable et trouvent du soulagement à éliminer les éléments fauteurs de trouble. Vous devrez faire des expériences pour trouver les aliments qui vous gênent mais les plus communs sont le blé, les produits laitiers, le sucre (de maïs ou raffiné).

Gestion de la douleur, modifications de votre regime de vie

Parlez à votre médecin. Certains médicaments en vente libre améliorent le sommeil et réduisent la douleur. Il existe aussi quelques médicaments spécialement approuvés pour la fibromyalgie mais, comme la réponse aux médicaments varie, votre médecin pourrait vous en prescrire d'autres médicaments. Beaucoup de malades sont hypersensibles aux médicaments et il peut être nécessaire de commencer par une dose réduite, avec augmentation graduelle, en contrôlant les effets avec soin.

Des thérapies complémentaires – acupuncture, massothérapie, hydrothérapie, etc. – peuvent aider, mais leur efficacité varie beaucoup selon les individus. Envisagez d'inclure la naturopathie dans votre choix d'outils de traitement.

Beaucoup d'études indiquent que l'exercice contribue à réduire certains symptômes, mais il faut y aller avec précaution. Commencez lentement et veillez à ne pas aggraver vos symptômes.

Vous constaterez que vous n'avez plus la même capacité d'activité qu'avant. Il est essentiel de gérer votre niveau d'énergie. Vous devrez y aller à votre propre rythme pour optimiser votre capacité d'activité sans jamais aggraver vos symptômes. Écoutez votre corps, respectez ce qu'il vous dit. Planifiez vos activités, connaissez vos limites et arrêtez avant de les dépasser. N'allez jamais au-delà de vos forces.

Gérer votre maladie vous imposera de modifier votre régime de vie. Vous devrez peut-être réduire vos activités quotidiennes mais, avec le temps, vous pourrez en faire plus en souffrant moins.

Le mental et le physique

As Il est important de comprendre que, comme pour toute maladie, il y a un lien entre le mental et le physique. Sans guérir votre fibromyalgie, beaucoup de thérapies peuvent vous aider à vous détendre, réduire le stress, développer un esprit positif et retrouver la maîtrise de votre vie. Avant d'entreprendre une thérapie, assurez-vous que votre thérapeute comprend que votre maladie est réelle et grave et veut vraiment collaborer avec vous.

Vous pourriez trouver avantage à faire de la méditation, des exercices de respiration, du yoga et du Tai Chi.

Luttez contre l'isolement

Un des plus grands défis pour les malades, c'est l'incompréhension de leur entourage, et parfois même de la collectivité médicale. La fibromyalgie cause l'isolement et beaucoup de malades souffrent de solitude.

- Il est important que tous les gens avec qui vous avez des relations (de parenté, d'amitié, de travail ou de soins) fassent preuve de compréhension et de soutien et apprennent aussi à connaître la maladie.
- Essayez de trouver un groupe d'entraide dans votre voisinage ou en ligne.

L'organisme NATIONAL ME/FM ACTION NETWORK

est une société canadienne reconnue sans but lucratif, qui travaille à faire connaître et comprendre l'encéphalomyélite myalgique/ syndrome de fatigue chronique et la fibromyalgie par l'éducation, le soutien et la recherche.

L'année 2018 marque son 25e anniversaire. En devenant membre, vous vous tenez au courant des nouvelles et des événements, et vous soutenez nos efforts.

Documentation sur notre site Internet :

1. **Syndrome de fibromyalgie : définition clinique et lignes directrices à l'intention des médecins– Abrégé du Consensus canadien.** *Carruthers BM et van de Sande MI, 2005/2006.*
2. **TEACH-ME – Guide de référence pour l'enseignement aux élèves souffrant d'encéphalomyélite myalgique / syndrome de fatigue chronique (EM/SFC) et/ou du syndrome de fibromyalgie (SFM).** *Bell DS, Carruthers BM, et le groupe de travail TEACH-ME 2e édition, 2005*

Autres lectures recommandées :

Bested AC, Logan AC, Howe R. **Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia. (Espoir et aide pour le syndrome de fatigue chronique et la fibromyalgie - en anglais)** *2nd ed. Cumberland House 2008*

Stein E. **Let Your Light Shine Through (Pour que brille votre lumière - en anglais).** *Stein 2012*
Télécharger à http://EleanorSteinMD.ca

Ce dépliant est présenté à titre informatif seulement et ne prétend pas remplacer les conseils de votre médecin.

Moving FM forward

What is holding FM back? FM is a medically complex condition where the underlying mechanism has not been established and biomarkers have not been found. FM's place in the medical system has not been settled. Plus there are a range of biases in the research, clinical and social systems.

*

Funding for FM research needs to increase. Out of $1.3B in CIHR funding in fiscal year 2020/21, only $162k went to FM research. Out of $845M already allocated for fiscal year 2021/22, only $56k is designated for FM research.

The problem is not a shortage of research ideas. A March 2020 international conference on Controversies in Fibromyalgia had 61 presentations (invited, oral or poster) covering a wide range of issues. A patient-focused project in Canada several years ago developed a list of 23 priority FM research projects.

In Quest 127, we discussed a series of studies of the US National Institutes of Health funding which showed that ME was proportionally the most underfunded of about 70 health conditions if funding were based strictly on burden of illness. The NIH did not calculate the burden of illness for FM so FM was not part of this study. CCHS data suggests that the burden of illness for FM would be in the same general range as the burden of illness for ME. NIH funding for FM is in the same low range as funding for ME. Based on illness burden, FM is likely as under-funded by NIH as ME is. The same studies have not been done for CIHR funding but there is little reason to believe that the result would be very different here.

One of the studies found gender bias in US NIH funding. The gender distribution of FM is heavily female. The study suggested lack of prestige (stigma) as another factor. Increasing FM prestige would be a long-term and difficult challenge. This suggests that FM research will be underfunded for the foreseeable future unless one of both of two things happens:

- There is a change in how CIHR allocates funding. CIHR is allocating public money. Why isn't it being allocated based on public need?
- Politicians step in and designate funding for FM research.

*

The FM health care delivery system needs to be reviewed. We know from the CCHS that Canadians with FM make multiple visits to family doctors, specialists and alternate care providers and yet they feel that their health needs are not being met. This suggests that a redesign of the care pathways is required. A redesign has the potential to increase patients' overall quality of life, to reduce frustration among health professional and to increase efficiency and effectiveness in the health system.

Health care delivery is complex. The Ontario Task Force on Environmental Health looked at the delivery of health care services for ME, FM and Multiple Chemical Sensitivities combined and provides a good model for provinces to implement.

*

The social services system needs to be reviewed. We know from the Canadian Community Health Survey that people with FM have high rates of unmet home care needs and high rates of poverty, food insecurity, and unemployment. We know that people with FM have difficulty qualifying for supports like home care, Long Term Disability, CPP-Disability or the Disability Tax Credit. This points to inequities in the social support systems that need to be addressed. We know that rates of social isolation are high. The FM community itself could help, but there is also a general lack of financing for FM support groups except in Quebec.

*

FM needs to be considered in long-COVID studies. A 2011 Toronto study of post-SARS patients concluded that "the clinical and sleep features of chronic post-SARS form a syndrome of chronic fatigue, pain, weakness, depression and sleep disturbance, which overlaps with the clinical and sleep features of FMS and chronic fatigue syndrome." There is some recognition the people having COVID might go on to develop ME, but there is little recognition that they might go on to develop FM. Long-COVID cases could put further strain on the healthcare and social services system that are already dealing poorly with FM and ME. However, long-COVID cases could bring new interest in this area and new research findings.

CIHR funding of research into chronic conditions
using keyword searches of the CIHR funded research database
For fiscal years 2020/21 and 2021/22
As of April 1, 2021

Keyword	**Canadian prevalence**	**Per patient funding 2020-21**	**CIHR funding 2020-21**	**Per patient funding 2021-22**	**CIHR funding 2021-22**
Parkinson*	99,000	$245.56	$24,310,843	$177.80	$17,601,760
Alzheimer*	395,000	$123.22	$48,670,620	$94.40	$37,289,545
Multiple Sclerosis*	108,600	$111.71	$12,131,182	$97.08	$10,542,599
Diabetes**	2,115,973	$40.16	$84,970,866	$26.35	$55,759,630
Cerebral palsy*	79,800	$38.52	$3,074,016	$29.35	$2,342,321
Epilepsy*	345,400	$37.40	$12,916,309	$26.06	$9,002,692
Heart Disease**	1,398,892	$35.46	$49,599,806	$23.01	$32,186,822
Dystonia***	50,000	$16.27	$813,333	$6.95	$347,340
COPD**	833,148	$6.01	$5,006,638	$2.99	$2,491,724
Asthma**	2,587,775	$5.63	$14,570,576	$3.48	$9,010,343
Osteoporosis**	1,446,111	$4.79	$6,929,957	$3.17	$4,582,111
Arthritis**	6,006,636	$4.44	$26,680,366	$3.04	$18,236,807
Scoliosis**	1,028,049	$1.46	$1,497,859	$0.94	$967,772
Chronic Fatigue Syndrome**	**572,440**	**$0.54**	**$309,204**	**$0.49**	**$280,000**
Fibromyalgia**	**508,410**	**$0.32**	**$161,667**	**$0.11**	**$55,833**
Multiple Chemical Sensitivities**	976,920	$0.00	$0	$0.00	$0
All projects			**$1,351,375,737**		**$844,909,461**

Notes:

CIHR funding extracted from the funded decision database

https://webapps.cihr-irsc.gc.ca/funding/Search?p_language=E&p_version=CIHR

The database includes a short description of each funded project. The inclusion of a keyword suggests but does not guarantee that this condition is a focus of the project. Projects often have multiple keywords (eg, diabetes and asthma).

Keywords include English variations and French equivalents

Data was extracted on April 1, 2021. Funding for 2021/22 is incomplete. Funding for 2020/21 could change slightly.

Source of prevalence figures

* Projected for 2016, Table 3-5
https://www.canada.ca/en/public-health/services/reports-publications/mapping-connections-understanding-neurological-conditions.html#toc

** Canadian Community Health Survey, Public Use Microdata File, 2015-16

*** Dystonia Canada website

The Canadian Community Health Survey excludes

- Canadians under the age of 12
- Canadians living in institutions, on reserves, or in remote regions
- Full-time members of the Canadian Forces

What we have done over the years

Here are some of our actions the National ME/FM Action Network has taken to help people with FM and ME.

- We spearheaded the development of diagnostic and treatment protocols for FM and ME (published in 2003).
- We wrote a guide for applying for CPP-Disability supports with FM and ME and have updated the guide several times.
- We wrote a sourcebook for teachers of students with FM and ME.
- We recognized that the 2005 Canadian Community Health Survey could be a valuable source of data on the disability, disadvantage and unmet needs of people with ME, FM and MCS. We compiled and published statistics from the 2005 and subsequent surveys.
- We insisted that FM be included on the agenda of the the international ME research and clinical conference held in Ottawa in 2011.
- We supported the establishment and growth of the Complex Chronic Diseases Program in BC which serves patients with ME, FM and Lyme disease.
- We have asked the federal government for changes to the Disability Tax Credit eligibility criteria to better reflect the types of disability experienced by people with FM and ME. We also asked for changes to CPP-Disability procedure to better recognize the experiences of people with FM and ME.
- We have supported the establishment of a research network for ME. We are very conscious that there is no research network for FM and hope to see the ME network expanded to include FM or a separate FM network established.
- We bring an FM and ME perspective to a project funded by the federal government looking at employment issues for people with disabilities.

The National ME/FM Action Network remains committed to helping both the FM and ME communities. We would like to repeat that we believe that FM and ME need to be considered together. As research progresses, their relationship (similarities and differences) will become more clear. That is the kind of information everyone needs.

Other News

Upcoming Conferences

The 3rd International Virtual Congress on Controversies in Fibromyalgia
24-25 June 2021
https://fibromyalgia2021.com

2021 IACFS/ME Virtual Conference
August 19 - 21, 2021

Submit Your Abstract/ Workshop Proposal now! Deadline is May 3, 2021, 5:00 PM New York City (USA) time.

https://www.iacfsme.org/2021-virtual-conference-abstract-call/

COVID Vaccines

Dr Stein produced an excellent newsletter on COVID vaccines in March, 2021. We distributed it through our circulation list. If you have not seen it, go to:

https://www.eleanorsteinmd.ca/blog/covid-faqs

CPP-D Guide Update

On February 15, 2021, we checked to see if there have been any changes to the CPP-D application and appeals process since we updated our guide in 2020. Several forms have been updated and moved on-line but these do not significantly change what we have written. The Social Security Tribunal is introducing the position of "navigator" to help appellants navigate the appeals process. This should make it easier to appeal decisions, but please remember that navigator is there to help you through the process, not to help you win your case.

Commonly Used Abbreviations

Below are the definitions for the abbreviations listed on page 1.

ACR	American College of Rheumatology
CBT	Cognitive Behavioural Therapy
CCC	Canadian Consensus Criteria for ME (2003).
CCHS	Canadian Community Health Survey (a Statistics Canada survey)
CDC	Centers for Disease Control and Prevention (US public health agency)
CIHR	Canadian Institutes of Health Research (funds health research in Canada)
CNS	Central Nervous System
CPP-D	Canada Pension Plan – Disability
DTC	Disability Tax Credit
FM	Fibromaygia
FMS	Fibromyalgia Syndrome (old term for FM)
GET	Graded Exercise Therapy
IACFS/ME	International association for ME
ICD	International Classification of Diseases (produced by the WHO)
IMHA	Institute of Musculoskeletal Health and Arthritis (part of CIHR)
IOM	Institute of Medicine (now called NAM)
LTD	Long term disability
MCS	Multiple Chemical Sensitivities
MCS/ES	Multiple Chemical Sensitivities/Environmental Sensitivities (newer, broader term)
ME	Myalgic Encephalomyelitis
ME/CFS	Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (old term for ME)
NAM	National Academy of Medicine (leading US health advisory organization)
NIH	National Institutes of Health (conducts and funds health research is US)
PEM	Post Exertional Malaise, a symptom of ME
SEID	Systemic Exertion Intolerance Disease (a diagnosis developed by the IOM)
WHO	World Health Organization

Living with Limited Energy

A member submitted this letter to her local newspaper early in the pandemic. Unfortunately it wasn't printed. We are sharing it with you because we think it reflects what many people felt at the time. In retrospect, people did not appreciate how long the pandemic would go on and how long it would be before life returns to normal. The isolation, loneliness, and frustration experienced by the public are even bigger issues than anticipated. People also failed to appreciate the extent to which some people with Covid19 would have long term health issues leading to continued isolation, loneliness, and frustration. Nevertheless, the basic message of this letter is as true as ever and should not be forgotten.

I am a senior living with ME/CFS/FM/MCS- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome/ Fibromyalgia/Multiple Chemical Sensitivities.

This illness dictates when, what, and how long I am able to do anything. On a good day, if I use up my limited energy, I can end up back in bed. I empathise with other people's struggles with isolation, loneliness, and frustration due to Covid19 as this is my normal.

When the restrictions are relaxed, people will go back to their regular activities, but my life will remain the same

http://mefmaction.com

http://www.facebook.com/
MEFMActionNetwork

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Our phone number is 613-829-6667