

Fibromyalgia & Chronic Fatigue Syndrome

Issues Survey November 2005

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480 Somerset Street West • Ottawa, ON • Canada, K1R 5J8
613.565.2423 • Toll-free: 877.437.HOPE (4673)
E-mail: office@fm-cfs.ca • www.fm-cfs.ca
Charitable Registration # 89241 7742 RR0001

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Executive Summary

As many as one-and-a-half million Canadians face the life-changing illnesses Fibromyalgia (FM) or Chronic Fatigue Syndrome (CFS), which is also known as Myalgic Encephalomyelitis (M.E.). Without sufficient medical, financial, or social support, they struggle to lead independent, productive lives. Society faces higher than necessary costs.

FM-CFS Canada has drawn on its knowledge of this patient community and Canada's health care system to present this report of the illnesses and their effect on the patient and extended community, and recommendations for minimizing or eliminating the problems that FM & CFS/M.E present to Canadians.

FM patients experience chronic neuropathic pain in their soft tissue in at least 11 of 18 tender points across their bodies. CFS/M.E. presents chronic profound exhaustion and non-restorative sleep; chronic widespread pain; two or more neurological changes; and a dysfunctional immune system, autonomic changes, or neurological changes.

The cause of the illnesses is unknown. They may have subgroups, as no one treatment seems to work for all. There's no cure. They may be related; or not - but they often present common symptoms. Complex, yes, but deserving attention? Immediately. Not only are the more than one million patients in dire straits, but it affects their families too, children.

FM and CFS/M.E. are poorly understood among both the general population and medical practitioners. Neither have been properly educated. We understand that this is the community's responsibility. The lack of education and a simple definitive diagnostic test have routinely resulted in misdiagnosis. Misdiagnosis leads to declining patient health as the person's true illness is not being treated. Some patients are not able to hold jobs, run their homes, or contribute to society. Everyone pays for this mess.

Every year these illnesses cost the Federal Government billions in lost taxes and disability insurance payments. Canadian taxpayers also pay for the poor management of these illnesses, the misdiagnoses, the missed early interventions, with an inefficient use of our medical system, increased demands on our social system, and reduced economic production.

Federal government funding of research, education, and social support for these patients would be a profitable investment, less than a penny on the dollar. FM-CFS Canada has a clear vision of a support system for FM & CFS/M.E. patients, modelled on those of the other major health charities. FM-CFS Canada's board of directors, community leaders all, have a passion to help.

Recommendations

Research:

- 1) Research the cause, treatment and cure of FM & CFS/M.E.
- 2) Build a patient registry, save research costs, make large studies easier.
- 3) Educate and involve the Research community.
- 4) Fund a research chair to aide the research.

Education:

- 1) Educate health care practitioners.
- 2) Provide patients & families with basic multidisciplinary advice, in printed form if needed.
- 3) Involve educated and instructor-certified patients to teach others.
- 4) Educate the public
- 5) Provide re-training programs for patients who are unable to work in their occupations.

Provincial Coverage & Treatment

- 1) Extend health-care coverage for more types of medications and for alternative care.
- 2) Provide adequate home care for bed-ridden patients.
- 3) Improve physician compensation to provide for sufficient time to treat patients.
- 4) Develop multidisciplinary teams to treat patients more efficiently and effectively.

Reconsider Disability Insurance Programs:

- 1) Provide an above-poverty-level income for patients unable to work
- 2) Require private providers to stop offering below poverty-level benefit packages

John Ernst
Executive Director
FM-CFS Canada
(Compassion in Action)
480 Somerset St. West
Ottawa, Ontario
K1R 5J8
<http://fm-cfs.ca>
hope@fm-cfs.ca
Toll-Free: 877.437.4673
Ottawa: 613.565.2423
Charitable Registration No.
89241 7742 RR0001

Introduction

More than one million Canadians battle Fibromyalgia (FM) and or Chronic Fatigue Syndrome (CFS), which is also known as Myalgic Encephalomyelitis (M.E.).

Approximately two million people - 10 percent of Canada's population - live with them.

A population of this size is a significant variable in Canada's economy, with a value on par with entire sectors of the economy. Society's response should be strategic; at present, it is a systemic neglect.

Health Canada, the USA's Centre for Disease Control and the World Health Organisation recognise these illnesses as real. The facts are real to patients too - that real suffering is being experienced, that lives are changed, employment often lost. Incomes reduced to below poverty, handfuls of pills consumed daily. These are facts, as is the cost to taxpayers.

In the following pages FM-CFS Canada and patient groups nationwide present the issues and the opportunities to resolve them. Fortunately, none of the solutions are difficult, indeed one has to look no further than the other major health charities for models.

Simply, we need help getting started. The course is clear.

Overview of the Illnesses

Definitions

Fibromyalgia (FM) and Chronic Fatigue Syndrome (CFS), also known as Myalgic Encephalomyelitis (M.E.) are widely prevalent illnesses unnecessarily causing a wide variety of problems in society.

Fibromyalgia (FM) is chronic pain in the soft tissues (not the joints) in at least 11 of 18 tender points found across the body. Many FM patients experience CFS/M.E. - like symptoms. Some patients have both conditions. Statistics Canada reports that 393,000 Canadians have been diagnosed with FM by a doctor, of what prevalence studies suggest is about one million or more Canadian patients.

Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/M.E.), afflicting 341,000 Canadians according to Statistics Canada. The expression of the illness includes four symptoms, with each symptom's intensity varying over time, and from person to person. Briefly, the four symptoms are:

- chronic fatigue, non-restorative sleep
- chronic widespread pain
- one of: dysfunctional immune system, autonomic change, neurological change
- two or more neurological changes (brain fog, memory loss, changed sensitivities, etc.)

The illnesses, chronic by definition, express themselves in a differentiated fashion across individuals, and are often accompanied with other conditions. The minimum two neurological changes identified with CFS are expressed in varying combinations across the population.

The severity of the illness varies over time, so seeing a patient in a moment of time doesn't present the entire picture (longitudinal data would be useful). There are early intervention opportunities.

Canadian Consensus Protocols

Both illnesses have had seminal diagnosis and treatment protocols developed by an international team of experts, funded by Health Canada, in an effort led by the National ME/FM Action Network, a patient group. International experts were recruited to provide documentation to the government. The consensus is widely cited and well-regarded, indeed countries around the world are basing their materials on what have become known as the Canadian Consensus Protocols. They need to be validated by research, to provide evidence-based protocols.

The results have been distributed to a small portion of the health practitioners in Canada, and have not been fully translated into French. They are the property of the US publisher.

Overview

Prevalence

Measuring the prevalence of FM & CFS/M.E. has been difficult because no definitive laboratory diagnostic test for FM & CFS/M.E. exists and many physicians have not learned about these illnesses. Thus, the number of people diagnosed with FM & CFS/M.E. is smaller than the true population (a census poll would not accurately determine the prevalence rate).

However, a rigorous and widely cited study conducted in London, Ontario in 1997 concluded that about 900,000 Canadians have FM. The study's upper limit suggests nearly 1.5 million Canadians are afflicted, which is in accord with U.S. studies that suggest that four to five per cent of their population suffers from FM.

There has not been a Canadian study of the prevalence of CFS/M.E. According to U.S. data, this illness affects over 800,000 Americans of all ages, races, socioeconomic groups and genders. Extrapolating these figures suggests more than 80,000 Canadians are affected.

341,000 CFS patients diagnosed by doctors.

Nearly 1 million FM patients. 393,000 diagnosed by doctors.

Factors contributing to the cause of the illness may have increased in recent years, so the incidence rate may be climbing, possibly sharply, or they may have been present for centuries.

If the one million FM/CFS patients had become afflicted at an even rate over the last fifty years, there would have been an incidence rate of 20,000 new cases per year (1,000,000 / 50 years). If the Canadian prevalence rate is (in accordance with most international findings) 1.5 million Canadians, then 30,000 new patients per year would fall ill. This is equivalent to the loss of a small city every year. Intuitively it is clear that Canada was smaller fifty years ago, and so the number afflicted each year then was smaller than twenty or thirty thousand, and therefore higher today. What today's number of new cases is, is not known.

AGE AND GENDER

More than 80 percent of patients are female, and most of them are first afflicted in early to mid-adulthood (age 20 to 40). These women are part of Canada's mothers and mothers-to-be. Children younger than ten are also afflicted. They are being pulled from enjoying the prime of their lives and are presenting long-term social, financial, and economic consequences to society.

Overview

Cause of the Illnesses

Scientists worldwide search for the etiology and pathophysiology of FM & CFS/M.E..

Generally, currently, they conclude FM & CFS/M.E.. cannot be understood based on a single measure of immune, endocrine, cardiovascular, or autonomic nervous system dysfunction.

Subgroups are suspected, misdiagnoses are a factor. There has been little research in Canada on these illnesses, relative to the illnesses' impact on society.

Arguably it is in the mandate of the governments of Canada to protect Canadians against widespread threats such as these, just as it invests in other health hazards and medical conditions.

Fortunately, governments can play a strong role in stimulating research, particularly when the patient community is volunteering to help researchers.

Needed: Prevention Measures

Growing public awareness of the illnesses will stimulate demand for prevention research.

A Patient Perspective

The onset of these illnesses is confusing and difficult.

Whether stricken quickly or slowly, patients rarely learn quickly what is wrong with them. Most patients report being misdiagnosed, some for a decade.

Patients are often confronted by the medical community's skepticism and are accused of faking or exaggerating their symptoms, or of not trying hard enough to be healthy.

Many are told to take a common pain reliever and get over the rest of their imagined symptoms. Or, they are mis-diagnosed. It logically follows that there is currently a misdiagnosed population being under- or misedicated, which can cause further damage to the patient's stressed and fragile health.

This skepticism can harm the person's ability to obtain disability insurance or social assistance as their claims need physician support. Often, insurers claim not to trust the patient's own physician, and insist on appointing their own.

These misperceptions can persist, even for years, and can extend from the doctor to family members, employers, and friends. The resulting social isolation and damage to relationships is certainly hard on any patient fighting a life-changing illness.

Losing one's ability to save, invest, and prepare for both life and retirement is a difficult loss in this society.

Patients have three employment problems: a loss of a career, ill health, and a need for training. Repetitive interruptions to employment lead to poor work histories, which reduce employment opportunities. And the workplace demands not just skill, but competitive effort; many FM & CFS/M.E.. patients are unable to compete hard enough to keep a job, let alone advance in their careers. Many will need training to remain in or to re-enter the work force, but their illness often presents another hurdle: the variations in the severity of the illnesses mean that patients can't predict which days they will feel well enough to work.

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The patient may have to relinquish their employment, which can have sudden and disastrous effects upon the patient and their family's ability to maintain their financial commitments, and usually changes the roles of family members.

If living alone, the patient may have no one to help them domestically, and no other income to help cover expenses. Disability insurance plans commonly stipulate that patients must not be able to do any job if they are to continue receiving benefits.

Patients approach poverty when financial support systems such as welfare require that they have no remaining liquid financial resources of their own, or because of delays before disability benefits begin, which is itself partly due to the long diagnosis period required to meet the definition of FM & CFS/M.E..

These facts, combined with public and private insurers' practice of attempting to remove patients from coverage and their lengthy re-admittance processes, increase the possibility of bankruptcy, causing hardship for the patients, their families, and their creditors.

How well educated about the illnesses that the patient is and their emotional and physical mastery of the illness plays another role in differentiation. Their ability to afford the services of additional practitioners can also affect the treatment options their doctor can rely on.

Yet some patients do respond well, in most cases because they are able to cover additional expenses. One was a top executive at Nortel who had to retire early. Another was a psychiatrist with a decade of education, twenty years of good practice, and many awards for ballroom dancing, this bright woman was largely stopped by CFS. Another is a woman who built a business career, broke new ground and achieved leadership positions; she has managed to continue, at a reduced rate. Another faces his pain while operating a hospital. Another was a martial arts expert, but lost her family, health, and wealth. All of these people had achieved, all contributed at a high level to society, but none of these people has anything to gain by adopting FM/CFS.

A definitive test would quickly enable disability insurance providers to ascertain a patient's claim of ill health. But the lack of such a test should not be held against the patient.

Health Care Workers' Perspective

The front line practitioners (particularly the designated front line, the family physicians) face many challenges but have access to few resources when addressing FM & CFS/M.E.. They are trying to manage more than one million FM & CFS/M.E. patients in an unsupported environment. They are to be commended for what they've accomplished, but these individuals and groups of doctors need help to make headway.

It must be noted that from the health care professional's perspective, diagnosing and describing the patient, particularly without the benefit of a single definitive marker, requires a detailed process if the physician is to fully understand the patient's needs and opportunities.

A factor out of the control of medical professionals is the patient's ability to pay for alternative care services, such as physiotherapy, chiropractic care, massage, etc. This determines the treatment opportunities available to the physician in planning care for the patient. For most patients, medication is the only affordable option, and in some provinces, the requirement to co-pay means that low-income patients may not routinely be able to afford the full range of medications they need.

A further complication for physicians is that given the variability of the illness in general and the varying level of each symptom on a daily basis, patients must apply a stringent discipline and learn some pharmacology to use the appropriate levels of medication. This too is largely beyond the control of the doctor, and likely worsened by an unsupportive environment.

Moreover, most (pain) medications were not designed for FM or CFS/M.E., so off-label use occurs. Fortunately, there is movement in the pharmaceutical industry to develop for this population.

Monitoring FM & CFS/M.E. patients must be done closely as most medications present a wide range of side-effects. The physician must also consider the effect of long-term use of a wide range of medications that these patients consume to counter their symptoms.

But possibly even more difficult for family physicians is the lack of a national support structure for the illnesses that can take the patient and serve their needs. In such an unsupported environment as exists today, the doctor becomes all things to the patient, placing too much of a demand on the physician, even a financial disincentive to take on such demanding roles with patients.

Beyond what is available to the doctor or the patient, it is widely acknowledged that chronically ill patients have a large role to play in the management of their own health. Some patients don't fare well; many aren't given much of a chance. Some weren't prepared for such a change in their life.

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Physicians often see patients living in poverty. This increases the presence of stress and depression, which can complicate the patient's health and break their will. Most cannot afford psychological counselling to deal with this, and don't have means to escape the poverty. This limits their ability to succeed, limiting the physician's effectiveness, again - a factor out of the control of the doctor.

There is a recognised widespread shortage of family physicians, limiting access to doctors and prescriptions and their renewals. Worse, some physicians become demoralised by serving people who don't seem to respond to treatment. The physician's desire to help people is frustrated by the chronic nature of FM & CFS/M.E.. It is understandable that some physicians get burned out and quit serving these patients.

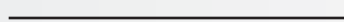
Further complicating the matter is that some physicians still question whether the illnesses are real. (The media once referred to CFS as Yuppie Flu).

In fact, FM-CFS Canada has repeatedly asked the last two Canadian Medical Association presidents for a letter of moral support and recognition. Not a single letter of moral support has been offered.

As a result, many patients generally visit a large number of wary or disbelieving physicians before being correctly diagnosed. They miss the opportunity for early intervention, when the chance to reduce the chronicity of the disease is greatest, as they may be misdiagnosed.

They may be prescribed suboptimal medications, a practice which can complicate the underlying condition, making eventual diagnosis and treatment even more difficult. Part of this is due to the fact that most M.D.s are not well-educated about chronic pain (anaesthesiologists are generally considered the 'pain' doctors). In fact, most M.D.s learned more in medical school about malaria than chronic pain.

This is the environment in which we find family doctors and the support network. FM & CFS/M.E. groups across Canada are willing to work to build the supporting infrastructure, adding local healthy people to the environment to alleviate the load on physicians and better care for patients. The situation facing doctors today can change.



Society needs a Cure

Health authorities around the world do not yet know of a cure for these chronic illnesses.

Health Canada could immediately encourage the development of knowledge and expertise by publicly calling for an exceptional research initiative, instead of waiting years for its next cycle to consider the merits of a research chair (in competition with others).

Health Canada can further improve its return on investment by helping develop the national patient registry where patients freely register and researchers freely find them. This will help large scale studies become technically more feasible, as well as less expensive. By helping educate physicians across a variety of disciplines, patients can be directed to the patient registry.

How Much Research is Appropriate?

Billions of dollars are being spent but not on FM & CFS/M.E. research. The cost has been incurred because of inaction, and is expected to increase if no action is taken. The current cost of patients to society is conservatively in the order of billions of dollars every year.

We do not know how many FM & CFS/M.E. patients are on disability insurance, but if just 10% of the lower Canadian estimate's 1 million patients are on disability insurance.

100,000 patients x \$10,000 per year in disability insurance = 1 billion dollars.

What would they have contributed to the economy if they were healthy?

If this 10% were healthy and earning the Canadian average income, \$30,000:
 100,000 patients x \$30,000 = 3 billion dollars

100,000 patients, of 1,000,000
Net difference to economy = 4 billion dollars.

Investing several millions to find a cure seems a prudent strategy to reduce or avoid already predictable long-term costs to society.

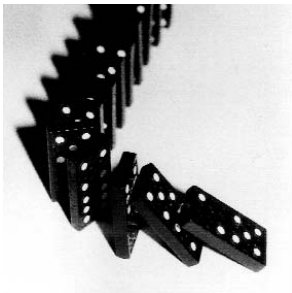
Fortunately, Canada's health sciences and medical research sectors have demonstrated world class results. We may have reason for optimism.

Social Consequences

Disabling illnesses that remove people from their careers in their prime, clearly change lives. This often leads people to draw upon community resources (from food banks to clothing services), and affects people dependent on them.

Contributions to society outside the home become more difficult. Volunteerism and financial donations are reduced. Given the size of the FM & CFS/M.E. population, this is not a trivial matter.

There is both a need for resources for the patient, and a loss of resources formerly provided by the patient.



The FM & CFS/M.E. Impact Circle :

Patients: 1 to 1.5 million
 Family living with Patient: 1 to 3 million
 Friends - at least one?: 1 to 1.5 million
 Medical Practitioners:
 Family physicians (~28,000)
 Rheumatologists
 Anaesthesiologists
 Neurologists
 Neurosurgeons
 Psychiatrists
 Psychologists
 Nurses, Practical, Visiting
 Pharmacists (~27,000)
 Physiotherapists (9,700)
 Chiropractors (6,300)
 Massage therapists (5,500)
 Naturopathic doctors (5,500)
 Dieticians
 Occupational therapists
 Social workers
 Government program employees
 Employers - loss of training investment
 Creditors - poor long-term prospects
 Business - reduced sales to patients

Ten Percent of Canadian Families?

Family Statistics

More than eighty percent of Canadians live in one of nearly eight million families. Holding this ratio true for the FM & CFS/M.E. community would mean at least eight hundred thousand patients of the minimum one million patients live in families. Ten percent.

Since each family has an average of three people, then more than one and a half million family members live with these illnesses every day. If there are one and a half million patients, the number of affected family members rises to two and a half million people, for a total population of perhaps four million Canadians living face-to-

Family Distress

While many impacts radiate out from the patients upon other family members, people around them, and institutions of various kinds, the illness can lead to patient isolation. The difficulty that these illnesses pose to family relationships seems to result in a higher than average percentage number living alone through divorce and non-marriage.

Several Consequences Follow:

Diminished Ability to Raise Children

If a single mother has FM & CFS/M.E., then her ability to raise a child will be hampered by greater constraints and challenges than otherwise. What impact does this have on society, and the next generation of children?

CANADA'S MOTHERS

These patients are in the main female, struck in the prime of their life, a worryingly large portion of the pool of mothers in Canada.

Lost Ability to Care for Parents:

Given the common need of senior citizens to receive support from their adult children, the loss of more than one million adults' livelihoods and health mean the seniors related to them will have less support than might be the case otherwise.

Lost Community Contributions

Many patients were very active members of their community, from senior business leaders, to sports leaders, to volunteers. Their combined ability to contribute to society, from developing the business community in off hours, to coaching athletic teams, to volunteering to help a good cause, is reduced. This loss, if experienced for decades, not only presents a community in need of others, but less able to help others, a significant social and economic loss.

Institutional Impact

There are economic impacts, covered more fully further on. From impacts on employers, businesses, tax bases, social investments, genius, and bankruptcy. Lost savings, new costs.

A Root Cause

These illnesses give rise to other social problems that will require attention as long as the initiating source remains. Food banks and other humanitarian groups will continue to need resources to help this population as long as their health does not improve and new patients join the community.

Solve the root cause and demand for other social services will decrease, permanently.

Living alone

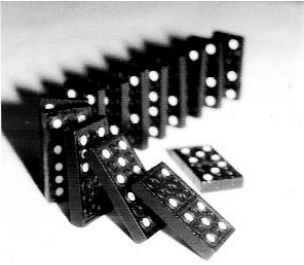
Living alone with FM & CFS/M.E. is very real for many patients. The illnesses change family relationships and roles.

Living alone with a chronic and wide-spread pain, cognitive challenges, and significant career and income changes, without the support system of a family, can lead patients to consider suicide.

For those living alone, particularly those who become bed-ridden for extended periods, home care is apparently more cost-effectively than hospital supervision.

They need help with daily activities such as cleaning, shopping, or preparing meals.

They also need a monitoring system because their condition can change rapidly. They may not be able to get out for help, or have someone to turn to.



Suicide

The World Health Organisation marked World Suicide Prevention Day on September 10 and identified the ten leading causes of suicide. Canadians with FM & CFS/M.E. experience most of them.

- poverty
- unemployment
- loss of loved ones
- arguments
- breakdown in relationships
- substance abuse
- childhood abuse
- mental disorders
- physical illness
- disabling pain

Practically, due to the nationwide shortage of knowledgeable physicians, front-line hospital emergency workers facing suicidal patients have little to offer. There is need for a knowledgeable crisis line.

According to the Agency for Health Care Policy and Research (AHCPR):

"... despite the high prevalence of depressive symptoms and major depressive episodes in patients of all ages, depression is underdiagnosed and undertreated by primary care and other nonpsychiatric practitioners, who are, paradoxically, the providers most likely to see these patients initially.

Depression may occur concurrently with other nonpsychiatric general medical disorders or with other psychiatric disorders; it may also be brought on by the use of certain medications. Major risk factors for depression include a personal or family history of depressive disorder, prior suicide attempts, female gender, lack of social supports, stressful life events, and current substance abuse. The social stigma surrounding depression is substantial and often prevents the optimal use of current knowledge and treatments. The cost of the illness in pain, suffering, disability, and death is high.

Economic Consequences

New Costs to Society

The preceding example shows how ten percent of the smallest population estimate indicates their public disability insurance cost would be about one billion dollars, the costs to the public are in the order of billions of dollars annually.

How many get disability insurance?

100,000 patients x \$10,000 per year in disability insurance = **\$1 billion dollars**

500,000 patients x \$10,000 per year in disability insurance = **\$5 billion dollars**

Medical costs

More certain is that 100 percent of the population (over one million patients) has health care costs, mainly for medications and physicians. The population has lost a significant portion of its ability to contribute to society. This situation will continue unless medical breakthroughs find the cause, improve treatment, or find the cure.

Lost Societal & Business Investments

The illnesses have struck people throughout society, in a wide range of economic circumstances and professions.

Employers and taxpayers completely or partially lose the benefit of their investment in education and training. With a large portion of patients becoming ill early in life (from pre-teens to early adult years) society will likely not see the same return on investment in this population as it would with healthy people.

- Employers lose training investments.
- Taxpayers lose normal potential of social investments.
- Charities lose volunteers and charitable contributions by patients and their families.

Some of these people were key people who had a significant impact on others. Society loses some measure of their contribution as family members turn their efforts inward to care for their loved one.

Who else could have been one of Canada's great entrepreneurs, scientists, cultural contributors? Who would want to lose another million employees in the coming decades to such a cause?

Role for Social Workers and Occupational Therapists

Canada's one million patients need assistance to re-enter the marketplace. Some will not be able to work full-time or on a sustained basis, but for those who feel they can, some assistance would help ensure they find a suitable position that allows them to work as long as possible.

Federal Costs

The two examples use 20% of one million patients, 20% of 393,000 FM patients

200,000 of 1,000,000 patients:
\$3.48 billion annual cost (Nearly \$10 million every day)

98,250 of 393,000 Statistics Canada FM patients:
\$1.7 billion annual cost (More than \$4 million every day)

Cost breakdown:

Disability Insurance and Welfare

200,000 patients (20% of 1 million) x \$10,000 per year disability insurance = \$2 billion

98,250 patients (20% of 393,000) x \$10,000 per year disability insurance = \$.9825 billion

Lost Income Taxes

200,000 x \$6,000 (20% tax x \$30,000 (Canada's average income)) = \$1.2 billion lost taxes

98,250 x \$6,000 (20% tax x \$30,000 (Canada's average income)) = \$.5895 billion lost taxes

Lost Sales Taxes

200,000 x \$1400 (7% of \$20,000 = \$30,000 - \$10,000 income drop)= \$.28 billion lost GST

98,250 x \$1400 (7% of \$20,000 = \$30,000 - \$10,000 income drop)= \$.13755 billion lost GST

...if 40% were on disability insurance, then the Federal cost would be about \$7 billion per year. Without treatment, what is expected?

FM-CFS Canada seeks \$10 million from the Federal Government to take action on this long-standing opportunity for better results. Short and Long-term savings will be realized, savings that can never be lost.

How much is spent on Medication?

1,000,000 x \$100 month = \$1.2 billion

Our research suggests it is much higher.

How much is spent on Physicians?

1,000,000 patients x \$25 month = \$.3 billion

Based on brief 5-7 minute meetings.

Most patients use more time.

Specialists' fees are higher.

+ Other costs:

Billions in non-reimbursed medications and therapies.

Hospital visits and extended stays.

Legal fees incurred seeking coverage.

Bankruptcies. Lost savings, RSPs.

Employer losses: employees, training.

New demands on local social services.

Societal investment losses. Lost genius.

Family costs. Break-ups. Human costs.

Suicide.

Are the costs more than you thought?

Lost Volunteer Contributions

Based on national averages: **\$.6 billion**

(Average: 25% of Canadians contribute 162 hours at an average of \$15 per hour.)

Disability Insurance

Poverty for Life

Many patients depend on private or public insurance plans as their sole source of income. Patients on government insurance plans must survive on usually less than \$900 per month for the rest of their adult lives. When an individual qualifies for income from two or more programs (e.g. a federal and a provincial program), one usually claws back the benefit of the other.

The federal public insurance plan pays out at a rate dependent on the number of years one has paid into the system. Since many FM & CFS/M.E. patients are afflicted as young adults, or even teenagers, they must live, according to the rules, on less than \$900.00 per month forever. Even without an undesirable illnesses, such an impoverished future is bleak.

Living for decades on government disability insurance may be considered a blessing, for it is income when there is no alternative. However, paying for rent, food, utilities, medications, non-covered medical therapies, clothing, and all other life expenses, including the periodic long term renewal of capital assets, mean these people are forced to become some of the country's most resourceful and economically minded people. It also means they must choose the cheapest of everything, often living in sub-standard housing. And financial failure on such a budget is bankruptcy, which causes further difficulties with housing, utilities, and wherever credit checks are routine.

Is this Canada's compassion?

Government must decide if the way these patients are treated is fair, and whether more can be done to improve patient health and their ability to work by limiting or eliminating the costs that can improve their health.

Do FM and CFS/M.E. patients qualify for disability insurance?

There are reports of patients who, having watched the disability insurance confrontations endured by FM & CFS/M.E. patients, have asked their physicians to record other reasons for their disability. If these illnesses are recognized by Health Canada, the World Health Organisation, and practicing physicians as disabling chronic illnesses, then they should receive support without confrontation.

Rather than resisting the patient and evaluating at each juncture, insurers should accept as self-evident that these people find no joy in their symptoms, in taking medications, and living below the poverty line.

The facts are that there is no easy lab-test diagnosis and that some patients are less severely affected than others. Moreover, physicians can have different measures of pain, and patients report pain subjectively. Therefore, the current system has a group of physicians hired by the insurance provider to systematically review patients. They often do not involve the primary physician attending the patient, sometimes employ private investigators, and have often prematurely decided against the FM & CFS/M.E. patients. Yet the common knowledge about the illnesses is clearly that a patient can have a good day, but sustained good days are merely a HOPE.

Possibly the answer is to recognize the special nature of these illnesses and introduce a system that is easier to step off and return to. Removing the fear of a challenge in returning to coverage would remove stress from the patient and help their health.

FM-CFS Canada does not know the portion of patients on private versus public insurance, nor even how many patients there are now on disability insurance and welfare (in part because of the previously noted methodology problems inherent in population measurement and due to misdiagnosis). Some patients have been eligible for benefits because of one of their less controversial disabilities.

But given the payment challenges widely reported by the FM & CFS/M.E. community, it seems the insurance industry may not have recognized or calculated the long-term cost of these patients in their actuarial planning and is acting to preserve formerly expected levels of return.

Patients routinely report challenges with private insurance firms despite having bought the proper insurance.

Read the Fine Print....

Many policies do not provide benefits after two years if the patient is capable of doing **any** job.

Pre-existing conditions & Private Insurance

If a person has FM or CFS/ME they will not qualify for a new insurance policy as their pre-existing condition precludes them from getting insurance, unless they are willing to pay what it costs to treat them and the profit the insurers need.

The private health care system advocated by some must contend with the large population of Canadians that can not get health insurance.

Private Insurance: Higher Premiums, Better Plans?

The private insurance plans of chronically ill FM & CFS/M.E. patients usually provide relatively small monthly payments. To add to the benefits received in the future will require higher premiums. Consumers may see value in paying higher rates to hedge against life-long poverty, given its apparently growing prevalence.

Government could require private insurers to provide plans that provide a sufficient payment to avoid poverty. Price competition between insurers may have led to the creation of insurance products that have little social value, specifically: long-term recipients paid below the poverty level. A large, poor, and chronically ill population will be a greater consumer of society's tax and non-tax resources (such as income supplements or food banks). Impoverished patients may be less likely to succeed in improving their health if health care doesn't cover all costs. Does our government want so many poor people?

Future Government Liabilities

The illnesses generally limit patients' financial preparations for old age, making them reliant on state assistance throughout their retirement.

FM & CFS/M.E. Health & Health Care

A million or more FM & CFS/M.E. patients consume provincial health care. There are several opportunities for government to achieve improved outcomes which we believe are of interest to all parties.

For example, physician education will produce significant permanent savings by lowering the number of diagnostic consultations needed, permitting more early interventions which can help reduce the severity of the illnesses, and reducing the number of patients that will be inappropriately medicated, which can further complicate their condition. As with other illnesses, a support system leads to more people being involved in the patient's care, freeing physicians to practice more efficiently with these patients.

In the long run, research to discover a cause, a definitive diagnostic lab test, and a cure, would provide further savings, again on the large scale of one million or more people.

There are several easy advances that can bring about short, medium, and long-term savings. The following section provides an overview of health care issues facing patients and the system.

Triage Is Needed

Triage is urgently needed. Of the millions of chronic pain patients in Canada, few have physicians knowledgeable about their conditions, or about chronic pain. Some have regular monthly meetings; others have none.

To reconcile these extremes in patient service, we need to determine who is in greatest need. All patients should have a course of action planned for them, through triage.

Patients who currently have a physician are concerned that they may lose their access. Some admit to scheduling more appointments than they might need, because they are afraid of not being able to access a doctor when they do need one. To allay their concern, the health system needs to assure them they can get more help when needed.

A triage could help use current resources more effectively. Triage combined with the many other elements to be presented, is then a useful component of an overall solution.

Wait Times

Canada has a severe shortage of chronic pain physicians, rheumatologists, and anaesthesiologists, and neurologists. Fewer still are those trained to help FM & CFS/M.E. patients.

Wait times are so long that many family physicians have stopped referring patients to the few provincially-covered specialists in each city.

Removing alternative pain relief such as massage and physiotherapy from public health care coverage further limits the choices available to most (low-income) patients.

Wait Times: The Ottawa Example

1. An independent report commissioned for the Ottawa Hospital Group concluded that for the nearly 100,000 chronic pain patients in the Ottawa catchment basin, there were hospital-based services for fewer than 10,000 per year, leaving 90,000 without service. The waiting lists are so long that most FM & CFS/M.E. patients are effectively without service.
2. Several knowledgeable prescribing physicians have left private practice in Ottawa leaving their FM & CFS/M.E. patients unable to renew prescriptions. Physicians held a press conference in 2003 to announce this crisis. Including hospitals, less than a dozen provincially-covered chronic pain physicians practice in Ottawa.

What is our government's advice for Ottawa's 35,000 to 50,000 FM & CFS/M.E. patients?

Country-Wide Shortage

FM-CFS Canada has consulted with patient groups across Canada and learned that all regions are experiencing physician shortages, and the limited public coverage for the other practitioners knowledgeable about chronic pain (such as chiropractors and masseurs) effectively removes this option from many patients. Psychologists are usually not covered. There is at once, both a great supply of potential practitioners, and a shortage, due to poor education and the non-inclusion of certain medical services.

Plan for More Physicians

Accounting for FM & CFS/M.E. patients is required in when adding spaces to medical schools. More chronic pain specialists are needed. Are they already factored into the proposals of the Canadian Medical Association, which isn't willing to offer even a letter of moral support?

More Than Anaesthesiologists

Traditionally, only anaesthesiologists have been taught much about pain. More disciplines of medical students, particularly front-line family physicians, need to learn about pain, prolonged pain, and chronic pain. Informally, medical students have told us that they learn little about fibromyalgia (less than about malaria), and the instructor's tone is often dismissive. For an illness that afflicts so many, we need physicians who are aware of what they're seeing, and of how they can help.

Six steps for relief:

- 1) Educate practicing physicians to reduce wasted visits and inappropriate medication.
- 2) Educate medical students in many disciplines to expand the future team.
- 3) Cover the cost of other healing therapists (including physiotherapists, myofascial therapists, and accupunturists). Recognize that chronic pain has a long history of treatment with methods other than modern pharmacology and surgery, and that these therapists can help the family physician be more effective. Note: The Arthritis Society in Ontario is able to arrange reimbursed physiotherapist assistance.
- 4) Cover the costs of psychological treatment to help people through this trauma.
- 5) Engage the help of dieticians to help ensure their diets are a helpful part of their treatment.
- 6) Provide a support network of healthy people to help patients, to relieve physicians.

What is the cost of Doctors?

With the increased co-morbidities faced by these patients, and because these physicians have fewer supports that when treating other illnesses, FM/CFS patients tend to want more consultation time than other patients the health system has become accustomed to serving.

However, even for a brief six-minute general consultation, once per month:

$$1,000,000 \times 12 \text{ visits per year} = 12 \text{ million visits} \times \$25 \text{ consultation fee} = \$300,000,000$$

If there are 1.5 million patients, some still misdiagnosed, but being treated:

$$1,500,000 \times 12 \text{ visits per year} = 18 \text{ million visits} \times \$25 \text{ doctor's fee} = \$450,000,000$$

Increased Co-Morbidity

Can We Afford to Continue the Wait?

As noted in the Definitions of the illnesses included in this submission, many FM & CFS/M.E. patients present a wide array of common symptoms and often develop other medical conditions due to weakened health. For example, they may have a greater need for flu or other vaccines. Many FM patients report symptoms of CFS/M.E.: fatigue, cognitive impairment, and increased colds, although their pain is more pronounced than their fatigue.

Depression and anxiety are also common in FM & CFS/M.E. patients, resulting from the impoverished circumstances in which these patients live, from the disbelief they face, from the loss of employment, and harm to their relationships, and from the fear their situation will never change. (Note that research has demonstrated that depression and CFS are biologically distinct illnesses that can be clinically differentiated.)

Anxiety is common, whether about paying bills, meeting needs, or the fear of their next severe flareup of symptoms.

Numerous medical research findings seem to have implications for this community.

The reduced amount of exercise experienced by most chronically ill patients can itself lead to a worsening of their general health.

Regarding cancer risk, the British Medical Journal (BMJ) reports that FM patients are at increased risk.

Studies suggest that emotional stress can weaken the immune system.

Chronic lower back pain seems to decrease the brain's grey matter density; this might be true of all chronic pain.

All of this and more is contrary to the popular notion that these patients' health is not deteriorating. Without treatment, they may present further conditions which will be even more expensive to treat.

Diagnostic Risks

A definitive laboratory test is needed for FM & CFS/M.E..

Diagnosis and treatment as currently practiced result in unnecessary problems and costs. Diagnosis is currently by process of elimination using a wide range of tests, which consume a wide range of health system resources.

Adding to this problem, the medical community is not well informed about the diagnosis (and treatment) of FM & CFS/M.E., with some not believing it is a real illness. As a result, many patients visit numerous physicians in search of assistance.

Further harm to the patient follows from widespread misdiagnosis. According to FM-CFS Canada research and consultations, most FM & CFS/M.E. patients have been initially misdiagnosed which can complicate their underlying condition.

Early Intervention

Not only is useful for all serious and complex illnesses, it could be considered critical in helping FM & CFS/M.E. patients come to terms with their new realities and gain advantage in the life-long fight before them and their families. All too often, early intervention opportunities have been missed. We now have to deal with the results of these missed opportunities.

FM & CFS/M.E. patients have to make significant changes in their lives and need to know what these changes should be. They will bear a great responsibility for management of their own health, more so than healthy people who can periodically neglect healthy routines without the severe repercussions faced by this community.

Given the government's role in paying for the medical service and financial aid delivered to this community, it can benefit from helping patients fully understand the many interdependent aspects of their new health regimes, from exercise to diet, to sleep, mood, and stress management, to careful medication use, and how to accomplish them on low incomes. Multidisciplinary teams have demonstrated in Canada, the UK and U.S., that delivering their services to a group of patients and their families is cost-effective, a useful method for triage, and more likely to be successful due to the multidisciplinary input.

Research has shown that early multidisciplinary advice that provides patients with an overall understanding of their condition and responsibilities, leads to reduced severity of their illness and overall better health. Educating the patient should be among the first actions taken upon early intervention.

MultiDisciplinary Care

Canadian Hospitals are offering more than Drugs Alone: Canada's leading edge

In 2003 FM-CFS Canada identified and contacted four Ontario hospitals offering a multidisciplinary approach to the treatment of Fibromyalgia. They agreed to participate in a study.

St. Joseph's Care Group, Thunder Bay, Ontario
 St. Joseph's, London, Ontario
 Southlake Regional Hospital, Newmarket, Ontario
 Royal Vic Hospital, Barrie, Ontario

FM-CFS Canada & Carleton University initiative: 2003-4

At the request of FM-CFS Canada, a graduate team at Carleton University conducted comparative research on the four Ontario hospitals offering multidisciplinary programs for FM patients.

Multidisciplinary Education Program, Program Administrator comments:

"People who go through the program are less emotionally distressed, take more appropriate medication, and return to work more."

"Following the program, we receive positive evaluations concerning relationship, marriage, support and understanding within the family structure."

"When people learn how to manage their own pain, their depression goes down 30%."

The research findings support the following recommendations:

- A holistic, biopsychosocial program model would best meet the needs of FM patients. It should be designed on a philosophy of chronic pain self-management.
- A multidisciplinary team of highly trained professionals is a required element of service delivery.
- Follow-up should be in person to reinforce the learning acquired during the program.

MultiDisciplinary Care

Despite the recent presence of four hospital programs, most patients have, at best, one physician knowledgeable about the illness, not a multidisciplinary team. Learning only one facet of their health strategy reduces their chances for success. Fortunately there are promising signs, such as physicians in some Canadian cities who are working in teams (often of their own formation).

According to the Federal Government, in a new initiative, Canada's primary health care system leaders are working together to facilitate more interdisciplinary collaboration. The Enhancing Interdisciplinary Collaboration in Primary Health Care (EICP) Initiative will engage primary health care providers, governments and Canadians in a national effort to create a framework for change and innovation in primary health care.

The Enhancing Interdisciplinary Collaboration in Primary Health Care (EICP) Initiative

Its objective is to encourage health professionals to work together to produce the best health outcomes for patients and for providers. We have an ambitious research agenda designed to gain new insights into successful primary care models in both urban and rural settings. We also plan to develop practical tools to encourage inter-disciplinary collaboration, and a supportive policy and regulatory environment. The Initiative will deliver a set of guiding principles and a framework for collaboration that will inspire health care providers and governments to ensure that Canadians have access to the right professional and the right services, at the right time.

A steering committee (physicians, nurses, social workers, physiotherapists, speech-language pathologists, audiologists, dieticians, psychologists, pharmacists, occupational therapists and a national coalition on preventative practices) will provide leadership and direction to the Initiative.

The EICP Initiative is funded by Health Canada's Primary Health Care Transition Fund.

(source: accessed October 28, 2004: <http://www.eicp-acis.ca/en/default.asp>)

FM-CFS Canada proposes that these multidisciplinary programs become standard responses for patients. Advice from a range of medical specialists can be packaged for easy and inexpensive distribution, in print and on the Web. Given the unqualified material available on the Internet, the provision of sanctioned advice will aid and reassure patients, old and new.

Expert Patients

Canada Needs Experts. With more than one million patients and too few physicians, we have a backlog of education to accomplish. Printed multidisciplinary materials will help. But what if we taught thousands of patients to help thousands more?

Canadian FM/CFS patients can benefit from the lessons learned in both domestic and foreign patient-education chronic illness programs. From diabetes to arthritis, patient education has become considered an essential element for healthy patients.

Expert Patient Genesis

The Arthritis Societies in Canada and the United States pioneered the use of Stanford University's Kate Lorig's ideas. Her programs for chronically ill patients were based on the recognition that patients with different illnesses have many common challenges that they could benefit from learning about, that they need to learn the specifics about their own illness, and that they have a role in managing their health. She appreciated that this could be packaged. Stanford University developed certified patient self-management education programs, now in use by the Arthritis Society in Canada (with its 13 centres teaching patient self-management courses).

The patients in these patient self-management courses can then be certified to educate other patients and health-care professionals. The Arthritis Society uses these patient-graduates to help educate physicians in the diagnosis of arthritis. This model would work for FM & CFS/M.E. patients. In fact, much of the course material and advice for arthritis patients is useful for FM patients, and many FM patients have been attending arthritis courses. Unfortunately, CFS/M.E. patients, and most FM patients, have not only fatigue or pain, respectively, but often cognitive changes, and depressed immunities which further complicate their daily regime, energy levels, and general health. They need advice beyond the Arthritis Society's course materials. Fortunately, there are already some sources of information.

Great Britain's expertise

The Long-Term Medical Care Alliance (LTMCA):

The UK has embarked on a strategy of educating all patients who suffer long-term medical care needs to ensure that they know all the things they can do to help themselves. Courses have been developed for FM & CFS/M.E. patients, and the LTMCA has shared both their program design materials and operating reports.

Support Networks Aide Health Practitioners

The support networks that surround most widespread illnesses can efficiently manage patients, with specialized resources applied to their various goals.

In example, a patient diagnosed with arthritis can use everything from a knowledgeable public to the many types of practitioners they interact and learn from, to support groups and special medical coverage, in some provinces.

Few of these resources exist when a patient is diagnosed with FM & CFS/M.E., so an undue burden is placed on the physician and other health practitioners.

Ideally, the patient is counselled and in the care of a team that can recognize and respond to their needs. A physician should be able to refer a patient to a patient-to-patient support system for ongoing moral support and education. The people living with the person should also be counselled, and may find support groups helpful.

Support groups benefit from patient self-management education programs, and can be the nucleus of local training centres where both patients and caregivers would be certified to educate others about the illnesses. Liaisons with local specialists in different professions can efficiently bring additional experience to a group setting where knowledge transfer aids the long term health of the patient.

A Critical Issue - Physician Compensation

Front-line physicians now bear most of the responsibility for helping FM & CFS/M.E. patients. Because we lack the institutional and community-based support systems that accompany other widespread conditions, the treatment process requires more time than it will when the system matures and the physician is able to efficiently treat the patient in a matter of minutes.

Indeed, patients recognize how isolated they are, how few physicians there are, how few of those even believe they have a real illness. These facts alone give them dread, fear, and can lead to depression and complicate the condition. Patient education and moral support has been left largely in the physicians' hands, leaving them to find materials and resources, and provide comfort. Because of the longer meetings that patients desire and need, it is more expensive on average to treat an FM & CFS/M.E. patient than many others. This limits the willingness of physicians to treat such patients as it imperils their financial viability. It is likely that a family physician could not profitably and capably serve the variety of needs of only FM/CFS patients under the current systems.

Yet more doctors are needed to attend to this million member population before it worsens.

Current billing codes used by physicians record addressed symptoms but not that the patient was suffering from FM or CFS/M.E.. New codes would provide governments with a better understanding of the health care costs of these illnesses. The Government of Ontario has recently recognised a code for CFS, but it does not provide for more time than a standard consultation.

Incentives are needed to encourage physicians to practice in this area. Providing a billing code that allows for longer meetings will help patients. Saving a few dollars on patient time may leave patients without time for the advice they need to successfully manage their condition, costing the system in the long run.

Penny wise, dollar foolish?

Medication

Many FM & CFS/M.E. patients take more than 100 pills per month; some as many as 500 per month. Aside from the high cost of medication, issues of great importance include patient pharmacological education, medication conflicts and side effects, efficacy, and reimbursement.

Pharmacologic treatment of fibromyalgia

Fibromyalgia is a chronic syndrome characterized by widespread pain, unrefreshed sleep, disturbed mood, and fatigue. Until such time as we have a clearer understanding of the trigger and/or pathophysiological mechanisms producing these symptoms, pharmacologic treatment should be aimed at individual symptoms.

Such treatment should ideally be offered as part of a multidisciplinary treatment program using both pharmacologic and nonpharmacologic treatment modalities. Critical components of any successful fibromyalgia treatment program include addressing physical fitness, work and other functional activities, and mental health, in addition to symptom-specific therapies.

The main symptoms that should be addressed include pain, sleep disturbances including restless leg syndrome, mood disturbances, and fatigue. Pharmacologic therapy should also be considered for syndromes commonly associated with fibromyalgia including irritable bowel syndrome, interstitial cystitis, migraine headaches, temporomandibular joint dysfunction, dysequilibrium including neurally mediated hypotension, sicca syndrome, and growth hormone deficiency.

Curr Pain Headache Rep 2001 Aug;5(4):351-8

Medicating FM & CFS/M.E. patients is complex, since the severity of symptoms can wax and wane, individually or in union. The patient must understand the relation of their medications to their symptoms, diet, sleep, mood, and activity cycles, and possible side effects. Patients, caregivers, and medical practitioners must be well educated if they are to achieve a greater return on the ongoing investment of time and medication.

Medications have limits to use due to patient suitability, medication conflicts, and side effects. According to patient reports and generally known medical knowledge, the side effects of many chronic pain medications are undesirable, particularly for long-term use.

Medication

Policymakers should bear in mind that medication conflicts can prevent patients from using pills to treat a symptom. Just because some pain relief is widely available in pill form, for example, doesn't mean that medications work for all patients. Some will need other strategies.

Truly effective remedies would allow patients to lead normal lives. The drugs now available do not sufficiently counter the illnesses' symptoms to routinely produce a good quality of life and steady employment. We must invest in research to find more effective medications.

Given the lack of attention paid to FM & CFS/M.E., can patients and government be assured that the pharmaceutical firms have properly tested their products on patients that have an illness that few acknowledged in the first place? Currently there is much off-label use. Some pain medications have reached the headlines after insufficient warnings raised the risk of heart attacks.

There are promising new treatments being examined that offer pain relief strategies with fewer side effects. Is our government ready to test measures to help the FM & CFS/M.E. community? Can some appropriate condition-specific expertise be developed within the Health Department?

Provincial health care policies usually reimburse patients for their use of approved pharmaceuticals, but not for alternative therapies (such as natural products, vitamin and mineral supplements, and other traditional medications). Most pharmaceutical products were derived from natural sources; it isn't unreasonable to believe patient reports that the natural sources may give greater relief. If the public policy goal is to make taxpayers and reduce those on financial assistance, then government should wish to expand coverage of the alternative therapies that lead some to better health. The patient and attending physician should be trusted to design a health strategy that works for the patient.

Furthermore, courts rulings on various illnesses (e.g. celiac disease) in some cases compensate patients for not only their therapy when using non-pharmacist recommended treatments, but also for shopping and preparation time. Such arguments could be made here, but first the problem of noncoverage of alternative medications needs to be addressed.

Mental Health Care

Psychiatric services are generally covered by publicly funded health care programs and should therefore be accessible to FM & CFS/M.E. patients. Psychological care is generally for fee, and thereby less available to low income patients.

Any patient undergoing a life-changing event in their life can benefit from counselling. Grief counselling is now widespread for accident victims and witnesses to horrible acts.

What of these patients finding themselves loaded with pills, no employment, no clear idea of what is wrong with them, and with little community support? Does our compassion not extend to them? The lack of education about FM & CFS/M.E. among general physicians also holds true for psychiatrists and psychologists: some believe the illnesses are real; others do not. They even disagree on the benefits of counselling, on an illness considered by many to be all-in-their-head.

The Diagnostic and Statistical Manual 4th Edition (DSMIV) is the guide used by physicians and psychiatrists to make a diagnosis. This standardized approach allows the rates and prevalence of psychiatric disorders to be compared across the world. Neither FM nor CFS/M.E. are listed.

There are differing opinions on the meaning of psychosomatic illnesses. Some practitioners believe that the patient has invented the symptoms, while others believe that the patient's brain has led the body to express real symptoms. These perceptual differences lead to different treatments.

A Critical Issue - Non-Pharmacological Care

Pharmaceuticals are not appropriate for pain relief for all patients all the time, so this community must find alternative forms of pain relief. Complementary and alternative medicine (CAM), therapeutic approaches not considered part of conventional medicine, may be recommended:

- to complement medications
- to provide pain relief when changing drug therapies
- when intestinal problems limit medication intake
- when there are conflicts between medications
- when the patient prefers to limit the intake of medications
- when physical repair is appropriate
(e.g. chiropractic treatment to treat improper posture caused by pain)

Which lasts longer, a touch or a pill? Sometimes the touch of hand can achieve more than a handful of pills, lowering the drug costs to government (an area of costs with faster rising prices than the non-pharmacological care sector relieving pain).

Patient poverty limits access to non-pharmacological care. The drug costs covered by government are generous when compared to the provision of alternative pain-relief services such as physiotherapy, chiropractic care, massage, or acupuncture. This patient community's demand for these services have not been met in most provinces, for most patients. De-listing such services in Ontario (Canada's largest jurisdiction) has forced patients to rely more on drugs.

Each of these professions should have courses (CME's) developed specific to FM & CFS/M.E. and may be able to integrate with support groups. FM-

Home Care

FM & CFS/M.E. patients with severe expressions of the illnesses are sometimes bed-ridden for many months, either asleep or lying in pain.

Many patients are unable to shop for food, clean house, pick up prescriptions, or cook. Home care programs (such as the VON) are essential to keep these patients out of hospitals without leaving them isolated at home, unable to care for themselves.

In public emergencies, someone needs to visit the patients living alone. Systems must be in place to prevent a repetition of France's heat wave tragedy. Isolated, media-deprived patients can be warned of dangers such as West Nile and vaccinated to protect their weakened immune systems.

Given widespread evidence that home care is preferable to hospital care from both the patient and health care system's perspective, recognizing this community's need and planning for them is prudent. The size of demand is not known at the present time, except that all patients are at risk of periods of immobilization. We are uncertain how many have a family member watching over them.

Community Building

Patients Helping Patients

Canada's other major health charities have shown that patients and their families can unite to help their cause. FM & CFS/M.E., which can make steady employment difficult for most people, affect the way patients can contribute, but there are still many opportunities, especially if the patients can become healthier from better treatment.

The FM & CFS/M.E.. community can contribute to patient support, and to research of the illnesses through:

Patient Volunteerism:

Patients can be a force for good, more so if they are united with a common objective, and many common goals may be shared over time.

Research Volunteers:

A national patient registry will help researchers find patients, with free access to the database. Patients can help maintain the registry through volunteerism and donations.

Donations to Research:

Patient contributions may become a significant source of research funds

Community Leaders:

Programs can be established to link patients to others (such as "expert patients" who liaise with health professionals) in the community to relieve the demand on the health system.

Community Support:

Newly-diagnosed patients can be welcomed into a knowledgeable community, with groups for patients and their families.

Learning, Exercise, and Social Groups:

Patients can advise the market of services they need (e.g. warmer pools) to avoid social isolation that often accompanies these illnesses, while getting appropriate exercise.

Public Education:

FM & CFS/M.E. patients and their families can work with government to educate the public.

Crisis Line:

Trained responders provide a telephone help-line.

Research

There is little research in Canada devoted to FM & CFS/M.E., and most of this research mentions these illnesses almost as an aside to the primary subject of study, such as arthritis.

The Canadian Institutes of Health Research conduct little research into the conditions due to a lack of demand for funding by researchers. An online search conducted on April 18, 2005, at the CIHR Internet site for the term 'fibromyalgia' produced one result, while the term 'cancer' resulted in more than 2,000 responses.

According to a letter from the Executive Assistant to the Federal Public Health Minister, there have been eight applications for Fibromyalgia research over the years, with only one being funded. They did point out that a lot of Arthritis research is being done.

Registering patients in a single electronic database can aid researchers seeking study participants. The current difficulty of finding participants deters researchers and limits the study sizes considered or proposed. A free central database would enable researchers to use larger samples while saving time and money and time. FM-CFS Canada provides an on-line registration form, and keeps a growing off-line database that now has more than 1,500 registrants. FM-CFS Canada also has experience in helping researchers.

Most well known health conditions are studied from many perspectives, including:

- cause
- primary risk factors
- definitive (laboratory) test
- number misdiagnosed
- improvements in treating symptoms
- finding a cure
- change in prevalence rates
- number with regular access to (knowledgeable) physician(s)
- number living alone, number with caregiver, if needed
- patients' economic situations
- special cases with different needs

Research Chair

Canada has hundreds of research chairs devoted to a wide range of health conditions, many with wide multidisciplinary interest presenting a multidimensional view of the problem. There is not a single FM & CFS/M.E. research chair to provide a nexus for researchers across disciplines.

FM-CFS Canada proposes the immediate creation of a medically-oriented research chair charged with seeking the cause of the illnesses, a definitive laboratory test for diagnosis, better treatments, and a cure. We believe that this cost would be a useful investment considering the certainty of billions of dollars being spent every year on these illnesses, year after year.

Center of Research Expertise

FM-CFS Canada's online Researchers' Hub provides an initial rallying point until we enjoy the centralizing efforts of a research chair. The site has begun to assemble the people and information needed by a research chair. In addition to posting information and news, the site can provide private conference forums and free online questionnaires for downloading to a database.

Answering Skeptics

Even if these illnesses were "only in their heads", we should learn how to avoid them. Can future generations avoid these disabling illnesses through education?

But why, why would many millions of patients around the world do this, all in the same way? And why would patients prefer pills and poverty to health?

Questioning and confronting these patients needs to end. Please empathize. Imagine yourself being viewed suspiciously while experiencing a life-changing illness. Whether or not these illnesses are psychosomatic, one million patients plus their families still need help. A supportive environment creates conditions for less stress and better health. A public demonstration of government support could help shift public and medical opinion.

FM & CFS/M.E. patients are generally impoverished by our financial support system's process delays; they must live on a below-poverty-level income; they are denied funded access to medical treatments; they are ignored and have their integrity questioned. Would we propose this path to healing to a patient suffering a broken leg, cancer, another condition?

On all counts, the system's response is at odds with our generally accepted principles.

Is care tied to finding all physicians willing to call it a real illness, instead of just some? Is not the idea of publicly-funded health care and the social safety net to keep people from bankruptcy while attending to their health? And are we not all vulnerable to physical or mental ill health? Is it their fault the medical professions have been slow to come around?

If skeptics want to hold on to their disbelief, we only ask that they not ignore the prima facie evidence that there is a societal problem of large consequence. And if, in fact, it is all in the patients' heads, then by all means, please help them put it out of their heads!

HOPE

Hope is recommended for restoring good health, yet little has been done in Canada in the past decade to give FM & CFS/M.E. patients hope; indeed, a negative stereotype has persisted. Having these illnesses in a society that ignores you, questions you, or even confronts you, is depressing. FM & CFS/M.E. patients can begin to hope when we recognize and research these illnesses, and provide needed medical, economic, and social support to those too ill to mount their own defence. Let's give hope; let's end the silence. Let our leaders lead.

Conclusion

For some, the clear cost of the problem compared to the solution is motive for action. But the cost of these illnesses bears even more heavily on individual patients and their families.

Patients reading this will see a broad scan of issues they know well. Patients with two conditions sometimes see dramatic differences in the attitude of the health system. Given Canada's promise on health care and the newsworthy efforts in so many other areas, it is cause for action, the same can be done here. There need not be so many issues unresolved.

Fortunately, the wide range of issues have ample resources available to address them, if we begin to invest rather than simply pay the cost of a broken system. Billions are spent annually at the Federal level on the costs of taxes and insurance, of which surely an investment in solutions would yield more than its cost.

We invite you to help.

Appendix

- Definitions of illnesses from Canadian Concensus Protocols
- A comparison chart of four Ontario Hospital-based Fibromyalgia programs
- Canada's Coalition of Patient Groups

More than 100 notes of Moral Support were originally included in this submission to the Federal Government, and are still available on our web site. They have been removed to make the download of this document easier.

CFS DIAGNOSTIC PROTOCOL

(extracted from the Journal of Chronic Fatigue Syndrome, Volume 11 Number 1, 2003, Carruthers et al. , The Haworth Medical Press)

Although it is unlikely that a single disease model will account for every case of ME/CFS, there are common clusters of symptoms that allows a clinical diagnosis.

Clinical Working Case Definition of ME/CFS

A patient with ME/CFS will meet the criteria for fatigue, post-exertional malaise and/or fatigue, sleep dysfunction, and pain; have two or more neurological/cognitive manifestations and one or more symptoms from two of the categories of autonomic, neuroendocrine and immune manifestations; and adhere to item 7.

1. **Fatigue:** The patient must have a significant degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level.
2. **Post-Exertional Malaise and/or Fatigue:** There is an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, post exertional malaise and/or fatigue and/or pain and a tendency for other associated symptoms within the patient's cluster of symptoms to worsen. There is a pathologically slow recovery period—usually 24 hours or longer.
3. **Sleep Dysfunction:*** There is unrefreshed sleep or sleep quantity or rhythm disturbances such as reversed or chaotic diurnal sleep rhythms.
4. **Pain:*** There is a significant degree of myalgia. Pain can be experienced in the muscles and/or joints, and is often widespread and migratory in nature. Often there are significant headaches of new type, pattern or severity.
5. **Neurological/Cognitive Manifestations:** Two or more of the following difficulties should be present: confusion, impairment of concentration and short-term memory consolidation, disorientation, difficulty with information processing, categorizing and word retrieval, and perceptual and sensory disturbances—e.g., spatial instability and disorientation and inability to focus vision. Ataxia, muscle weakness and fasciculations are common. There may be overload phenomena: cognitive, sensory—e.g., photophobia and hypersensitivity to noise—and/or emotional overload, which may lead to “crash” periods and/or anxiety.
6. **At Least One Symptom from Two of the Following Categories:**
 - a. **Autonomic Manifestations:** orthostatic intolerance—neurally mediated

hypotension (NMH), postural orthostatic tachycardia syndrome (POTS), delayed postural hypotension; light-headedness; extreme pallor; nausea and irritable bowel syndrome; urinary frequency and bladder dysfunction; palpitations with or without cardiac arrhythmias; exertional dyspnea.

b. Neuroendocrine Manifestations: loss of thermostatic stability—subnormal body temperature and marked diurnal fluctuation, sweating episodes, recurrent feelings of feverishness and cold extremities; intolerance of extremes of heat and cold; marked weight change—*anorexia* or abnormal appetite; loss of adaptability and worsening of symptoms with stress.

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

7. The illness persists for at least six months. It usually has a distinct onset,** although it may be gradual. Preliminary diagnosis may be possible earlier. Three months is appropriate for children.

To be included, the symptoms must have begun or have been significantly altered after the onset of this illness. It is unlikely that a patient will suffer from all symptoms in criteria 5 and 6. The disturbances tend to form symptom clusters that may fluctuate and change over time. Children often have numerous prominent symptoms but their order of severity tends to vary from day to day. *There is a small number of patients who have no pain or sleep dysfunction, but no other diagnosis fits except ME/CFS. A diagnosis of ME/CFS can be entertained when this group has an infectious illness type onset. **Some patients have been unhealthy for other reasons prior to the onset of ME/CFS and lack detectable triggers at onset and/or have more gradual or insidious onset.

Exclusions: Exclude active disease processes that explain most of the major symptoms of fatigue, sleep disturbance, pain, and cognitive dysfunction. It is essential to exclude certain diseases, which would be tragic to miss: Addison's disease, Cushing's Syndrome, hypothyroidism, hyperthyroidism, iron deficiency, other treatable forms of anemia, iron overload syndrome, diabetes mellitus, and cancer. It is also essential to exclude treatable sleep disorders such as upper airway resistance syndrome and obstructive or central sleep apnea; rheumatological disorders such as rheumatoid arthritis, lupus, polymyositis and polymyalgia rheumatica; immune disorders such as AIDS; neurological disorders such as multiple sclerosis (MS), Parkinsonism, myasthenia gravis and B12 deficiency; infectious diseases such as tuberculosis, chronic hepatitis, Lyme disease, etc.; primary psychiatric disorders and substance abuse. Exclusion of other diagnoses, which cannot be reasonably excluded by the patient's history and physical examination, is achieved by laboratory testing and imaging. If a potentially confounding medical condition is under control, then the diagnosis of ME/CFS can be entertained if patients meet the criteria otherwise.

Co-Morbid Entities: Fibromyalgia Syndrome (FMS), Myofascial Pain Syndrome (MPS), Temporomandibular Joint Syndrome (TMJ), Irritable Bowel Syndrome (IBS), Interstitial Cystitis, Irritable Bladder Syndrome, Raynaud's Phenomenon, Prolapsed Mitral Valve, Depression, Migraine, Allergies, Multiple Chemical Sensitivities (MCS), Hashimoto's thyroiditis, Sicca Syndrome, etc. Such co-morbid entities may occur in the setting of ME/CFS. Others such as IBS may precede the development of ME/CFS by many years, but then become associated with it. The same holds true for migraines and depression.

Their association is thus looser than between the symptoms within the syndrome. ME/CFS and FMS often closely connect and should be considered to be "overlap syndromes."

Idiopathic Chronic Fatigue: If the patient has unexplained prolonged fatigue (6 months or more) but has insufficient symptoms to meet the criteria for ME/CFS, it should be classified as idiopathic chronic fatigue.

Source: Haworth Press, Journal of Chronic Fatigue Syndrome, 2003.

The Fibromyalgia Syndrome:

A Clinical Case Definition for Practitioners

Editor: I. Jon Russell, MD, PhD

(extracted from the Journal of Musculoskeletal Pain, Volume 11, Number 4, The Haworth Medical Press)

1. Compulsory HISTORY of widespread pain. Pain is considered widespread when all of the following are present for at least three months:

- pain in both sides of the body
- pain above and below the waist [including low back pain]
- axial skeletal pain [cervical spine, anterior chest, thoracic spine or low back].

Shoulder and buttock involvement counts for either side of the body. "Low back" is lower segment.

2. Compulsory PAIN ON PALPATION at 11 or more of the 18 defined tender point sites.

- Occiput [2]—at the suboccipital muscle insertions
- Low cervical [2]—at the anterior aspects of the intertransverse spaces [the spaces between the transverse processes] at C5-C7
- Trapezius [2]—at the midpoint of the upper border
- Supraspinatus [2]—at origins, above the scapular spine near its medial border
- Second rib [2]—just lateral to the second costochondral junctions, on the upper rib surfaces
- Lateral epicondyle [2]—2 cm distal to the epicondyles [in the brachioradialis muscle]
- Gluteal [2]—in upper outer quadrants of buttocks in the anterior fold of muscle
- Greater trochanter [2]—posterior to the trochanteric prominence
- Knee [2]—at medial fat pad proximal to the joint line
- Validity. The two compulsory pain criteria were validated as classification criteria applicable to groups of subjects for the purpose of research study. In that setting, they yielded 88.4 percent sensitivity and 81.1 percent specificity for a research classification of FMS. They have not yet been validated for clinical diagnosis of symptomatic individuals in a medical care setting.

3. Additional clinical symptoms & signs. In addition to the compulsory pain and tenderness required for research classification of FMS, many additional clinical symptoms and signs can contribute importantly to the patients' burden of illness.

Two or more of these features are present in most FMS patients by the time they seek medical attention. On the other hand, it is uncommon for any individual FMS patient to have all of the associated symptoms or signs. As a result, the clinical presentation of FMS may vary somewhat, and the patterns of involvement may eventually lead to the recognition of FMS clinical subgroups. These additional clinical symptoms and signs are not required for the research classification of FMS but they are still clinically important. For these reasons, the following clinical symptoms and signs are itemized and described in an attempt to expand the compulsory pain criteria into a proposed Clinical Case Definition of FMS

- **Neurological manifestations:** Neurological difficulties are often present such as hypertonic and hypotonic muscles; musculoskeletal asymmetry and dysfunction involving muscles, ligaments and joints; atypical patterns of numbness and tingling; abnormal muscle twitch response, muscle cramps, muscle weakness, and fasciculations. Headaches, temporomandibular joint disorder, generalized weakness, perceptual disturbances, spatial instability, and sensory overload phenomena often occur.
- **Neurocognitive manifestations:** Neurocognitive difficulties usually are present. These include impaired concentration and short-term memory consolidation, impaired speed of performance, inability to multi-task, easy distractibility, and/or cognitive overload.
- **Fatigue:** There is persistent and reactive fatigue accompanied by reduced physical and mental stamina, which often interferes with the patient's ability to exercise.
- **Sleep dysfunction:** Most FMS patients experience unrefreshing sleep. This is usually accompanied by sleep disturbances including insomnia, frequent nocturnal awakening, nocturnal myoclonus, and/or restless leg syndrome.
- **Autonomic and/or neuroendocrine manifestations:** These manifestations include cardiac arrhythmias, neurally mediated hypotension, vertigo, vasomotor instability, sicca syndrome, temperature instability, heat/cold intolerance, respiratory disturbances, intestinal and bladder motility disturbances with or without irritable bowel or bladder dysfunction, dysmenorrhea, loss of adaptability and tolerance for stress, emotional flattening, lability, and/or reactive depression.
- **Stiffness:** Generalized or even regional stiffness that is most severe upon awakening and typically lasts for hours as occurs with active rheumatoid arthritis. It can return during periods of inactivity during the day.

B. Application of the Clinical Working Case Definition

In a clinical setting, the physician must apply the compulsory criteria for the classification of FMS but also appreciate the clinical spectrum of FMS manifestations and the range of distress it can cause. Thus, in addition to identifying FMS, using the two compulsory pain features, the clinician should assess the patient for other symptoms and signs that typically embody FMS, in order to establish the patient's total illness burden and to direct appropriate treatment for all of the manifestations in a timely fashion. The following diagram indicates the steps to be followed in each patient exhibiting distress associated with chronic productivity, and non-supportive family members or acquaintances.

4. Quantify the Severity of the Major Symptoms, and Their Impact on Lifestyle

An assessment of the severity of each major symptom, quantified on a symptom hierarchy/severity scale, and their impact on the patient's life is important in developing a treatment program and in assessing disability and prognosis. Compare the symptoms severity and impact to the patient's premorbid state of health and activity level.

Canadian Hospitals are offering more than Drugs Alone: Canada’s leading edge

Fm-CFS Canada has been searching for examples of hospitals offering a multidisciplinary approach to the treatment of FM & CFS/M.E. These eight centres have been identified, but more may exist.

St. Joseph's Care Group, Thunder Bay, Ontario
 St. Joseph’s, London, Ontario
 Southlake Regional Hospital, Newmarket, Ontario
 Royal Vic Hospital, Barrie, Ontario

Wasser Chronic Pain Clinic, Toronto
 XXXXXX Clinic, Calgary, Alberta
 XXXXXX Clinic, Edmonton, Alberta
 The XXXXX Centre, Vancouver, British Columbia

Four Ontario Hospitals Compared

(FM-CFS Canada & Carleton University initiative: 2003-4)

At the request of FM-CFS Canada, a graduate team at Carleton University conducted comparative research on four Ontario hospitals offering multidisciplinary programs for Fibromyalgia patients.

The research findings support the following recommendations:

- A holistic, biopsychosocial program model would best meet the needs of FM patients. This model should be designed on a philosophy of chronic pain self-management.
- A multidisciplinary team of highly trained professionals is a required element of service delivery.
- Follow-up should be in-person to reinforce the learning acquired during the program.

Hospital Comparison Tables:

The tables below provide program comparisons for four Ontario hospitals providing education.

4 ONTARIO HOSPITAL PROGRAM DESIGNS

	Hospital A	Hospital B	Hospital C	Hospital D
NUMBER OF GROUP MEETINGS	5 per week	5 per week	1 per week	5 per week
LENGTH OF THE MEETING	Full day	Full day	2.5 hours	5 hours
LENGTH OF THE GROUP SESSION	4 weeks	1 month	8 weeks	6 weeks
NUMBER OF PROGRAMS IN A YEAR	On-going	6	<ul style="list-style-type: none"> ▪ 5-6 per year ▪ 2 sessions per program 	8
AVERAGE NUMBER OF CLIENTS IN EACH GROUP	18	10	30	24

4 ONTARIO HOSPITALS' FM PROGRAM DELIVERY PERSONNEL

Hospital A	Hospital B	Hospital C	Hospital D
1. Occupational therapists 2. Physiotherapists 3. Nutritionists 4. Psychologists 5. Social workers 6. Pharmacists 7. Physician	1. Occupational therapist 2. Physiotherapist 3. Occupational therapy assistant 4. Physiotherapy assistant 5. Social worker 6. Secretary 7. Psychologist 8. Coordinator	1. Social work 2. Pharmacist 3. Physical therapist 4. Kinesiologist 5. Secretary	1. Social worker 2. Therapeutic recreationist 3. Psychometrist 4. Psychologist 5. Physiotherapist 6. Occupational therapist 7. Kinesiologist 8. Rehabilitation assistant 9. Clerical As needed service providers: 10. Nurse 11. Pharmacist 12. Pastoral care 13. Dietician 14. Community partners

4 ONTARIO HOSPITALS' FM EDUCATION TOPICS

Hospital A	Hospital B	Hospital C	Hospital D
1. Fitness 2. Functional activity 3. Nutrition 4. Swimming 5. Relaxation 6. Medication review 7. Vocation 8. Goals 9. Sexuality 10. pacing and energy conservation 11. back and body care 12. alternative sources of income 13. illness behaviour 14. self-talk 15. sleep 16. assertiveness 17. community resources 18. stress 19. relationships	1. cognitive 2. assertiveness 3. relaxation training 4. grief/loss 5. pain behaviour 6. theories of fibromyalgia 7. pacing 8. body mechanics 9. strengthening 10. family issues 11. cardiovascular	1. overview of FM 2. FM research 3. Exercise 4. Lifestyle 5. Medications 6. Posture 7. Cognition 8. Summary	1. Pacing 2. Relaxation 3. Leisure 4. Communication 5. Anger management 6. Posture and body mechanics 7. Anatomy 8. Exercise principles 9. Coping strategies 10. Family 11. Nutrition 12. Pharmacy 13. Employment 14. Community resources

Multidisciplinary Education Program, Program Administrator comments:

“People who go through the program are less emotionally distressed, take more appropriate medication, and return to work more.”

“Following the program, we receive positive evaluations concerning relationship, marriage, support and understanding within the family structure.”

“When people learn how to manage their own pain, their depression goes down 30%.”

FM-CFS Canada & a network of patient groups, in support of a new future:

National Groups

FM-CFS Canada

National ME/FM Action Network

British Columbia

ME/FM Society of BC (includes regional chapters)

M.E. Victoria Association

Penticton Association

Nelson FM Support Group

Alberta

The ME / FM Society of Alberta (Calgary) (includes regional chapters)

ME Society of Edmonton

FM Society of Edmonton

Cardston FM & M.E. Support

Lethbridge FM & M.E. Support

Medicine Hat F.A.C.E.S

Red Deer FM & M.E.

Saskatchewan

FM Association of Saskatchewan (includes 20 regional chapters)

Fibrohugs, Regina - online forums

Manitoba

Fibromyalgia Support Group of Winnipeg

Ontario

Fibromyalgia Society Ontario (includes regional chapters)

FM Association of Sault Ste. Marie & Algoma District

FM Association Niagara (includes regional chapters)

St. Catherines FM

Windsor FM/CFS/M.E.

Orangeville Fibromyalgia Support Group

Brampton FM Support Group

Toronto FM Support Group

Richmond Hill FM Support Group

Mississauga Fibromyalgia Support Group

Ontario - continued

Seaway M.E./FM Self Help Group

ME Association of Kingston
Brockville M.E. Association
Rockland FM/CFS/ME Support Group
Ottawa FM Support
M.E. Self Help (M.E.S.H.) Ottawa
FM Support Ottawa West
Franco-Fibro

Quebec

Association québécoise de l'encéphalomyélite myalgique
Fédération québécoise de fibromyalgie
Association de la fibromyalgie de l'Abitibi-Témiscamingue
Association de la fibromyalgie du Bas-Richelieu
Association de la fibromyalgie du Bas-Saint-Laurent
Association de la fibromyalgie des Bois-Francs
Association de la fibromyalgie de Duplessis
Association de la fibromyalgie région Île-de-Montréal
Association de la fibromyalgie des Laurentides
Association de la fibromyalgie région de Québec
Association de la fibromyalgie du Saguenay-Lac-Saint-Jean
Association québécoise de fibromyalgie
Association de la fibromyalgie de Manicouagan/Haute Côte-Nord
Association de la fibromyalgie Mauricie/Centre-du-Québec
Association de la fibromyalgie région de la Montérégie
Association de la fibromyalgie région Chaudière/Appalaches
Association de la fibromyalgie de Laval
Association de la fibromyalgie région de l'Estrie

Newfoundland and Labrador

FM St. John's
FM Cornerbrook

New Brunswick

Fredericton FM Support
Moncton support group
Greater St. John Fibromyalgia Group

Prince Edward Island

Charlottetown Fibromyalgia Group
Nova Scotia
Nova Scotia FM Support Group