



EASING THE ECONOMIC AND SOCIAL BURDEN OF A CHRONIC CONDITION

ADDRESSING THE M.E./CFS EPIDEMIC

Recommendations to the Federal Minister of Health

**The Myalgic Encephalomyelitis Association of Ontario
2/27/2008**





What is M.E./CFS?

M.E. is an abbreviation of the medical term Myalgic Encephalomyelitis. M.E. is also known as Chronic Fatigue Syndrome. This is a complex multi-system neurological condition that has eluded easy answers for those who live with its disabling effects, for their families who struggle to understand it and for health care professionals who wish to understand and treat it.

We will refer to myalgic encephalomyelitis or “M.E./CFS” rather than “CFS” or “Chronic Fatigue Syndrome” as myalgic encephalomyelitis is the medical term recognized by the World Health Organization (ICD 10 G93.3) as a neurological disease in the International Classification of Diseases (ICD). Chronic Fatigue Syndrome is included in that definition. As well, the term is still used in many research studies internationally and therefore it has not been dropped entirely from our organization’s vocabulary. It is important however to highlight that the fatigue related to M.E./CFS is a pathophysiological exhaustion and is only one of many symptoms required for diagnosis. M.E./CFS is a distinct, biological, clinical disorder.

Fatigue - new onset, unexplained, persistent mental and physical fatigue. Fatigue that substantially reduces activity.

Post-exertional Malaise or Fatigue - after physical or mental exertion there is an abnormally slow recovery time of at least 24 hours.

Sleep Dysfunction*- sleep is unrefreshing and patients wake up tired even after sleeping for 10 - 12 hours.

Pain - in muscles and joints*. Often significant headaches of new type, pattern or severity.'

Brain Function Problems - At least one symptom in two categories: automatic (autonomic) functioning, hormonal (neuroendocrine) functioning and immune system functioning.

The Illness has been present at least six months in adults and 3 months in children; onset of the illness is usually sudden, but can be gradual.**

* In a small percentage of patients, there is no pain or sleep dysfunction, but no other diagnosis fits, except CFS/M.E. CFS/M.E. can be diagnosed when this group has an infectious illness type onset.

** Some people have been unhealthy for other reasons prior to the onset of CFS/M.E. and lack detectable triggers at onset and have a more gradual onset of the illness.



Myalgic encephalomyelitis is a complex medical and public health problem that is associated with:

- severe personal suffering and loss
- economic loss
- social loss
- familial loss
- as well as loss of health and ability.

According to researchers in the United States:

- the median duration of the illness is 7 years,
- a quarter of those with the illness are unemployed or receiving disability,
- and the average affected family forgoes approximately \$20,000 (USD) in annual earnings and wages.

Despite more than 4,000 articles in the peer-reviewed medical literature, the exact pathophysiology of M.E./CFS is not well understood. There are no diagnostic laboratory abnormalities or clinical tests. There is currently no public health control or prevention strategy for M.E./CFS.¹

“We know that CFS has identifiable biologic underpinnings because we have research documenting a number of underlying pathophysiological processes, involving the brain, the immune system, the neuroendocrine system and the autonomic nervous system”

Professor Nancy Klimas
University of Miami Medical School in “The State
of CFS Research”

¹ Reeves WC, Jones JF, Maloney E, Heim C, Hoaglin DC, Boneva1 RS, Morrissey M, Devlin R: Prevalence of chronic fatigue syndrome in metropolitan, urban, and rural Georgia. *Population Metrics* 2007, 5:5



How prevalent is M.E./CFS?

“CFS is a serious problem of epidemic proportions.” (CDC)

Estimates of the prevalence of M.E./CFS vary considerably around the world depending on the definition used and the population studied and point to the need for further research in this area.

- A recent study from the Netherlands estimated the prevalence of what they termed “CFS-like caseness” in the working population to be 3.6%².
- The Centers for Disease Control in Atlanta, Georgia have determined that 2.54% of adults and 0.7% of children have M.E./CFS in the United States.³
- Similar prevalence rates have been found in people of different socio-economic status and in all ethnic groups⁴.
- Women seem to be at higher risk than men of developing the illness with a relative risk of 1.3–1.7, depending on the diagnostic criteria used⁵.
- Although the illness can affect any age group, including children, it commonly presents in those aged 30 to 55 and therefore at a time of life they have the greatest earning potential.⁶

CDC Rates Converted to Canadian Population Figures

2.54% of adults =
Approx. 1 in 40 adults

0.7% of children =
Approx. 1 in 140 children

² Huibers MJH, Kant IJ, Swaen GMH, Kasl SV. Prevalence of chronic fatigue syndrome-like caseness in the working population: results from the Maastricht cohort study.

Occupational and Environmental Medicine 2004, **61**(5):464–466.

³ Reeves et al, *Population Metrics* 2007

⁴ Lawrie SM, Manders DN, Geddes JR, Pelosi AJ. A population-based incidence study of chronic fatigue. *Psychological Medicine* 1997, **25**:895–905.

⁵ Wessely S. The epidemiology of chronic fatigue syndrome. *Epidemiologic Reviews* 1995;**17**(1)139–151.

⁶ White, Peter D. How common is chronic fatigue syndrome; how long is a piece of string? *Population Health Metrics* 2007, 5:6



Statistics for Canada from the Canadian Community Health Survey (CCHS) show 5% of Canadians aged twelve and over (or an estimated 1.2 million) reported being diagnosed with what are labeled Medically Unexplained Physical Symptoms or (MUPS), including M.E./CFS, Fibromyalgia and Multiple Chemical Sensitivities.

From the results of the CCHS, the prevalence rate of M.E./CFS was estimated by Statistics Canada to be approximately 1.3% or 341,000.⁷ As this survey was based on self-identification, we believe that further study is needed to validate these results. In addition, this figure does not include children under the age of 12 with the condition and those who were not yet diagnosed.

How does M.E./CFS compare to other chronic illnesses?

M.E./CFS is one of the most common illnesses in North America and yet few people are aware of how widespread it is and how devastating an impact it has on Canadian families and society.

M.E./CFS is:

- More than 4 times more common than Parkinson's
- Almost 8 times more common than HIV/AIDS
- More than 12 times more common than Breast Cancer
- The number of Canadians living with M.E./CFS is approximately the same as the number of stroke survivors

⁷ Park J, Knudson S. Medically unexplained physical symptoms. Health Reports, Vol. 18, No. 1, February 2007 Statistics Canada, Catalogue 82-003. Also accessible at: <http://www.statcan.ca/Daily/English/070112/d070112b.htm>



How much does it cost Canadians?

While no Canadian based studies have been done on the costs to the economy and productivity in Canada, studies in other parts of the world have shown a significant economic cost:

- A UK study of M.E./CFS in primary care has shown that there are substantial economic costs on society, mainly in the form of informal care (care provided by friends and family) and lost employment⁸.
- A study from the United States estimated a 37% decline in household productivity and a 54% reduction in labour force productivity among people with the illness.
- The estimated annual total value of lost productivity in the United States was approximately \$20,000 USD per person with the illness.⁹
- If we were to use the United States estimates as a base to loosely estimate the costs in Canada there are approximately 341,000 Canadian adults with the illness which at \$20,000 CAD would equal \$6.82 billion. That is a significant cost to our economy and is likely understated.

Approximately 341,000 Canadian adults with the illness at \$20,000 CAD per person in lost productivity would equal a \$6.82 Billion cost to our economy.

⁸ McCrone P, Darbishire L, Ridsdale L, Seed P. The economic cost of chronic fatigue and chronic fatigue syndrome in UK primary care. *Psychological Medicine* 2003, **33**(2):253–261.

⁹ Reynolds KJ, Vernon SD, Bouchery E, Reeves WC. The economic impact of chronic fatigue syndrome. *Cost Effectiveness and Resource Allocation* 2004, **2**:4.

RECOMMENDATIONS

"We've documented, as have others, that the level of impairment in people who suffer from CFS is comparable to multiple sclerosis, AIDS, end-stage renal failure, chronic obstructive pulmonary disease.

The disability is equivalent to that of some well-known, very severe medical conditions."

Dr. William Reeves
(Chief of Chronic Viral Diseases Branch- CDC)

A National M.E./CFS Strategy

First and foremost we believe that the only efficient and effective way to implement all of the recommendations described below is to do so under the auspices of a National M.E./CFS Strategy. M.E./CFS is a very complex and multi-faceted neurological condition and as such it will require multi-faceted approaches to address it. Individuals with M.E./CFS and their families must be included in the consultation process to develop the Strategy and play a role within the Strategy itself. The strategy must receive adequate ongoing funding in order to be effective, and it should strive to achieve consistency across the country in terms of information dissemination, assessment, treatments and supports.

Therefore, we recommend that:

The federal government, in collaboration with the provinces and territories, establish a comprehensive National M.E./CFS Strategy to address elements including treatment, research, surveillance, awareness campaigns, community initiatives, education, home care and social services;

All stakeholders, including individuals living with M.E./CFS and their families, be consulted on the components that should be part of the Strategy; and,

The Strategy should include both youth and adult treatments and supports as the two populations are different and cannot be treated in exactly the same manner.



While we acknowledge that this would be a significant undertaking by the federal government that cannot occur overnight, there are a number of urgent initiatives that the federal government could, and should, implement over the next two years which would have an immediate impact on the challenges faced by adults and children living with M.E./CFS as well as their families. These initiatives will reduce the stresses for those affected by the illness as well as increase our knowledge base for this debilitating disability.

Access to Treatment

Access to treatment for myalgic encephalomyelitis is problematic for a number of reasons.

- There are few clinicians who have experience treating such a complex and multi-system condition with multiple co-morbidities.
- Other proven interventions are not exclusively “health services” but include a wide range of psychological, social and nutritional services.
- There is the jurisdictional aspect to consider in the funding and provision of services.

While we agree that provinces and territories have jurisdiction over the provision of health care systems (either through the health, education, social and community service sectors), the federal government has the ability to finance treatment models through its spending power.

Treatment and rehabilitation requires the participation of a multidisciplinary team. For example, medical practitioners, psychologists, social workers, nutritionists, naturopathic doctors, occupational therapists and special education providers all have a vital role to play in the recovery of an individual with M.E./CFS.

“Early intervention is important because learning to manage symptoms can dramatically improve quality of life,”

Dr. Eleanor Stein, Calgary



Due to the shortage of trained health care providers in many jurisdictions, immediate additional funds will not be helpful if there is no one to provide the treatment. Because of this, there must be sustained capacity-building to attract, train and retain specially trained doctors and other health care professionals, such as, but not limited to, psychologists, nutritionists, occupational therapists and special educators.

Education of family physicians is also vital in ensuring early detection of myalgic encephalomyelitis. Currently, family physicians are not adequately trained about M.E./CFS and available treatment options.

We fully acknowledge that the provision of health care, education and social services, including those relevant to M.E./CFS, are provincial/territorial responsibilities with federal funds being provided for these in the forms of the Canada Health Transfer and the Canada Social Transfer. Although federal funds make up a substantial portion of the budgets in these areas, the provinces and territories have the sole authority to decide how the money is spent.

In spite of this there are actions the federal government can take which will assist with treatment. Therefore we make the following additional recommendations:

Knowledge Exchange Centre

Even though one in 80 adults in Canada will have myalgic encephalomyelitis, most Canadians, including many health professionals, do not understand what the condition is. In the early years of research into the condition, the more common term was “Chronic Fatigue Syndrome” which received an inaccurate and unfair moniker from the media of “The Yuppie Flu”.

In 2006, the Centers for Disease Control in the United States saw that an awareness campaign was needed in order to enhance public understanding of M.E./CFS. Lack of understanding also extends to professionals who would benefit from ongoing education to ensure that adults and children are not mislabelled and improperly assessed.

- There is currently no dedicated, medically-based, central source of information on M.E./CFS and treatment options.
- A vast body of information exists but it is not being made readily available in terms that are clear and concise and that the general public can appreciate.
- There is a mix of inaccurate information as well as considerable accurate information with no way for individuals to distinguish between them.



As such, there is a need for:

- a centralized, unbiased and credible source for information,
- and a need for knowledge exchange and for effective communication of research findings.

Towards that end, a dedicated Health Canada page on its website to guide the public to M.E./CFS information available through the Canadian Health Network and other resources is crucial.

Given the contrasting views and opinions about treatment options and the introduction of unproven therapies in the private sector, it will be crucial for the department to consult all interested parties to ensure that information is presented in an unbiased fashion.

There is a great need to consolidate areas of education, clinical expertise and research endeavours to enhance and facilitate collaborative efforts.

There is an immediate need for a clearinghouse of “best practices” (including international experiences) which would allow each province or territory to develop or enhance its own provision of services.

It would also serve as the means to provide individuals with M.E./CFS and their families with an unbiased source of accurate information including current research findings.

Individuals and families affected by M.E./CFS are already under considerable stress and it is unfair to make them spend their precious resources and what little time they have wondering what to do, where to go for help, what help to get, whom to trust and whom to believe.

A focal point for M.E./CFS information, provided by a trusted source, would save individuals from navigating the current confusing and unreliable maze and could sort out the accurate from inaccurate information.

As a corollary, there is a need to provide the centralized infrastructure for the dissemination of information that is helpful, accurate and supportive and to put scientific findings into plain language. A teaching hospital setting, in our view, is the most appropriate as it is often seen as unbiased and trustworthy.



Thus, we recommend that:

The federal government provide funding for the creation of a M.E./CFS Knowledge Exchange Centre;

The Centre should include an Internet-based web portal for access to reliable data and credible links for those seeking M.E./CFS information, with a section targeted at health care professionals and another targeted with plain language at the general public;

The Centre should, working with the CMA and provincial/territorial medical/professionals associations, ensure the wide dissemination of the ***Canadian Clinical Working Case Definition, Diagnostic and Treatment Protocols***¹⁰.

The Centre be at arm's length to government; and,

The Centre should be mandated with the dissemination of best practices based on authoritative research and scientific consensus.

Public Awareness Campaign

There is a general lack of understanding among Canadians about M.E./CFS and its spectrum of disabilities and co-morbidities.

A greater understanding of M.E./CFS by all Canadians could help to reduce the stress experienced by these individuals and their families.

The general population should be made aware of the associated early signs and symptoms in order that both adults and children might pursue assessment at the earliest possible stage.

Such a campaign could also serve as a tool to promote the Knowledge Exchange Centre (discussed above).

¹⁰ Carruthers et al. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols. *Journal of Chronic Fatigue Syndrome*, Vol. 11 (1) 2003, pp. 7-116



We therefore recommend that:

Health Canada, in consultation with individuals living with M.E./CFS and other stakeholders, implement a national public awareness campaign similar to the CDC campaign to enhance knowledge and understanding about M.E./CFS; and,

Health Canada create a dedicated webpage as one component of a public awareness campaign.

“This is real It’s more than being tired. It comes in and it completely destroys your life. Some days I wished I was dying so that I’d know there was an end to this.”

Sarah Lacy, diagnosed with the condition at the age of 12.



Need for Research

Research has a vital role to play in the provision of reliable information. A search of the CIHR website found reference to only one research study on M.E./CFS being funded for a total of less than \$300,000.¹¹

M.E./CFS research is not an area that lends itself to industry investment as most current treatments are not pharmacological in nature. Private donations to support health research are not sufficiently stable from one year to the next and have not been significant enough to fund any large multi-centred studies in Canada. Therefore, funding by the federal government in a substantial and on-going manner is imperative.

Research funding is greatly needed in areas such as:

- the incidence,
- causes,
- effective screening tools,
- and treatment development including:
 - pharmacological,
 - psychological and
 - psychosocial interventions.

The National Institutes of Health (NIH) in the United States “recognize CFS as a multi-systemic illness that requires a thorough interdisciplinary approach encompassing the scientific missions of many of the NIH institutes and centers”.

The Canadian Institutes of Health Research (CIHR) are currently set up in 13 different institutes, each dealing with ‘important health problems such as “Infection and Immunity”, “Genetics” or “Musculoskeletal Health and Arthritis”.

¹¹ LIBMAN, Eva. Chronic fatigue syndrome and sleep disorder. *Sir Mortimer B. Davis Jewish General Hospital Montreal*. Search of CIHR website with search terms “Chronic Fatigue Syndrome” and “Myalgic Encephalomyelitis” Accessed February 12, 2008 (www.cihr-irsc.gc.ca)

While these, without question, are important areas, M.E./CFS is applicable to these and other CIHR Institutes.

M.E./CFS ends up being an “orphaned illness” without any research focus and very little funding.

The National Institutes of Health in the US “*recognize CFS as a multi-systemic illness that requires a thorough interdisciplinary approach encompassing the scientific missions of many of the NIH institutes and centers*”.

In order to deal with this a Trans-NIH Working Group for Research on Chronic Fatigue Syndrome has been established which is convened monthly in an effort to have all of the different institutes in the National Institutes of Health contribute to the research that is ongoing and needs to continue.

There is a great need for research in Canada to:

- include multidisciplinary research teams;
- include programs that train medical clinicians in M.E./CFS treatment;
- provide the long-term, randomized, controlled trials required to properly measure treatment effectiveness;
- facilitate collaboration;
- include public policy research;
- and consult with individuals living with M.E./CFS and their families in identifying priorities.

As such, we recommend that:

The federal government create a M.E./CFS Research Network and provide substantial new funding for this through CIHR; and,

The M.E./CFS Research Network work collaboratively with all stakeholders, including individuals with M.E./CFS and their families, to develop a research agenda.

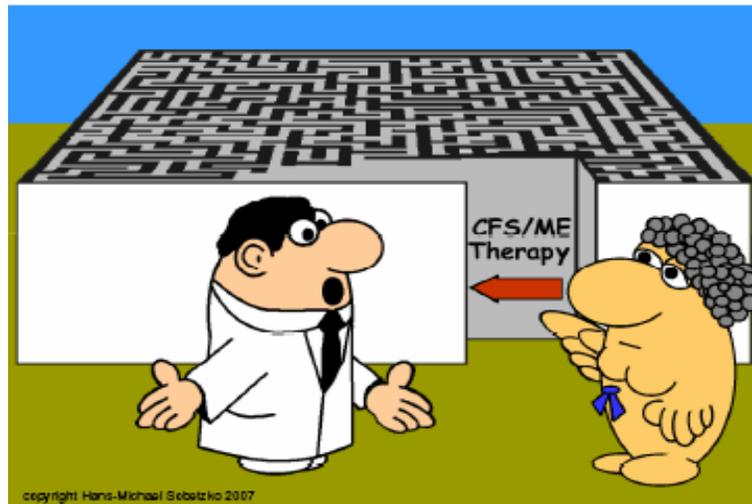
Human Resources Initiative

Medical practitioners need to be better trained to identify the signs and symptoms of M.E./CFS. The need for a multi-disciplinary approach to M.E./CFS assessment, diagnosis, treatment, training, education and research cannot be overstated. More must be done to increase the number of physicians trained in M.E./CFS diagnosis and treatment. Much must be done to encourage recruitment, and to optimize retention of these individuals, including perhaps improved remuneration.

The shortage of human resources is of paramount concern in the context of diagnosing and treating those with this illness.

While respecting the jurisdictional constraints in this area, we recommend that the federal government:

work collaboratively with the provinces and territories to address the human resource issues including recruitment and training of physicians in the field of M.E./CFS



Okay, it is a little complicated.
But right now, it's the best we can do!



Consulting with All Stakeholders

M.E./CFS is a very complex and disabling chronic illness that cannot be efficiently and effectively resolved without extensive consultation with all stakeholders.

As new research from the international community is published, the diversity of opinions about the causes of M.E./CFS, the effectiveness of treatments and interventions, etc., requires considerable consensus building in order to identify priorities and achieve common goals.

In 2003 a great milestone in consensus building was achieved in Canada with the publication of the Canadian Clinical Working Case Definition, Diagnostic and Treatment Protocols¹².

However, progress and knowledge translation can be achieved only through ongoing consultations with all interested parties. In particular, the perspective of individuals living with M.E./CFS needs to be included.

Therefore, we recommend that:

Health Canada sponsor a M.E./CFS stakeholder symposium in 2009 to encourage the development and sharing of M.E./CFS knowledge among health care professionals, researchers, community groups, teachers, individuals and families;

Health Canada must invite individuals living with M.E./CFS and their families to attend the symposium and be given the opportunity to contribute as equal partners in an exchange with other participants;

Health Canada must ensure that the symposium is conducted with a clear set of goals and defined outcomes and is based on consensus building; and that

Further such symposia be undertaken on a regular basis in keeping with the goals of the proposed National M.E./CFS Strategy.

¹² Carruthers et al. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols. *Journal of Chronic Fatigue Syndrome*, Vol. 11 (1) 2003, pp. 7-116



Conclusion

- Myalgic encephalomyelitis is a neurological condition affects a significant proportion of the population at a time in their lives when they have the greatest earning potential (30-55). M.E./CFS costs the Canadian economy billions of dollars each year.
- There is a great lack of understanding both in the medical community and in the general public about the symptoms, effects of and treatments for myalgic encephalomyelitis. There is also a lack of research in Canada on the prevalence, causes and effective treatments for myalgic encephalomyelitis.
- In addition, there is a desperate need for more trained health care professionals who are able to efficiently and effectively treat individuals living with M.E./CFS
- Myalgic encephalomyelitis affects one in 80 Canadian adults yet receives little to no funding to study and treat this illness.
- Myalgic encephalomyelitis has become a serious health problem in this country with a system not equipped to diagnose, treat and manage this illness that disables hundreds of thousands of working-age Canadians.
- The burden on the economy and our health care system is as heavy as the personal burden on individuals and families affected by M.E./CFS

We recommend that:

- The federal government, in collaboration with the provinces and territories, establish a comprehensive National M.E./CFS Strategy which will study and address issues such as treatment, research, surveillance, awareness campaigns, community initiatives, education, home care and social services.
- The federal government provide funding for the creation of a M.E./CFS Knowledge Exchange Centre to address the knowledge-gap among health care professionals, provide individuals and their families with credible information on services and treatments and increase general knowledge about the symptoms and effects of this disabling illness.
- Health Canada implement a national public awareness campaign similar to the CDC campaign to enhance knowledge and understanding about M.E./CFS
- The federal government create a M.E./CFS Research Network and provide substantial new funding for this through CIHR to discover the prevalence, causes and identify the best treatment mechanisms for this complex disabling condition.



- The federal government work collaboratively with the provinces and territories to address the human resource issues including recruitment and training of physicians in the field of M.E./CFS
- And Health Canada immediately begin work to sponsor a M.E./CFS stakeholder symposium in 2009 to encourage the development and sharing of M.E./CFS knowledge among health care professionals, researchers, community groups, teachers, individuals and families.