



CareNow Ontario is an organization representing and supporting the medical conditions of **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)**, **Fibromyalgia (FM)** and **Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS)**

CareNow ONTARIO: OUR VISION AND CALL TO ACTION

For a 3-Tiered system of care for people in Ontario with Myalgic Encephalomyelitis (ME), Multiple Chemical Sensitivities (MCS) and Fibromyalgia (FM)

Over 1 million people in Ontario are living with Myalgic Encephalomyelitis (ME), Multiple Chemical Sensitivities (MCS) and Fibromyalgia (FM). And this number is growing.

These are life altering and disabling conditions, yet there is no care in our public health care system in Ontario for people living with these chronic complex and environmentally linked conditions. Despite international research and exemplary clinics around the world, Ontario has no standards, no clinical pathways, only a small handful of doctors who understand these conditions, no medical schools that teach, let alone specialize in these conditions, and no systematic research.

Since 2013, the Government of Ontario has had the blueprint for a system that would address these deficits – and more - in its hands. It simply needs to move forward to implementation.

Calls to Action to the Government of Ontario:

1. To implement and fund the recommendations in the Business case for an Ontario Centre of Excellence developed in 2013 and validated by the Minister’s Task force on Environmental Health in 2018, including a system of care comprising:
 - Tier One: Centre of Excellence in Toronto, with specialist status
 - Tier Two: Regional, MCS safe clinics across the province
 - Tier Three: Local, specifically trained primary care providers.
2. Immediately release **Laying the Groundwork**, an action plan to implement the recommendations in the Business case and the Task Force on Environmental Health final report, developed by Dr Brian Schwartz, former Vice President Public Health Ontario in 2021.

Chronic, complex, debilitating, disabling.
“My wife’s symptoms include ... ‘post-exertional malaise.’ Malaise is not really a good description. She says it’s more like having the flu and PMS at the same time, and it’s pretty miserable. She has ... a lot of sensitivity to noise, so she wears ear plugs a good deal of the time; she can’t have music on. She is very sensitive to light, so she wears a visor even in the house to keep some of the bright lights off her eyes. She still has her irritable bowel and various gut upsets, although it’s not as painful as it was. She has some cognitive dysfunction – sometimes trouble finding words, but also, any time that there’s mental multi-processing going

3. Immediately fund the development of case definitions and clinical guidelines for best practices and clinical pathways by expert physicians; and fund development of clinical curriculum and require Ontario universities to incorporate this along with research projects into medical schools and public health schools.

See backgrounder below for more information.

For more detailed information about the stages and the reports of the most recent 13-year process to obtain care and support for MCS, ME and related fibromyalgia at <https://recognitioninclusionandequity.org/>.

For questions and information about:

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- Multiple Chemical Sensitivities - Varda Burstyn, varda.burstyn@paradigmconsultants.ca

**Nobody can see what is‘
happening in my body**

“When I am exposed to perfumes and other chemicals ... nobody can see what is happening in my body, they don’t understand. So, my body is burning. My eyes are burning. My throat is burning. I think I am going to throw up. I get migraines. I get shaky and then those other symptoms that I describe, I am also dealing with as well. It is kind of like a package deal that feels like every system in your body is going into hyper-drive and you don’t feel a sense of control of your body and of your life.”

Hope, individual living with Multiple Chemical Sensitivities

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BACKGROUND:

The scope of the problem:

Today, as the provincial government promises imminent plans to address the recent victims of Long COVID, it still refuses to act to assist equally sick people with similar and co-occurring conditions who have been needing and working to obtain care for decades. We completely support the need to take comprehensive action on Long COVID but consider the continued exclusion of our communities to be a grotesque violation of health care universality and social justice, especially when they have so much in common.

The Ontario Task Force in Environmental Health found that of the nearly 900,000 people in Ontario who had one or more of MCS, ME and FM at that time, roughly 80 per cent reported two or three simultaneously (2016 Canadian Community Health Survey). These figures are very conservative as many people go undiagnosed. They also do not include chronic Lyme disease, mold, mycotoxin and sick building illness and other frequently underlying or co-occurring conditions.

According to the 2020 CCHS report, the number of people living with MCS in Ontario comprised the largest group of patients among these conditions. It also demonstrated that their numbers had increased from 2.1% to 3.5% of the population between 2005 to 2020. Today, a significant number of people are living with ME-like Long COVID as well. This is a major silent epidemic that keeps on getting worse, while the government refuses to implement previously promised action.

15% of adults in Canada who have had suspected or confirmed COVID have symptoms beyond 3 months (i.e., long COVID).¹ A significant subset of these people – numbers yet to be determined, but some estimates suggest as much as 50% of the total – now have the long-term disabling symptoms of ME, the hallmarks of which are post-external malaise (PEM) and multi-system impacts. So, an important number of Long COVID sufferers are effectively swelling the numbers of those with ME. For this compelling reason, proposed plans for research into Long COVID must also include ME.

The Vision and its Blueprint

CareNow Ontario, formerly The Myalgic Encephalomyelitis Association of Ontario (MEAO), has been advocating for a system of care with a focus on health needs, disability rights, social service supports and research for people living in Ontario with Myalgic Encephalomyelitis (ME), Multiple Chemical Sensitivities (MCS) and Fibromyalgia (FM) since 2010.

The blueprint for this system, and supporting research documents, emerged from a two-year study process (2012-2013) funded by the Ministry of Health and the Ontario Trillium Foundation to develop a business case for an Ontario Centre of Excellence in Environmental Health. Patient experts from the ME and MCS communities played a leading role in that study, along with health economists, experts physicians, and senior health administrators. Its core recommendations for the 3-tiered system were reaffirmed in the final report of the Ontario Ministry's Task Force on Environmental Health (2016-2018).

And still no action.

¹ <https://www150.statcan.gc.ca/n1/daily-quotidien/221017/dq221017b-eng.htm>

Today, we urgently call for significant funding to develop this three-tiered system of care, embedded within our health care system, to meet the needs of hundreds of thousands of people in Ontario who desperately need care and support to provide for their health, disability and social support needs.

The three key components of the proposed system are:

TIER 1: A TORONTO-BASED CENTRE OF EXCELLENCE WITH SPECIALIST STATUS.

- A hospital and university affiliated, medically independent centre.
- Led by recognized experts with strong track records of clinical care in the conditions served.
- Provides advanced clinical care for the sickest patients; develops education curriculum for medical schools, hospitals, post-grad studies and on-site training programs; acts as a referral centre for other physicians in the province, and develops ongoing policy to ensure capability is present for our people along the entire continuum of care, from primary care to end of life, in the broader health care system.
- Creates a research agenda – clinical, epidemiological, and basic – and works with the partners best suited to this research.
- Provides a chemically-safe space for MCS patients.

TIER 2: REGIONAL, MCS-SAFE CLINICS ACROSS THE PROVINCE.

- Between 6-10 regional centres where specially trained primary care physicians work in a chemically and COVID safe spaces to deliver front-line, hands on care to our groups, much closer to home.
- State-of-the-art diagnostic services, treatment plan development, treatment procedures (e.g., IV infusions, sauna deuration), informed prescribing
- Key health professional services (e.g. physiotherapy, chiropractic, acupuncture, counselling or psychotherapy) to be provided in a safe space.
- Referral sources and supports to local health care agencies, such as hospitals, home care, long-term care and individual family physicians.

TIER 3: INDIVIDUAL, LOCALLY DESIGNATED, PRIMARY CARE PROVIDERS, SPECIALLY TRAINED.

- Every community needs a minimum of primary care providers (PCPs) who are “condition-literate” and can identify, diagnose and, where knowledge, resources and safe sites are present, treat the three conditions.
- These PCPs can liaise with the nearest regional clinic and/or Toronto centre for more advanced assistance and referral.

This is the vision outlined in the 2013 Business Case for an Ontario Centre of Excellence in Environmental Health. The Business Case remains the blueprint for our Call to Action. It is the standard by which all subsequent reports by the Ministry of Health are reviewed. Ensuring strong voices of patients and expert clinicians in the process remains critical.

In 2016, the then Minister of Health Minister Eric Hoskin established the Task Force on Environmental Health and released its final report in 2018. **The Care Now: An Action Plan to Improve Care for People with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/ Multiple Chemical Sensitivity (ES/MCS)** report validated the recommendations in the Business Case.

CareNow Ontario and other advocates began again to press to get action on the implementation of the best recommendations that were made in both the first study phase (OCEEH business case, 2013) and the final task force report (2018).

In 2020, then Minister of Health, Minister Christine Elliott appointed Dr Brian Schwartz, Vice President Public Health Ontario to develop an Action Plan to implement the recommendation in the Task Force report. This report **Laying the Groundwork** was submitted to the Minister of Health in the summer of 2021. Since that time, CareNow Ontario (formerly MEAO) has received no response to countless requests for updates and release of the report. No action has been taken.

Appendix A: Business Case and supporting documents:

The business case and its three supporting research reports (2012-13)

Find all documents at: <http://recognitioninclusionandequity.org/resources/>.

- **Recognition, Inclusion and Equity: Solutions for of Ontarians with ES/MCS, ME/CFS and FM – The Business Case Proposal** (Steering Committee of the OCEEH Business Case Project, 2013) was the sequenced, budgeted, costed plan that was developed from the three research documents written to inform the best design. It made recommendations on the required programs, professionals, dedicated housing personnel, special safe-building specifications, education, training and public awareness programs – all as relevant today as they were nine years ago.
- **Recognition Inclusion and Equity – The Time is Now: Perspectives of Ontarians Living with Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS), Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM).** 2013. Major research report addressing current state (survey of patients' experience, needs, gaps in services); special analysis of women's, children's, stigmatization issues; in-depth exploration of proposed model of care and delivery system; in-depth discussion of issues in barrier removal (disability issues) across government and the public sector, providing detailed explanation for the design of the components specified in the business case.
- **Chronic, Complex Conditions: Academic and Clinical Perspectives** (Molot, 2013), comprised of a literature scan, descriptions and definitions, and a proposed approach to the clinical framework of best and promising practices in a research framework for new clinical programs. This report explained and affirmed the biophysical approach and rejected the psychogenic approach and built from this foundation.
- **The Quantitative Data**, Erika Halapy, Epidemiologist, with Margaret Parlor, Statistical Analyst and President, ME/FM National Action Network, 2013. Submitted to support this business case, a first-ever compilation and analysis of statistical findings in Canada and Ontario with respect to our three groups.

Government Responses (2014-18): More study and the striking of another task force.

- **Time for Leadership: Recognizing and Improving Care**, Task force Phase 1 Interim Report July 2017 https://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2017/default.aspx
- **Care Now: An Action Plan to Improve Care for People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS)**, Final report of Task force, December 2018. https://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2018/default.aspx