NATIONAL ME/FM ACTION NETWORK
SINCE 1993

Quest Newsletter



www.mefmaction.com | Quest 150, Fall 2026 | mefminfo@mefmaction.com

Introduction

To address the situation facing Canadians with ME and FM, the federal, provincial and territorial governments all need to be involved. The first section of this newsletter discusses what provinces need to do. We draw on work done by CareNow Ontario, (formerly The Myalgic Encephalomyelitis Association of Ontario), which is the Ontario association for ME, FM and MCS.

In the second section of this newsletter, we highlight four reports looking at the Canadian health system generally. The first is a news bulletin which notes that the federal-provincial agreement on health-system funding is coming up for renewal and looks at what is at stake. The next one shows results from a recent public opinion survey on health care in Canada. The third is an economic report looking at the costs of a problematic health care system. And the fourth is a 2024 study predicting demands on the Ontario health care system in 2040.

In the third section, we look at recent work from other countries that touch on ME/FM issues – a US book on the role of diagnosis, an opinion piece from the UK that looks at the hierarchy of illnesses, a study from Germany that looks at the economic costs of ME and Long Covid, a US study that suggests that the US could have been seriously underestimating the prevalence of ME, and recent reports from Austria and from an international ME forum which provide guidance on dealing with people with severe ME.

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Moving ME and FM Forward Provincially

In Quest 149, we looked at what governments in Canada need to do to provide better services for people with ME and/or FM. The short answer is that they need to stop avoiding the topic and start taking concrete steps..

What do the provinces need to do? CareNow Ontario has put a lot of work into articulating the actions that provinces need to take.

CareNow Ontario started in 1992 under the name of The Myalgic Encephalomyelitis Association of Ontario. In the early years, MEAO worked to reach out to patients but also to government with a focus on the health and education systems.

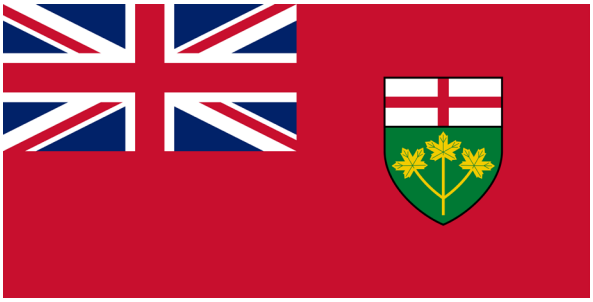
Around 2010, MEAO decided to write a business case explaining why Ontario should develop a centre of excellence in environmental health covering ME, Fibromyalgia and Environmental Sensitivities/Multiple Chemical Sensitivities (MCS). That progressed to a Task Force which made recommendations on what was needed, then to another report suggesting how to implement those recommendations. One recommendation from the latest report has moved forward but not completely, while the rest have not.

The Ontario Business Case

Around 2010, MEAO received funding to develop a business case for addressing ME, FM and MCS issues. This led to a set of reports in 2013 outlining what was needed and how it could be implemented. These reports can be found at *https://recognitioninclusionandequity.org/resources/* .

The business case report put together a list of health and social services that would be needed to serve the ME/FM/MCS community. See the box on page 4. This shows the breadth of issues that people with ME, FM and MCS face in the health system and beyond.

The Ontario Task Force Report



In 2016, the (Liberal) Minister of Health appointed a Task Force to pursue these ideas. It included patient representatives, health professionals and Ontario government officials.

An interim report was released in July 2017. Work was halted in 2018 when a provincial election was being run, but was restarted sometime later by the new (Conservative) Minister of Health, Christine Elliot. The final report, somewhat rushed, was submitted in December 2018. Both the interim and final reports can be found at the previous link. Note that the final report was entitled “Care Now” which was the inspiration for the new name of MEAO to signify that it deals with all three conditions.

The box on page 3 shows key paragraphs from the letter that the task force chair sent to the minister when submitting the report. The box on page 5 shows the recommendations of the task force.

Laying the Groundwork report

In January 2020, Minister Elliot asked Public Health Ontario to advise her within six months on how to operationalize the recommendations. Then COVID intervened and Public Health Ontario became very busy. The report, which was titled “Laying the Groundwork”, was delayed by a year and was submitted to the Minister in summer 2021.

Sometime after that, a new Minister of Health, Sylvia Jones, was appointed. She delayed releasing the report. The health critic for the NDP asked for the report through the access to information process and finally got the document in June 2025 and shared it with CareNow Ontario.

This document recommends a coordinating group (the "Environmental Conditions Office") to implement the action plan focusing on care, education, research and policy development. It recommends a budget starting at around $3M per year to coordinate and oversee the necessary work.

The box on page 6 shows a CareNow Ontario summary of the report.

What has Happened Since

The one topic that the Ontario Ministry of Health has acted on was hiring an organization to write clinical guidelines. There are now Ontario guidelines for ME, FM, and POTS (postural orthostatic tachycardia syndrome, the speeding up of heart rate when standing up). *https://cep.health/clinical-products/fm-mecfs-and-pots/*. The organization could not agree on guidelines for MCS so these still do not exist.

We referred to the guidelines in Quest 142 (2024). The guidelines are posted on a non-government website and the Ontario government has not drawn attention to them.

When it finally received a copy of the Laying the Groundwork report, CareNow Ontario wrote the Minister asking for some specific, concrete actions:

- to identify a contact person in the Ministry,
- to provide training around the clinical guidelines that were published, and
- to develop and publish MCS clinical guidelines.

This shows that, despite years of hard work by the patient community, the Ontario government is still avoiding the topic and not taking ME, FM and MCS seriously.

Letter from Ontario Task Force Chair to Minister of Health

On behalf of the Task Force on Environmental Health, I am pleased to present our final report. It sets out a practical, evidence-based action plan that will allow Ontario to create a comprehensive, cost-effective, patient-centred system of care for people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM) and environmental sensitivities/multiple chemical sensitivity (ES/MCS) – one that will support patients, families and providers. It will improve access to timely, high quality care. It will shift responsibility for care out of acute care hospitals and into the community, closer to where people live. It will make highly efficient use of the skills of both primary care and specialized providers. It will actively engage patients and families in managing their health. Most importantly, it will provide urgently needed care now and, in the process, gather the data and enable research that will help Ontario understand, diagnose and manage these poorly understood conditions more effectively. It will also help raise awareness and reduce the stigma associated with ME/CFS, FM and ES/MCS. The need for action is urgent. About three-quarters of a million Ontarians are suffering with these debilitating conditions, and they and their families deserve effective care and support now...

We believe that Ontario has the potential to become a global leader in the diagnosis and management of ME/CFS, FM and ES/MCS. Our proposed action plan provides a cost-effective way for Ontario to significantly improve care for people living with these conditions while reducing the need for them to seek care in emergency departments and acute care hospitals.

We are asking you to take the critical steps recommended in this report to enhance awareness of ME/CFS, FM and ES/MCS, improve knowledge and care, and lay the foundation for a patient-centred system of care for people living with these devastating complex chronic diseases.

DIRECT SERVICES (that Ontario should provide for ME, FM and MCS)

Excerpt from Recognition, Inclusion and Equity: The Time is Now
The Ontario Centre of Excellence in Environmental Health Business Case Proposal, 2013

 HEALTH PROVIDERS and SYSTEM NAVIGATORS

- Trained physician and nurse practitioner care for assessment, diagnosis and treatment
- Trained supports from other health professionals to create comprehensive and integrated care
- Outreach to PCPs in the community to support patients
- Outreach to other HSPs in community to create appropriate reception for clients

 MODALITIES OF HEALTH CARE

- Medical diagnostics and treatments, including prescription pharmaceuticals and nutriceuticals
- Physiotherapy, chiropractic, massage, acupuncture, nutrition
- Detoxification supports
- Oxygen therapy
- Nutritional and immune enhancing IVs
- Mind-body modalities
- Self-management activities
- Safe hospital reception for ES/MCS
- Quiet resting rooms for ME/CFS and 'clean rooms' for ES/MCS in all major para-public sites and health care facilities.
- Condition-competent hospital services for all conditions - emergency, acute, elective needs
- Training for para-medics and system navigation/advocacy with other HSPs, notably hospitals and CCACs.

 SOCIAL SUPPORTS ADDRESSING SOCIAL DETERMINANTS OF HEALTH

- Condition-competent, fragrance-free, trained personal support workers for personal hygiene and health (e.g., blood draws), mobility needs, laundry, cleaning, shopping and maintenance
- Services for food security
- Services for transportation (appointments, necessities, social needs - isolation reduction)
- Support services to family caregivers: education, peer-group, respite
- Support services to sick parents with children; support services to parents with sick children
- Income support services (social assistance, ODSP, WSIB, etc.); legal assistance to access these
- Psychological supports
- Advocacy for workplace, daycare and educational institutions, legal support services
- Advocacy for ES/MCS safe housing - shelters, residential, supportive - assisted, long-term care, palliative
- Advocacy for ME/CFS & FM competent and friendly social housing assisted living and long term care;
- Personal support services for residence search; advocacy and legal assistance with landlords when needed.

PCP=primary care provider, HSP=health service provider, CCAC=community care access centre, ODSP=Ontario disability support program, WSIB=workplace safety and insurance board

Task Force Report (2018) Summary of Recommendations

Recommendation 1: Develop a one-to-three year awareness campaign that targets the general public, health care facilities and providers and primary care settings.

- Recommendation 1.1 – Develop awareness materials that target the general public and specifically engage priority groups, starting with employers and landlords.
- Recommendation 1.2 – Create materials and tools designed to promote awareness of ME/CFS, FM and ES/MCS and explain how to accommodate patients with these chronic conditions in priority health care settings, starting with hospitals, long-term care homes and key home care providers.
- Recommendation 1.3 – Increase awareness of ME/CFS, FM and ES/MCS, clinical tools and information, and the need for accommodation, in all primary care settings in Ontario.

Recommendation 2: Develop and disseminate clinical tools and information that support evidence-informed treatment and management.

Recommendation 3: Establish a system to develop and support a cadre of primary health care and specialized providers skilled in managing ME/CFS, FM and ES/MCS.

- Recommendation 3.1 – Establish a community of practice to provide training and support the network of primary care clinics that will provide chronic disease management for people with ME/CFS, FM and ES/MCS across the province.
- Recommendation 3.2 – Fund a comprehensive strategy to increase the pool of skilled, specialized providers to reflect the high demand for interdisciplinary care.

Recommendation 4: Create and support a network of enhanced primary care programs throughout Ontario.

Recommendation 5: Develop a shared care planning tool.

Recommendation 6: Modernize the OHIP K037 fee code to include all three conditions and use it to help gather data on their prevalence.

Recommendation 7: Support research to fill critical gaps in knowledge about the pathogenesis, prevention and treatment of ME/CFS, FM and ES/MCS.

- Recommendation 7.1 – Leverage the Health System Research Fund (HSRF) to fund priority research into patients' experience with the health system and improve care and efficiency.
- Recommendation 7.2 – Work with funding organizations such as the Canadian Institutes of Health Research (CIHR) and the US National institutes of Health (NIH) to support funding research projects that explore questions related to the pathogenesis and prevention of ME/CFS, FM and ES/MCS.

Recommendation 8: Create a centre of excellence in ME/CFS, FM and ES/MCS care, education and research in Ontario.

Recommendation 9: Establish a transitional implementation committee to provide the leadership in the initial phases of putting this plan into action.

Recommendation 10: Provide regular updates and progress reports on the implementation of the proposed action plan.

Laying the Groundwork Report

CareNow Ontario Summary

The starting point for that report was

- little recognition of the seriousness and severity of ME, FM and MCS
- shortage of knowledgeable care providers
- lack of clinical tools to support and guide care
- shortage of services and supports for people with these conditions
- lack of research and leadership
- failure to acknowledge stigma and its impact

The action plan emphasized the need for the following:

- leadership
- emphasis on primary care
- clinical guidelines
- research and evaluation

Recent Canadian Developments

Provincial premiers meet

This report came from Santis, a management consultant company that focuses on health issues. Provincial premiers met in July 2026.

Premiers focused their initial discussions over July 21-22 on health care, safe communities, cost of living and affordability, economic growth, and strengthening Arctic security and sovereignty. A primary concern for Premiers was the future of CUSMA and Canada's general trade relationship with the U.S...

With regards to health care more specifically, Premiers were primarily focused on access to timely and appropriate health care services, including treatments and medicines. They called on the federal government to renew funding agreements set to expire throughout the next few years, including Aging with Dignity, Drugs for Rare Diseases, and mental health and addictions funding. They also sought a commitment from the federal government to continue a minimum 5% Canada Health Transfer (CHT) growth rate annually rather than letting it revert back to 3% after March 31, 2028, as currently planned. New



Brunswick Premier Susan Holt pointed out in the post-meeting press conference that the federal share of health costs had dropped to 21%, well below the 50-50 cost-share agreement under the original National Hospital Insurance Act of 1957.

https://santishealth.ca/insights/council-of-the-federation-meeting-summer-2026-wrap-memo/

Note that provincial health care costs would increase with inflation, but would also increase with population growth and population aging. Costs would also be influenced by population health, which would be influenced by factors such as smoking patterns, weight patterns, co-morbidity patterns or mental health patterns.

Public Opinion Survey

[Press Release]

TheSantis-Nanos Canadian Health Perspective is a national public opinion survey tracking Canadian attitudes and sentiment on health care delivery, priorities, and system innovation, powered by Nanos Research and Santis Health. The inaugural survey is the first in a series looking at Canadians' experience in health care, their priorities, and desire for improvement and innovation. It was conducted in May 2026.

Key findings:

91% of Canadians agree it is important for the system to change now, a view held across all demographics and geographical regions.

This demand for change is driven by discontent, with **70%** of Canadians reporting they feel "worried" or "frustrated" by the current state of care.

Canadians have lost their confidence in the health system, with **55%** reporting that the health care system is moving in the wrong direction.

https://santishealth.ca/canadian-health-perspective/

The Health-Productivity Gap

[Press Release, 22 Sep 2026]

Poor health cost Canada more than $100 billion in economic output in 2025: Deloitte Canada

New Deloitte analysis finds Canada could unlock more than $25 billion in annual economic gains by reducing health-related barriers to workforce participation

A new Deloitte Canada report reveals that poor health and related caregiving is not only a social challenge, but a significant constraint on Canada's workforce and economy. Using a first-of-its-kind Health Productivity Gap (HPG) framework, the analysis finds that health-related barriers to workforce participation cost the country more than $100 billion in economic output in 2025, while reducing those barriers by 25% could recover more than $25 billion annually.

Canada's productivity performance has lagged other advanced economies for more than a decade, while health outcomes have deteriorated and workforce pressures related to chronic disease, mental health challenges and caregiving responsibilities continue to grow. Deloitte's HPG framework, which quantifies the economic cost of poor health and caregiving in Canada, suggests these trends are closely connected yet insufficiently recognized, with health-related barriers increasingly limiting labour force participation and constraining economic output.

"Productivity is one of Canada's most pressing challenges, yet health is rarely considered part of the productivity agenda," says Michelle Theroux, National Health Leader at Deloitte Canada. "We cannot expect technology, AI, or workforce upskilling to solve Canada's productivity challenge if people are increasingly sidelined by illness, poor mental health, or caregiving responsibilities. Better health is not just an outcome of a strong economy. It is a prerequisite for one."

The analysis identifies two major opportunities to improve outcomes: 1. The prevention gap, reflecting capacity lost to preventable illness, and 2. The participation gap, reflecting capacity constrained by chronic disease, mental health challenges and caregiving responsibilities....

https://www.deloitte.com/ca/en/about/press-room/the-health-productivity-gap.html

Projected Patterns of Illness in Ontario

This report was published in 2024. The purpose was to predict the patterns of illness in the various health regions of Ontario in 2040 for planning purposes. The predictions were primarily made by looking at historical illness data and the expected demographic changes.

Overall, Ontario's population is expect to grow 36% between 2020 and 2040, with the number of seniors growing by 60% and the number of people over 85 more than doubling. Other factors that can affect frequency and patterns of illness include immigration, socio-economic conditions and health behaviours such as smoking patterns.

The study selected 18 chronic conditions which "were selected based on previous evidence demonstrating a high health system burden in Ontario". The report predicts that osteoarthritis, hypertension, diabetes, asthma and cancer will be the most frequent conditions in 2040. The report predicts that renal failure, hearing loss, osteoporosis and cancer will show the largest increases.

ME/CFS and FM not among the 18 chronic conditions examined, but we predict that they will show a major increase for two reasons. Firstly, ME and FM are often triggered by infection and COVID has triggered a considerable number of new cases. Secondly, there is a recent study suggesting that ME has historically been extremely under-counted. We don't know how well FM is counted.

In short, we believe that, by leaving ME and FM out, the study missed a major issue.

https://pophealthanalytics.com/wp-content/uploads/2024/10/Study-Projected-Patterns-of-Illness-in-Ontario-Released-October-16-Final.pdf

Recent International Insights

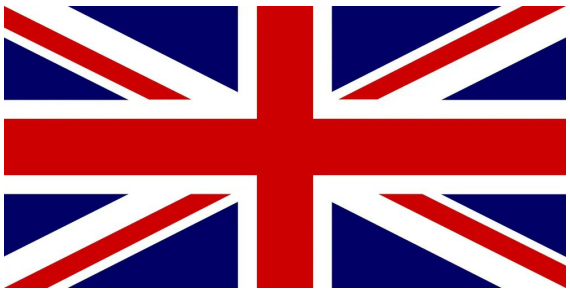
The Importance of Diagnosis

Extract From: The Elusive Body - Patients, Doctors, and the Diagnosis Crisis, by Alexandra Sifferlin, 2026

A diagnosis is the most important piece of medical information a person can receive. It's an explanation of symptoms, the fitting of a person's observable signs and experiences of illness into a known disease. But it's much more than a label or an exercise in matching. The moment of diagnosis is profound, whether it is for something as ordinary as strep throat or as frightening as cancer. Patients and doctors seek diagnoses not just for understanding but for relief, or at least hope for it. Delivering a diagnosis is an essential medical act. A diagnosis allows doctors to develop a treatment plan. It can unlock clinical trial eligibility or determine whether insurance will cover care. A diagnosis is an answer to sometimes decades of mystery; it gives people permission to be sick and access to a community facing the same challenges. A new diagnosis can even change medicine and society for good, alleviating uncertainty for people living with a condition they didn't have the terminology for or an understanding of before.

But there's a pocket of people for whom getting a diagnosis is a journey they may remain on for months, years, even a lifetime. Being undiagnosed can be one of the most frustrating and isolating medical experiences there is – and it's all too common.

Living without a diagnosis can mean a person is excluded from nearly every opportunity for treatment and community. Care without a diagnosis can be ineffective, sometimes even counter-productive. Without knowing the underlying cause of a patient's illness, clinical providers are limited to managing their symptoms, like prescribing an inhaler for labored breathing or medication for pain. If therapies don't work or exacerbate a person's symptoms, the doctor-patient relationship can become infused with skepticism and distrust, making an eventual resolution even harder to reach. Patients and their families are left largely in the dark. This is a demoralizing experience known to tens of millions of people worldwide.



The Hidden Hierarchy of Illness

Modern medicine presents itself as a neutral arbiter of disease. Yet in conditions such as ...ME/CFS...what is most visibly at stake is often not treatment, but legitimacy. Who is recognised as genuinely ill? Who is granted empathy? And who is quietly repositioned as difficult, weak, or morally suspect?

This is the beginning of a 2 page opinion article published in Advances in Rehabilitation Science and Practice. The author is Tarek A.Z.K. Gaber, a doctor of rehabilitation medicine in the U.K. A little farther on he writes:

Several patients whom I have followed for years, disabled by profound fatigue, cognitive dysfunction, and loss of function, were later found to have incidental MRI findings that supported a diagnosis of multiple sclerosis. Each time, I expected devastation. Instead, more than one patient told me that the day they were given the diagnosis of MS was 'the best day of my life'. Not because their suffering had changed, but because, for the first time, it had become legitimate. They were no longer exhausted without cause, disabled without explanation, or ill without status. They had crossed an invisible threshold from a condition that required justification into one that commanded recognition.

He talks of a divide in the medical community between "lesion-based medicine" which focuses on causation and fails to recognize ME, versus rehabilitation medicine which focuses on functioning and does recognize ME. He suggests that disability determinations should be made by the latter.

https://journals.sagepub.com/doi/full/10.1177/27536351261431723



Updated Costs of ME in Germany

A report estimating the economic costs of ME in Germany was released in April 2026. This report updated a study published in 2025.

The report found that, at the end of 2025, there were 657,000 cases of ME in Germany, a rise of around 250,000 cases since 2020. The study found that the economic cost of ME in 2025 was 32.8B euros, 0.73% of Germany's gross domestic product, indicating that ME had a non-trivial impact on the economy.

The figures for long-Covid were 758,000 cases and 31.6 B euros or about 0.71% of GDP.

Germany has almost exactly twice the population of Canada so this would translate into around 328,000 cases of ME in Canada plus around 379,000 cases of long-Covid at the end of 2025.

Canada's GDP in 2025 was $3.24T in Canadian dollars, so ME and long-Covid would have cost the Canadian economy around $2.3B each in 2025.

The authors note that "one of the main factors driving the societal cost of Long COVID and ME/CFS is the low rate of recovery from these diseases, ME/CFS in particular". So they suggest that Germany put an immediate research focus on treatment development.

They note that currently most research funding is looking at health care services and relatively little is looking at biomedical issues. They recommend that much more emphasis be put on biomedical research.

They recommend that researchers, patients, clinicians and managers work closely together so that promising leads can be identified and course-adjustments can be made quickly.

They recommend that research be collaborative and that information be shared openly.

They point to the need for good disease surveillance to minimize new cases.

https://mecfs-research.org/en/costreport-long-covid-and-mecfs-2025/



ME Prevalence

A stunning statistical report on the prevalence of ME in the US was published in May 2026.

Prior to Covid, the US estimated that there were 1 to 2.5 million individuals with ME.

The 2015 Institute of Medicine report had already cast the estimated prevalence of ME in doubt, suggesting that 84% to 91% of cases were missed.

The 2026 report identifies "narrow diagnostic criteria, fragmented care systems, limited clinical recognition, and structural undercounting" as reasons for under-estimation. Plus COVID has added many new cases.

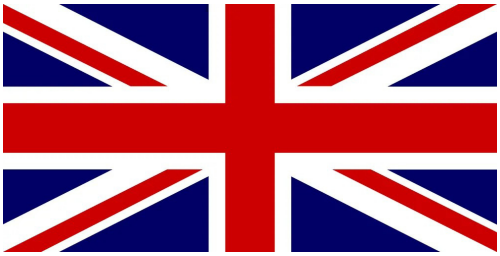
The author of this study estimates that there are now actually 18-26 million adults with ME. Adjusted for population, that would suggest that there are now 2-3 million Canadians with ME.

Wow. Let's see if this estimate holds up under scrutiny.

https://papers.ssrn.com/sol3/papers.cfm?abstract_id=6835159

Guidance on Severe ME

Two documents were released this summer on the management of severe and very severe ME. The two documents are very different in style, but their messages are the same: It is not known how to make people with ME better (but that still can happen). It is, however, known how to make people worse – over-exertion and too much environmental stimuli – so those should be carefully managed.



The fact sheet "Management of severe and very severe ME/CFS" was written by Jonathan Edwards, a retired professor of medicine in the UK and frequent contributor to the Science for ME forum. He emphasizes that "We do not know what ought to be the best way to manage ME/CFS. That being the case, care must focus on practical steps to minimise symptoms. Patients and carers should be encouraged to work out what routine works best for the individual, rather than being given protocols based on expectations that may not apply". The fact sheet goes on to discuss a number of aspects of care.



The consensus paper "Guidance on Home-Based Care for People with Severe ME/CFS: A Transdisciplinary Expert Statement" was written by a team based in Austria that included patients, caregivers and health professionals. It was published in German in June 2026 and in English a month later.

Section 1 is a short introduction and says that the objective of the guide is to structure care measures in a way that prevents overexertion and promotes stability.

Section 2 describes how the document was compiled.

Section 3 discusses clinical issues like post-exertional malaise, pacing, and possible co-morbidities.

Section 4 discusses very practical ways that front-line caregivers could provide assistance in the following areas:

- eating and drinking
- toileting tasks
- personal hygiene (including oral care) and dressing (including bedding)
- rest and sleep
- mobility, positioning and transferring
- safety, protection against sensory overload, and infection control
- communication, social interaction and presence of people
- emotional and existential needs
- roles in family and partnership

Section 5 is about supporting front-line care. It is aimed at professionals who provide medical support, plan home care or visit from time to time.

Wouldn't it be wonderful if the professionals, along with the family, friends and personal service workers who provide care, were informed about the information in these two documents.

https://s4me.info/threads/fact-sheet-4-management-of-severe-and-very-severe-me-cfs.51793/

https://link.springer.com/article/10.1007/s10354-026-01182-3#Sec21

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